**Learning from experience: A thematic analysis of parent narratives concerning the emotional lives of young children with autism and without language.**

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# Abstract

Understanding of autism has changed dramatically during the last 70 years. One change which is beginning to occur relates to the emotionality of young children with autism although it is an aspect of their lives which can still be overlooked and sometimes completely disregarded. The DSM-V, a publication of the American Psychiatric Association, 2013, continues to significantly underestimate the emotional lives of individuals with autism (Wu, 2013). This study sets out to question the conceptualisation of emotionality in children with autism, and focuses on the emotional lives of non-verbal young children with autism, in the hope of making an improvement to the efficacy of service responses. However, given the centrality of parents in the lives of those children with autism and who are without language, it is the views of the parents about the emotional lives of their children during their early years which are examined through a thematic analysis of narrative accounts from two families in the UK and two families in Taiwan.

What emerges from these parental accounts is their understanding of a fundamental complexity of individuals with autism. There is little evidence to suggest that children with autism experience emotions differently and indeed the parental narratives in this study suggest that children with autism experience a range of emotions and can enjoy a sense of humour, develop relationships and have preferences. Recommendations are made that children with autism must be considered by professionals and those who offer ‘treatment’, as human beings with emotionality.

Key words: Autism; Emotion; Narrative; Young children; Emotional lives; Non-verbal

**Table of contents**

[Abstract i](#_Toc428976676)

[Table of contents ii](#_Toc428976677)

[List of figures vi](#_Toc428976678)

**List of tables…………………………………………………………………………....vi**

[List of appendices vi](#_Toc428976679)

[Dedication vii](#_Toc428976680)

[Acknowledgments viii](#_Toc428976681)

[Chapter 1 Introduction 1](#_Toc428976682)

[1.1 Background and Context of Study 2](#_Toc428976684)

[1.2 Brief Autobiographic Details based on Reflection and Positionality 5](#_Toc428976685)

[1.3 Organisation of the Thesis 10](#_Toc428976686)

[1.4 Research questions 12](#_Toc428976687)

[Chapter 2 Literature Review 13](#_Toc428976688)

[2.1 Introduction 13](#_Toc428976689)

[2.2 Autism in the UK and in Taiwan 14](#_Toc428976690)

[2.2.1 Policy 15](#_Toc428976691)

[2.2.2 ‘Treatment’- Education 16](#_Toc428976692)

[2.2.3 Current Diagnosis/Assessment Practices 18](#_Toc428976693)

[2.2.4 Treatment, Intervention Programmes and Approaches 20](#_Toc428976694)

[2.3 Exploring emotional life 22](#_Toc428976695)

[2.3.1 Hypersensitivity 25](#_Toc428976696)

[2.3.2 Theories of Emotions 27](#_Toc428976697)

[2.3.3 Other theories of emotions 29](#_Toc428976698)

[2.4 Teaching emotions to children with autism 33](#_Toc428976699)

[2.5 Individuals with Autism do have Emotions and Feelings 36](#_Toc428976700)

[2.5.1 Testimonial or Insider Accounts 43](#_Toc428976701)

[2.6 How Society Treats Individuals with Autism 58](#_Toc428976702)

[2.7 Difficulties Facing the Family of a Child with Autism 64](#_Toc428976703)

[2.7.1 Blame in the family of an individual with autism 68](#_Toc428976704)

[2.8 A different view of the current system 70](#_Toc428976705)

[2.9 Conclusions from the Literature Review 74](#_Toc428976706)

[Chapter 3 Methodology 76](#_Toc428976707)

[3.1 Introduction 76](#_Toc428976708)

[3.2 Epistemology and Ontology 77](#_Toc428976709)

[3.3 Qualitative research methods considered 88](#_Toc428976710)

[3.3.1 Action research 89](#_Toc428976711)

[3.3.2 Ethnography 90](#_Toc428976712)

[3.3.3 Interpretative Phenomenological Analysis (IPA) 91](#_Toc428976713)

[3.3.4 Narrative 92](#_Toc428976714)

[3.3.5 Conclusion 97](#_Toc428976715)

[3.4 Research methods 98](#_Toc428976716)

[3.4.1 Interviews 99](#_Toc428976717)

[3.4.2 Choice of research method 103](#_Toc428976718)

[Chapter 4 Research procedure 105](#_Toc428976719)

[4.1 Data collection 106](#_Toc428976720)

[4.2 Use of an interpreter 109](#_Toc428976721)

[4.2.1 Selection of an interpreter 110](#_Toc428976722)

[4.3 Participants 111](#_Toc428976723)

[4.4 Three-stage approach 115](#_Toc428976724)

[4.5 Interview questions 116](#_Toc428976725)

[4.5.1 The first interview 118](#_Toc428976726)

[4.5.2 The second interview 119](#_Toc428976727)

[4.5.3 The third interview 119](#_Toc428976728)

[4.6 Document analysis 120](#_Toc428976729)

[4.7 Data analysis 121](#_Toc428976730)

[4.8 Cross-cultural considerations 123](#_Toc428976731)

[4.9 Ethical considerations 129](#_Toc428976732)

[4.10 Scope and limitations 132](#_Toc428976733)

[Chapter 5 Parental narratives from my research 133](#_Toc428976734)

[5.1 Thomas 139](#_Toc428976735)

[5.1.1 Individual 140](#_Toc428976736)

[5.1.1.1 History 141](#_Toc428976737)

[5.1.1.2 Emotionality 142](#_Toc428976738)

[5.1.1.3 Behaviour 153](#_Toc428976739)

[5.1.2 Family 157](#_Toc428976740)

[5.1.2.1 Parents 157](#_Toc428976741)

[5.1.2.2 Siblings 166](#_Toc428976742)

[5.1.3 The Education System 167](#_Toc428976743)

[5.1.4 The Medical System 171](#_Toc428976744)

[5.1.4.1 Diagnosis 171](#_Toc428976745)

[5.1.4.2 Medication 175](#_Toc428976746)

[5.1.4.3 Many Faceted Approach 176](#_Toc428976747)

[5.1.4.4 Suggestion or Feedback 176](#_Toc428976748)

[5.1.5 Policy 177](#_Toc428976749)

[5.1.6 Society, Community, Nation 180](#_Toc428976750)

[5.1.6.1 Societal Pressure 180](#_Toc428976751)

[5.1.6.2 Resources 181](#_Toc428976752)

[5.2 Balaravi 184](#_Toc428976753)

[5.2.1 Individual 185](#_Toc428976754)

[5.2.1.1 Emotionality 186](#_Toc428976755)

[5.2.1.2 Behaviour 194](#_Toc428976756)

[5.2.2 Family 200](#_Toc428976757)

[5.2.2.1 Mother 200](#_Toc428976758)

[5.2.2.2 Father 205](#_Toc428976759)

[5.2.2.3 Grandparents 206](#_Toc428976760)

[5.2.2.4 Other family members or friends 207](#_Toc428976761)

[5.2.3 The Educational System 207](#_Toc428976762)

[5.2.4 The Medical System 212](#_Toc428976763)

[5.2.5 Society, Community, or Nation 214](#_Toc428976764)

[5.2.5.1 Cultural View toward Children with Autism 214](#_Toc428976765)

[5.2.5.2 On a Child in India 215](#_Toc428976766)

[5.2.5.3 Neighbour’s Reaction 216](#_Toc428976767)

[5.2.5.4 Societal Pressure 216](#_Toc428976768)

[5.2.5.5 Resource 218](#_Toc428976769)

[5.3 Harry 219](#_Toc428976770)

[5.3.1 Something About Taiwan 219](#_Toc428976771)

[5.3.2 Introduction 220](#_Toc428976772)

[5.3.3 Individual 221](#_Toc428976773)

[5.3.3.1 Emotionality 222](#_Toc428976774)

[5.3.3.2 Behaviour 229](#_Toc428976775)

[5.3.4 Family 237](#_Toc428976776)

[5.3.4.1 Parents 237](#_Toc428976777)

[5.3.4.2 Sibling 255](#_Toc428976778)

[5.3.4.3 Grandparents 256](#_Toc428976779)

[5.3.4.4 Other Family Members or Friends 257](#_Toc428976780)

[5.3.5 The Educational System 258](#_Toc428976781)

[5.3.6 The Medical System 263](#_Toc428976782)

[5.3.7 Policy 266](#_Toc428976783)

[5.3.7.1 Welfare 268](#_Toc428976784)

[5.3.8 Society, Community, Nation 268](#_Toc428976785)

[5.3.8.1 Cultural View 268](#_Toc428976786)

[5.3.8.2 Societal Pressure 270](#_Toc428976787)

[5.4 Han 272](#_Toc428976788)

[5.4.1 Family Background 272](#_Toc428976789)

[5.4.2 Individual 273](#_Toc428976790)2

[5.4.2.1 Emotionality 274](#_Toc428976791)

[5.4.2.2 Behaviour 279](#_Toc428976792)

[5.4.3 Family 282](#_Toc428976793)

[5.4.3.1 Parents 282](#_Toc428976794)

[5.4.3.2 Sibling 293](#_Toc428976795)

[5.4.3.3 Grandparents 294](#_Toc428976796)

[5.4.3.4 Network 295](#_Toc428976797)

[5.4.4 The Educational System 295](#_Toc428976798)

[5.4.5 The Medical System 297](#_Toc428976799)

[5.4.6 Policy 301](#_Toc428976800)

[5.4.7 Society, Community, Nation 301](#_Toc428976801)

[Chapter 6 Critique and Discussion 302](#_Toc428976802)

[6.1 On my research 303](#_Toc428976806)

[6.2 Response to my research question 308](#_Toc428976807)

[6.3 Conclusions and Implications 345](#_Toc428976808)

[6.3.1 The individual and emotionality 346](#_Toc428976809)

[6.3.2 Family and emotionality 347](#_Toc428976810)

[6.3.3 The educational system and emotionality 348](#_Toc428976811)

[6.3.4 The medical system and emotionality 348](#_Toc428976812)

[6.3.5 Policy and emotionality 348](#_Toc428976813)

[6.3.6 Society and emotionality 349](#_Toc428976814)

[6.3.7 Implications 350](#_Toc428976815)

[6.3.7.1 Suggestions for practitioners 351](#_Toc428976816)

[6.3.7.2 Suggestions for further research 351](#_Toc428976817)

[6.3.7.3 Suggestions for policy-makers 352](#_Toc428976818)

[References 354](#_Toc428976819)

**List of figures**

Figure 1: Data collection process 108

Figure 2: the relationship between each of the themes identified in this research 138

**List of tables**

Table 1: An overview of participants 114

**List of appendices**

Appendix 1 DSM-IV and DSM-V diagnostic criteria for autism 423

Appendix 2Comparing the systems related to preschool children with autism 428

Appendix 3 Taiwanese regulations relating to young children with special needs. 429

Appendix 4 Comparing the assessment or diagnosis related to preschool

 children with Autism 430

Appendix 5 Comparing diverse treatment and intervention programs

 and approaches 431

Appendix 6 Therapies in Taiwan 432

Appendix 7 Ethical Review Form 436

Appendix 8 Interview questions 452

Appendix 9 Sharing material for parents 456

Appendix 10 Sharing material for parents (Taiwanese version) 459

Appendix 11 Participant Information Document 462

Appendix 12 Participant Consent Form 466

Appendix 13 Participant Information Document (Taiwanese version) 468

Appendix 14 A letter for Taiwanese participants 471

**Dedication**

I dedicate this work to my family and many friends. In particular Ray & Rita Wu, who have supported my decision to study in the UK and allowed me piece of mind knowing that my family has been well looked after during my long absence from Taiwan.

I especially want to thank Kevin Smith and Tony & Sally Esdaile for their patience and perseverance through many hours of proof-reading.

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**Chapter 1 Introduction**

This research focuses on the emotional lives of children with autism, but specifically through their parents’ narratives. The existing literature shows that there are different views on this subject. Some authoritative figures focus on various difficulties which may include difficulties in social communication and social interaction, as well as having a low emotional ability (Baron-Cohen, 1993). On the other hand, there are more recent arguments which challenge the deficit model of autism (Timimi et al., 2011) and emphasise different ways of conceptualising autism which would suggest that children with autism do possess emotions, although expressing themselves differently from other children. For instance, Kahneman (2011) states that emotion is present in all human actions, a view further supported by Davidson and Begley (2012) who argue that all children, even before they can speak, have an emotional life.

This study therefore seeks to investigate the ways in which parents consider the issue of the emotionality of their children. Before moving into more detail, it is important to clarify the way some concepts are employed in this study as this may differ from other studies.

It has been a huge challenge for me to resist the medical model. Autism itself almost seems to have been ‘created’ according to medicalised discourse. I acknowledge my shifting positionality in this thesis as a consequence of the overwhelming nature of the medical model in our society and professional training. There is little positive discourse on emotional life of young children with autism. My position is to challenge the prevailing medical discourse/deficit model (DSM-V). It is my contention that the diagnosis criteria for ‘autism’ are actually vague yet impose a stigma of ‘mental illness’ on the individual. Ideally, I would prefer that the label be removed. However this will create a dilemma, as parents currently need the label to gain access to support. In order to reduce the stigma it would be necessary to find an alternative approach to satisfying their need for support as unfortunately our systems dictate ‘no diagnosis, no service’.

I believe that the term ‘people with autism’ as opposed to ‘autistic people’ is more appropriate when speaking of autism. The difference may appear to be insignificant, but autism does not describe all that there is to know about a person. Additionally, although many professionals use the term “Autism Spectrum Disorder” (ASD), I will instead be using autism. Disorder is a term that implies some kind of deficit, or mental illness - and I do not believe that autism is a mental illness. Clearly, however, some people with autism do encounter difficulties in living their lives.

It is my cherished hope that the outcome of this study will ultimately aid the development of more effective teaching methods for children who are experiencing these difficulties.

## 1.1 Background and Context of Study

The term autism was first used by Eugen Bleuler around 1911 to refer to one group of symptoms of schizophrenia. Later, it was used by Leo Kanner in the early 1940s to describe certain children who apparently had social and emotional problems. Around the same time, Hans Asperger proposed the term ‘Asperger’ to describe a group of children with similar conditions. In the 1970s it was observed that autistic characteristics could occur in a continuum and this led to the use of the concept of ‘Autistic Spectrum Disorder’ (ASD) (Timimi et al., 2011).

Between the 1930s and the 1970s, research into the treatment of autism focused on therapies and medication such as electric shock and lysergic acid diethylamide (LSD-25) (Waltz, 2013). These methods were criticised as being inhumane and, hence, the search for alternative treatment methods continued. Since the 1960s, professionals have mostly utilised behavioural therapy and highly controlled and organised learning environments to manage autism (Waltz, 2013). Research into the treatment of autism continued and more theories were generated as scientists attempted to identify its cause. Researchers wanted to establish whether autism was a hereditary state related to specific genes or whether it resulted from certain vaccines or changes in the brain structure.

The Diagnostic and Statistical Manual of mental disorders (DSM), published by the American Psychiatric Association (APA), is used to classify mental disorders. Autism was added to the third edition of the manual (DSM – III) in 1980 and its description was further developed in DSM-IV which was published in 1994, with text revision in 2000. In the DSM-V (APA, 2013), Asperger’s disorder and pervasive developmental disorder are combined within the autism spectrum disorder group. Since the DSM classifies mental disorders it follows that the inclusion of autism in the DSM, labels those who are diagnosed with autism as having a neurodevelopmental disorder and/or of being mentally ill.

According to medical accounts in the DSM, children with autism have deficits in social-communication and social interaction. In order to qualify for diagnosis, individuals with autism must show their symptoms by age 3. Some research shows that children with autism have one or more of the following: language delay (Bennett et al., 2008; Loveland; Landry, 1986); repetitive behaviour (Bodfish et al., 2000; Thakkar et al., 2008; Turner, 1999); hypersensitivity (Baron-Cohen et al., 2009; Gomot et al., 2002); and some may be addicted to certain objects or topics (Baron-Cohen and Wheelwright, 1999; Russell et al., 2005).

The reviewed literature thus indicates that the general research focus has been on establishing the difficulties associated with autism, such as a lack of eye contact, difficulties with relationships, lacking Theory of Mind (ToM) [ToM refers to ‘the ability to understand that other people have their own plans, thoughts, beliefs, attitudes and emotions’ (Timimi et al., 2011, p.67)] and possessing uneven motor skills. Only a few voices speak out about the strengths of people having autism. For example, some people with autism have strong root memory, good detailed memory, excellent spatial concept, and gifted artistic capabilities. The emotions of those with autism can clearly be seen in their narratives (see Donna Williams’ *Nobody Nowhere,* Temple Grandin’s *Emergence: Labelled Autistic*, and Naoki Higashida’s *The Reason I Jump: One Boy's Voice from the Silence of Autism.* Also see these videos: [Arman Khodaei](https://youtube.com/user/armankhodaei?feature=watch)’s *Insights from an Autistic: Emotions,* and *Autism, Asperger’s, Emotions and Anger* on the website adultswithautism.org.uk). All this indicates that far from not possessing an emotional life, people with autism can feel happy, sad, depressed, frustrated, angry and afraid. They can also be eager to be loved as well as to be independent.

Clinical and educational professionals have different specialised backgrounds, and they view and deal with children who have autism differently. For the benefit of these children, teachers and carers need to work more closely with the clinical system to help families of children with special needs to understand all the difficulties of their daily lives. Whilst the clinical system gives diagnoses - and possibly some medical treatment - usually the time available to the clinician is limited. The real hope for children with autism is that they experience humane understanding from the education system and from their families. Happé (1999) points out that individuals working with children and young people with autism should put emphasis on the ‘assets’ of individuals with autism rather than the ‘deficits’, This view is supported later by Billington (2006). Similarly, ‘[people with autism] have characteristically autistic styles of relating to others, which should be respected and appreciated rather than modified to make them “fit in”’ (Autistic Network International, 2010).

Children with autism may display their emotions in a subtle manner, or not at all. However this does not mean that they have no emotional life. Children with autism constantly challenge the way we think about what it is to be human. With care and understanding these children may change their behaviour and this indicates acknowledgement of their emotionality. For this reason my research focuses on exploring the emotional lives of children with autism through the narratives of their parents.

## 1.2 Brief Autobiographic Details based on Reflection and Positionality

As a child growing up in Taiwan, I was thought to have a learning difficulty and considered to be mentally retarded, or autistic, by my kindergarten teachers. This was due to my behaviour and learning progress. I can look back to those times and recall that nobody seemed to care about me and that the only thing they did was to blame me for my behaviour. At the age of nine, I had very low self-esteem and I stammered quite badly. This added to my already poor communication ability. My peers had a great deal of difficulty understanding what I had to say, which led to me having almost no friends. I felt helpless and useless. Around that time, my class teacher discovered my interest and ability in writing and composition. She helped me and encouraged me to enter some interscholastic competitions. My teacher always made a point of praising my strengths in public, and always overlooked my rude manners or words. Whenever my odd behaviour or communication caused embarrassment, she would say ‘never mind’ and made little of it. In class, she would teach proper behaviour without drawing attention to me. During the time she was my teacher, I built my confidence gradually and eventually began to win interscholastic competitions. My teacher was the first person to make me feel as if I was worthwhile. From that time onward my academic performance was solid. I was accepted at university where I read for a bachelor degree in early childhood, and special needs education. Later I worked for 13 years as a special educational needs teacher during which time I studied for my masters degree. My work and my thesis have been inspired by my primary school teacher’s encouragement and my childhood experience. This highlights the importance and value for all children of a good teacher. I do believe that my experience is an example of how important having an empathic teacher with the correct approach can be to children with autism. My teacher treated me with respect as a human being and, as such, had assumed that I possessed an emotional life however different I was to other students.

Finding the potential in individuals with autism, and motivating them to achieve more and do better, is critical to their education. This is a fundamental hypothesis to be considered.

During my time teaching, children would often come to me with a diagnosis of autism (being non-verbal and with a tested IQ in the order of 70 or less). In most cases, the doctors, child psychologists or speech therapists considered these children to be ‘low functioning’.

However, as argued by Gardner (1999), IQ (Intelligence Quotient) is not the only way to measure an individual’s capability. It cannot be used to fully predict an individual’s potential. Various other factors also affect achievement (Gardner, 1999), for example, zeal, hard-work, education, environment and social ability.

From my experience of IQ tests as a child, and later as an SEN teacher having to test many children, I have found that many variables affect test results, such as a new environment, an unfamiliar examiner, an examinee’s physical and mental condition, antecedent events, sounds and lights in the assessing environment and so on. Therefore, IQ scores cannot be reliably used as an indicator of a child’s ability. Strikingly, when teaching preschool children with special needs in Taiwan, I often found that once they became comfortable with their surroundings and settled into my classroom routine, they might often prove capable of tasks that would be expected of children with average or above average IQ. For example, a child might completely dismantle a toy and then reassemble it without difficulty, or operate a computer and surf the internet without assistance. Some of these children could also perform arithmetical calculations or produce detailed drawings of complex objects. These accomplishments clearly demonstrated hidden abilities that had escaped the attention of the professionals. Further examples of these hidden abilities may be seen in my research, for example, where Balaravi surfs the internet to find a Yogi to help his mom (PB1.93) and Han uses an i-phone to aid his communication with his parents (C&J 2.36).

My approach with the children in my class was to develop trusting relationships with strong, consistent rules. Through intensive observation and direct participation in their activities, I would attempt to discover their strengths, desires and the things which inspired them. I would use this information to encourage them to grow. Using the things they most enjoyed doing, I was able to get them to participate. I maintained a consistent routine so that they always knew what to expect. When they continued on to primary school, a significant proportion of the children I worked with went on to study in mainstream classes and performed well. Others, although moving into resource classes were able to form fundamental relationships (attachments). Of course, like anybody, they all have their most favourite and least favourite teachers and subjects. After graduating from my class, they would always say "hello" or wave their hands to me whenever they would see me.

As a result of my childhood difficulties and later my experiences as a teacher, it became my intention to understand the emotions of individuals with autism rather than to moderate their behaviour. I do believe that understanding and addressing an individual’s desires and needs will inspire them to step into the social world, however in this thesis, rather than pursue the children, I intend to listen to the voices of their parents. There are ethical issues in scrutinising young lives and a decision was made early in the development of my research that I should focus on their emotional lives-as perceived by their parents. Indeed, most ‘adults routinely set themselves up as the understanders, interpreters and translators of [their] children’s behaviour’ (Waksler, 1991, p.62). However, I am aware that children have their own voice, and their parents’ understanding might not be the objective truth. Mayall (1994) argues that the knowledge that parents gain from their experiences with their children is not in line with ‘theoretical psychological understandings’, and ‘the differential power relationship between children and adults in the research process lies at the level of interpretation of data, rather than at the point of data collection’ (ibid., p.125). Interpretation of the parent’s testimony is therefore a critical part in achieving my purpose. I choose to use their accounts, because parents are a valuable source of information and knowledge as they spend the most amount of time with their children (Boucher, 2009; Jupp, 1993). In this research it is non-verbal young children with autism who are being discussed, which adds further problems to the already unequal power relations at work when adults claim to speak on behalf of children.

For me, conducting this research was a reflective process and at times it has seemed like I have been rebuilding myself. Burman (2006, p.324) cautions that ‘reflexivity is vulnerable to the charge of offering a new technology of subjectivity that educates the emotions, and normalises some subjective accounts while pathologising or silencing others’. While always aware of this, I have found engaging reflexively throughout my work and research has enabled me to revisit my own experiences as a child with autism, and this has brought to the surface many old memories, causing me to give thanks to those who took the time to work with me and who did their best to help others like me. These individuals have inspired me to work with and study children with autism. In many cases, the turning point in an intervention or individual’s development has been through motivation (Nutbrown, 1999). Smith (1995) wrote that professionals who intend to reach out to the ‘hard to reach’ must seek reliable sources and be careful that the participant’s story is truly representative of their identity and psychological world. Who could be better placed to find that motivation and passion inside a child with autism than those who surround the child?

## 1.3 Organisation of the Thesis

This research explores what parents think about the emotional lives of their young children with autism. Whilst a research study it was perhaps anticipated that the process might also help parents to better understand their children and perhaps even to modify their intervention strategies and further enhance their relationships. I chose to interview parents for my research due to the ethical issues involved in forming trusting, short term relationships with children who have autism. Behavioural anomalies that might arise from the relationship could have affected the data.

In this thesis, I will first give an overview of research into autism since it was identified in the early 1940s by Leo Kanner and Hans Asperger, to the present day. After this, an attempt will be made to illustrate how the study of autism has evolved, which has been dominated by medicalised discourses of research and practice, which for example, labels those diagnosed with autism as being retarded, mentally ill, and perhaps completely devoid of emotion. Whilst widely accepted, and the focus of much research, there is no conclusive biological evidence that could be used to diagnose autism. Perhaps it is a cultural issue (Timimi et al., 2011). It is for such reasons that social science is important. We have to find a different route to examine the socio-cultural aspects of autism.

My argument, which has been supported by my research, is that children with autism do have emotions, but lack the facility to communicate by conventional means. From parent narratives in this study, parents of children with autism believe their children have emotions, sense of humour, imagination, attachment with close people, and detect parents’ emotions. Moreover, I have spent many years working with pre-school children with autism in Taiwan and have drawn on this experience to substantiate my contention with a view from another culture. I have included a section that explains how autism is treated in Taiwan and because one of my research candidates is from India, I have also been able to include a culturally different perspective. I will describe something of dominant consideration of emotions and emotional competence, theory of mind, teaching emotions to children with autism, and autism in Taiwan. Then I will discuss the methodology of this research. Finally, I will summarise my research and the conclusions that I have drawn from it.

My thesis is divided into 6 chapters starting with the introduction, in which I postulate professional opinion regarding the emotional lives of individuals with autism, and then explain my position, the intent of my research and the source of my data. I discuss the factors that motivated my study and include a brief autobiography. I also take a brief look at the history of research into autism.

In Chapter 2, I give an overview of autism in the UK and in Taiwan and how it is treated. I present material that supports the existence of emotions in individuals with autism and offer some accounts written by individuals with autism. In my summary I explain why I have used parent narrative for my research.

Chapter 3 contains my methodology. I review various research methodologies and I discuss my selection of qualitative narrative methodology and the use of interviews.

In chapter 4, I discuss the theoretical and analytical approaches used to examine parents’ accounts. I also explain the use of an interpreter and translation issues that I encountered.

Chapter 5 describes my research data and analysis. Interviews from the UK and Taiwan were analysed and categorised into six themes: individual, family, educational system, medical system, policy, and society.

In Chapter 6, I discuss the parental narratives in this study and compare with existing literature and look for the answer to my questions. Finally I provide conclusions about the influence of the educational and medical systems on the family of an individual with autism, as well as the impact of society and its policies. This is followed by recommendations drawn from my study, and how they might inform different stakeholders, including practitioners, researchers, and policy-makers.

## 1.4 Research questions

The aim of my research is to explore the evidence that non-verbal children with autism do have emotions. I intend to do this by collecting and examining narrative from their parents. This data will be utilised in an attempt to answer the question:

What factors affect the emotional lives of children with autism and their families?

# Chapter 2 Literature Review

## 2.1 Introduction

In this chapter I present the literature in the areas related to autism which include:

* Policies, diagnosis and treatment practices in the UK and Taiwan.
* Stories/biographies of people with autism.

There were over **695,000** cases of autism in the UK in 2011, representing around 1.1% of the population (**2011 UK census figures**). A survey conducted in 2009 in England indicates that the ratio of males to females with autism is 9:1 (Brugha et al., 2009). The cause of autism is unknown, although genetics and the environment are each considered to play a major part in its origin (Boucher, 2009; Li et al., 1993; Lord and Risi, 2005).

When examining relevant material (such as books, journal articles, on-line blogs, videos), that relate particularly to medical accounts of autism and the way it is traditionally viewed, it becomes clear that the emotional life and awareness of the person with autism has been overlooked.

There is a great deal of information concerning the cause, diagnosis and treatment of autism, often referred to as Autism Spectrum Disorder (ASD), collected through research and clinical observations by an increasing number of specialist professionals, including, psychiatrists, paediatricians and psychologists. For example, Williams (1992), Baron-Cohen (1993), Happé (1995), Hobson (2002), Billington (2006), Grandin (2008), and Boucher (2009).

An often overlooked potential source of information is from the young individuals with autism themselves. In particular, there is a dearth of information purely regarding their emotions and feelings. It is only as we move into the 21st Century, that professional services have begun to take seriously the potential of these young individuals to contribute their own knowledge, although this is often not straightforward, given the non-typical manner of presentation by children with autism.

Encouragingly, the BBC (2010, 2011) made a documentary series about some teenagers with high-functioning autism who were all talking about their lives. The audience may have been given a rough picture of these ‘intelligent’ individuals with autism, however who speaks for the children with autism who are non-verbal and who do not possess language to express their emotional worlds?

Many disciplines claim to speak varying ‘truths’ about autism, the most dominant of which I will now discuss in the next section.

## 2.2 Autism in the UK and in Taiwan

**In the UK, over 695,000 persons may have autism, or approximately 1.1 % of the UK population (2011 UK census figures).** Professionals, such as governors and teachers are concerned about this situation. All of them attempt to address the difficulties encountered by children with autism.

In Taiwan, there is a growing population of children diagnosed with autism, which rose from 6,185 in 2006 to 13,366 in 2013, and in 2014 **approximately 0.6% of the population of Taiwan were diagnosed with autism** (Department of statistics, 2014).

### 2.2.1 Policy

In the UK, ‘The Autism Act 2009’ provides guidance for diagnosing, assessing, identifying, staff training, and relevant services for adults with autism (The National Autistic Society, 2013; Waltz, 2013).

Other well-known regulations related to autism are ‘The Equality Act 2010’ and the forthcoming ‘The Children and Families Bill’ (2014). This new Bill will replace the existing ‘Statement of Special Educational Needs’ as well as Section 139a Learning Difficulty Assessment’ with the ‘Education, Health and Care Plan (EHCP)’ which applies to children with SEN from when they are born up until they are 25 years old. It was issued in September 2014.

The Department for Education is the main administration in the UK relating to autism. As for the policies in Taiwan, there are three administrations responsible for special education. These are the Executive Yuan, the Ministry of Education, and the Ministry of the Interior. Among these departments, the Executive Yuan is the ‘House of Administration’ and it has higher status than other departments. In theory, they all cooperate with each other. However in practice, they work independently. This situation leads to a waste of resources, funds, time and energy.

Government acts and regulations dominate the work of the education, social welfare and medical systems in both the UK and Taiwan. Therefore, it is important to have an understanding of the regulations in order to utilise the autism-related resources and protect the rights of individuals with autism. For example in Taiwan, according to ‘The Act of Special Education’ (see appendix 2), preschool children with autism are permitted to study in regular classrooms.

Both the UK and Taiwanese education experts, scholars and governors have advocated inclusive education in recent years, so more and more students with autism can now study in regular classes.

### 2.2.2 ‘Treatment’- Education

Barnard, Prior, and Potter (2000) conducted research on the parents of children with autism under 20 years old who are studying in inclusive educational settings in the UK. They found that almost a half of parents think their children get better service at mainstream schools despite having to fight hard for their children’s rights. 76% of parents of children with autism consider their children to be happy. Around 60% of parents agree that their children are making good progress in their academic and social skills and 68% of parents think Learning Support Assistants are doing a very good job. On the other hand, 31% of parents of children with autism are not satisfied with the resource and staff provided for their children in inclusive primary schools, and comment that teachers need more professional training for their children. Sadly, parents of secondary school aged children with autism have a higher rate of dissatisfaction.

Chen (2007) conducted research in Taiwan and found that most “normal” children show a high acceptance towards their peers with autism by helping and reminding them that they are sensitive humans. It is, however, observed that some autistic characteristics cause difficulties in building these relationships. On the other hand, the teacher’s strategies and thoughts also have an effect on the way other children react to the children with autism.

The Taiwanese Government support is insufficient to meet the goal of total inclusive education. Therefore strictly speaking, it should not be defined as an implementation of full inclusion. For example, I was employed by the Taipei Government to visit schools with special needs children throughout Taipei, to work with difficult cases and give advice to teachers and parents. These schools would not necessarily have special education trained teachers, and extra support workers (such as therapists, teaching assistants, and so on) among their staff. Two teachers are needed to educate around 30 children (including several children with special needs).

In Taiwan, there are many children with medium to serious degrees of autism, having poor self-care ability and difficulty with communication and social interaction. Teachers are under huge amounts of pressure to manage children with serious emotional and behavioural issues.

Although being doubtful and anxious, the majority of parents are in agreement with full inclusion and parents of children with special needs consistently believe that inclusive education should be fully implemented to give learning opportunities for their children (Lai, 2007).

### 2.2.3 Current Diagnosis/Assessment Practices

In terms of diagnoses and assessments, psychiatrists, paediatricians, psychologists, and qualified teachers in both countries adopt various tools to judge whether a child is autistic or not and then decide where the child shall be placed, and what fundamental abilities the children with autism possess. They utilise diverse intervention approaches to improve the abilities of preschool children with autism, such as Physical Therapy (PT) (Bhat et al., 2011; Lobo et al., 2013), Picture Exchange Communication System (PECS) (Cihak et al., 2012; Ganz et al., 2012), and Pivotal Response Training (PRT) (Coolican et al., 2010; Minjarez et al., 2011).

Boucher (2009), a UK scholar, emphasises that diagnosis and assessments in the field of autism are carried out for a variety of different purposes. The use of diagnosis and assessments is helping individuals with autism and their families to facilitate communication with practitioners by providing information required for the provision and financing of services.

Boucher (2009) also believes that some doctors regularly misdiagnose children with autism, thus leading to distress in families as a result of prejudice or shame. Parents are usually the first to observe their children’s different behaviour. Therefore, when child psychiatrists assess young children’s difficulties, they tend to make a judgement using statements from the child’s carer(s) (Yapko, 2003).

There are a number of standardised tests and questionnaires used by professionals to assist in the diagnosis of autism in Taiwan, especially in the medical system. The Social Welfare System supports the diagnosis from the Medical System or the Educational System, and then provides welfare to the affected families. Trained teachers use a Behavioural Rating Scale for Children with autism, WPPSI-R, Vineland Adaptive Behaviour Scales to assess preschool children, and a Developmental Scale for Children with Autism (see appendix 3).

Every test has its limitations and diagnoses are only able to provide clinical data. It should be considered that clinicians from diverse cultures and communities interpret the criteria accordingly and patients explain the symptoms and describe syndromes in various ways (American Psychiatric Association, 2013). Besides, ‘cultural variables’, family relative data, ‘pathogenic and pathoplastic factors’, ‘explanatory models’, and a ‘patient’s strengths and weakness’ all affect the result of a diagnosis (Alarcon, 2009). Professional staff should not overuse these tools and rely on them to draw fixed conclusions. The diagnoses should be used only as an aid in deciding how to best help individuals with special needs.

Molloy and Vasil (2002) think that diagnosis of Asperger’s syndrome is a provisional concept. They consider that the clinical categorisation of Asperger’s syndrome is improbable and that there is inconsistency between the views of clinicians with respect to diagnosing Asperger’s syndrome.

Considering that during formative years there is a great deal of change in the subjects, so that a true diagnosis would have to be dynamic to be meaningful (ibid.). In DSM-V, Asperger’s syndrome is eliminated from the manual. However, ‘individuals with a well-established DSM-IV diagnosis of Asperger’s disorder should be given the diagnosis of autism spectrum disorder’ (American Psychiatric Association, 2013, p.51).

### 2.2.4 Treatment, Intervention Programmes and Approaches

Treatment (meaning the approach used to manage certain behaviour), intervention programmes and approach in the UK and Taiwan are similar. Teachers and parents have many options to choose for an individual with autism. The role of the teachers and parents of students with autism in planning essential elements of teaching approaches will be discussed.

There is no clear boundary between conventional and radical forms of intervention for autism. Many ‘alternative’ remedies in the treatment of autism are developed and advocated by doctors, therapists, parents and parent groups (Boucher, 2009). Radical forms of intervention do not always yield significant evidence of effectiveness, such as play therapies, art therapy, acupuncture, diet and nutritional supplements, medication, and animal assisted therapies (Research Autism, 2013).

Diverse treatments are applied in different sites, such as schools, hospitals, and homes. Structured teaching, picture exchange communication system, and pivotal response training are adopted in schools. In terms of hospitals, clinical staff utilise occupational therapy, play therapies, art therapy, music therapy, acupuncture, speech-language therapy, physical therapy, and medication.

As for home-based intervention, carers espouse diet and nutritional supplements, animal assisted therapies, picture exchange communication system, and pivotal response training (see appendix 4). Among all treatments, Applied Behavioural Analysis (ABA) (or Behavioural Therapy) is widely used and recognized as a safe and effective treatment for autism so far. For example, Lovaas (1987) explored Behavioural Therapy with a view to improving the intellectual functioning of young children with autism, unfortunately the study failed to consider the emotional life of these children.

Medication is used in some cases, but primarily educational methods are used to help children with autism adjust to the ‘social world’. Teachers and parents are major educational method users. Parents in particular, tend to treat their children as normal and try to give them the same opportunities as their peers and siblings (Goodley and Lawthom, 2006).

According to Hsieh (2007), parents will take into consideration their child’s fundamental abilities when selecting resources for intervention. Other factors will be the parent’s active and positive attitude, professional knowledge and the exchange of information relating to the outcome.

Tsai et al. (2008) found that there is not much evidence to support that the mothers of children with intellectual difficulties treat their children in the context of a specific diagnosis. To explore this phenomenon specifically with respect to the mothers of children with autism, the study used a grounded theory approach to develop a hypothesis to explain the parenting and behaviour management processes used by mothers in Taiwan. Tape recorded interviews were used to collect data from twelve mothers who have children with autism, aged between three and seven years. Tsai et al. (2008) found that after analysis of the transcripts, it became apparent that these parents managed the complex needs of their children by ‘integrating nurturer–trainer roles’. There were four components to the process: effective treatment, developing training and nurturing competencies, negotiating roles, and adjusting expectations. The ‘integrating nurturer–trainer’ processes fell into four categories: trying it all, going along, insisting on training, and facilitating the child's strengths. The mothers who facilitated the child’s strengths were better at integrating the nurturer–trainer roles, experienced better role preparedness, less strain, and positive emotional reactions. These data can be used to help health care providers understand the demands on these mothers and thus help them to develop appropriate interventions that facilitate the process of integration of the nurturer–trainer roles.

There are many therapies used in Taiwan, such as occupational therapy, play therapies, art therapy, music therapy, the TEACCH program, acupuncture, speech-language therapy, physical therapy, diet, medication, animal therapy, and so on (see Appendix 5).

## 2.3 Exploring emotional life

Emotions are a crucial part of the human experience and are also our most reliable indicator of how things are going in our lives. Feelings can be a conscious experience, while emotions originate on an unconscious level (Damasio, 1994). These feelings stimulate and organise the meaning of our experiences, and then lead our perceptions, thoughts, and actions (Greenspan et al., 1998; Izard, 1991). Emotions, both positive and negative, guide and motivate an individual’s learning and behaviour from the time that they are born. Since 2010, most autism research focuses on utilising technology to conceive emotion recognition ability (see Harms et al., 2010; Jones et al., 2011; Mazefsky et al., 2013; Samson, et al., 2012; Sucksmith et al., 2013; Tracy et al., 2011) and teaching emotions to individuals with autism (see Golan et al., 2010; Tanaka et al., 2012; Williams et al., 2012). For me, it is a fundamental scientific and/or clinical error to conclude that the inability to express or respond to emotion appropriately indicates that no emotions exist. Technology at this stage cannot comprehend the complexity of emotion. In addition, teaching emotions should be based on the understanding of the fundamental emotionality of individuals with autism.

An individual’s emotional life is affected by various factors – natural (body, temperament) and nurtural (culture, relationships with adults and peers, family environment) (Hyson, 2004). Emotional competence encompasses an individual’s ability to recognise the emotions of others and to act on it, display or show the capacity for empathy with another person, or to understand their emotional state and how they express and control their emotions.

Dowling (2000, p.57) believes that ‘young children’s understandings and use of their feelings will be heavily influenced by the significant people around them, initially their parents’. Additionally, ‘young children need to have experienced a range of emotions before they begin to understand them’ (Dowling, 2000, p.60). Young children find it hard to comprehend and predict mixed emotions (Dowling, 2000). Further, Grusec (2011) believes that, in all cultures, parenting affects the development of a child’s moral values and social usages by providing guidance and interaction in parent-child and group relationships. Goleman (1998) indicates that, children’s emotional intelligence is reduced whilst their intelligence quotients (IQ) increased.

The government may concern itself with academic achievement, but emotional life is critical to success and ‘young children’s emotional development is rapid and closely tied to other areas of development’ (Dowling, 2000, p.63).

Although a young child initially expresses its emotions and feelings by showing rather than verbalising them (e.g. via a smile, laughter), oral language is still important for them to learn to cope with their emotions, and a child’s working memory is affected by their negative emotions (Dowling, 2000, p.55).

In early development studies, Kubicek (1980) had the opportunity to study twins who were videotaped from the age of 4 months, one of whom was diagnosed with Autism. Whilst the twin without autism exhibited “normal” emotions, the twin with autism showed no facial expression, lacked eye contact and showed rigid posturing.

In the same vein, Osterling and Dawson (1994) studied children at 12 months old and found that autism was evident through an absence of gestures and lack of response. On the other hand, Dale (1992, p208) indicates that babies with autism often communicate by evoking intensely felt emotional states in individuals ‘which cannot be processed or understood at an intellectual level’, leaving the recipient with an unexplained feeling of emotion.

#### **2.3.1 Hypersensitivity**

Accounts of autism are beginning to emerge in which the individual with autism is hypersensitive to their surroundings, resulting in a neurological or psychological shut down due to the ambient level of sensory stimuli (sound, light, touch, odour) (American Psychiatric Association, 2000; Billington, 2000, 2006; Kern, 2002). As the noise level alters so does the perceived sensitivity of the subject. Rather like not being able to hear a pin drop in a crowded room, or being able to see a star in the sky at night, but not during the day. This transmigrates to all areas of communication.

Billington (2000, 2006) suggests that by controlling the environment and reducing the noise level, an elevated sense of security might be induced in the child. Then, working with an especially sensitive and considerate adult, the child may be prepared to open the door to communication. This theory is supported by Kaufman (2010) who indicates that children with autism are susceptible to over-stimulation often from sound, light and smell. For example, the child might be situated in a quiet and simple room to instil a feeling of comfort. An attitude of non-judgmental optimism on the part of the person working with them will reduce the likelihood of withdrawal and promote interaction. If you want to create a connection or a bridge between their world and yours it will be necessary to show that you respect them and their sensitivity.

Carlisle’s (2007) view is further developed by Kaufman (2010). Carlisle (2007, p.225) asserts that ‘[individuals with autism] may present [a different] reaction or response to sensations, which is described as a sensorial defence to the tactile, oral, visual and sound modalities’. Also Kern (2002) observed that individuals with autism presented different reactions to sensorial stimuli resulting in their difficulty in processing information correctly. In the same vein, Gadia and Tuchman (2003) argue that children with autism are particularly sensitive to sensory input, such as sound light and touch further noting that their participants were fascinated by some particular visual stimulus and exhibited different stereotyped movements.

Later, a prospective study was carried out by Gomes et al. (2004) aiming to verify if the clinical behaviour of hearing hypersensitivity in individuals with autism corresponded to their audiological consequences. Results showed that behavioural reactions to sounds were not associated to the hypersensitivity of auditory pathways; they were associated with difficulties in higher processing, involving systems, such as the limbic system, that are usually compromised in individuals within autism. The same seems to happen with the other changes in sensitivity and behaviour associated with them, such as fear and distortion of reality. The latter are complex interactions derived from higher level processing and not from specific hypersensitive pathways (Gomes et al., 2004).

Recent studies have examined the basis of sensorial issues and neurophysiologic mechanisms in an individual with autism, presupposing that sensorial functioning is essential in their development and considering that many of the sensorial issues may contribute to these individuals’ poor social interaction. There are, however claims that for these studies, the research is methodologically flawed and uses retrospective evaluative data as well as videos and autobiographical questionnaires (Harrison and Hare, 2004; Iarocci and McDonald, 2006).

### 2.3.2 Theories of Emotions

The following theories are important when considering emotions: Psychoanalysis (Freud, 1991; Erikson, 1950, 1958, 1963, 1964, 1968); Piaget’s cognitive development theory (Piaget, 1958); neo-Piagetian theories; Vygotsky’s social constructivist theory (1978); Albert Bandura’s social learning theory (1977); and social information processing theory (see Crick and Dodge, 1994; Dodge, 1986).

From the sociological view, theories of emotionality involve individual–environmental mutual transmission (Cross and Huang, 2012; Lazarus, 1991; Lazarus and Folkman, 1984; Seyfert, 2012), and external milieus affect an individual’s psychic experiences (Seyfert, 2012). Human interactions may create common and shared gathered feelings which result in emotions being felt by and interpreted by the interacting individuals (Ahmed, 2004; Collins, 2004; Hochschild, 1979; Kemper, 1978; Seyfert, 2012; Thoits, 1989). An emotional experience is an interactional process which is determined by society (social norms and value) and an individual (belief, motivation and personality) (Denzin, 1984; Lazarus, 1991, 2001; Winograd, 2003). The depth of emotion will be determined by the individual’s view of the result, which in turn is dependent on the individual’s personality and beliefs (Cross and Hong, 2012).

As opposed to the prevailing medical deficit model, Bronfenbrenner (1979, p.291) cautions that it is important ‘to recognize the deficit model [of human development] often underlying the choice of problems, variables, methods, and research design’ because professionals, researchers, and practitioners tend to explore the fault of an individual or extending to his/her family rather than admit that something is wrong with the existing systems. Similar to the sociological view, Bronfenbrenner's ecological system (hypothesis) also illustrates how the surrounding environments influence a person's emotional development. An individual’s emotional development is the emergence of their experience, expression, understanding, and regulation of their emotions from birth all the way through adolescence. Their emotional lives do not occur in isolation; emotional development is impacted by neural, cognitive and behavioural development as well as by sociological, cultural and contextual influences (Moissinac, 2003). According to Moissinac, as children enter school, they gain a sense of self and a deeper understanding of their emotional self, and it is important to interact with them as they grow in themselves, so they can gain a better understanding of their emotions and how to handle them. In a microsystem the family plays critical key roles in a child's emotional development (Howe, et al., 1999). A family must be purposeful in guiding a child’s emotional life and must focus on their emotional needs. Stronger familial bonds will result in higher acknowledgement of emotional needs, which can help to make the child feel supported in exploring their emotions. Along with this, it is important for family members to model healthy emotional relationships. Children mimic those in their immediate surroundings, this includes the way emotions are handled and the way family members relate to one another. When parents can manage their emotions in a healthy way, it can demonstrate to their children how to manage their emotions in a healthy way. An important part of modeling healthy emotions is also teaching children how to handle negative emotions so they can handle negative experiences in a healthy way (Howe et al., 1999). As for the role of education in emotional development, Raver established a strong link between social and emotional development and behavior and school success, describing the relationship between emotional development, social development, and academic performance as complex (Raver, 2002). Emotional understanding can positively affect social behaviour, which in turn can affect school performance. Individuals who cannot regulate their emotions and/or feel as if their emotions are not understood or supported can begin to display disruptive behaviour in school, spending less time focusing on tasks and receiving less individual instruction and less feedback (Raver, 2002). In a mesosystem, different settings can have an effect on one another. If an individual is not getting the emotional support they need from their family at home, it can negatively affect their performance at school, which in turn can negatively affect how their teachers and peers interact with them. Unless broken, this becomes a vicious cycle in which individual family members can feel unsupported. In an exosystem, a family member may not directly influence an individual, but they can indirectly influence them. For example, grandparents may not interact with their grandchild, but they may influence the parents’ child-rearing approach which affects how the child is treated or the parent's expectations for the child. If a parent has a job that keeps them away for long periods of time, that child may not be able to get the emotional support they need from home. On the other hand, if a parent has a job that allows them to be home with their child, that child has a higher chance of getting their needed emotional support.

As Mullin (2006) pointed out, we must not assume that a child with difficulties cannot form a social relationship. Caregivers should always attempt to develop relationships with their charges. A failure to do this may not be due to prejudice, or disinterest on the part of the carer, but may be due to lack of support in other areas.

### 2.3.3 Other theories of emotions

There are an increasing number of theories and a mounting body of evidence relating to the early emotional development of children with autism (for example, Ozonoff et al., 2010). It is an underlying hypothesis of this study that while young individuals with autism may be socially isolated and struggle with communication, their emotions exist all the time, hidden and suppressed under a veil of autistic difficulties.

Chen and Liu (2010) conducted research into emotions using 8-12 year-old children with high-function autism (HFA) and compared them to a control group of similar aged children without autism in Taipei, Taiwan. The purpose of the research was to examine the response of the children to spoken stories. They found that the participants with autism took longer to react and were less accurate in discriminating the types of emotion expressed and had a poor ability to express emotional intonations.

According to Damasio (2000), emotions are instinctive reactions that give rise to ‘nonconscious’ physiological changes in an organism and that there are:

[T]hree stages of processing along a continuum: a state of emotion, which can be triggered and executed nonconsciously; a state of feeling, which can be represented nonconsciously; and a state of feeling made conscious, i.e., known to the organism having both emotion and feeling. (ibid., p.37).

Denham (1998) divides emotional competence into three components—expression, understanding, and regulation.

Expression may be in the form of gestures such as hugs for empathy, which could be shown by kissing a child’s scraped hand better, the demonstration of complex emotions such as guilt, shame or pride and understanding complex inverted displays of emotion, for example someone who feels fear, but hides it from their expression.

Understanding could be knowing your own emotional state – such as sadness, anger, or fear, or knowing the emotional state of others and using the vocabulary of emotion, for instance words that describe emotion.

Regulation, for example, could be tempering laughter or angry exclamations and controlling emotional expression.

According to Goleman (1996), emotions are not normally verbalised, but shown in other ways. ‘The key to intuiting another’s feelings is in the ability to read nonverbal channels: tone of voice, gesture, facial expression, and the like’ (ibid., p.96). He continues that we ‘unconsciously’ attempt to mimic the emotional display of others as ‘through this imitation people re-create in themselves the mood of the other person’ (ibid., p.115).

Damasio writes that human emotions and feelings are evoked from outer stimuli causing reactions in the internal milieu and viscera (Damasio, 1994; 2000; 2003; 2010). This view is supported by Goleman (1996), Blaylock (2010), and Grossberg (2014). Goleman (1996) illustrates that human emotions and human organs interact with each other. Blaylock (2010) and Grossberg (2014) shows that autism is considered to be a form of developmental differences in the cerebellum based on the clinical research findings that the cerebellum supports cognitive functions, including language and executive functions, as well as affective regulation.

The cerebellum connects our senses to our emotion centres. Cerebellar lesions are associated with irritability, impulsivity, expressive language difficulties, and emotional lability. Cerebellar children are hypersensitive to taste, smell, texture, and so forth. They have decreased sensitivity to visceral cues (such as hunger, thirst, pain, and fatigue).

Damasio also adds that individual development and cultures have influence on human emotion (Damasio, 2000, p.57). Damasio (1994, p.130) thinks that emotions ‘play a role in communicating meanings to others, and they may also play the cognitive guidance role’. Damasio (2010, p.114) further supports his view; he writes that ‘the processing of images in the cerebral cortex is itself affected by the on-going emotion. Cognitive resources such as attention and working memory are adjusted accordingly’.

Zahn-Waxler et al. (2009) found that emotions, particularly relating to stress, triggered pro-social behaviour and measurable physiological changes such as changes in heart rate and skin conductance. They also found that girls have better pro-social skills than boys, and boys get angry more easily than girls.

Dodd (2004) asserts that an individual’s emotional response will be dependent on his experience and that feelings are subjective. For example, a child with autism may feel happy to be alone in a playground and sad when surrounded by too many people and too much noise. According to Dodd, many children with autism ‘have no basic understanding of empathy. Empathy is not an emotion that can be taught to people but individuals can learn to recognize different emotions in people by looking for certain physical signs’ (2004, p.185). Perhaps they understand and express empathy differently to others.

The severe communication and social interaction difficulties associated with autism result in individuals feeling confused, frustrated and anxious. People with autism have [communication issues] that include both receptive and expressive language as well as [difficulties] relating socially. (Dodd, 2004, p.195).

Some studies suggest children with autism lack emotion. For example, Grayson (2006) notes that, ‘joint attention behaviour, such as pointing, showing gestures and gaze monitoring are seen to develop between the ages of 9 and 14 months in typically developing children’ (Grayson, 2006, p.170). However, children with autism have difficulty interpreting other’s emotions by ‘mind reading’. They have mental rigidity and difficulty switching attention from one subject to another. Grayson considered this to be executive difficulties and a feature of the cognitive style of an individual with autism (Grayson, 2006).

## 2.4 Teaching emotions to children with autism

There have been several attempts to teach emotions and emotional concepts to children with autism. Some noted examples are; Shore et al. (2006) who showed that children with Asperger’s syndrome can be taught how to recognise self-emotional states by utilising emotion thermometers. Emotion thermometers are divided into three regions representing happy, neutral and sad. These are placed on a 100-point scale with happy being 100, neutral 50, and sad 0. It is possible that researchers may have been looking for the presence of emotion through physical expression and perhaps denying that the inner child has feelings which are frustrated by an inability to show them.

Hadwin et al. (1996) conducted a study of a number of children with autism aged between 4 and 13 who were taught pretend play production, understanding emotion, and understanding belief. The children were divided into three groups with each group only being taught one of the subjects in daily half hour sessions over 8 days. The results showed that some children passed emotion tasks and some belief tasks. However, there was no evidence to show that a child from any one group improved in the other areas of understanding, that is to say any improvement was not generalised. Unfortunately, the study did not use a control group to see how children with autism might differ from children without it, or those with Down’s syndrome. Also the study was not performed in a natural environment - which might have given a different outcome.

Swettenham (1996) built on this study, teaching False Belief through the use of computers to preschool children with autism (False Belief as described previously in more detail under Theory of Mind). In this study there was a control and a clinical group. Interestingly, in the false belief tasks, the children with autism attained a similar score to the typically developing 3-year-old children, but the score of the clinical group (Down’s syndrome) was lower than the control group. In the distance transfer tasks, the children with autism were unable to pass, showing a difficulty to generalise what they had learnt from other false belief tasks. Swettenham (1996)’s conclusion is that children with autism may have what they refer to as a central coherence issue, or a difficulty to extract meaning in context. He suggests children with autism should be taught to apply knowledge in a wide variety of situations.

Stafford (2000) conducted a study of a single case of a non-verbal, low functioning child with autism. The study considered whether emotion can be taught successfully. Stafford chose to teach sad, happy, angry and surprised emotions to the child. This was done over six months using visual clues, on a one to one basis, in its own home. Photographs were used of individuals that the child knew that displayed the different emotions. The results were tested with novel photographs of familiar and unfamiliar individuals and demonstrated that the child had learnt the four emotions and the concept had been successfully generalised to the novel photographs.

It might be reasonable to conclude from this that the apparent lack of emotion could be due to early poor communication. Children without autism learn to express and regulate their emotions at an early stage through communication with those who surround them, for example, their parents and teachers. On the other hand, children with autism may lack the communication mechanism to learn how to express and regulate their emotions.

However, there is a critical literature that documents some problems of teaching emotions to children. According to MacLure et al. (2008), educators in our take-for-granted education system are the ones who decide what deviant behaviour is and who set the rules. To control children’s deviant behaviour, they establish norms, which can operate to medicalise and pathologise ‘different’ children. An educator’s attitude affects children’s attitude towards those who are different and then affects the child’s emotions. While educators teach emotions to children, they evaluate and modify a child’s feelings and emotions by correcting given answers and encouraging ‘good’ behaviour. Under these circumstances, MacLure et al. doubt whether children display their real emotions or the taught ones. This raises some questions. For example, what kind of programme is good for students? To what extent should an educator be involved? Burman (2006, 2009) believes that how to interpret emotionality is an essential issue. In addition, emotional experiences are subjective and culturally influenced. Teaching children emotions focuses on taming children rather than exploring their inner emotions and feelings. It could be considered to be an alternative means to suppress children through professional (adult) privilege.

The assumption here is that the children with autism are emotionless and perhaps the conclusion is that we should teach them emotion. However, it is clear to see from biographies, such as Donna Williams (1992), Temple Grandin (2008), and Naoki Higashida (2013) that individuals with autism have various emotions which are shown differently from typical-development individuals. Williams (2013) questions the means of teaching children with autism to identify emotions via pictures. He questions whether individuals can be sure that the picture they pick is demonstrating their understanding of the emotion or simply meeting teachers’ and parents’ expectations? Also, do they generalise their life experiences with pictures?

## 2.5 Individuals with Autism do have Emotions and Feelings

Most of the existing literature tends to highlight that people with autism have limited or no emotions, but in this section I will present arguments from individuals with autism which are centred on demonstrating that people with autism do have emotions.

Jean-Dominique Bauby, who was diagnosed with ‘Locked-in Syndrome’, was paralysed by a cardiovascular accident. He was unable to breathe, swallow or eat without assistance. He connected with others via blinking his left eyelid at the most frequently used letters of the alphabet. Bauby (1999, p.24) mentions that ‘a domestic event as commonplace as washing can trigger the most varied emotions’ and ‘I am alive, I can think, and no one has the right to deny me these two realities.’

The above reference illustrates how we often lose sight of the inner being. Bauby (1999) could be denied the right, by the observer, to have emotions. Children with autism are often viewed in the same way because the way they communicate is different from that of other individuals. What you see is not all you get.

A medical diagnosis of autism implies some form of mental retardation. The DSM-V, defines Autism as possibly having ‘deficits in social-emotional reciprocity’ (American Psychiatric Association, 2013, p.50). However, such explanations tend to overlook the fact that poor communication leaves an impression of low or no emotion.

The DSM-IV has been revised, but are the changes acceptable? Allan (2011) writes in their ‘Response to the American Psychiatric Association: DSM-5 Development’ criticism of the proposed changes in diagnoses, saying that they are ‘clearly based largely on social norms, with “symptoms” that all rely on subjective judgements... not value-free, but rather reflect current normative social expectations’, highlighting concerns over the existing criteria.

Allan (2011) also commented on the American Psychiatric Association website saying that the DSM continues to ‘medicalise’ client responses that fall within ‘normal individual variation’ giving rise to a negative effect on the client. Their ‘primary specific recommendation’ is to change from ‘diagnostic frameworks’ to a descriptive diagnosis that is based on the individual and their specific difficulties with consideration to ‘psychosocial factors such as poverty, unemployment and trauma [being] the most strongly-evidenced causal factors’ (Allan, 2011, p.3). They go on to say that the use of a diagnostic label has limited value. While it may bring relief to the client by way of recognition of the difficulty, the label is too broad to be of use, whereas descriptive diagnoses would help define the ‘treatment response’ (ibid., p.3).

Over the past 15 years, parents, teachers and individuals with autism themselves, claim the emotions of people with autism are just the same as those of everyone else. My personal experience and the testimonies of other individuals with autism support this view. I believe that by exploring the stories of those closest to children with autism - their parents - I can shed more light on the understanding of, and belief in, their capacity for emotion.

Some professionals may misapply IQ tests which could lead them to consider that individuals with autism tend to have a low IQ and lack emotion and sensitivity due to their non-verbal abilities and different reactions. Williams (1996) challenges the medical concepts and treatment of autism, in particular ABA, ‘hug therapy’ (ibid, p.55) and eye contact training. This type of treatment may be extremely distressing, and could amount to a form of torture, for individuals with autism who may be hypersensitive, or cannot stand direct eye contact (ibid.). Furthermore, she talks about the features of autism being issues relating to tolerance, control, and connection to others. She believes that it is important to give individuals with autism the opportunity and time to stay in the mainstream. Even though they may not express emotions, some individuals with autism do have ‘empathy, emotions, a sense of pain, a sense of humour, imagination (and interest and curiosity)’ (Williams, 1996, p.12).

Their seemingly bizarre behaviour, which is only ‘bizarre’ if not viewed from the child’s viewpoint, is a means to help them maintain control and remain calm. Williams advises speech therapists to reduce information and emotion related overload in the environment. This will allow the child to improve the process, and access and monitor their own speech related mechanics. Further, Williams relates that speech therapists may be dedicated individuals and that some of them combine their dedication with daring and imagination taking an approach that ‘few autism professionals are yet trained to do’, perhaps because not many are able to ‘see beyond non-autistic theories and the artificial categorisation these theories created’ (ibid., p.238).

In the same vein, Mannoni (1999), who uses painting therapy, illustrates the situation of a child with autism who, when asked about his mother, expresses extreme separation anxiety and a fear of personal annihilation, through paintings. The child constructs an autistic world to protect himself from destruction. After therapy however, the child apparently loses the ‘autistic armour’ but is vulnerable and has suicidal thoughts (Mannoni, 1999, p.136).

Mannoni is suggesting that following therapy, the child is somehow improving or becoming less autistic. This seems unlikely. The therapy has simply changed the child’s outward expression. The child still has separation anxiety and fear of annihilation. Mannoni appears to believe that autism is a disease that can be cured. From experience, I believe that this is not true, it has been shown that autism is a state of mind that probably results from hypersensitivity and communication issues. When these issues are controlled, we can experience the person within although they will always have autism.

Happé (1994) has argued that, to be useful, psychological theory must address the positive as well as the negative aspects of autism. Many researchers subscribe to the belief that individuals with autism experience emotion, but they may just express their feelings in a different way, for example, Harris (1989) who posits that;

One of the key symptoms of autism is an inability to enter into affective contact with other individuals. Children with autism feel and express emotion, but they have difficulty in making sense of other individuals’ emotions. One possible explanation for that difficulty is that they lack some basic perceptual mechanism that allows the normal child an immediate apprehension of other individuals’ emotional states from their mode of expression—from the gestures, tone of voice and facial expression that they display…. (Harris, 1989, p.213).

The available evidence suggests that children with autism fail to achieve this insight into the capacities of other people. Even though children with autism can engage in simple object-based pretend play when prompted to do so, they have particular difficulties with this more complex make-believe or pretend mode. As a result, their appreciation of other individuals’ desires, beliefs and emotions is restricted. (ibid., p.214).

According to Saarni (1999), psychopathology commonly referred to as ‘madness’ has been related to an excess of passion, or emotion, and a lack of logic, or reason, but the control of emotion alone is not the whole answer. There is a negative cycle of emotions that results from the way a child is treated by their family and people they come into contact with - at school for example. For any interventions to be effective they would have to address the whole environment of the child.

Saarni (1999) thinks that the emotional incompetence of an individual with autism is shaped by the dynamic interaction between the individual himself and people around him. The variables that affect an individual’s emotionality are age, culture, behaviour, cognitive, social and language abilities, and how people respond to them. Saarni further illustrates that emotional experiences and abilities of individuals with autism are affected by their language abilities because they lack the understanding of each other’s words.

Weeks and Hobson (1987) conducted research on children with autism, children who were considered to be mentally retarded and neuro-typical children, asking them to sort photos of human facial expressions. Unlike the other groups, the children with autism evidently tended to sort the photos by some feature (for example, a hat) rather than by facial expression. This kind of characteristic might explain why children with autism show little empathy toward others. Interestingly, Camras et al. (1983), Feldman, White, and Lobato (1982), and Walker (1981) investigated children with emotional difficulties (such as from abuse) and found that these children also exhibited some issues in their understanding of facial expressions and emotion, showing their facial expressions, and discriminating between emotional expressions.

Facial expressions are very important. A child can use their facial expressions to communicate, socialise, and convey their feelings, emotions and thoughts to others (Lewis and Michalson, 1983; Lewis and Sullivan, 1996). Yirmiya, Kasari, Sigman, and Mundy (1989) indicate that children with autism express more negative emotions rather than positive emotions. Yirmiya et al. (1989) further point out that children with autism show more flat and ambiguous facial expressions than typical-development children. This situation may be related to the difficulties of recognising and empathising with emotions in others. Another factor may be that children with autism utilise a stronger means of expression when trying to catch the attention of others, because they are keen to have their needs met (mostly when in a negative mood). In contrast, when they are enjoying the moment they do not need to get attention (mostly when in positive moods).

Another researcher, Dale (1992, p.192) explains that ‘sometimes one has to go “inside” and to examine one’s own emotional response before one can understand what is being communicated’.

Perhaps Bogdashina (2006), who studied at Sheffield Hallam University, sums it up;

People with autism may not show emotions in a traditional way, but this does not mean that they have no emotions. In fact, they show their emotions with a greater intensity. People with autism do have problems recognizing emotions…, but they do not lack them. (p.87).

It would be a mistake to assume that they do not experience emotions because they do not recognise or show emotion in the way others do (Rankin, 2000). I maintain that children with autism do have emotions and feelings and deserve our respect and consideration in this regard.

### 2.5.1 Testimonial or Insider Accounts

It is my view that children with autism are the same as all humans; they are emotional beings. Higashida (2013) and Williams (1996)’s emotions and feelings are evidenced in their biographies. Although they may, however, be frustrated by an inability to express their feelings. Barnbaum (2008, p.77) thinks that ‘no one doubts that persons with autism are conscious of other persons’. It is clear to see the whole picture by looking at accounts from individuals with autism and those who spend time with them. Then we are able to see their emotions. In this section I present a few stories, including mine, which I consider to be relevant.

As a child, my senses overwhelmed me. When put into new or strange surroundings it was very difficult to adjust to the sensory stimuli. Even today, I am stressed by strange or new situations. This may be because I have to spend a great deal of energy tuning down the extraneous sensory information, so that I can deal with the relevant.

At high school, my IQ was tested twice and found to be around 95 with a cognitive level of 75 (1 being the highest and 100 the lowest). These results were possibly due to the trauma of the testing environment together with limited time being allocated to the testing. This illustrates the unreliability of IQ tests because, at the time of writing this paper, I have a master’s degree in Early Childhood Education and I am now working towards a doctorate degree. It seems unlikely that my IQ is below average! I am not unique in this, as there are many who have had similar experiences and yet have made significant and valuable contributions to society. In fact, we cannot judge a child’s future or ability simply through diagnosis or IQ tests. Consider the Pygmalion Effect, if a child is given a low IQ score from doctors, teachers, or parents, this will lead them to believe that they are not very smart and are incapable of achieving anything. That is to say, they will live down to the IQ result and possibly deteriorate further. On the other hand, if a child receives positive reinforcement relating to their intelligence, they will view themselves as being capable of doing anything. The result is more likely to be an improvement in performance and behaviour. I am concerned that IQ scores are not particularly related to an individual’s capability or ability to succeed. I think that other abilities play more essential roles in our lives. For example, emotionality is more relevant than IQ. Children with high emotional abilities who are hard-working can be successful even if they have a low measured IQ. In my opinion, IQ tests cannot accurately predict a child’s real capability or ability to have a successful life.

Howard Gardner (1983) posits an idea that every individual has multiple intelligences and advises that educators and parents should respect and develop each child’s intelligences in diverse domains rather than focusing on a single cognitive ability (IQ).

Goleman (1996) supports this view pointing out that important decisions involve our feelings as well as logic. Intelligence cannot predict future success, ‘people with high IQs can be stunningly poor pilots of their private lives’ (Goleman, 1996, p.34). He believes that our destinies are more determined by emotional characteristics such as motivation, persistence, self-control and positive or negative mood control, none of which are particularly related to IQ (ibid).

In spite of this, societal pressure is toward academic achievement without consideration of ‘emotional intelligence’ (Goleman, 1996). Judging children with autism by IQ might imply that these children have reduced capacity in all areas of functioning. Wolman (2008) questions the validity of Intelligence Quotient (IQ) tests, comparing the Wechsler and Raven tests. The Wechsler test uses questions which are posed verbally and although not time limited there is a requirement for communication with the examiner and arguably the results can be highly influenced by anxiety, fatigue, and motivation. Emotional Intelligence (EI) is becoming more and more popular, however it is worth noting that EI measurement could potentially be used in ways to further exclude children with autism when lack of emotionality is commonly regarded as a weakness of individuals with autism. Burman (2009) indicates that the notions of IQ and EI both require the setting of a standard for a personality/ temperament/idiosyncrasy that is known to vary widely across the population, which then becomes a tool for manipulation in our economies. It becomes obvious that ‘emotional, disciplinary and learning issues are [inevitably] intertwined’ (Maclure et al., 2008, p.11). Ecclestone and Hayes (2009) also point out that an individual’s emotional experience is unavoidably influenced by his/her cultural and educational values (such as ‘schooling, curriculum content, teaching activities, and assessment’) (ibid., p.383). Bendelow (2010) argues that mental disorders in contemporary diagnosis manuals utilise ideas of emotional health without acknowledging that these are affected by societal, cultural, biological and psychological factors. Ecclestone (2004) cautions that individuals labelled with emotional unintelligence might be disempowered. The problem with thinking of individuals as being emotionally unintelligent might result in low educational expectations and negative impressions/images. In conclusion, emotions might be interpreted diversely in various cultures. Therefore the concept of emotional unintelligence in autism is doubtful and needs to be implemented cautiously because the criteria have arisen from western societal and educational norms.

Siegel (1989), in her research, also questions the relevance of IQ testing when trying to define a learning disability. The research makes the following points: reading ability is not related to IQ because some children with low IQ scores are good readers; the ability to achieve and intelligence are not related; and, IQ tests claim to measure short memory, knowledge and language ability yielding low scores for children who are weak in these areas.

Researchers and practitioners often prefer to use the Wechsler IQ test as it is easy to implement. However, the high proportion of verbal questions may give a deceivingly low score for some children. The Raven’s test uses a series of progressive matrices that do not require language or communication skills. Dawson et al. (2007) conducted a study of almost 100 individuals approximately half of whom were diagnosed with autism. All of the participants were given both Wechsler and Raven’s IQ tests. Although the non-autism participants obtained similar results in both tests, for the most part the Wechsler test showed the individuals with autism as having pervasive mental retardation. In the Raven’s test these individuals scored more than 30 % higher than they had scored in the Wechsler tests.

Fundamentally, the accuracy of commonly used IQ tests is questionable, because these tests are limited to linguistic and logical capacities and the results can easily be affected by the testee’s culture or whether they belong to an ethnic minority, the test environment, if they are economically poor, and variations between the tester and testee (Suzuki and Aronson, 2005).

When assessing children with autism across multiple intelligences (Gardner, 1999), it is easy to explain the outstanding strength of idiot savants and appreciate a child’s other abilities, such as, bodily-kinesthetic intelligence, musical intelligence and spatial intelligence. We thus need to be cautious about labelling a child based on our belief that we know how to assess intelligence and considering that ‘the determination of an intelligence represents a lasting judgment’ (Gardner, 1999, p.139).

Except for welfare resource issues, I doubt that there is much use for labelling in autism. Some support for this is given when Flynn (1991), Goleman (1996) and Hyson (2004) argue that achievement has an emotional component (such as emotional self-regulation, self-awareness, enthusiasm, motivation, empathy, persistence, and social skills) rather than depending on IQ, and that children’s emotional abilities affect their academic and school performance.

For educational purposes, educators need to pay attention to their students’ emotions and feelings. Their observations reinforce my reasons for choosing to study the emotions of children with autism.

All children experience emotions when faced with different situations. Two common examples would be:

1. Having to go to school or class; or

2. Being asked to perform a task, like read a passage, or do some mathematical calculations.

Teachers control these negative emotions by establishing rules which normalise the students’ behaviour, and then apply comfort or distraction.

Chen (2010) in her study supports this and suggests that teachers should consider that children with autism, although they experience emotions, do not respond in the same way as other children and therefore, different strategies need to be applied.

Dafydd, a 15-year-old Asperger guitarist, describes his thoughts in ‘Autistic superstars’ (2010) as follows;

Autism is doing the same things as other people, differently. It is just the way you do it. ...It is the processes involved. It is kind of like the difference between Mac and Windows PC. They both do different jobs but a Mac is probably terrible at one job, but can excel greatly at other jobs, so it is a bit like my autism makes it easier for me to understand music. But, there, I compensated somewhere else.

In ‘Insights from an Autistic: Emotions’(2010), the speaker with autism mentions that he does have emotions, such as happiness and anger as well as sadness, although his emotional expressions are different from other individuals. He went on to say that he is not a robot lacking emotions.

Sacks (1985) illustrates a 21 year-old patient, José who is non-verbal with autism and who has ‘intractable seizures’ and distinguished and detailed visual memory. Sacks detects José’s emotions, imagination and sense of humour through his drawings. Alvarez (1992) describes a client’s sensory issues, behaviour, feelings, withdrawn states, development, and emotional changes over a ten-year treatment period (from 7 years old to 17 years old).

He was, in his outside life, frequently overwhelmed by terror, of dogs barking, the thud of a taxi’s engine, the sound of its windshield wipers, work on building sites. He often felt that bright lights hurt his eyes, and once, when a lorry thundered past he covered his whole head, not just his ears, saying ‘it hurts my brain’. He used instead of eyes and ears, his nose as his main avenue of sensory investigation. He smelled literally everything...He seemed to have practically no capacity for methods of projection and projective identification of bad feelings or objects or parts of the self. (p.41).

He did, however, manage to feel he occasionally attained to this desirable inside place himself. One of his ways of doing this was to lie on the couch, with his cheek on the pillow and his eyes gazing into mine, as though he felt he was right inside me. When this state was not achieved, however, a veritable avalanche of feeling was pouring from him, which by now the parents were unable to contain. His fears, his distress and anguish over any separation, from them or me, his sexual mischievousness with women friends of theirs, were overflowing even his parents’ tolerant boundaries, and could certainly not be contained in once-a-month treatment. (pp.46-47).

Alvarez (1992) further describes this client as being autistic and having imagination and the ability to express his emotions, which were fear, frenzy, being thrilled, upset, sad, and excited. The client was also using verbal repetition. She emphasizes that the therapist must use care to ‘process the boredom and the feelings of distaste about the shallow thrills that the patient is indulging in’ (Alvarez, 1992, p.214).

The following testimony from the father of a boy with autism highlights how those close to a child can find the area of motivational passion needed to drive the child forward:

My son's ability to focus on a task is stunning. He decided he wanted to learn to write and also make picture stories so he spent a minimum of 3 hours a day, 7 days/week, practicing. This was his own choice. I only provided paper, mainly to stop him from writing in books, and if anything I discouraged/disrupted his work to keep a mix of activities and keep him on somewhat of a regular stim diet (roughly speaking keep him moving). He initially got some very basic instruction on the order of strokes for constructing the letters but the rest was effectively self-motivated, self-directed, and self-taught. The result in one year was printing on par with mine. Well that isn't a BIG feat I guess, but he easily prints single line height, or smaller, and very legibly. He also switches between a number of 'typefaces' depending on context and purpose. For example in his drawings spoken and narrative text is all uppercase (speech is in bubbles) and the action/sound words have thickness and sometimes are drawn with changing height from one end to the other, like the comic books he reads. He also uses 3D perspective in most of his drawings. Not a focus of purpose and success in achieving the goal that you'd expect from a 4 year-old. (Durden, 2007).

In line with this story, the requirement for a motivating factor is recognized by Nutbrown (1999, p.3) who highlights the importance of a child’s motivation, ‘young children cannot be taught effectively if planned learning is always artificially divided into man-made compartments called subjects’.

Nutbrown (1999) also poses that:

Children who are apparently repeating actions which seem aimless should be observed carefully by staff who can note precisely what children are doing. Staff can try to decide from their observations how valuable children’s activities are. New experiences and interventions need to be based on detailed observations underpinned by the educator’s knowledge of each child as an individual learner. (ibid., p.11).

Temple Grandin who has autism, works with animals. She says that her method is to examine the animal’s behaviour and work with it. In the same way we should find the child’s talent and motivation and work with this (Grandin and Scariano, 1986). Grandin and Scariano (1986) describe in detail Temple Grandin’s emotions, feelings, hypersensitivities and her passion for animals in this book. They also mention that Temple is a visual learner and thinker.

Grandin and Scariano (1986, p.13) wonder ‘how is it possible that a young child whose parents were told she might have to live her life in an institution can confound the “experts”? How does a child, labelled autistic, emerge into the real world?’ Although Grandin still has difficulties in building relationships with other people, she is ‘surviving and coping with the world’ (ibid., p.13).

Grandin’s mother points out that some of the characteristics of autism can turn up in all children. It’s just that the child with autism will be more compulsive (Grandin and Scariano, 1986). She goes on to say that the most effective therapy is love. It seems that Temple compensates for an inability to share love as a child by showing love to those around her and because of this her teachers enjoy teaching her (Grandin and Scariano, 1986).

I ached to be enfolded in her arms, but how could she know? I stood rigid as a pole trapped by the approach/avoidance syndrome of autism. I drew back from the kiss, not able to endure tactile stimulation—not even loving, tactile stimulation. (Grandin and Scariano, 1986, p.69).

Grandin makes the following suggestions for working with children with autism. She points out that each child is unique and we should ‘look for what interests your child and captures his fancy’ (ibid., p.145). She believes that the ‘squeeze machine could help some children with autism overcome their tactile defensiveness so that they would allow people to touch them and receive their affection’ (ibid., p.146).

Temple warns us to observe with caution, constantly rechecking the situation, as children are dynamic. We should ‘encourage the child with autism to use his kinaesthetic senses as in motor learning and educating the musculature of the body’ (ibid., p.147). Like all individuals, children with autism need their secret places where they can escape from the world. She also tells us to ‘be cautious in introducing pets to the child with autism. Because of perceptual disorganization, mistreatment of a pet is not unusual’ (ibid., p.147).

Another method could be behaviour modification, but because of the problems with generalising, each task should be taken on its own. ‘Be aware. When generalization takes place, your child is moving closer to reality’ (ibid., p.147). She says to watch their diet and limit the use of drugs (ibid., p.148), while maintaining a stable and secure environment (ibid., p.149). When speaking to the child use simple language in short sentences and look directly at them.

Try to make eye contact. ‘This is so difficult for [children with autism]. Their eyes seem to see everything except the one who is speaking to them’ (ibid., p.150). Body language is very important with emphasis on key words. Finally she advises to keep abreast of research and keep in touch with other families who have children with autism.

If we can find the individual’s ‘trigger’, their prime motivator, we can use their passion to drive their developmental progress. Emotion can affect the results of learning (Damasio, 2000, p294-295). Williams (1996) said:

Education doesn’t begin at school, nor at home, nor in the community. It starts with the person. It starts with the motivation of the learner to ‘HAVE’. The motivation to ‘have’, ideally, should be driven by ‘need’ or ‘want’ or even ‘like’. ‘Like’ can be sensory-based and can drive ‘want’. (p.283).

Billington (2006) believes that children with autism have emotions and feelings, and questions the ability of the current education and clinical systems in the UK to understand the best way to treat autism.

Rankin (2000) in her daily reflections of working with her son with autism admitted that ‘it is hard to tell [his emotions] really, he appears so indifferent to us most of the time’ (p.28). He longs to make friends, has the emotions of sadness and happiness, and a sense of humour. She further mentions that even though her son is not showing any ‘usual signs of affection’ it does not ‘mean it isn’t there or cannot grow’, and parents ‘need to recognize that the aloofness is part of them and their way of being human’ (p.38).

These stories clearly show that individuals with autism have an excess of emotion rather than a lack of it. Understanding how to control their sensory overload could be a key to bringing these emotions to the point of expression.

Williams (1992, pp.176-177) describes her behaviour, her physical and emotional suffering as ‘not mad, not stupid, not fairies, not aliens, just people trapped by invisible crippled emotional responses. At the same time, it would be misleading to think that such people do not feel…As much as one might want to, one cannot save another’s spirit. One can only inspire it to fight to save itself. If love can’t inspire it, external fear greater than one’s inner fear might, but I suggest one tries love first’ (ibid., p.188).

There are also a number of documentaries that enable us to glimpse into the emotional life of individuals with autism. Grunberg (2009) filmed a documentary, called ‘Portraits of Emotion: The Story of an Autistic Savant’, that looks at four years of the life of 14-year-old Jonathan Lerman, an artistic prodigy who is diagnosed with autism. Jonathon is able to make remarkable portraits which show human emotion, although he is unable to express emotion himself. Collectors have paid as much as $2000 for his work of which he has sold over one hundred pieces. Jonathon seems like most teens with a passion for rock music and baseball, but he is, in fact, completely different and isolated in his autistic world. The story gives an intimate peek at Jonathon’s life. When he is exposed to the world, there is little understanding of autistic faux pas which creates much stress for his parents, for example, due to the staring and comments from the individuals who encounter him or her. This type of stress often leads the families of children with autism to withdraw from the community.

In ‘The Autistic Me - One Year On’ (2009), a BBC documentary, the audience can see and hear the feelings, desires, emotions as well as the struggles of three youths with autism over a one year period. Their mental status and difficulties are just like those of other typically developing youths. They, range from 16 to 25 years-old, feel themselves useless, helpless, depressed, and frustrated as they struggle with the transition into adulthood while emerging into society, finding work, looking for love and striving for independence.

‘Autism Every Day’, a film by Thierry and Watkins (2006), looks at parents of children with autism. The emotions of the parents become apparent with comments that include ‘I was drafted, I did not enlist’, ‘autism is a whole life job’, ‘I wish my child could speak, he has never spoken one word’. In this film, the parents comment that they are often criticised and judged by other parents as not having control of their child. Parents of other children are intolerant of the behaviour of a child with autism. The parents experience stress when the school calls to complain about the child’s behaviour. They say that there are not enough teachers to cope with the extra individual requirements of children with autism. There is also stress created from debt as not all the cost is covered by insurance. The stress for them is so bad that at times the parents say they would consider suicide with the child rather than carry on. Sadly, much of the stress may not come from the child per se as much as from the lack of social safety nets and support networks.

Fleischmann (2004, 2005) conducted studies of 33 websites self-published by parents of children with autism using grounded theory and a methodology that was derived and adapted from Labov (1982). He found similarities in that, after the enlightenment of diagnosis, the parents experienced a period of readjustment and then were able to prepare themselves for action. Seeing themselves and their children in a positive light, as “daring mountain climbers”, they were then able to help other parents deal with the difficulties associated with bringing up children with autism.

To understand the inner life of children with autism, Boucher (1996) gives first-hand accounts from individuals with autism. The author analyses how individuals with autism experience the outside world (sensation, perception of the object world, perception of social signals-face and speech, and feelings associated with the external world) and illustrates the knowledge and mental activity of persons with autism. ‘Almost all first-hand accounts of autism stress the difficulties which people with autism experience in interpreting the meaning of facial expression, and particularly in interpreting meaning signalled by the eyes’ (ibid., p.86). Many able individuals with autism take ‘medication to help to control the stress which they experience on a daily basis’ (ibid., p.89).

Testimonies from individuals with autism further illuminate my argument. For instance, Higashida, an individual with autism and without oral language, expressed himself by using an alphabet grid and a computer keyboard. At the age of 13, he made the following comment which resonates with my argument:

One of the biggest misunderstandings you have about us is your belief that our feelings aren’t as subtle and complex as yours... But of course, we experience the same emotions that you do. And because people with autism aren’t skilful talkers, we may in fact be even more sensitive than you are. Stuck here inside these unresponsive bodies of ours, with feelings we can’t properly express, it’s always a struggle just to survive. And it’s this feeling of helplessness which sometimes drives us half crazy, and brings on a panic attack or a meltdown. When this is happening to us, please just let us cry, or yell, and get it all out. Stay close by and keep a gentle eye on us, and while we’re swept up in our torment, please stop us hurting ourselves or others. (Higashida, 2013, pp.149-150).

What Higashida highlights in the above quote is true, particularly in the case of non-verbal children as they can be very difficult to engage with. It is important for people to apply similar attitudes to those used by most parents with their children during the early stages of their development when they cannot speak. Child to parent communication is developed through an increasingly more complex exchange of emotional signals and children start to communicate their needs to their parents through a display of emotions. Parents are particularly sensitive to their childrens’ emotions often knowing precisely what they need. I believe that this is also true for the parents of children with autism and that fundamental communication between parents and children with autism is developed through emotions.

From these testimonies spoken by individuals with autism, it may clearly be seen that individuals with autism have emotions and feelings in much the same way as anyone else. These emotions, feelings and passion should be used to their advantage. My study seeks to explore more information regarding the emotional lives of children with autism through talking to their parents and teachers.

Thoreau (2012, p.210) wrote that ‘if a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away’.

## 2.6 How Society Treats Individuals with Autism

Most modern societies accept that we should treat all individuals as equal and that our social systems should be designed to allow all diverse types of individuals to develop their potential. We need therefore to treat an individual with special needs with respect on the basis of right mindedness.

Let us consider some ideologies on which most modern societies are based. Two obvious examples are Marxism and Cosmopolitanism. A basic concept of Marxism is that individuals should be treated with equality and justice, no matter what their status. For example, in terms of value, class and state (Sarup, 1978). The concept of Cosmopolitanism is that we should concentrate on the needs of the individuals rather than those of nations, and also place these needs before the consideration of ethics (Nussbaum, 2007).

Other ideologies that talk of respect for individuals with autism are World Health Organization (WHO) regulations, Foucault’s Normalization, and Freire’s concept. Here is a brief discussion of these works:

The World Health Organization (WHO) (2011, p.9) through the Convention on the Rights of Persons with Disabilities (CRPD) outlines the civil, cultural, political, social, and economic rights of persons with disabilities. Its purpose is to ‘promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity’.

The CRPD applies human rights to everyone including people in need, thus making general human rights specifically apply to persons with disabilities (Megret, 2008), and clarifying existing international law regarding disability. Even if a state does not ratify the CRPD, it helps interpret other human rights conventions to which the state is party. Article 3 of the CRPD outlines the following general principle:

1. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;

2. Non-discrimination;

3. Full and effective participation and inclusion in society;

4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

5. Equality of opportunity;

6. Accessibility;

7. Equality between men and women;

8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Foucault (1995) focuses on inequality and argues that disability is defined by culture and majority opinion, not by itself. He made the following comments:

Normalization becomes one of the great instruments of power at the end of the classical age. For the marks that once indicated status, privilege and affiliation were increasingly replaced—or at least supplemented—by a whole range of degrees of normality indicating membership of a homogeneous social body but also playing a part in classification, hierarchization and the distribution of rank. In a sense, the power of normalization imposes homogeneity; but it individualizes by making it possible to measure gaps, to determine levels, to fix specialities and to render the differences useful by fitting them one to another. It is easy to understand how the power of the norm functions within a system of formal equality, since within a homogeneity that is the rule, the norm introduces, as a useful imperative and as a result of measurement, all the shading of individual differences. (Foucault, 1995, p.184).

In Freire (1996)’s somewhat cynical view of teaching, ‘the banking concept’, he tells us that teachers download data to students who accept it like a computer, without true comprehension and then file the data into a bank - or hard drive as it were. He refers to this as ‘narrative education’, or ‘banking’. He further describes the relationship between teacher and student in many western mass education systems: ‘The teacher presents himself to his students as their necessary opposite; by considering their ignorance absolute, he justifies his own existence’ (ibid., p.53). He continues ‘an educated person is an adapted person’. In other words they have been conditioned to fit into a “mould” created by society, as the ‘oppressors’, in which unquestioning individuals suit their purpose (ibid., p.57).

Barnbaum (2008) states that individuals with autism are unquestionably human (biologically); however they are not guaranteed to have ‘a good human life’ since they may not receive ‘the same moral considerations as other humans’ (p.71), or exclude them from the society, or restrict them from implementing their own life plans due to some typical development individuals’ narrow definitions (moral impairments; deficits), such as DSM, Piers Benn, Peter Hobson, Derek Parfit (well-being), Thomas Scanlon (well-being), Martha Nussbaum (human capabilities), and Uta Frith (p.71). Barnbaum (2008) and Timimi et al. (2011) conject that moral theories/normative ethics (lacking of sympathy and empathy), developed by typical development professionals, overlook or underestimate the humanity of individuals with autism because they view things from their particular deficit model.

Considering Barnbaum (2008), and Freire (1996)’s concepts, I might expand on this by saying that the majority of individuals are typically developed, and individuals with autism are in the minority. The majority attempts to make the minority ‘fit’ into the world. In this ‘fitting’ procedure, the majority do not consult and listen to the minority’s thoughts and wishes. Meanwhile, the majority attempts to control the minority. Therefore, typically developed individuals can potentially become oppressors and individuals with autism become oppressed. Individuals with autism might be encouraged to understand their situation, then develop their critical awareness (consciousness), and potentially speak out for their humanity. Then they will become empowered themselves.

Freire (1996) continues,

The truth is, however, that the oppressed are not ‘marginals,’ are not individuals living ‘outside’ society. They have always been ‘inside’—inside the structure which made them ‘beings for others.’ The solution is not to ‘integrate’ them into the structure of oppression, but to transform that structure so that they can become ‘beings for themselves.’ Such transformation, of course, would undermine the oppressors’ purposes; hence their utilization of the banking concept of education to avoid the threat of student conscientização. (Freire, 1996, p.55).

Freire (1996) further implies that control is obtained by those who speak out and that this ‘must not serve as a crafty instrument for the domination of one person by another’ (Freire, 1996, p.70) and that schemes often fail because the designer has not considered ideas other than his own; he has failed to consider the viewpoint of his customer, albeit student, voter, or the user (Freire, 1996).

In order to enjoy success in bringing children with autism into our ‘social world’ we must first not consider them as different and therefore somehow lesser beings. When making a plan/program or performing some kind of test or assessment, we must try to look through their eyes and imagine the world from their perspective with open mind and wide acceptance. Do not be a ‘narrative teacher’ and try to teach them to mimic our lives. For instance with emotions: when you are hurt you cry; when you are happy you make this kind of face,...and so on.

Failure to recognise that individuals with autism experience and express emotion suggests that they are something less than human and therefore not worthy of respect and consideration. Many professionals, medical staff and scientists, look for and focus their attention upon the things that they consider wrong with individuals with autism - such as their impairments, dysfunctions and deficits, - with the intention of giving them a label. I prefer to think of them as normal, but with diverse behavioural differences. Just like any other human they deserve our respect and acceptance.

Many professionals working with individuals with autism centre on genetic and neuropathological factors. I prefer to consider the uniqueness of these individuals rather than regard them as mentally ill. Researchers tend to confine themselves to the realms of medicine and science. I would rather explore the depth of their emotions, because humans are not objects to be measured and observed. Humans are complex and their actions, emotions and feelings could be explained in many ways. Labelling an individual through a text book definition is not helpful as everyone is unique.

Individuals with autism and those without, share the same characteristics as shown by Baron-Cohen et al. (2001) An AQ (The Autism-Spectrum Quotient) test that they conducted on individuals with and without autism, showed that all participants displayed some characteristics associated with autism (ibid.). Also autism cannot be detected through genetic testing like other diseases such as William’s syndrome or Down’s syndrome.

## 2.7 Difficulties Facing the Family of a Child with Autism

Within the research literature, raising a child with autism is considered to be an arduous task (Ann, 2009; Divan et al., 2012; Neely et al., 2012). The families of individuals with autism experience a huge amount of stress and depression (Divan et al., 2012; Neely et al., 2012; Paynter et al., 2013). They encounter social withdrawal in the beginning and social reintegration later (Divan et al., 2012; Neely et al., 2012). They are eager to learn the skills required to cope, and to acquire knowledge concerning their child’s difficulties (Paynter et al., 2013). They are keen to access social support, social networking and the health care system (Divan et al., 2012; Neely et al., 2012; Paynter et al., 2013). They also need professional awareness of their family’s huge economic and emotional burden (Divan et al., 2012; Neely et al., 2012).

Blacher (1984) finds that the factors relating to the stress of the families of individuals with special needs are their children’s irregular sleep patterns as well as toileting, stereotypical and self-injurious behaviour, and aggression on the part of their children.

Family stress affects the family in many ways, including their relationships with family members and others. Their finances also put a physical and mental strain on the parents (Blacher, 1984; DeMyer and Goldberg, 1983).

This influence can begin even before a diagnosis is made. Different behaviour may start at around six months and become more obvious at 18 months (Bolton et al., 2012; Howlin and Asgharian 1999). Actual diagnosis is not often made until the child is between 3 and 7 years old, depending on the severity of the state. For example, Asperger’s syndrome might be diagnosed closer to age 7 (Mandell et al., 2005).

With the diagnoses comes an element of relief, as it offers an explanation of their child’s difficulties (Midence and O’neill, 1999; Moore, 2008). A solid diagnosis also provides many practical advantages, such as educational resources, social service payment (Disability Living Allowance), and out-of-school care help (Moore, 2008). However, according to Chamak et al. (2011) in the order of 63 % of parents are unhappy with the way the diagnosis is presented. Shyu et al. (2010) claim that the manner in which the diagnosis is delivered has a profound effect on the parents’ wellbeing and subsequently on the interventions that they choose.

Baxter (1989) points out that the parents of a child with special needs prefer to take their child to a close and familiar group rather than to an unfamiliar group. And Altiere and Kluge (2009) find that mothers found more support from friends and family than did fathers.

Ann (2009) interviews 12 parents of children with autism, and concludes that even though parents know there is an issue with their children, doctors sometimes take years to make a diagnosis. Once the diagnosis is made, the parents often find that there is no day care arrangement, so one of the parents has to stop work. This is a huge financial burden for them to bear. They may be placed in a position where they have to choose between the child with autism and their other children, or family, or friends. There is a feeling of being a social outcast and they may develop all kinds or paranoia as to why their child has difficulties. Many issues could be eased with proper thoughtful medical and educational support.

Neely et al. (2012) point out that the parents of young children with autism are concerned with the following issues: diagnosis, dealing with other family members’ emotional reactions, making treatment decisions, developing a social network, building good relationships with service providers, and accessing useful resources.

Shu and Lung (2005) conducted a 10-week mother support group, serving as an intervention for the mothers of children with autism. Their research findings were that the support group only saw significant improvement in the mother’s subjective well-being and employment status. Based on these results, Shu and Lung (2005) recommended the provision of regular carer support groups as well as providing advanced training in the skills necessary to enhance the capability of the nurses who lead the group.

In terms of the responsibility of looking after children with autism, Dunn and Kendrick (1982), Fisher and Goodley (2007), Moss (1991), Parker (2012), and Shu and Lung (2005) found that the mother is the main carer of children with autism. However, Parker (2012) interviewed four mothers of children with autism in the USA, and found that they look for useful resources, service and support from the government. In addition, mothers feel stressed and judged by society for the behaviour of their child rather than being blamed for causing their child’s autism. Timimi et al. (2011, p.291) illustrate that children with autism and their parents may ‘feel insulting, heartbreaking, confusing, malicious’ and parents of children with autism (especially a mother) ‘may feel like being blamed’.

Parker (2012) suggests that the father should share the care burden of looking after the children. It is undeniable that a father plays an important role in child-rearing and children make better progress in socio-emotional, physical activity, cognitive, academic aspects because of their fathers’ involvement (Beets and Foley, 2008; Cabrera et al., 2000; Fagan and Iglesias, 1999; Koestner, Franz, and Weinberger, 1990; McBride, Schoppe-Sullivan, and Ho, 2005; Ninio and Rinott, 1988).

Runswick-Cole (2013) conducted a 2-year research project, in which the carers of children with difficulties, children themselves, professionals and family members were interviewed. It was found that mothers often attempt to hide or change their feelings towards their children, so they appear to be ‘nicer’ than normal even in hostile situations involving their children. The emotionality between mothers and their children is complicated. Children sometimes experience their mother’s emotions both from their support and embarrassment. Sometimes they have shared experiences with their mothers through developing strategies and interacting with other individuals’ emotions. Similiarly, Reay (2000) notices that mothers and their children have mutual relationships of emotionality.

In summary, both the UK and Taiwanese families of individuals with autism are not satisfied with diagnosis process, experience huge stress and depression, feel isolated from society, are keen to access social networks and useful resources, and hope that professionals from every domain are aware that they have a huge emotional and economic burden.

### 2.7.1 Blame in the family of an individual with autism

Blame is ‘the action of censuring; expression of disapprobation; imputation of demerit on account of a fault or blemish, reproof, censure, and reprehension’ and it is also ‘the responsibility for anything wrong’ (Online Oxford English Dictionary, 2013). Blame is a negative approach towards bad things that have happened; it is associated with negative emotions (such as, shame, fear, and anxiety), morality, social-cultural regulation, and it is a mechanism of self-defence.

There can be blame of others and self-blame. In a paternal society, like most countries, women take the responsibility for raising children. Therefore, the mother is blamed for having a child with special needs, and she even blames herself.

Up until the 21st century, most child psychologists blamed the mother for her child’s difficulties (Caplan and Hall-McCorquodale, 1985). For example, Winnicott (1949) thought that mothers know the needs of their infant better than experts, paying close attention to their children’s health, they are the bridge between their children and the outer world. Implying that a mother should take whole fostering responsibility of her child’s difficulties. Additionally, a ‘good enough mother’ should be sensitive to her infant’s needs, provide physical and mental care and the best environment for her child. Winnicott’s concepts unconsciously put mothers into the position where they are responsible for how well their babies develop.

Quite often, individuals with special needs will also have emotional and physical issues. When we experience the birth of a child with special needs, this reminds us of our human frailty. This can cause us to take all kinds of personal precautions and lead us to allocate blame, or experience shame (Sinason, 1992, p.12). No matter how difficult a person may be there is still likely to be an emotional sentience inside. In order to reach this ‘emotional intelligence’, Sinason tells us that we have first to deal with both the ‘guilt of the patient’ and ‘the guilt of the worker for being normal’ (Sinason, 1992, p.74).

According to Neely et al. (2012), if a child is born apparently without special needs and then later develops some difficulties, the parents may blame themselves for their child’s difficulties and, because of “family norms”, this guilt may be repressed. Ultimately this could have a deleterious effect on the relationships in the family and with those who work with the child.

## 2.8 A different view of the current system

Abraham Verghese (2011) accounts that, when medical staff are examining or assessing their patients with state-of–art technology, they are turning them into statistics, spending more time ordering tests than in examining patients directly. They are losing the ‘heart’ of the patient-physician relationship. He suggests that physicians should utilise their senses to probe deeper into their patients’ physical and mental states. Verghese (2011) gives the following example:

I recall one patient who was at that point no more than a skeleton encased in shrinking skin, unable to speak, his mouth crusted with candida that was resistant to the usual medications. When he saw me on what turned out to be his last hours on the earth, his hands moved as if in slow motion. And as I wondered what he was up to, his stick fingers made their way up to his pyjama shirt, fumbling with his buttons. I realized that he was wanting to expose his wicker-basket chest to me. It was an offering, an invitation. I did not decline. I percussed. I palpated. I listened to the chest. I think he surely must have known by then that it was vital for me just as it was necessary for him. Neither of us could skip this ritual, which had nothing to do with detecting rales in the lung, or finding the gallop rhythm of heart failure. No, this ritual was about the one message that physicians have needed to convey to their patients. Although, God knows, of late, in our hubris, we seem to have drifted away. We seem to have forgotten – as though, with the explosion of knowledge, the whole human genome mapped out at our feet, we are lulled into inattention, forgetting that the ritual is cathartic to the physician, necessary for the patient—forgetting that the ritual has meaning and a singular message to convey to the patient. And the message, which I didn’t fully understand then, even as I delivered it, and which I understand better now is this: I will always, always, always be there. I will see you through this. I will never abandon you. I will be with you through the end.

The above example points out some issues with the medical model of disability which is commonly applied both in the UK and in Taiwan. The medical model considers that an individual with a disability has a deficit, impairment, or is abnormal and needs to be treated and cured by professionals.

Overemphasising the medical model has devalued the legal status and social conduct of individuals with disabilities (Gill, 1987). On the other hand, the social model believes that a disability is a difference and is an issue between the individual and society (Gill, 1987). Take Beardon (2014) as an example, he argues that individuals with autism ‘have their own, valid, skill set’ and ‘it is time that society recognises the potential value of being autistic, and the necessity of learning to understand each individual as a person in their own right.’ Based on this social model, parent empowerment and advocacy arise.

Since the medical model still dominates the current systems in the UK and Taiwan, inevitably individuals with autism have to carry the label of autism. Gillman et al. (2000) and Hodge (2005) contend that clinicians should carefully consider the influence of a diagnosis on a child and his/her family and only make it when it is necessary for accessing resources. Mallett and Runswick-Cole (2012) are concerned that the dangers of the autism label might lead people to the diagnosis rather than the understanding of an individual with autism. In the same vein, Hodge (2005) believes that support/resources should be dependent on the child’s needs rather than the diagnostic label.

Hodge and Runswick-Cole (2008) interviewed the parents of children with autism to try to understand parent-professional partnerships. The parents related that the professionals maintain their ‘expert’ status, and consider that the parents’ opinions are over-emotional and uninformed. Consequently the parents are frustrated and seek information and support from other parents of individuals with autism. The essential characteristics of good partnerships are ‘open-mindedness, free-thinking and a willingness to take on board new perspective’ (Hodge and Runswick-Cole, 2008, p.645).

Regarding medical diagnosis, Rosenberg (2007) points out,

We have never been more aware of the arbitrary and constructed quality of psychiatric diagnoses, yet we have never been more dependent on them than now, in an era characterized by the increasingly bureaucratic management of health care and an increasingly pervasive reductionism in the explanation of normal, as well as pathological, behaviour. ( Rosenberg , 2007, p.50).

Doctors should be cautious about employing psychiatric labels and classificatory systems due to the criteria of establishing the validity of psychiatric diagnosis, classificatory principles or the definition of symptoms are questionable (Kendell and Jablensky, 2003; Zigler and Phillips, 1961). Dyck, Piek, and Patrick (2011) investigate typical-development children and some non-typical-development children (receptive expressive language disorder, autism, developmental coordination disorder, mental retardation, and attention deficit/hyperactivity disorder), and ‘the results imply that there are no natural boundaries between disorders or between disorders and normality’ (ibid., p.2704).

Some researchers (Kirschner, 2013; Timimi, 2014; Timimi et al., 2011) claim that autism is a difference not a disorder and the label ‘should be abolished’ (Timimi et al., 2011, p.286; Timimi, 2014, p.1). The reasons are that autism is embedded in socio-cultural and political frameworks (Kirschner, 2013; Timimi et al., 2011; Timimi, 2014); increasing stigma (Kirschner, 2013; Timimi, 2014); ‘the legitimacy of the diagnosis’ of autism is questionable; and the label of autism is unscientific and unhelpful for finding suitable treatment and may harm the sense of self, identity, and cosmology of individuals with autism (Timimi, 2014; Timimi et al., 2011). Meanwhile, ‘autism has become a “ticket” for specific services, creating a two-tier system for help and support among this group of obviously disabled young people’(Timimi et al., 2011, p.293).

Supposedly, diagnostic manuals aim to assist patients to get help and treatment. For autism which has wide ranging behaviour and huge diversities, professionals working with individuals with autism (such as doctors, teachers, and social workers) should be mindful of using the label to judge individuals with autism. Instead looking at what capacities they lack and try to cure them, it is better to find what they have and help them to immerse into the society (Billington, 2006a).

## 2.9 Conclusions from the Literature Review

In this review, I have explored issues surrounding the diagnosis and treatment of autism. Emotional competence and understanding are discussed.

From the studies referenced, it is clear that the general focus is on engaging with autism via the lens of a medical model which positions the young person with autism as having a deficit. Only a few voices speak out about the strengths of this approach when considering autism. In addition, it would seem that most researchers tend to ignore the possibility that individuals with autism have emotional ability. The emotions of individuals with autism can be seen clearly from their own narratives. For instance; they feel happy, sad, depressed, frustrated, angry, frightened, and are eager to be loved as well as to be independent.

The real hope for children with autism is humanistic understanding from the education system and from their families.

Happé (1999) points out that individuals working with children with autism and other young people should put emphasis on the ‘assets’ of those with autism rather than their ‘deficits’. This view is supported later by Billington (2006).

Similarly, people with autism ‘have characteristically autistic styles of relating to others, which should be respected and appreciated rather than modified to make them “fit in”’ (Autistic Network International, 2010).

The medical system dominates contemporary diagnoses and treatment, mostly observing individuals with autism as objects. There is a tendency for clinicians to regard autism as an ‘abnormality’, ‘deficit’, ‘impairment’, ‘disorder’, ‘dysfunction’, ‘schizophrenia’, and to view people with autism as being ‘handicapped’.

Some parents and teachers, on the other hand, who are working with children with autism, treat children with autism as human beings rather than ‘robots’ who lack emotion. Indeed, individuals with autism have feelings and are capable of affection. This is highlighted though the work of noted celebrities with autism, some examples being; Jonathan Lerman (an [American](http://en.wikipedia.org/wiki/United_States) [outsider artist](http://en.wikipedia.org/wiki/Outsider_artist)),Temple Grandin (2008), and Donna Williams (1996).

Children with autism constantly challenge the way we think and the way we see and hear. With care and understanding these children, professionals might change their definitions of difficult behaviour and children’s behaviour might change because of their change of attitude. In order to resist the prevailing accounts of autism and also in order to illuminate the issue of emotionality, my research has focussed on discovering the emotions and passions of children with autism through the narratives of their parents.

# Chapter 3 Methodology

## 3.1 Introduction

This chapter presents the methodology of my study. The concept of research methodology is defined differently in the literature, as a result of this, in the first part of this chapter I will clarify how the concept is interpreted in my study. This will then be followed by a detailed discussion of the philosophical framework underpinning the choice of methods employed in my research. The chapter will then conclude by highlighting and discussing the methods employed to generate answers to my research questions.

Bassey (1990, p.35) defines research as a ‘systematic, critical and self-critical inquiry which aims to contribute to the advancement of knowledge’. This view is further buttressed by Clough and Nutbrown (2008, p.5) who assert that, ‘research is the investigation of an idea, subject or topic’ that ‘enables the researcher to extend knowledge or explore theory’. They go on to demonstrate that research is a critical process and is involved with ‘radical looking’, ‘radical listening’, ‘radical reading’, as well as ‘radical questioning’. This implies that the research process requires a careful consideration of methods to be used which allow the generation of credible knowledge. It is therefore, important to define the research methodology clearly.

As indicated earlier on, research methodology has been defined variously, for instance, Kumar (2008, p.5) asserts that ‘research methodology is a way to systematically solve the research problems. It may be understood as a science of studying how research is done scientifically’. It is beyond the scope of my study to explore all the different definitions of methodology, however, in my study, research methodology shall be interpreted in line with the definition proffered by Wellington et al. (2005, p. 97) who posit that: ‘methodology refers to the theory of [generating] knowledge and the activity of considering, reflecting upon and justifying the best methods’. This view resonates with Clough and Nutbrown’s (2002, p.27) observation that, ‘one of the tasks for a methodology is to explain and justify the particular methods used in a given study’.

In conducting my study, a number of different approaches and methods were analysed to facilitate the choice of an appropriate methodology. I would like to clarify that my choice of research approach and specific method was influenced, among other things, by my ontological and epistemological positions which are explained in the following section.

## 3.2 Epistemology and Ontology

The methodology that is adopted in research is embedded in the ontological and epistemological assumptions of the researcher. Researchers often hold different worldviews or paradigms. Denzin and Lincoln (2008, p.31) define a paradigm as a ‘net that contains the researchers’ epistemological, ontological and methodological premises’. In this section ontological and epistemological assumptions that underpinned the conduct of my study will be discussed. Soanes et al. (2006, p.520) define ontology as, ‘a branch of philosophy concerned with the nature of being’ and ‘epistemology’ as ‘the branch of philosophy that deals with knowledge’. Raadschelders (2011) highlights that: ‘ontology generates theories about what can be known (epistemology), how knowledge can be produced (methodology), and what research practices can be employed (methods)’ (p. 920).

Ontology has been defined by many authorities as the theory of existence or being (Rawnsley, 1998; Runes, 1984; Russell, 1945; Stanley and Wise, 1993; Urmson and Ree, 1989; Williams, 1989). It focuses on ‘what we think reality looks like and how we view the world, for example, the question of ‘what kind of being the human being is’ (Denzin and Lincoln, 2008, p.31) or to interrogate ‘the nature of phenomena, or entities, or social reality’ (Mason, 2002, p.14). On the other hand, epistemology explores issues such as: ‘what the relationship is between the inquirer and the known’ (Denzin and Lincoln, 2008, p.31), and ‘what might represent knowledge or evidence of the social reality that is investigated, and what is counted as evidence’ (Mason, 2002, p.16). The researcher’s judgement of the appropriateness of different research approaches is informed by their epistemological assumptions. As a result, in any research study it is significantly important to identify what can be considered as credible knowledge. This view is illustrated by Lakomski (1992) who posits that:

The application of any type of research method and the defence of the results of inquiry thus obtained implies a view, or views, of what is to count as knowledge. The point of preferring one set of methods over another is to believe that the chosen set will lead to knowledge rather than mere belief, opinion or personal preference. (p.93).

As argued by Guba and Lincoln (1989) I am aware that different views about the nature of investigation and research into social phenomena arise out of the assumptions made about, and philosophical stances taken on, issues of ontology and epistemology. In the same vein, Creswell (2009) argues that the types of beliefs held by individual researchers will often lead to adoption of one of the three approaches to research namely qualitative, quantitative or mixed method.

From Hennink et al. (2011), Liamputtong and Ezzy (2005), and Wellington (2000, p.18), quantitative research relies on the principles of positivism, statistical models, epistemological approach, etic perspective, theory laden (theory determines practice), hypothetico-deductive, involves hypothesis testing, replication and search for generalisation, the research must be ‘objective’, value-free and neutral. The definition of ‘positivism’ is: ‘a philosophical system recognising only that which can be scientifically verified or which is capable of logical or mathematical proof, and therefore rejecting metaphysics and theism’ (Online Oxford Dictionaries, 2014). According to Clough and Nutbrown (2008, p.18), Willig (2008), as well as Willig and Stainton-Rogers (2008), quantitative research includes ‘social surveys and experiments’. The results and research design are determined from statistical data and repeatability, or data that is obtained from mass sources, such as questionnaires.

Qualitative research is a type of ‘subjective’ research, but even researchers keen to keep as neutral as possible cannot isolate the influence of their own involvement. The data will be contaminated by the researchers own positionality. Their cultural background, experience and beliefs will certainly have an influence. The consequence is that any researcher will produce a different result from the next, making it impossible to duplicate the results. This view is supported by Flyvbjerg (2001) who says that:

The social sciences appear unable to demonstrate the kind of progress which is supposed to characterize normal science. The difference between the natural and social sciences seems to be too constant and too comprehensive to be a historical coincidence. (p.32).

Qualitative research can claim a deeper understanding of behaviour and belief and may focus on issues of meaning and interpretation. Deriving a greater amount of data from the participants is essential (Hennink et al., 2011, p.17) and data is often in the form of written or spoken accounts. The researcher is central in this type of study. Methods used for qualitative research are typically interviews and questionnaires with open-ended questions. Qualitative research can refer to the study population as participants or interviewees. If interviews are used they can be structured or semi-structured in a manner predetermined by the researcher. Qualitative research tends to use a small sample size of purposively, non-randomly, selected case studies, interviews, focus group discussions, observation and participant observation. When using interviews the path and structure are determined by the interaction between the interviewer and participant. Case studies are good examples of qualitative research, where the data is gathered by direct participation of the researcher who then subjectively interprets it. The results of qualitative research are typically unrepeatable as there are numerous variables involved, and much depends on the interpretation of current phenomena and participants, as well as the interaction between researchers and participants. According to Clough and Nutbrown (2008), social science research is ‘persuasive’ (ibid.p4), ‘purposive’ (ibid., p6), ‘positional’ (ibid.,p10), as well as ‘political’ (ibid., p.12). Qualitative research is interpretivist, adopts an emic perspective (‘inside’ perspective), reflexive, value-laden, and inductive. Qualitative research is descriptive, and subjective. Data collected for qualitative research is textual evidence (or image-based). The researcher is the key instrument and is situated in the world being studied. Researchers are part of the situation and the processes of research are central. In qualitative research, however, any reality is subjective and constructed. Qualitative research involves ‘the interpretative study of a specified issue or problem in which the researcher is central to the sense that is made’ (Banister et al., 1994, p.2). Banister and his colleagues go on to say that qualitative research tries to look at the inner self. Exploring and elaborating systematically the identified phenomenon and shedding light on the issue. There are many forms of qualitative research and the significance of the results will depend on the suitability of the interpretive approach. Each qualitative method has its own strengths and weaknesses, and does not claim necessarily to be scientifically correct. Banister et al. (1994) indicate that;

There is a significant difference between the image of science that most psychologists adore and the nature of science. It does not have one fixed nature: the procedures that a science should follow have been disputed, as have the claims made for it as the only purveyor of truth. (p.8).

Banister et al. (1994) quote Harré (1974) who says that it is human nature to reflect on your actions and that a study of experience should utilise this in its methodology to remain scientific. ‘Positivist research in psychology that tries to ignore the powers of human beings is unscientific’ (ibid., p.9). Harré also says realists will accept nomothetic research (collect objective and generalized data using scientific research methods), but will want to use ‘intensive study of particular cases’ (idiographic research). The realist’s view is perhaps a more scientific one. Finally the sampling used in quantitative research is probabilistic, but in qualitative research it is opportunistic and purposive.

Further, Liamputtong and Ezzy (2005, p.2) and Hennink et al. (2011) think qualitative research produces rich data that relies on the interpretive skills of the researcher. They list the theories and techniques that are used as including; interactionism, psychology, feminism, cultural studies, symbolic interactionism, phenomenology, utilizing interviewing, observation, narrative analysis, life history, ethnography and focus groups (see Denzin and Lincoln, 2000; Merriam and Associates, 2002; Seale et al., 2004). Qualitative data is intended ‘to capture lived experiences of the social world and the meanings individuals give these experiences from their own perspectives’ (Corti and Thompson, 2004, p.326). Denzin and Lincoln (2008, p.4) think that qualitative research should be conducted in a natural environment for the participant and that the researcher will interpret the collected data considering the environment and the participant’s history. Nightingale and Cromby (1999) and Willig (2008, p.10) believe that qualitative research methodologies differ in the degree of reflexivity employed by the researcher and the ‘role of language’, the researcher will inevitably become an essential part of the data, through influence and interpretation. Their views are applicable to my own experience in this study as discussed earlier in my autobiography.

Willig (2008) combines Henwood and Pidgeon (1992)’s and Elliott, Fischer, and Rennie (1999)’s ideas of evaluating qualitative research, and then advocates that good practice in qualitative research ‘will not only be rigorous, but must acknowledge’; ‘idiosyncrasy and creativity in the research process’; ‘fit, integration of theory, reflexivity, documentation, theoretical sampling and negative case analysis, sensitivity to negotiated realities, and transferability’ are also important (ibid., p.150).

Willig (2008) suggests qualitative researchers to utilise Elliott et al.’s (1999, p.220) guidelines which are ‘owning one’s perspective, situating the sample, grounding in examples, providing credibility checks, coherence, accomplishing general versus specific research tasks, and resonating with readers’ to evaluate their qualitative research data.

My experience as a child and later working with children with autism, together with my educational background will, I believe, provide a different viewpoint of the emotional lives of young children with autism from the traditional clinical view.

Mixed method approach involves the blending of the other two main paradigms, that is, quantitative and qualitative. Rorty (1979) explains the argument between hermeneutics and phenomenology and thinks that the mixed approach will obtain the most useful results.

Cohen, Manion and Morrison (2007) describe three types of research approaches namely normative, interpretive and critical research approach. Each approach has its own application as may be seen from the following explanations. Normative approach is often used for medium to large scale research. This type of research is anonymous and impersonal and looks at the forces regulating behaviour. Using a model of natural sciences, normative approaches aspire to objectivity, the research is conducted from the outside and generalises from the specific, tries to explain the behaviour and seek the cause. Normative research can look at macro-concepts, such as society, institutions, norms, positions, roles as well as expectations. It is used by structuralists and is of technical interest (Cohen et al., 2007). Interpretive approaches tend to consider individuals and are often used for small scale research, examining human actions continuously, re-creating social life. This non-statistical research might engage with subjectivity. It will interpret the specific and explore understanding and meanings rather than causes. That which is taken for granted will be questioned and critiqued. Interpretive research looks at micro-concepts, the individual perspective, constructs and meanings. It is often used by practitioners, phenomenologists, symbolic interactionists and ethnomethodologists. The research is of practical interest (Cohen, Manion and Morrison, 2007). A critical approach looks at societies, groups and individuals, and considers political, ideological factors, power and interest shaping behaviours. This research approach uses ideology, critique, action, and collectivity and mostly requires participant researchers and facilitators. It will critique the specific, look for understanding, interrogating, critiquing and transforming actions and interests. That which is taken for granted will be investigated. The critical approach looks at macro and micro-concepts which have political and ideological interests and the operation of power. It is used by critical theorists, action researchers and practitioner researchers. The research is of emancipatory interest (Cohen et al., 2007).

My study involved understanding the emotional lives of young children with autism and without languages. Hennink et al. (2011, p.14) assert that ‘understanding people’s lived experiences from the perspective of people themselves is often referred to as the emic perspective or the inside perspective’. The epistemological approach in this research is rooted in empiricism. Findings in the research are based on collected and analysed data from participants. My view is that human beings are complex creatures, our thoughts, ideas, emotions, feelings and behaviour are modified and constructed from our own personalities, gender, cultural background, previous experience, and the current milieu. This is a dynamic interactive process. Therefore, when conducting research, my participant is inevitably affected by me and by my interpretation of the participant’s behaviour and the words they use will be altered by on-going data analysis. When analysing data, numerous variations need to be considered. Gathered data and research findings cannot necessarily be generalised to different societies, areas and eras. Different researchers might have diverse means to interpret and analyse data; therefore, they may draw differing conclusions.

Regarding the ontology and epistemology of research, most existing research of emotions is experimental, that is, positivist. In this kind of research it is hard to explain some complex emotions and why individuals behave accordingly. This implies that alternative forms of research should be undertaken and one viable alternative to positivism is constructivism. Constructivism ‘adopts a relativist ontology, a transactional epistemology, and a hermeneutic, dialectical methodology’ (Denzin and Lincoln, 2011, p.92) which is the position I have taken for this research. Constructivism assumes that an individual is continually integrated with and shaped by social phenomena/realities (Bryman, 2012). Essentially, I have utilised the concept from Freud (1989, sublimation is the process of transferring sexual instincts into acts of higher social valuation, and is a sign of maturity/civilization which allows people to function normally in culturally acceptable ways), Winnicott (1971, transitional objects), Bronfenbrenner (1979, ecological system theory), and Gergen (2009), in which an individual’s behaviour, belief, and values are inevitably influenced and socialised by external organisations (such as family and schools) and cultures (Bryman, 2012). External organisations and cultures have hierarchies and represent social orders. An individual is expected to obey laws and regulations and is shaped and accommodated by widely accepted social values and customs (Bryman, 2012, p.32). I consider that it is important to be able to elicit the individual experiences of each participant because according to the constructivist stance every individual has unique experiences. It is also critical to realise how external environments interact with an individual’s development/experience. Individuals’ emotional lives cannot be measured using experimental methods or be interpreted according to a single variable. External organisations (such as educational systems, medical systems, policies, and societies) are worth scrutinising. It is my intention to scrutinise the factors which might influence an individual’s emotionality in this research.

My review of the different approaches now formed the basis of my choice of the best solution for my research. It is not an easy task to identify the best approach as Sikes (2004, p.15) contests, when educational research involves individuals in social settings inevitably there will be many interpretations and perspectives. Researchers should not consider that it will be straightforward and should take into consideration all possibilities. The nature of autism complicates all types of study. Typically the presence of the researcher might perhaps instil fear into the child with autism, or at least create a change in the environment and hence produce non-credible data. Considering that this study examined emotions a methodology that obviates external influence would be most attractive. Direct communication can be difficult, especially for those who are not on intimate terms with the child. In addition, Dodd (2005) indicates that it is difficult to explore emotions and feelings of young children with autism, because although the emotions and feelings are physically and sometimes deeply felt, they are abstract concepts and young children in general have difficulty understanding and explaining how they feel, more so children with autism. It follows then that for meaningful data to be collected directly from the child it would be necessary to consider long term contact with the child. The quality of the data would be dependent, somewhat, on the relationship developed between the researcher and the child. Even then the researcher would only be privy to a snapshot of their life, which could be aberrated by circumstances which are not apparent. For these reasons the data were collected through interviews with those who have established long term relationships with these children, rather than directly from the children themselves.

It is difficult to find large numbers of participants and control all the variables of this type of research. Additionally, it would be unethical, in my consideration, to build a control group and an experimental group for my research results, therefore to try and understand the emotional lives of children with autism through the views of their parents. A qualitative process was utilised for my research purposes. Qualitative research is subjective and in this case involves the analysis of interview recordings. According to Holloway and Wheeler (1995), qualitative research uses observation, interviews and discussion and the view of the participants.

Other comments on qualitative research that were considered were from Creswell (2007) and Banister et al (1994). Creswell (2007) and White and Epston (1990) say that the narrative approach is concerned with detailed chronological re-telling of stories or life experiences, usually of one person or a small number of individuals, within a sense-making framework. Narrative approaches are labour intensive in that they generally require information to be gathered over a considerable time period and from a number of sources (e.g. interview, diary, and observation). They also necessitate the collecting of contextual information for the story (Creswell, 2007). Bannister’s view is that ‘a qualitative researcher…will be focusing on the context and integrity of the material and will never build an account directly, or only from quantitative data’ (Banister et al., 1994, p.1). According to Hennink et al. (2011) qualitative research is the most appropriate when studying emotions as the researcher will be better able to consider the participant's view. They will be able to discover ‘complex and sensitive issues’ which might not have come to the surface using qualitative methodology (ibid., p.10).

In the following section I discuss different qualitative research approaches and highlight the rationale for my selected research approach.

## 3.3 Qualitative research methods considered

Considering the nature of my research study, I identified qualitative design as the most appropriate to meet the research aim of exploring the emotions of individuals with autism through parents’ views. In my search for an appropriate approach for the study, I considered the following qualitative approaches: action research, ethnography, Interpretative Phenomenological Analysis (IPA), and narrative. In the subsequent section, I will briefly explain each one of these approaches and highlight why I chose narrative as the appropriate approach for the study.

### 3.3.1 Action research

According to Cohen et al. (2007, p.29), action research ‘impacts on, and focuses on, practice’ and ‘recognizes the significance of contexts for practice; locational, ideological, historical, managerial, social’ (ibid., p.29). Further, it empowers the researcher giving them the freedom to express their own views (Carr and Kemmis, 1986; Cohen et al., 2007; Grundy, 1987), ‘participation in decision-making, and control over their environment and professional lives’ (Cohen et al., 2007, p.29). According to Banister et al. (1994) and Wellington (2000), when conducting action research, action and reflection-evaluation proceeds separately but simultaneously. The structure of such research should be: planning; select the general area. Discuss, observe, read and decide on your first action. Then take your action and monitor it. Examine the information collected. Be critically aware; reflect upon what you have done. Evaluate the processes and outcomes. Plan the next action. Take the next action. Continue and repeat. Data collection: collect all documentation, keep a detailed diary, observation notes; questionnaire surveys, interview transcripts, tapes, video, still photographs and triangulation.

Its strengths are that it can be used to subordinate and defuse debate and conflict between dominant and marginal groups rather than to empower them. Its disadvantages are that action researchers allow their own assumptions to take control. They often become too cosy and grandiose thus losing the essential evaluative cutting edge of this approach.

### 3.3.2 Ethnography

Liamputtong and Ezzy (2005, p.16) assert that ethnography attempts to describe and analyse logically a cluster of folk’s pattern of life by describing their culture and social phenomena (for example, language as well as actions).

Ethnography is defined by Wellington (2000) as being a part of anthropology. Ethnography looks at social relationships, societies and institutions. Wellington (2000, p.45) believes that researchers must get “inside” the participant and probe for ‘views, prejudice and taken-for-granted assumptions by asking questions that may seem awkward and naive, adding to the observer effect and possibly limiting access to meaningful data’.

According to Banister et al. (1994), ethnography involves: the gathering of data from a range of sources; studying behaviour in everyday contexts rather than experimental conditions; using an unstructured approach to data gathering in the early stages, so that key issues can emerge gradually through analysis; in-depth studies of one or two situations. Its structures are; make observations and draw inferences; interview; construct a working hypothesis; Act on it. Its advantage is research in real situations. Its disadvantages are; researchers have specific problems with recording evidence in situations where they are being ‘bombarded with material’; memory can play tricks.

Hennink et al. (2011, p.46) suggest that when conducting ethnographic research it is important to spend time on establishing a trust relationship with the participants, this is often done by physical and emotional immersion in the local daily life.

In my research I was one stage removed from the subjects, so the connection had to be established with the parents of the child. This was done in their home environment and my personal and work experience helped to strengthen the connection.

### 3.3.3 Interpretative Phenomenological Analysis (IPA)

IPA attempts to view and understand the world as seen by the subject. Smith and Osborn (2007) describe IPA as ‘the aim of interpretative phenomenological analysis is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants’. The account is analysed from the point of view of the subject and not the interviewer. The object is to enter the world of the subject and see the account in their terms of reference. Clearly the process is complicated by the researcher’s perspective (Smith and Osborn, 2007), and ‘the nature of the interaction between researcher and participant’ (Willig, 2008, p.57). According to Smith & Eatough (2007), IPA is most appropriate for research that seeks to understand how individuals perceive and understand significant events in their lives. However, Willig (2001) points out that even though IPA endeavours to explore a participant’s experience from their own perspective, the approach recognises that this kind of exploration necessarily implicates the researcher’s own view of the world, and may be influenced by the nature of the interaction between the researcher and participant (Willig, 2001). It follows that IPA involves interpretation on two levels requiring a balance between empathy for the participant’s experience and the need for a critical understanding of the data (Smith and Eatough, 2007).

According to Smith (2009), ‘IPA is phenomenological’ because it tries to interpret the experiences of the subject through their own eyes, also IPA is a commitment to study discrete facts or events in each individual case.

### 3.3.4 Narrative

Narrative is concerned with the detailed chronological re-telling of stories or life experiences, usually of one person or a small number of individuals, within a sense-making framework (Creswell, 2007; Liamputtong and Ezzy, 2005; Riessman, 2002; White and Epston, 1990). Narrative approaches are labour intensive in that they generally require information to be gathered over a considerable time period and from a number of sources (e.g. interview, diary, and observation). They also necessitate the collecting of contextual information for the story (Creswell, 2007; Liamputtong and Ezzy, 2005; Riessman, 2002).

Narrative can be used to explore the individual’s life history and through this, attempt to understand the whole story through the process of listening to their life experiences (Riessman, 2002). Children with autism can be viewed from several different perspectives, those of the parents and the carers, adding depth to the data obtained. The researcher’s influence on the children is reduced to a minimum, as the data is not obtained from them directly though the researcher may still have an effect on the parents.

However, it should be considered that there may be influence from the narrator referring to contemporary anthropology and feminism studies, that point out ‘narrative analysis typically takes the perspective of the teller, rather than that of society…’(Manning and Cullum-Swan, 1994, p.465) state further ‘conclusions are often defined poetically and artistically and are quite context bound’ (ibid., p.465).

Bruner (1986, p.143) suggests that narrative might not tell the whole story because ‘life experience is richer than discourse. Narrative structures organize and give meaning to experience, but there are always feelings and lived experience not fully encompassed by the dominant story’. This could present a problem when trying to discuss or give meaning to the rich inner worlds of children with autism.

White and Epston (1990, p.16) offer a very specific technique to enrich the data by encouraging the participant to externalise the problems identified in their story.

According to White and Epston (1990), individuals form their experiences into stories and then their lives are influenced by their stories suggesting our lives are a narrative. ‘They have a beginning, a turn of events and an ending. Thus, narrative is not constrained to literary texts’ (White and Epston, 1990, p.79).

Telling a life story gives order and depth which may not be derived from the answers to a series of ordered questions. The narrative temporalises the data and gives it greater depth, it can be expanded to a wider coverage of instances and the feelings of the narrator. ‘Narratives, then, allow for lived experience to be construed in lived time and rendered eventful by being plotted into a story’ (White and Epston, 1990, p.127).

White and Epston (1990) in their writing ‘Narrative means to therapeutic ends’ illustrate that to help family members who have problems, therapists need to use ‘externalizing of the problem’ to ‘identify unique outcomes’. For my research purposes, I preferred to explore a neglected domain (emotions and feelings) of education of young children with autism rather than be a consultant and consider that young children with autism are or have problems in their family. Therefore, I did not adopt their theoretical framework.

Riessman (2002) is chary of giving voice. Riessman thinks what a researcher needs to do is hear voices by interpreting participants’ recording transcriptions well and truly rather than give voice. ‘Representational decisions cannot be avoided; they enter at numerous points in the research process, and qualitative analysts, including feminists, must confront them’ (Riessman, 2002, p.220). He also points out that it is hard to present the interaction between an interviewer and interviewees and some features of conversation which ‘are critical to analysing the structure of the narrative are excluded from the representation of it (e.g., pauses and discourse markers)’ (Riessman, 2002, p.244). Riessman (2002) further illustrates that;

The task of identifying narrative segments and their representation cannot be delegated. It is not a technical operation but the stuff of analysis itself, the "unpacking" of structure that is essential to interpretation. By transcribing at this level, interpretive categories emerge, ambiguities in language are heard on the tape, and the oral record--the way the story is told--provides clues about meaning. Insights from these various sources shape the difficult decision about how to represent oral discourse as a written text. (Riessman, 2002, p.249).

Riessman (2002) asserts that four criteria for validating narrative are persuasiveness, correspondence, coherence, and pragmatic use.

A collaborative idea (co-researcher) arises among narrative approaches. In theory, this kind of research gives the participants data more weight as they are not simply participating in the research by answering questions, but have equal status to the researcher by entering into discussion and further having the right to review their input. Therefore, they give louder voice, and contribute more knowledge and opinions than typical participants (see Aarsand, 2012 and Chadwick et al., 2013).

In conclusion, it goes without saying that narrative is an approach involving a researcher’s positionality, subjectivity, reflexivity, ontology, epistemology, and interpretation since narrative is one sort of qualitative research and narrative is blended by the researchers’ and the participants’ experience (Choi, 2006; Trainor, 2013).

Begeer et al. (2011) interviewed 25 children with high functioning autism and 25 neuro-typical children. Researchers use a semi-structured interview to explore the children’s ability to interpret their basic emotions, such as anger, fear, sadness and happiness. The children with autism in the study have less emotional display rules (and knowledge) than the typical-development children. They also gave fewer reasons for hiding their emotions and motives than the typical-development children.

Minne and Semrud-Clikeman (2012) interviewed 5 children with high functioning autism, whose ages were between 6 and 7 years, and also their caregivers in a group to explore their opinions relating to intervention. Semi-structured interviews were utilized in the study. Each interview lasted 30-50 minutes for the parents, and 20-30 minutes for the children. Researchers found that the children built relationships with other people, improved their social interaction abilities, and were more aware of other people’s social clues, facial expressions, and perspectives through these group sessions.

Lin (2005) uses narrative research to explore the stories of two savants with autism. She uses in-depth interviewing of the parents and teachers of her subjects and the individuals with autism themselves. She also uses observation, and documentary collection to produce data. Lin describes numerous aspects of two individual with autism’s learning processes, including their emotions, such as anger, pride, frustration, hope and so on. The researcher finds that various factors relating to parents, teachers, the education system, the individual, as well as society affect the performance of savants with autism. Through the use of narrative research, many emotions and details relating to the case’s life history are discovered.

After checking 12,600 theses relating to Bronfenbrenner and narrative through Google Scholar, the terms of narrative, interpreting narrative, narrative analysis, systematic narrative review, narrative inquiry, and historical narratives are present in the literature. I think that Annan, et al. (2006)’s article ‘Narrative Psychology: A tool for ecological practice’ might be the best fit for my thesis. According to Annan, et al. (2006), narrative inquiry is the best approach to apply ecological theory in educational psychology which relocates these issues ‘from within individuals to the interaction between people and their environments’ (p.20). However, while using narrative into the ecological theory, researchers need to be well aware of the strong relationship between thought and language. ‘By relocating problems through use of externalising language, people not only gain authority over undesirable occurrences, but they are immediately positioned to move from the problem to the solution’(p.22).

### 3.3.5 Conclusion

Having considered the above research methodologies, I chose narrative as my preferred research methodology. My initial thought was that IPA would have been the best choice, however, following my upgrade viva, I considered an opinion expressed by one of my examiners and took into account the following points: IPA might lead me to an overly subjective approach and away from the intended focus i.e. the parental narratives. IPA and narrative have many concepts in common, and both of them met my research needs. However, a narrative approach, and utilising thematic analysis seemed to offer the most flexible and appropriate means of accessing the parental points of view.

While embarking on my research, I gave consideration to my personal influence on the research. Wellington (2000) highlights the importance of being reflective and having reflexivity, while realizing that these are not the same thing. Wellington explains that reflexivity is a subset of reflectivity. The researcher must consider the way in which they, themselves, influence the data by their presence, or even by asking the questions or conducting the research. The researcher must also reflect on the object of the research and the way in which it is conducted always considering ways of improving it (Wellington, 2000).

When looking for, or examining emotions, qualitative research would appear to be a more appropriate tool than quantitative research. The statistical advantages that are offered by quantitative research are outweighed by the ability of qualitative research to explore the subjects’ intimate human history. After considering many research methodologies, I chose narrative as my research methodology. The four main reasons for doing this were; firstly, the purpose of my research was to explore the views of those close to the children and not at this stage to improve their emotional lives. For this reason narrative was a better choice than Action Research. Secondly, I wanted to investigate the common characteristics of the child’s emotions rather than to find the different features between two cultures. Hence, narrative is more suitable in this research rather than ethnography. Thirdly, narrative might dig more deeply and widely inside the theme than IPA. Atkinson (1998) comments that a person telling his own story in an interview will give more information than could be gained from other research methods. Finally, Annan, et al. (2006, p.20) suggest that narrative and Bronfenbrenner's ecological theory are the best approaches for practitioners to explore all the issues considering the relationships between individuals and their milieu. Hence I adopted a narrative approach, collecting authorised recorded data from my participants, in the form of 3-stage interviews, medical reports, school reports, diary, and blog articles. After interviewing, I analysed the transcriptions (reviewing the UK transcriptions with my interpreter to double check them). Following on from the analysis of my transcription, I set up themes and classified the data into diverse themes after scrutinising the data. The following section discusses the methods used in this study in detail.

## 3.4 Research methods

There exist various methods for gathering data in qualitative research and each method has its own advantages and disadvantages. Having adopted the narrative approach as my research methodology, interviews became my main consideration.

### 3.4.1 Interviews

‘I interview because I am interested in other people’s stories. Most simply put, stories are a way of knowing’ (Seidman, 2006, p.7). Seidman tells us that in order to recount an experience an interviewee must reflect on its elements and process them into a meaningful order. ‘Telling stories is essentially a meaning-making process’ (Seidman, 2006, p.7). In the same vein, Webb and Webb (1932, p.130) think of interviews as ‘a conversation with a purpose’. According to Wellington (2000, p.71) interviews allow us to examine an interviewee’s account of what has transpired as well as their thoughts and prejudices on the subject. Further Seidman (2006, p.9) says that in-depth interviewing is a way of examining the ‘lived experience’ of the interviewee and what they make of the experience. In the same vein, Atkinson (1998, p.24) thinks that ‘people telling their own stories reveal more about their own inner lives than any other approach could’.

Wellington (2000) says that interviews give the interviewee an opportunity to say what they think on the subject. In a newly formed relationship, such as the one that I established with the parents and considering the above, it is reasonable to expect that not all responses were totally honest. Schutz (1967) says it is impossible to completely understand another person as we would have had to share their experiences, we can only try to comprehend them by examining their actions.

Brooks (2011) believes that we learn from the individuals we love and that this is true across society, in schools and in personal relationships. This is because humans are social creatures; we are driven by our emotions, not logic. As cultures develop they fool themselves into thinking that they have become logical. The result of this is that we have more and more difficulty talking about emotions, preferring instead the material. Brooks (2011) writes that emotions cannot be separated from reason; in fact, they are the foundation of reason given that they influence our values. He further observes that wisdom comes from educating your emotions.

When interviewing the parents of children with autism, some consideration must be given to the parent’s attitude towards the problem. Perhaps they feel guilt for the condition of their child and may have a sub-conscious belief that they are responsible in some way, for any of a number of reasons. They may feel anger at having to endure this burden (Anderson, 2010; Mercer et al., 2006). They will most probably be concerned that they are doing everything that they can for their child and that what they are doing is in their child’s best interest. Evidence shows that the parents of children with autism experience more stress than the parents of children with other special needs (Anderson, 2010; Schieve et al., 2007).

Interviews can take many forms; after comparing at least thirty interview approaches, I eventually reduced the choice between two, a three-stage method (Billington, 2012; Seidman, 2006) and creative interviewing (Douglas, 1985). Both interviewing approaches claim that their function is to explore and understand the participant’s feelings and emotions which match my research purpose. Considering my abilities as a novice qualitative researcher, and the pros and cons of these two methods, I decided the use of a three-stage interview approach would be preferable. Douglas (1985) claims that novice interviewers should not be afraid to use creative interviewing, and that it is all up to interviewer’s motivation. However, it was possible that my lack of experience in probing the interviewee’s real meaning behind their words could have impacted the result of my research, as Ratcliffe (2002) suggests.

Douglas (1985) assumes that only the interviewers influence the data and the results. However, Nunkoosing (2005, p.700) offers a different view, he believes that both the interviewer and the interviewee use ‘creative artfulness’ and influence the data and the results.

Seidman describes the Dolbeare and Schuman (Schuman, 1982) designed interview technique. This style of interview is divided into three parts. During the first interview, the participant’s relevant experience is reviewed. In the second interview, the experiences are put into context. The third interview allows the participants to reflect on the experiences and their significant meaning.

Seidman (2006) and Wellington (2000) advise us that when conducting interviews we should observe these three principles;

1. Respect the individual’s autonomy;

2. Maximise the benefit and minimise the risk of harm to the individual;

3. Select the participants in an equitable and just manner.

Further, it is important to have a genuine interest in the interviewee and the value of their experience. They should not be treated as just a source of data.

Birch and Miller (2000) and Fisher and Goodley (2007) also advise that interviewing may present some ethical considerations, because interviewing may cause the participants to recall some painful experiences and there is a blurred line between therapy sessions and research interviews.

Banister et al. (1994) make the following points concerning interview methodology: Uniting the many models of interviewing is a concern with subjective meanings rather than with eliciting responses within a standard format for comparison with other individuals or groups. Similarly, Kvale (1996) thinks that an interview is an interchange of views between two or more individuals on a subject of mutual interest. The researcher should consider that human interaction is centre focused and to make sure that all voices are heard in good faith when analysing the data. Interviews can permit exploration of issues that may be too complex to investigate through quantitative means. Conducting interviews is a salutary lesson in research practice.

The purpose of in-depth interviews is ‘to identify individual perceptions, beliefs, feelings and experiences’ (Hennink et al., 2011, p. 53). The advantages of in-depth interviews are that you ‘gain in-depth information, identify personal experiences’, you establish ‘life histories as well as feelings’ and they are ‘useful for sensitive issues’ also they can ‘identify context of participants’ lives’ (ibid., p. 53). The disadvantages of in-depth interviews are ‘no interaction or feedback from others, individual perceptions only, multiple interviews, needed to identify range of issues’ (ibid., p.53), ‘need skills to establish rapport, use motivational probes, listen and react to interviewees; mass transcription is needed; and flexibility needed to change topic order in interview guide following interviewee’s story’ (ibid., p.131).

The advantages of using interviews have been discussed widely in literature.

These include:

1) The presence of the interviewer can help to clarify queries from the respondents and can stimulate the respondent to give full answers to an on-the-spot supervisor rather than an anonymous researcher known through an introductory letter;

2) Face-to-face encounters increase response rates;

3) Interviews can be flexible, interviewers are able to probe and explain more fully;

4) Face-to-face interviewing can help respondents who have limited reading and writing abilities to answer questions and encourage interviewees to participate more by using non-verbal behaviour;

5) Interviews can be conducted in a controlled environment that eliminates distractions and provides privacy (Bailey, 1994; Cohen, Manion, and Morrison, 2007; Robson, 1993; Webb and Webb, 1932). It is also evident from the same sources that there are some factors that will affect the results of an interview, for example, the interviewer’s personality; this can be kept to a minimum by bringing a secretary or other colleague with you. Also a lack of standardisation is in the interview research. Interviews are time consuming and costly.

### 3.4.2 Choice of research method

I have chosen in-depth interviews as my research method, because; firstly, the parents of children with autism may be sensitive, as amongst other things, they may have experienced trauma relating to their children’s wellbeing (Anderson, 2010; Mercer et al., 2006). In addition, every child with autism is unique. Utilising focus group discussions would likely not bring out intimate and sensitive issues. Some parents might be inclined to withdraw from the conversation, especially considering that there will be different levels of success for each child. For instance, what might seem a big achievement for one child might not be for another? Secondly, I discounted observation as my research method, because I did not have existing relationships with the children and establishing a relationship could have been a lengthy process. It is easy to misinterpret a child’s behaviour if you do not enjoy any kind of in-depth relationship with them. Considering that I could inadvertently be the cause of the child’s different behaviour during my observations, especially for children with autism, it was important to have the least impact possible on the participants while at the same time, trying to gather the most meaningful and reliable information. I also had to consider that it might be difficult to find willing participants for this research. Parents of the children that I am interested in have been through the mill and are usually consumed with their children and are therefore not very willing to accept a further intrusion into their lives, so I believed that it would be difficult to gather a meaningful sized group of parents. My interest was to gather in-depth information and explore the personal experience of these parents. Hennink et al. (2011, p. 53) think in-depth interviews are ‘useful for sensitive issues which identify the context of participants’ lives’. For these reasons, I chose in-depth interviews as my research method. The research questions are included in appendix 6.

# Chapter 4 Research procedure

The aim of this study was to explore what parents think of the emotional lives of their young children with autism. Emotions and feelings are hard to measure and individuals with autism are a small portion of the population. Qualitative research rather than quantitative research was selected as the most suited approach to understand the emotions of individuals with autism. Semi-structured interviews were used for data collection as this enabled the gathering of data in sufficient depth and quality to provide a detailed picture of the participant’s experiences. It was anticipated that this would be pertinent for the parents in this study, given the significance that understanding the emotions of a child with autism is likely to hold for some individuals. Semi-structured interviewing is considered as a more open and flexible research tool, ‘can document perspectives not usually represented (or even envisaged by researchers), and hence the approach can empower disadvantaged groups by validating and publicizing their views’ (Burman, 1994, p. 51).

My own autistic temperaments/idiosyncrasies, life experiences (see Chapter 1.2 Brief autobiographic reflection), and ‘positionality’ have driven me to perform this research and to use my personal ‘insider view’ to further understand the emotional lives of children with autism through parent narrative. This is supported by Billington (2006a) and Moore (2000) who assert that not only professionals but also ‘insiders’ have a right to contribute their knowledge and make decisions about their lives. Avdi et al. (2000) and Billington et al. (2000) suggest that ‘insider’ accounts’ should be considered useful in aiding professionals in their work creating and developing services and practices.

## 4.1 Data collection

At first I considered conducting my research while continuing in my position as a teacher in Taiwan. However, it was decided that the interviews in the UK and Taiwan should be completed on the same basis for consistency. Therefore I decided to focus solely on my research until after the interviews were completed (2011, January 17, research diary). I then had to return to my employment for 6 months in order to retain my tenure, before taking further leave to allow me to finish the analysis and write this thesis.

When deciding on the participants and the direction the research should take, I considered making a comparison between verbal and non-verbal children. However, it proved very difficult to find willing participants in either category, so I concentrated my efforts on non-verbal children and was fortunate enough to find two families in the UK who were willing to take part (2011, January 17, research diary). In March of 2012, I contacted 10 autism groups and special schools in Taiwan. During this process, I encountered many children with autism, but most of them had oral language skills. The staff from one of these groups suggested that this might be because parents in Taiwan take their children to see a specialist at the first indication of a problem. While obviously beneficial to the children, this was unhelpful to the research (2012, March 27, research diary). Taiwanese participants were located through contact with my former work colleagues.

The Interviews were designed to gather information from parents of four children who have autism and who are non-verbal. The aim of the research design was to look for common ground and to examine the extent to which individuals with autism experience and cope with emotions. I did not interview or observe the children directly as I believe I would not have been able to build a trusting and non-obtrusive relationship with them in the amount of time that was available. Any observations that would have been made, had I chosen to interview the children directly could have been misinterpreted due to the influence of my presence and my lack of familiarity with the children.

The data collection process is shown in Figure 1 below:



Figure 1: Data collection process

## 4.2 Use of an interpreter

Due to my characteristics of autism, the prospect of conducting interviews with English speaking participants, who may also have strong dialects was potentially a major cause of personal stress. Additionally English is not my first language and I speak it with a strong accent, which would have made it difficult for the participants to fully understand my questions. This did indeed prove to be the case. When with individuals that I am unfamiliar with who speak with a strong dialect, I have difficulty understanding some of the nuances of their conversation. The assistance of an interpreter was a logical solution.

I utilised the services of an English speaking interpreter to help me with the precise meaning of the language used in the interviews and my transcription of the narrative. Some researchers believe that the role of an interpreter is translation; they are a cultural broker, as well as cultural consultant (for example, Raval, 2003). Some researchers believe that translators change written text into other languages and interpreters change spoken languages into another spoken language (Jones and Boyle, 2011; RIC International, 2007). I think ‘interpreter’ is the correct term for my application. I chose to utilise my life partner who is a native English speaker to help me feel at ease during the interviews and to assist with language issues when English was spoken in my research interviews. This included help with verbatim transcriptions of the tape recordings of interviews that contain English. The detailed terms of reference for the use of an interpreter are in the form of a contract with the interpreter. After the interviews, I sent transcripts to the interviewees and asked them to check the content. Unfortunately, although they all gratefully acknowledged receipt of the transcripts, none of the participants gave me feedback on the transcripts. I assumed that there were no disputes with the content of the interview transcripts and proceeded to analyse the data.

### 4.2.1 Selection of an interpreter

For my interpreter I chose Peter Robert[[1]](#footnote-1), who was my husband and partner for more than three years at that time (we are still married). Peter is very familiar with my accent and English talking style as well as the type of thinking logic that I use. I also chose to use Peter to help me to conduct the interviews in a relaxed atmosphere, as I lack confidence when speaking with individuals that I do not know in a language that I am not completely comfortable with. That is to say, I am able to overcome my fear of interacting with unfamiliar individuals; however, this is made harder for me when I cannot completely understand them. Peter’s presence made it much easier to create a relaxed environment for both the parents and myself.

Peter is a retired businessman who was born in the south of England. His business career has been divided between the UK and North America. He speaks international English and has lived and worked in the Sheffield area for over 6 years. During this time he has acquired a reasonable understanding of the Yorkshire dialects. Prior to the research my supervisor and I explained to him the goals of my study, the interviewing procedures that were to be utilised and the role of the interpreter. In addition, I asked that the interpreter maintain the participants’ confidentiality, convey the context accurately, and hold a non-judgemental attitude (Raval, 2003).

I asked my supervisor to help me address cultural and linguistic issues as I may have been ‘unable to understand the cultural nuances of the second language spoken if that language was learned outside the culture’ (Lange, 2002, p. 414) and I also considered cultural competence as an important part in my research. Riessman (2011, p. 324) further supports this view, ‘there is a need for culturally sensitive applications of the methods in non-western contexts with focused attention to language translation issues’.

In Taiwan the interviews were conducted in Mandarin and with the exception of the first interview with Catherine and John[[2]](#footnote-2), I conducted and transcribed the interviews by myself. Peter assisted me as ‘interpreter’ in the first interview with Catherine and John, because John is from the Philippines and does not speak Mandarin, so his conversation at home is in English. Having lived in the UK for over three years, my cultural concepts have broadened beyond those that I held in Taiwan, so during the coding and analysis process I used member checking (for example, participants or educational professionals) to address this cultural issue. Only the results of the research have been translated from Mandarin into English.

## 4.3 Participants

In deciding on participants for my research I considered different possibilities. Initially, I planned to interview 3-6 year old children with autism, their parents and teachers. However, on reflection, I considered that it would be difficult to build short term relationships with children who have autism. Behavioural anomalies due to the relationship could have affected the data.

My second plan was to interview parents and teachers of 3-6 year old children who have autism and who were non-verbal. Focusing on non-verbal children with autism to prove that emotions exist in individuals whether they have spoken language or not, especially since some professionals (such as Grayson, 2006) believe that individuals with autism have difficulties on theory of mind, have different brain development, and different cognitive and language abilities, hence, their emotional competences do not meet the professionals’ criteria which implies individuals with autism have fewer or no emotional competences. Unfortunately, despite contacting many educational settings, it proved to be very difficult to find participants. Schools with special needs children are reluctant to cooperate with researchers unless there is an existing relationship.

Therefore in my third plan I took into consideration my experience as a front-line teacher and concluded that it would be more useful to understand the parents’ views rather than the teachers’. I decided to limit the research to just the parents of 3-6 year old non-verbal children with autism.

I attempted to contact specialist schools and parent groups by phone, email, advertisements and in person with no success. I found that preschool children with autism are undiscoverable. For the most part I could only find willing participants with children of around 10 year-old in the UK. As a result of this, for my research I decided to further change my target population.

Following discussions with my supervisor, I realised that 3-6 year old children are likely to be recently diagnosed and that their parents may still be struggling with the issue and might not be able to provide a clear observation. Parents of older children, however, would be able to reflect on their experiences from when their children were younger. There are many instances of children with autism who can talk for themselves, so I chose to interview the parents of children who are non-verbal. I was looking for the emotional being trapped inside the child who, because of their lack of language, is incorrectly considered low-functioning. Wolman (2008), on his blog describes Baggs, a woman with autism and without oral communication skills, ‘she has strange repetitive behaviour: slapping a piece of paper against a window, running a hand lengthwise over a computer keyboard, twisting the knob of a drawer. She bats a necklace with her hand and nuzzles her face against the pages of a book’; meanwhile, she can use a keyboard to express her thoughts, use a digital camera to shoot video, edit it, and upload it to YouTube. From a psychologist’s point of view, Baggs is a female with low-functioning autism, who totally relies on other individuals’ assistance. Nevertheless, in the real world, she is the leader of an autistic movement, and capable of using many advanced technological products. She is clearly not low-functioning.

Given the difficulties of gaining access and entry, the purpose of my research, and the methodology employed in the study, my participants were chosen using purposive sampling. Parents of young children who have been diagnosed with autism were the participants. I selected the parents of two young children with autism from the UK and two from Taiwan. I found the UK participants with the help of an educational organisation. In Taiwan I was able to find suitable participants with the help of my former colleagues. According to Yapko (2003), parents are usually the first to observe their children’s different behaviour consequently psychiatrists take the comments of a child’s caregivers very seriously. Most importantly the participants needed to take part voluntarily as based on this circumstance, ‘participants would then be willing to share their experience, fulfilling all demands and requirements of a main idea, and exhibiting their knowledge, insight or understanding of their life experience’ (Hollway and Jefferson, 2000, p.11).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Participants** | **Ethnicity** | **Country** | **Interviewer** | **Collected data** |
| Larry and Patricia (child’s name: Thomas) | British | UK | Researcher and an interpreter | Recorded interviews, some medical reports, some school reports, diary |
| Paavai (child’s name: Balaravi) (father was working abroad) | India | UK | Researcher and an interpreter | Recorded interviews, |
| Catherine and John (child’s name: Harry) | Taiwan and Philippines | Taiwan | Researcher (an interpreter only present at the first interview) | Recorded interviews, some medical reports, some school reports, diary, blog articles |
| Ya (child’s name: Han) (father was looking after children while interviewing) | Taiwan | Taiwan | Researcher | Recorded interviews, some medical reports, some school reports, diary |

Table 1: An overview of participants

By examining the lives of participants in Taiwan and the UK, an extra dimension was added. Also this was further enriched as one of my participant families in the UK was from India, giving insight into a small part of Indian culture. It was important however to take these points into consideration when analysing the data as these cultures are widely divergent. The data had to be filtered, giving consideration to ethnological and sociological factors, at the very least those relating to the culture of the researcher and subject. As I conducted my research in both the UK and Taiwan, it was necessary to give consideration to the parents’ expectations and aspirations for their child. These are quite different in each of the countries.

As a mature PhD researcher, I was fortunate in that I am of a similar age to the parents that I interviewed and also it was very helpful that as a special needs teacher I am experienced in speaking to the parents of the children in my care. To ensure anonymity and confidentiality of participants, all participant names used in this thesis are pseudonyms.

## 4.4 Three-stage approach

A narrative research methodology was adopted and I chose to use a three-stage process as detailed by Billington (2012) and Seidman (2006) to collect data. Every story has a beginning (or a history), a middle (or a present) as well as an ending (or a future) (Seidman, 2006; White and Epston, 1990, p10). This took the form of three sessions of approximately one hour (actually most sessions were longer, up to two hours in some cases, perhaps because of the parents getting involved in their stories) with each of the children’s parents. There was an audio recording made of each of the interviews and the recordings were transcribed. The whole procedure was facilitated to some degree by drawing upon my childhood and work experience. It was an interactive process as some of the questions I asked were based on the answers I had been given. During the interviews I attempted to provoke and stimulate the interviewee to remember and consider their child’s actions, expressions and past events. Further I made a conscious effort to be an active listener, and learner of the participant’s narrative. I did not try to lead the participant toward the conclusions that I had hoped for and did my best to respect their account. I found that the three sessions allowed me to develop a relationship with the participants which gave more depth and validity to their anecdotes. The period between interviews allowed myself and the participants to reflect on our topic which may have clarified their memories and thus enriched the data.

## 4.5 Interview questions

I made use of open-ended questions in the interviews (see interview questions guide in appendix 8) in light of Hollway and Jefferson’s (2000) advice to use open-ended not closed-ended questions to elicit more information. Every attempt was made to create a comfortable, relaxed environment to aid the participants to express their thoughts. I gave due consideration to Spradley (1979)’s guideline of using four different types of questions including descriptive, structural, contrast and evaluative. Furthermore I took into account Wellington’s (2000) advice of avoiding five types of questions namely ‘double-barrelled questions’, ‘two-in-one questions’, ‘restrictive questions’, ‘leading questions’, and ‘loaded questions’ in an attempt to gain the best quality data from my participants.

Before interviewing my participants in the UK, I discussed all my questions (based on my research purpose, research questions, information from contacting them and previous interviews) with my interpreter to find the best expressions [taking into consideration the sequence of questions (interview agenda) as well as participants’ ages, socioeconomic status, cultural background and language usage], to allow my interpreter to have a full understanding of my research, to enhance the accuracy of the interpretation and to modify my pronunciation where necessary. In terms of interviewing my Taiwanese participants, I set a similar series of questions which I derived from my research purposes, questions, information from contacting them and previous interviews. I also considered the interview agenda and participants’ background (such as age, socioeconomic status, cultural background and language usage). Following each interview, I sent them a thank-you letter which consisted of the theme of the interview and the next meeting time.

In order to empower my participants, I respected their decisions. The participants could decide what kind of material they were willing to provide and were allowed to choose whether or not to answer any of my questions. I could not anticipate the answers that they would give and at times the thread of our conversation did lead away from my research interest. Also, at times their answers were the opposite of my expectations. An example of this was my hope that my participants would agree that a label of ‘autism’ would be a negative thing. To this end I threw in some questions relating to the issue. In the end I had to accept that the diagnosis is necessary to allow access to the resources that the child needs. Another example was that I had not considered that cultural difference would be a major issue, however, the issue became more significant as I analysed the data. Therefore, to reasonably analyse the data from my interviews, cultural differences had to be taken into account.

### 4.5.1 The first interview

Prior to interviewing, I described my research to the participants and asked them to complete a consent form during the first interview session. At that point the ‘narrative time’ began and the recording was started. I asked the parents to tell me the story of their child’s life, in particular, focusing on any areas relating to emotion. However, in general, details on emotions were only related after some specific probing later in the interviews. During the first part of the interviews I tried to build a rapport with the participants, trying to make them feel at ease. I attempted to steer the conversation towards their child’s emotions, but for the most part the parents wanted to tell the story of their hardships and the trials that they have had to endure during the early years of their child’s life, so I encouraged them to talk freely with only guidance prompts from me to test behavioural accounts. The hypothesis was that parents might focus on diagnosis, behaviour and resources and they did. I asked each of the parents if they had any material or assessments of their child made by professionals and if so, I requested them to bring the reports to our next meeting. Then at the end of the first session I gave each participant a diary and asked them to make notes about their observations of their child’s emotions and feelings before our next meeting. I considered that a diary is an effective way for researchers to gain more related information while he /she is not present. It might also be an opportunity for interviewees to reflect on their thoughts. One consideration though was that writing a diary might be a burden or a negative influence for participating in the research for someone who does not enjoy writing as argued by Willig (2008, p.30) when he says, using a diary: ‘does suffer from poor recruitment and high drop-out rates, due to the high demands it places upon participants. Its success depends very much on the participants’ motivation and commitment to the study’. However, it is also argued that, ‘keeping the diary may sensitize participants to certain experiences’ (ibid.).

### 4.5.2 The second interview

During the second interviews, I attempted to discuss the observations that the parents had made in their diary with more or less success, in some instances the diary had been used with a degree of enthusiasm, but in others as Willig (2008) suggested, I believe that the diary was too much of a burden for the very stressed parents. Following this I shared some transcripts of evidence from individuals with autism and again I had mixed reactions to this which may have been due to cultural differences leading to a different understanding of the material.

After reading the material I asked if they had any documents relating to previous assessments from teachers or doctors and if I could make copies. The participants in Taiwan were very happy to show me everything that they had. However, UK participants were more guarded and only gave me some school reports or avoided showing me any documents at all.

In between sessions 2 and 3, I reviewed all the material before drafting my questions for the final interview.

### 4.5.3 The third interview

At the final stage, I discussed both details from the records that I previously copied, and any observations that the parents had made in their diaries. I also asked them if any of their views had changed upon reflecting on our previous meetings. I attempted to gain further insight into their feelings about their children’s emotions. Then finally, of course, I thanked them for their participation and promised them a copy of the transcription for their approval. Following the interviews, when the transcriptions had been made I sent copies to all the participants. I received acknowledgements from all the participants except one of the UK participants. None of the participants made any comments.

## 4.6 Document analysis

The participants were asked to keep a diary of events between the interviews. Wellington (2000, pp.119-120) and Oppenheim (1966, p. 215) caution that when using diaries we should consider these three issues:

A. Practically: the participant may not be able to devote much time to the diary. They may not be comfortable about writing down their thoughts and observations.

B. Ethically: who owns the diary and would I be given unfettered access. I would have to make my requirements very clear at the outset.

C. Accuracy: the entries may be swayed by the writer, the research may cause them to see emotions that do not exist, or stimulate the provocation of emotion.

Diaries were kept by all the participants except one of the UK participants (Paavai). Larry and Patricia did not return their diary, but read what they had written in interviews two and three. The two Taiwan participants sent me the contents of their diaries electronically prior to each interview. In addition Harry’s mother gave me permission to access her blog which recorded in detail Harry’s development history since he was born.

In terms of documents, Atkinson and Coffey (2011) and Prior (2011) indicate that researchers should be cautious when analysing documents. The scrutiny of original information, the author of documents, intertextuality, and information resource are necessary for checking a document’s validity and reality. I had no reason to doubt the authenticity of the documents that were shown to me by the participants. Larry and Patricia gave me copies of the documents that they were willing to share. I photographed the documents shown to me by the participants in Taiwan, with their verbal permission. The photographs were taken in their presence.

Prior (2008) and Prior (2011, p.95) propose that there are four means to gain knowledge from documents. They are: the document content, how the content came about, the use of the document and ‘approaches that focus on how documents function in and impact on schemes of social interaction, and social organization’. For my research purpose, I have chosen the first approach, which involves focusing on analysing the content and building themes from it, to make sense of my documents.

## 4.7 Data analysis

Following the interview transcription, the data was analysed using ‘thematic analysis’. ‘Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data’ (Braun and Clarke, 2006, p.79). The interview guides helped identify some of the themes used in the analysis; however, there were some themes that emerged during the interviews that were not captured by the original interview questions. Ritchie and Spencer (2002, p. 309) argue that: ‘qualitative data analysis is essentially about detection and the tasks of defining, categorising, theorising, explaining, exploring and mapping are fundamental to the analyst’s role’. The analysis was very time consuming as Lofland and Lofland (1984) indicated when they said you need roughly two to five times as much time for processing and ordering the data as the time you needed to record it. Each interview transcript was analysed and written up as a case study in its own right (Smith, 1995) in the data presentation chapter. In particular the transcription process was very lengthy especially those from UK participants, perhaps due to the complex dialects spoken by the UK participants. All the interviews were recorded. The recordings were transcribed verbatim with added notes relating to the participants’ tone and expressions. The data has been anonymised, classified and catalogued.

According to Clough and Nutbrown (2008, p. 95), ‘the interpretation of research voices is not an issue to be confined to purely qualitative or ethnographic research. The important point here is ‘faithful’ interpretation of what is heard, arising from radical listening which has the characteristics of honesty and integrity’. For my research purposes, human action is more important than statistics, so cross-validation was not being considered. Cooperative inquiry is a form of research where all the parties in the interview work together contributing to the project. ‘This is not research on people, but research with people’ (Heron, 1998, p. 235). I was fully immersed in and engaged with, the participants’ experience; therefore, cooperative inquiry was not used. I did, however, use triangulation and utilise the counsel of third parties to help me verify the data particularly because of language and cultural issues. These parties were my supervisor, my husband, who is British, and a Taiwanese colleague. I utilised a Thematic Analysis to code, sort, reference, categorise, and organise data. The themes of this research were generated from the recording transcripts, and unguided by specific theory or frame. However, there is no doubt that some pre-knowledge unconsciously occurred in my mind when I analysed the data. Realising this situation I utilised the concept of Bronfenbrenner (1979)’s Ecological Framework, though not in detail, in which each system interacts with each other in this theoretical construction and may affect an individual’s psychological development. Therefore, strictly speaking, I had adopted thematic analysis in my research.

When I first read my transcriptions, I became lost in the words and I did not know how to present the interview so that my readers would experience the same feelings as me, at the spoken words of my participants. While writing up the thesis, many questions arose, for example; “Could the words be trusted?”, “What were the limitations of the data?”, “Were there any meanings beyond the words?”, “Were there any meanings not caught by the words?” “Each interview was unique. Would the result have been different had alternative questions had been asked?”, “Would translation influence the analysis?”, “Was it possible to translate from one culture to the other?”, “How did culture affect the way individuals expressed their emotions?”, “Was it a appropriate to use one standard for the whole world, for example, would it be proper to utilise the USA standard (DSM IV/V) to judge our UK/Taiwan culture or children while DSM-V (American Psychiatric Association, 2013, p57) admits that social, socioeconomic, and gender factors might affect the norms of diagnosis?”

## 4.8 Cross-cultural considerations

When conducting interviews and during the analysis of the interview data the impact of culture on how people behave and use language was evident, hence it was necessary to be culturally sensitive in the process.

 ‘Culture is a network of knowledge, meanings, ideas and social rules shared by a group, often referred to as an ethnic group, who may also share geographical origins, religion and language. Culture will affect how illness is understood, the presentation of symptoms, and expectations regarding treatment and treatment choice.’ (Butler et al., 2011, p.713).

‘The type of education and care we offer young children will inevitably reflect the values and beliefs that are held by society and reflected by the government of the day’ (Dowling, 2000, p. xiii). This thesis is written in English and will be considered, at least initially, by academics who are situated in a western culture. I am Taiwanese and my culture comes from a mixture of American, Chinese and Japanese societies. My husband is British and his cultural background is British/American, I mention this because he has had influence on my cultural practice and belief. In reviewing the data it is true that there are things that, because of our cultural differences, would seem alien to me, my husband and you the reader, however, I do not believe that the relevant data falls under this umbrella. The data that relates to the emotional lives of these children is common and it shows that regardless of the child’s culture, they are all emotional beings. Nevertheless, culture may affect the understanding and expression of emotions. Culture is, however, an issue when conducting interviews, particularly in the cases where the participants are from a society that is easily embarrassed by excursions from their norm. This applies particularly to interviewees from Asian cultures, in this case India and Taiwan. Cultural competence is dependent on a number of factors such as socio-economic, education and policy. The researcher must remain detached and be aware of their own culture. The researcher has to consider the environment and their own feelings and emotions and social-cultural background. It will be important to engage the participant through respectful enquiry into their lifestyle (Butler et al., 2011; Hedegaard and Tudge, 2009; Tseng and Streltzer, 2004), for example, someone from a highly respectful and polite society may withhold important detail for fear of offending the researcher. This is illustrated by Kleinman and Benson (2006) and Butler et al. (2011, p. 713) who tell us that a doctor’s patient could find normal questioning during an examination “intrusive or stigmatizing”. They suggest the Explanatory Models Approach could avoid this type of occurrence.

Expectations of a child’s development vary from one culture to another. ‘Various cultures…recognize, define and assign different developmental tasks to the same biological agenda’ (Nsamenang, 1992, p.144). Hedegaard and Tudge (2009) have a similar concept, and think that:

Young children were referred to as ‘non-social’ or ‘pre-social’, and later came the notion of ‘normal’ and ‘abnormal’ phases of children’s development, which were taken up into the public psyche in relation to children’s growth and development in many Western countries. (p. 4).

As the child develops, cultural influences will become a more significant factor as described by Hedegaard (2002). Motives are the goals which characterise the actions of children in different activities over an extended period of time (ibid.). Leontiev (1977) also considers that ‘cultural values’ imposed by ‘institutional practices’ will influence a child’s development. This idea is further reinforced by Nsamenang (2008) who considers, ‘culture, as in social heritage and cultural tools, is a determinative complement of genotype that shapes human psychosocial differentiation in the direction of a given people’s cultural meaning systems’ (ibid., p. 73). Nsamenang (2007) also postulated that love for descendants ‘is packaged in a wide variety of cultural and emotional expressions, such that no way of loving children might translate as a universal fact of humanity’ (ibid., p. 10).

Kincheloe (2002, p.76) reminds us not to overlook the ‘diversity and complexity of childhood’, for example, what appears to be deficient behaviour may be considered as normal in another society calling for ‘rigorous forms of analysis’ when studying children’ (ibid.). This is further supported by Prout and James (1990), who advocate that ‘comparative and cross-cultural analysis reveals a variety of childhoods rather than a single and universal phenomenon’ (ibid., p. 8). Kleinman (1987), Rack (1982), and Butler et al. (2011, p. 714) indicate that in every culture, symptoms can be psychological as well as somatic and that many somatic symptoms are the result of mental distress, medically it may be that a somatic presentation is more socially acceptable.

Translation has also had to be a major consideration as half of my interviews were conducted in Mandarin. The Mandarin vocabulary to describe emotions and feelings, for example, is somewhat limited as in Chinese cultures it is not customary to show emotions and certainly not to strangers. Temple and Young (2004, p. 175) point out that translation can have a positive or negative impact on cross-cultural relationships with a potential to affect research outcome and Oishi (2010, p.35) comments that in ethnographic studies there is, ‘a surprising lack of some equivalent concepts in different societies’. Russell (1991) also noted that in literature concerning emotion some cultures do not have words for emotions, such as happiness, fear, and anger, According to Russell, Chewong language in peninsular Malaysia has no word for happiness; in Tahitian and Chewong, no word for sadness; in Ifaluk, Utku, and Pintupi, no word for fear; and in Fore, Dani, Malay, and Ifaluk no word for surprise. Oishi (2010, p.36) thinks that language concerning emotions ‘should result in predictable cultural differences in the frequency and intensity of these emotions’ and that in different cultures, evoked emotions may differ (ibid). On cultural differences, Chen (1992) reminds us, for example, that in some Chinese cultures the western concept of human rights is second to an individual’s loyalty, obligations, obedience and duty. Confucius (552-479BC) and other outstanding ancient scholars taught that in order to maintain ‘peace, harmony, stability and a good society’ the individual should be considered after society as a whole (ibid.). Lewis (1999) adds that the contrast of Western tradition, which considers the individual first then the rest of the community, against the Chinese tradition of personal obligations and altruism, may be characterised as individualism versus collectivism.

Ho (1996, p.155) in describing Chinese culture tells,

How children should behave to their parents, living or dead, as well as to their ancestors. It makes stringent demands: that one should provide for the material well-being of one’s aged parents, perform ceremonial duties of ancestral worship, take care to avoid harm to one’s body, ensure the continuity to the family line, and in general conduct oneself so as to bring honour and avoid disgrace to the family name…filial obligations…are overriding in importance, rigidly prescribed and are binding from the time one is considered old enough to be disciplined until the end of one’s life. (ibid).

When considering the view of individuals with special needs in the Far East, Lewis (1999) tells us that in Chinese societies people with special needs are considered to be a burden to their family who may think they are being punished in some way, so the child with special needs is an embarrassment or brings shame to the family and the parents might hide children with obvious disabilities from public, or even family view. In Chinese societies, children have an obligation to support their parents in their dotage, so a child with special needs who cannot fulfil this obligation is seen as a burden rather than an asset. Chinese culture will not make allowances for personal deficiencies, considering that hard work will make up for lack of intellect or ability (ibid.). Stevenson and Shin Ying Lee (1996) cited in Lewis (1999) explain that hard work is key for success and if an individual works hard then disability will not be barrier. Lewis (1999) then goes on to tell us a Chinese proverb which reinforces this concept: ‘with hard work, even an iron bar can be refined to a needle’ (ibid). Lewis (1999) continues by quoting Chan (1992) who reports that mothers in Far Eastern cultures instil the importance of hard work and effort in their young children, believing that this will be the main factor in their academic success.

In support of these points, I can personally confirm that this is indeed the case. Children in Taiwan spend plenty of time doing school work, for instance, they start school at 8am and after school they are expected to attend after-school classes which often finish at 7pm for elementary school students and 10pm for students from high school, they will also work on Saturdays and even Sundays for older students. I understand that from a Western culture point of view this may seem extreme; however, one has to consider that normal working hours in Taiwan are longer than in the West. For example, a teacher in Taiwan starts work at 7.30am and the children start lessons at 8.00am. The children will leave at 4.00pm, but the teachers will be expected to work until 7pm and in some cases teachers finish work as late as 9 or 10pm. In addition to this, teachers will have to attend conferences on weekends at least once per month. I make these points because teachers’ work situation is not atypical, so it might be considered reasonable to prepare children for long working hours in Eastern cultures.

## 4.9 Ethical considerations

Ethical issues for researchers are very important from the beginning of conducting research (Brinkmann and Kvale, 2008; Clough and Nutbrown, 2008; Willig, 2008). Clough and Nutbrown (2008, p.173) point out that University research has to be approved to ensure that ethical standards are maintained, in order to assure the safety of all parties involved, that ‘informed consent is given by the participants’ and that all data is anonymized. This is not just for ethical reasons, but also to ensure that the research meets a standard that is acceptable in society, and that while the process of review may vary from university to university the basic precepts will be the same. Similarly, Brinkmann and Kvale (2008), Cohen et al. (2007), Hennink et al. (2011), and Willig (2008) point out that researchers need to consider several aspects, such as informed consent, access to research settings, participant’s self-determination, minimisation of harm, privacy, no deceit, debriefing, and confidentiality.

As a researcher, I have adhered to sound ethical procedures. First, this research was subjected to the University of Sheffield’s ethical review procedures and permission to carry out this research was sought from the School of Education’s Ethics Research Committee. Second, I identified potential participants, explained the nature of my study and sought their informed consent. Third, the research was carried out in the participants’ homes, by their invitation. In all cases I offered alternative venues, but all of them chose to be interviewed in their own homes. Fourth, I provided sufficient information to my participants to allow them to make an informed decision about their participation in my research. Fifth, I did my best to avoid any harm to my participants as a result of my research methods, attitude or material. Finally, in order to protect the participant’s anonymity and confidentiality, I have concealed the participants’ real names and other personal information. In addition, the participants were given an opportunity to review and approve transcripts of the interviews. The authorisation of all participants was obtained before including any data relating to them in the research.

There was no potential for physical harm. My research involved interviews with parents. I am experienced at interviewing the parents of children with autism in a professional capacity having worked in a similar environment for 13 years. On some occasions they were overcome with emotion. This possibility was anticipated as in some cases their child had recently been diagnosed, or reflecting on some events from the past can evoke powerful emotions. I endeavoured to empathise, both on a personal and professional level and was able offer some comfort on the few occasions that this happened. Both my interpreter and I are of a calm nature and we did our best to obviate this possibility. However, when I perceived that a participant was becoming distressed I stopped the interview and allowed them to recover. At no time did the participants have to answer any questions. The children were not present during the interviews, with the exception of one of the Taiwanese participants, whose child was present, but in the care of their live-in child minder. All of the interviews were conducted in as sensitive a manner as possible.

Some individual ethical dilemmas arise while conducting research involving three cultures (UK, India, and Taiwan), such as a cultural/translation dilemma. For example, during the interviewing process, Paavai repeatedly and unconsciously mentioned that she is in high status of the Hindu Caste System, and her English is embedded with strong Indian philosophy. I faced the dilemma of analysing her data literarily, or taking into consideration her cultural background. In order to obtain what I believe to be the best results from her narrative, I tried to remain non-judgemental, exploring Indian culture and being cautious with interpreting and analysing the data, while at the same time believing that everyone is born equal and being unfamiliar with Indian culture. Another dilemma that I faced was with the data from Ya’s interviews. Should I focus on the transcription itself, or include some of my observations and data from her diaries. Considering Taiwanese culture which tends to be self-deprecating, I felt that it was essential to include some of my observations, some of Han’s teachers’ comments and the political background. For example; Ya told me several times that she beat/hit (打) Han when he behaved inappropriately. Considering that I did not see any bruises or scars on Han’s body, and Taiwanese regulations in which clinical and educational staff have a mandatory obligation to report signs of abuse on children to police or the child protection agency, I prefer to use the interpretation ‘slap’ rather than ‘beat/hit’.

In addition, it is necessary to consider the participant’s real behaviour. For Ya, even though she always keeps Han in good physical condition, cooks healthy/nutritious food, finds useful resources, brings him to attend treatment and intervention, and spends time playing with him, she still thinks that she has not done enough. She blames herself as a bad mother, because she takes an afternoon off per week to do exercise, instead of spending more time teaching Han. She blames herself for Han’s state and for not raising Han to be as capable as other children. A literal translation of her data, without giving consideration to her real behaviour and societal expectations / pressure on a mother might create a false illusion of objectivity and mislead my reader to believe that she is selfish and irresponsible.

## 4.10 Scope and limitations

As autism manifests itself in different ways, children with autism will have very diverse difficulties. This makes it difficult to compare the progress of one child against another. That is to say that, although individuals with autism share some common features, no two individuals are the same. In addition to this, the pattern and extent of difficulties may change with development. Common characteristics help us to understand the general needs associated with autism, but it is important to combine this information with the knowledge of specific interests, abilities, and the personality of each child.

Without doubt, parent narrative is affected by the participants’ knowledge of child development, expectation, cultural background, observational skills in detecting differences in development, memory for those differences …and so on. After thinking through the pros and cons of parent narrative, I attempted to reduce the impact of the disadvantages. For example, I attempted to get medical and educational reports of the children, through their parents, to support the parents’ verdict.

# Chapter 5 Parental narratives from my research

This chapter is organised into four main sections which consist of the stories of four families who participated in the study. Each family had either one or two children with autism. The stories were generated through interviews which were conducted on three different occasions with parents of each family. My research purpose is to explore the emotionality of non-verbal young children with autism through parent narrative. My research question is ‘what factors affect the emotional lives of children with autism and their families?’ I am aware that my shifting positionality in this thesis is a consequence of the medical model being dominant in our society and professional training. I use the term autism in an attempt to describe a temperament/idiosyncrasy/living style rather than use the medical model terms which imply that autism is a disorder. I am also aware that a child has the right to speak for himself/herself (James and Prout, 2001), and ‘the importance of listening to the voice of the child rather than talking to children’s proxies’ (Runswick-Cole, 2013, p.105).

Parker and Burman (1993) highlight three issues: firstly, a researcher’s interpretation of narrative might violate various ‘possible interpretations’ (p.156). Secondly, instead of empowering their participants’ voice, a researcher might overpower them to meet their own academic, organisational or political needs. Finally, lacking cultural knowledge could affect a researcher’s judgment when interpreting data. As these children, who were from three different cultures, were unable to tell their own stories, their parents were the best alternative information source to help me understand their emotionality. Rather than analyse small sections of data in detail, in order to maintain the purity of the parent narrative and to avoid misinterpreting their stories in diverse cultures, I have allowed the stories to ‘speak for themselves’.

Meanwhile, sociological views of emotionality were adopted instead of more biologically informed accounts. Bronfenbrenner (1974, 1979, 1995) asserts that the process of human development is continually shaped by the interaction between an individual and his or her surroundings. Bronfenbrenner’s Ecological model has five systems—individual, microsystem, mesosystem, exosystem, and macrosystem. The microsystem refers to the institutions and groups that most immediately and directly impact the child's development including: family, school, religious institutions, neighbourhood, and peers. In the microsystem, the quality of the husband-wife relationship needs to be considered, because it affects the quality of the parent-child relationship and child performance (Bronfenbrenner, 1995; Crockenberg & Smith, 1982; Moss, 1967; Moss & Robson, 1968; Robson, Pedersen, & Moss, 1969). Bronfenbenner (1990) also emphasises that increasingly complex reciprocal interactions are necessary to a child's emotional, intellectual, and physical development, and that they require considerable effort and attention from both parties. Cole, Teti, and Zahn-Waxler (2003), Cox and Paley (2003), Eisenberg et al. (1999), as well as Morelen and Suveg (2012) also find reciprocal influence in parent–child emotional interactions (positive and negative emotions). The mesosystem refers to the interconnections between the microsystem and the wider interactions between the family and teachers, the relationships between the child’s peers and the family. It is worth noting that intermediate-involving second-order social networks have two vital functions. One is to be an agent when parents are eager to receive resources, but the source is unavailable for their own abilities. For example, a working mother can detect what happened in parents’ meetings at a school from a friend even though she cannot attend it. The other is to identify human or material resources. For instance, a mother asks her relatives for help in finding a job. ‘Perhaps the most important mesosystem function of social networks is unintended: they serve as channels for transmitting information or attitudes about one setting to the other’ (Bronfenbrenner, 1979, p.216). The exosystem involves links between a social setting in which the individual does not have an active role and the individual's immediate context. For example, a parent's or child's experience at home may be influenced by the other parent's experiences at work. The parent might receive a promotion that requires more travel, which might increase conflict with the other parent and change patterns of interaction with the child. The macrosystem describes the culture in which individuals live. Cultural contexts include developing and industrialized countries, socioeconomic status, poverty, and ethnicity. A child, his or her parent, his or her school, and his or her parent's workplace are all part of a large cultural context. Members of a cultural group share a common identity, heritage, and values. The macrosystem evolves over time, because each successive generation may change the macrosystem, leading to their development. Therefore each macrosytem is unique. In summary, external milieus also play critical roles in shaping an individual’s emotionality, such as family (Bronfenbrenner, 1979), educational settings (Bronfenbrenner, 1979; see Kenway and Youdell, 2011; Zembylas, 2011), clinical settings (Bronfenbrenner, 1979), policy (Bronfenbrenner, 1979; see Wilkinson, 2009), and society (Bronfenbrenner, 1979). When compared to the popular, medical deficit model, I agree more with Bronfenbrenner (1979, p.291)’s statement ‘the deficit model often [underlies] the choice of problems, variables, methods, and research design’ because professionals, researchers, and practitioners tend to blame an individual’s difference or the person’s family rather than change the whole system. Here I adopted Bronfenbrenner (1974, 1979, 1995)’s concept, in which an individual’s experiences are deeply affected not only by him/herself but also by external milieu, rather than his whole ecological system in detail, which might overlap some relationships between microsystem and mesosystem because of first-order and second-order network issues.

Therefore to better understand the emotionality of children with autism, each story is presented in a separate section and the data are organised into six main themes which arose from the Thematic Analysis. The 6 main themes are: individual, family, educational system, medical system, policy, and society. Briefly speaking, the ‘Individual’ theme consists of the history, emotionality and behaviour of young non-verbal children with autism. The ‘Family’ theme consists of all family members (parents, grandparents, and siblings), relatives, and parents’ friends. The ‘Educational System’ theme consists of professionals and staff working in the educational systems. The ‘Medical System’ theme consists of professionals and staff working in the Medical systems. The ‘Policy’ theme consists of regulations and laws in a nation and the ‘Society’ theme consists of the immersed cultures/sub-cultures that the children with autism are in.

Each of the main themes has several sub-themes and branches. I have utilised a branch chart (see figure 2 below) to show the relationship between each category. The chart used below is an attempt to show how the main themes and subthemes that emerged in the study interact with each other and gives an idea of the existing hierarchy between the themes as demonstrated by Bronfenbrenner’s (1979) Ecological Systems Theory and Gergen’s (2009) book ‘Relational being: Beyond self and community’. As can be seen from the chart, the individual child with autism is shown at the centre of the research and the themes which emerged. Other main themes are placed in accordance with their relationship with increasingly larger social contexts.

**MEDICAL SYSTEM**EFFICIENCY
DIAGNOSIS
TREATMENTMEDICATION
SUGGESTION
THE CHARACTERISTICS OF GOOD DOCTORS
PATIENT-DOCTOR RELATIONSHIP

Figure 2: the relationship between each of the themes identified in this research

Within each individual theme (sphere) my analysis generated four sub-themes including autism, history, emotionality, and behaviour. Within each family theme (sphere), parent, sibling, grandparent, other family members and friends were generated. The medical system and educational system are at the same hierarchy. In the medical system domain (sphere), efficiency, diagnosis, resource (treatment), medication, suggestion, parent-doctor relationship, the characteristics of good doctors are generated themes. With respect to the educational system, resource class, mainstream class, tool, progress, resource, the characteristics of good teachers, placement, and parent-teacher relationships are generated themes. The cultural view toward children or autism, the neighbour’s reaction and societal pressure are generated themes in the society domain (sphere).

This study involved working with two families who were living in the UK and two families who were based in Taiwan. One of the UK families was originally from India. Among my research participants, their families are all nuclear families. In two families, the father is the main caregiver of their non-verbal child with autism. In the other two families, the mother is the main caregiver of their child with autism. The parents told me about their life experience of dealing with autism and in particular about how their children communicate through their emotions and how the children interpret the emotions of their parents. The following section presents the four stories.

## 5.1 Thomas

On November 17th 2011, I first interviewed Larry and Patricia concerning their son Thomas who was nine years old at that time. All three interviews were conducted in their home.

Larry and Patricia are around 50 years old, their ethnicity is white British and they are both university graduates. They live in Sheffield. Patricia works as a teaching assistant at a school for children with special needs. Larry previously worked for a mental health charity but currently he is a full time carer for their children.

Larry and Patricia proved to be a very welcoming and relaxed couple, with strong Sheffield accents, who seemed keen to tell us their story. My interpreter, Peter was present during all three interviews.

My interviews were focused on Larry and Patricia’s experience with their son Thomas. Thomas is the second born child in the family and was diagnosed with autism when he was nearly four. This was confirmed in his reports between 2010 and 2011. He was also diagnosed with Severe Learning Difficulty (SLD), extreme anxiety disorder with obsessive compulsive presentation and as being proprioceptive in 2010. He is considered non-verbal and is incontinent. Thomas is a physically attractive boy who displays a competitive and somewhat wilful nature often surprising his parents and those who are around him.

Larry and Patricia also have two other children, Edward who is eight and has also been diagnosed with autism and Jordan who is nineteen. Jordan is mostly living away from home, and attending university. There is no indication of a diagnosis of autism for Jordan.

### 5.1.1 Individual [[3]](#footnote-3)

ASD implies that individuals with autism lack some abilities relating to their emotional competence (American Psychiatric Association, 2013). However, Larry and Patricia prefer to see that although their sons have autism, they are still bright, expressive and feeling children.

This family has two children with autism. Larry and Patricia tell me that both are different and unique in terms of their behaviour, emotional disposition and abilities, and that they have to use different approaches to meet each child’s needs. In some cases they cannot predict the outcome of their approach, for example:

L:…they are very complex in their own way and have completely different needs…They’re a complex set of issues, however a lot of that is how you respond to them, or how we’ve responded to them. (L & P 1.29)[[4]](#footnote-4).

The first sign of autism in Thomas occurred when he was 35 months old. Flapping gave his parents concern that there was something different about him. Although they did indicate that they had other concerns. For instance in the early stages of Thomas’s development he had a limited vocabulary which, according to his parents, he then lost. They said that, ‘you know he was using words then, he probably had a vocabulary of about ten to twelve words, at that point in time. In terms of his development, ‘that’s lost’ (L&P 1.83).

#### **5.1.1.1 History**

No doubt most parents hope that their child will grow in good health. After Thomas was born, his physical condition appeared to be somatic. For example, he had a problem in his digestive system which had to be corrected with surgery. Then, his parents were told that he had a hole in his heart. In the end they found that the hole would heal itself.

After solving and living through all these difficulties they were finally faced with autism - and this time there was no specific approach or treatment to deal with it. Larry and Patricia told me despairingly ‘we thought we were all clear then. We’d had all this trauma and then that was just the start really’ (L&P 1.62). Later, a doctor suspected that Thomas might have Prada Willis syndrome. After medical investigation, the doctor concluded that this was not the case.

#### **5.1.1.2 Emotionality**

Thomas’s parents observe that Thomas is now showing more types of emotion, has emotional competence (ability to control and understand his emotions and discern the emotional state of others), and ‘gets in a bit of a circle’ (L &P 1.194-1.196). According to Thomas’s parents, he has exhibited a range of emotion. At times, he can feel vulnerable. He can enjoy, or like, things or experiences. He gets stressed, particularly when he encounters the unexpected, or if he has to wait. Thomas expresses his emotions mainly through his body language as well as through facial expressions; therefore, his parents distinguish his emotions and feelings by his sounds and behaviour, although they sometimes feel confused about his emotions. Was it that his emotions were always there in a full spectrum but just masked by his behaviour, or has his becoming calm allowed him to develop more complex emotions through the observation of others?

They describe an instance of Thomas’s grumpiness and happiness: Thomas expressed his desire to go to Grays Park through the Picture Exchange Communication System (PECS); however, his parents considered his brother’s needs and decided to go to Cleethorpes instead. At first Thomas was grumpy, but later he controlled his temper, enjoyed the trip, and asked for a further trip to the park he likes. His parents thought that it was a good experience for Thomas because ‘the old range of emotions that go with communicating have become more prominent’ (L&P 3.86).

When he is motivated, Thomas is stimulated and he will do the things that he likes continuously without supervision. Thomas’s situation resonates with Durden (2007)’s testimony. His motivation is sometimes affected by his mood. He will become easily irritated and has no consideration for time or the circumstances. Sometimes, he will discard a toy in the corner, and then play with it again several weeks later. Thomas’s motivators are food, being driven around, and other things that he particularly likes (drum, acoustic music).

Thomas has formed emotional attachments to his parents and his favourite teachers. He is excited to see them and prefers to interact with them in a group. His parents believe that ‘attachment with other people…is important’ (L&P 3.328), and ‘knows he can transfer that …and then demonstrate that’ (L&P 3.330-3.332) even though ‘he doesn’t show it all the time, perhaps to varying degrees’ (L&P 3.325). However, I think that this is more like social interactions. Nevertheless, Thomas might have interests in human beings and attempt to socialise with them. He uses facial expression, gestures, body language, sounds (‘mun’; L&P 3.320) and behaviour (wants kissing and to snuggle up) to show his attachment or social interactions.

During the interview process, Thomas’s parents told me that his social interaction with others (such as turn-taking and interacting) is developing as is his cultural-shaped protocol comprehension with other people. For example, he gives male staff a handshake and female staff a hug at school. After reflection, they realised that Thomas does have some interests beyond his personal needs and has started to have social interaction with others. In one example, Thomas brought his favourite toys (Teletubby, Toy Story Three) to his parents and wanted them to press the button, and then he hid under a blanket. In another example Thomas has started to play throw-and-get ball with others. This has come about since we started my research interviews with his parents. Thomas also likes to be tickled. Larry thinks that Thomas might generalise his school experience into family.

His parents told me that Thomas can definitely recognise his parents and other family members. His parents believe that he seeks the attention of those around him to meet his needs. Is a person in his eyes just a tool or someone to develop a relationship with? Mostly, Thomas seeks either parents’ or teachers’ attention to meet his needs, for example, driving him around. ‘Thomas does have different people for different jobs and he will go to whoever he thinks is more likely to help him…He does seek attention for things he wants you to do to satisfy his needs’ (L &P 1.198), ‘and sometimes he can be quite loving as well… He will come up and he’ll want kissing, he likes kissing he likes you to kiss him on his head’ (L &P 1.200).

His parents gave an example of Thomas’s sense of humour;

P: I think he can be mischievous as well. I think he understands that, because we’ve got Sky TV and I thought there was something wrong with it and was calling their service not very nice words. Saying “It’s rubbish this sky, It keeps going off. What’s the matter with it” de de de and I actually was in here and I saw it wasn’t anything to do with.... Thomas’s been pressing the buttons and he looked and he was laughing and I think he was a bit proud that he’d been doing it, but he was mischievous about it. (L&P 1.225.2).

In the past Thomas has evidently displayed many negative emotions, but at the time of the interviews I was told that he had started to control these. Does this mean that he has developed the ability of emotional regulation?

P: I think school have said as well that they have noticed it. They’re quite proud of him at school because they know, obviously within any school day there will be some things that Thomas will like better than others. There will be things that he will find more difficult than others. They’ve said they are really quite proud of him, because... I don’t think he is very into PE anyway and they said that even things that he found difficult, they felt that he was trying to control... someone said he had control of his emotions really..yeh didn’t they... that were a new star of the week, because even things he’s find difficult he’d try to... I think he’s got more skills to try and help him do you know what I mean… like I might say to Larry, “I don’t think that that was right and you have upset me, but he can’t say that can he? because he can’t speak. (L&P 1.249).

Interestingly, Larry and Patricia do not think that Thomas can recognise emotions in other people. Yet they provide several anecdotes to demonstrate that Thomas does recognise the emotions of people working with him. Thomas has demonstrated that he recognises his parents’ happiness and other emotions, such as pride, anger, pleasure, surprise, fear, liking, and disliking. Perhaps for Thomas, he only distinguishes the emotions of those who like and accept him.

In addition to this, his parents told me that Thomas has his favourite people, and this is usually because they like him first, and Thomas can sense it, so he likes them back. Furthermore, they think that Thomas is sensitive to other people’s emotional states from the tone of their voice, or body language, but not their facial expression.

P: But I think he can tell. If you’re angry, if you’re cross yeh. By his then reaction to it, because he’s obviously reading some emotion there. Coz he’s then reacting in a negative...well not a negative way but he’s then showing his emotion by going on his knees. (L&P 3.96).

Larry and Patricia told me that Thomas detects if someone likes him. The bus crew were changed and he liked the new crew better.

P: I was just thinking about the escorts on the bus. …he’s now got a different driver and a different escort and he’s took to them better. I think these two were maybe just a little more laid back. Very different styles and I think that’s helped Thomas. I think yes he would pick up if somebody was in a bad mood and he would go to somebody else. I think he would. It might be driven by something he wanted. (L&P 2.135).

According to Thomas’s parents, he can tell when they are surprised because they usually verbalise and show their emotions to him, and his reactions are dependent upon what the surprise is. They also told me he likes to surprise them by showing them the things he is proud of.

His parents believe that Thomas can sense whether people accept him and he can identify who is in charge in a group. The following is an example;

L: That time he took her (Aida) to the door, Patricia’s auntie, and she doesn’t give off very good vibes at all. She’s very domineering… and she came and Thomas took her straight to the door. Oh I’d so like to do that. So I think he can read people and he can perceive people, but what’s really interesting to know is they always seem to know who’s the boss, or who’s in charge, or where the power lies …Who’s in charge, who’s the gaffer or he always seems to understand the hierarchy for whatever reason. (L&P 2.123).

These anecdotes lead me to the conclusion that Thomas does have empathy and emotional competence. These emotions are capricious and extreme. He uses facial expression, body language, and behaviour to express his emotions and affections to others. His parents and I wonder if his emotions were always there in a full spectrum, but just masked by his behaviour, or has his becoming calm allowed him to develop more complex emotions through the observation of others?

The parents reflected on a number of emotions. For example, Thomas feels happy when he is swinging and he shows his sadness by weeping silent tears or crying. When he becomes angry, he shows it by his behaviour, such as banging, hitting, slamming doors (such as the cupboard, or the oven), and by falling to his knees. His parents told me of an absolutely devastating moment when Thomas showed his sadness;

P: He’ll sink to his knees quite dramatically...just like crush, drop to his knees, won’t he? And he’ll either put his fingers in his ears, or sorta pulls his eyes like that and we were thinking that maybe that’s probably him as well, you know like we were saying last week about being hypersensitive, because he’s obviously not happy about something, or maybe it’s something he can see or whatever. He’s trying to sorta block it out. (L&P 2.12).

Thomas can be grumpy, upset and jealous. He shows his jealousy by sometimes fighting for his parents’ attention. One example of his jealousy was when Larry was lying on the bed with Edward, Thomas dragged Larry away from Edward and snuggled with Larry. In most cases his jealousy takes the form of sibling rivalry resulting from his parent’s pride in his brother which he demonstrates through aggressive behaviour. Larry and Patricia elaborate further:

P: Yeh, coz they’re unpredictable, aren’t they, children. Do you know what I mean? All children are, I mean we’ve got two photos on that cupboard door. Haven’t we? Int’ kitchen and one’s of Thomas and one’s of Edward. Edward’s is like a collage from school of things he did in his class last year and Thom’s took to sort of hitting it, writing on the photo, the big photo of Edwards face and I sort of said, the other day, “Oh look yes it’s Edward.” And he looked at me and (makes growling sound) you see and I thought that wasn’t the right thing to say. (L &P 3.102).

Larry and Patricia told me that they think Thomas feels embarrassed, or ashamed if he has a bowel movement when someone else is present. If his toilet routine is interrupted he will be angry. With regard to shame, Larry and Patricia were unsure about the definition of shame, but they said they know Thomas can tell right from wrong. Thomas also knows his parents dislike him doing certain things, although he will look straight at them and still do it. Does Thomas’s behaviour show he enjoys challenging his parents’ limits just like other children?

Referring to disgust, Larry and Patricia jokingly told me that ‘I’ve never known anyone worse than Thomas with disgusting habits. He just beats the world’ (L&P 3.205). Mostly, he shows a disgusted face in the school photos or being ‘unhappy with things’ (L &P 3.214).

Thomas does have a sense of pride; when he accomplishes something new he is very pleased with himself. Sometimes, he will show his pride to his parents by demonstrating his new learned skills, such as being able to use a swing.

They also told me that Thomas has a fear of the unexpected, of swimming pools, and anybody new. He will react to these things by hiding under a blanket or climbing up something. Notably, his parents think that hiding under his blanket is a way for Thomas ‘to try and hide from the world, to demonstrate how scared and frightened he is, and how overwhelming sometimes things are for him’ (L&P 3.177). Perhaps it is just a case of sensory pain/discomfort, or seeking security from a familiar smell and cosily wrapped fabric. According to Thomas’s parental accounts, no matter which, sensory issues play an important role in Thomas’s emotional life.

Thomas likes to feel secure and safe; he suffers from anxiety (worry). Thomas is anxious about things happening unexpectedly especially in a flexible boundary scenario (such as at school and at respite) without visual clues. When faced with a scenario that he does not understand, he will show his worry in different ways. Thomas does have the emotion of worry and, to alleviate his anxiety, his parents have found an alternative organisation (similar to school) for holidays, and they take him there no matter how far it is.

Some other examples; he also shows his likes and dislikes making his feelings quite clear. If he dislikes wearing something ‘he will take it off and throw it or try to hide or discard it or whatever’ (L&P 3.237). He can become frustrated and he can be content -although it is rare for him to exhibit stable or middle level emotions. Based on the information Thomas’s parents provided, they wonder that his behaviour is due to his limited language ability, so he expresses his will through his strong actions.

Thomas gets excited by many things, in particular lights – like the Blackpool Illuminations -watching television, jumping on a trampoline, or playing on a swing. He shows his excitement mostly by ‘jumping up and down’ (L&P 3.30).

He exhibits shock and surprise, and normally dislikes surprises. ‘He likes to be pre-warned’ (L&P 3.263). As an example, some of his classmates were invited to Edward’s birthday party and when Thomas saw them he went upstairs immediately and refused to join in. Larry and Patricia thought that this might have been because of the noise. At Christmas, he was surprised at seeing the Christmas lights suddenly come on even though he has no idea about Christmas (such as wrapped gifts, Christmas decorations, Christmas parties, or concerts).

Sometimes, he will surprise his parents by showing them his new skills, or by unexpected behaviour (such as enjoying a Christmas party). Larry and Patricia tried very hard to find an example of Thomas showing empathy, and ended up giving me this one. I am unsure if it is a good example of empathy but it might be a case of responding to Joint Attention (RJA).

In this example of empathy, Thomas took the register to the office accompanied by a teacher and a classmate with limited mobility.

L: [T]ypical Thomas, he sort of raced off ahead, because he would do, that’s how he is by nature and on this particular occasion. The little girl who was accompanying him was one with quite limited mobility, so obviously a member of staff would go with Thomas, anyway, but the member of staff was actually helping the little girl to actually get her way round the school. Thomas obviously got to a point and he realised that they weren’t near him really. He was quite safe; do you know what I mean? And he actually stopped and waited for them to catch him up. Now whether or not that is showing empathy for the little girl, or maybe an awareness of that whole situation we’re not terribly convinced, because it may well have been that Thom couldn’t get into the office without the member of staff, who was with the girl. … I do remember as well the member of staff saying that she was saying! “Oow Thomas. Wait a minute. Hang on”. Not really expecting him to and he did actually stop and did actually wait for them to... to come to that point. (L &P 2.14).

Larry and Patricia identify some factors that trigger Thomas’s positive emotions. For example, he likes to be driven around, having his own space, he likes drinks, eating (very strong tasting food, sauces and boiled rice), playing on a swing, flicking his blanket, things to be in order, sitting on a rocking chair, a specific page in a book, certain cups, being cuddled for a short time, being tickled, a certain toy train, some acoustic music, predictable routines and things, the colours red and purple, climbing (L&P 3.43), and the lights. These things make him calm down and feel happier. His parents explained how space affects his emotions:

P: Space is so important to him and that’s true at respite as well because it’s a very big place. So it’s all linked, it’s linked to his emotional wellbeing as well, because then he’s less distressed, he’s comfortable and he’s in his comfort zone, its where he feels comfortable (L&P 1.205).

Thomas’s parents thought that the factors that trigger his negative emotions are his lack of language ability (poor communication), hunger, pollen, hypersensitivity, medication, daylight, seasonal changes, the unexpected, loud noises, and waiting.

#### **5.1.1.3 Behaviour**

Thomas has many unique behaviours. For instance, he is a really bad sleeper waking up often during the night - although going to school has made him sleep much better. He flaps, walks on tiptoe and is self-injurious. He plays with his navel and bites his hands. He will run up and down continuously and is self-stimulating.

Thomas is very poor at communicating due to his lack of oral language. He has been heard to say ‘banana’ and ‘mom’ in an appropriate manner (L&P 2.154), but he cannot express himself, so he feels frustrated and angry. He has gradually developed a different way to express himself and his emotions based on his level of communication. Thomas’s parents made the following comments concerning his different approach:

L: He used his behaviour to communicate; he used his self-injurious behaviour to communicate, that’s really all he knew, to be fair to him, he must have been that frustrated and that angry and he had no way really of dealing with that. It was horrific, he was very bruised, we were really struggling to cope...(L & P 1.105).

Thomas becomes excited by changes in the light on television and in light displays. He has his preferences, he likes to use certain cups at home, a particular sauce, ‘have different foods on different plates’ (L&P 2.150), and he has a favourite toy train.

His parents say that ‘Thomas has really challenging behaviour’ (L&P 2.145), such as aggression and self-harm. He becomes fixated and has to have a specific type of bottle, routine, and objects in a specific location he wants to ‘have different foods on different plates’ (L&P 2.150). When he eats he has very bad manners and is hard to be fed. Using Thomas’s bad manners we can have a glimpse of the issues his parents encounter in daily life.

P: There are some aspects of it that aren’t Thomas-like, but he has always been obsessed with it and he doesn’t like other people eating. Like if we were all eating now he’d be going round picking food off everybody, you know he hoards the food. He would have to have the food…(L &P 1.112.2).

Thomas is generally very non-cooperative. He has an excellent memory of roads and routines and dislikes changes of route, routines or schedules. He is a visual learner and prefers to have visual clues to tell him what will happen next.

Thomas has many sensory issues: his parents suspect that his hypersensitivity affects his emotions and feelings, and makes him have bigger negative reactions because he is overwhelmed by sensory stimuli. Nevertheless, he enjoys sensory experiences such as playing in mud and slime on the beach and learns better through his senses.

Thomas is self-directed and needs to be motivated to gain his participation. His poor communication skills cause him to be extreme in his expression of his emotions. He has a high pain threshold.

Thomas prefers adults to children and he likes certain people in particular. He is ‘wary of people in the first instance’ (L&P 2.117). If he dislikes a person, ‘he will just take them to the door’ (L&P 3.258). Some people stimulate him and he “gets something from them” (L&P 2.113), if they engage him more, understand him or meet his needs. However, there was one exception. Normally Thomas would ‘look a bit’ and then ‘walk straight past’, but on this occasion he encountered a warm lady and had a social interaction with her (L&P 2.122).

His parents have noticed that Thomas’s mood and anxieties affect his contact with other individuals. Opening a door and meeting an unfamiliar person is just like ‘a trigger for his anxiety and stuff’ (L&P 2.125). When Thomas meets an unfamiliar person ‘he’d much prefer to probably make that judgment and suss people out a little bit so maybe he does show his emotions’ (L&P 2.126). I wonder if his first impression of an unfamiliar person affects his desire to socialise. They also believe that Thomas ‘can read and perceive people’ (L&P 2.123, L&P 2.134). He might pick up on another individual’s body language. Additionally, he ‘seems to know who’s the boss, or who’s in charge, or where the power lies’ (L&P 2.123), and ‘his favourite is a team leader’ (L&P 2.124).

Thomas needs his own place, and dislikes it when other people (such as his grandparents) visit his home. If someone steps into his territory, he will drag them away or ‘put his head under his blanket or something’ (L&P 3.288). He likes to put his own toys and stuff in a specific corner untidily in the living room, but he definitely knows where to find the thing he wants even after several weeks.

Thomas is impatient about waiting, especially for food. He shows his impatience by hitting himself. He is irritable particularly at bath time. At times he loves it and sometimes he hates it. While he is in a ‘dislike’ mood, his parents opt not to bathe him for health and safety reasons (L&P 3.239).

Thomas generalises his school experiences at home. When he learns something new at school he will use it at home, for example if he learns a new game at school he will try to play it at home. He is easily bored by routine and enjoys some variety, which is not typical of autism.

Thomas shows an interest in computers when they are played by other children at school, he ‘was just observing and watching and laughing’ (L&P 3.10). He has little tolerance for children who are younger than him and prefers the company of older children and adults.

He has a strange toilet routine and likes to go outside to have a bowel movement, because ‘Thomas is incontinent, obviously doesn’t go to the toilet like the rest of us do’ (L&P 3.167). His parents think that he is embarrassed to do his bowel movements when there is someone present. If someone is there or interrupts his routine, he will be angry.

Thomas has his own way of getting the things that he wants. He will drag people to the place he wants or use the picture system to express his needs, or sometimes he will do the thing he wants by himself. Strategically, he gets the thing he requests by making arrangements for his parents. If his parents refuse his arrangements, he will break their rules and do the things he wants.

### 5.1.2 Family

Many researchers find that parental emotionality has an impact on their child’s emotionality (such as Denham, et al., 1997; Strayer and Roberts, 2004). For this reason I have put family as one of the factors affecting the emotionality of children with autism. Under this theme I have identified two subthemes namely ‘parents’ and ‘siblings’ which will be discussed below. I found it useful to discuss how Thomas relates both to his parents and his siblings.

#### **5.1.2.1 Parents**

Thomas’s parents both went to university. They articulated their experiences working with autism and autism-related knowledge. During my interviews with them, Larry finishes Patricia’s sentences a lot. She seems to look up to Larry, and there is a close bond between them. At times their answers are as if from one person with each one often finishing the sentences of the other. Larry told me that he and Patricia are very compatible. He said ‘Patricia and I are like a colouring book. I draw the outline and Patricia does all the colouring. I blurt out the obvious and Patricia goes into greater detail’ (L&P 3.306).

When I asked Larry his views on autism he told me that autism is an atypical neurology disorder. Larry and Patricia discussed their denial of Thomas’s autism. They said that they underwent approximately a one-year denial stage. They referred to Kubler-Ross’s (1997) theory as a theory about grief after the death of a loved one. According to the Kubler-Ross Grief Cycle, the five stages of grief are: denial, anger, bargaining, depression, and acceptance. Denial is therefore the first stage of grief. At the time of his diagnosis, Thomas was 3 years old and his parents’ first reaction was denial. They needed someone to push them to face the issues of their child’s difference. They admit that they ‘were both in blissful ignorance for a period of time’ (L & P 1.146).

The parents of a child with autism have to make many sacrifices; they have to face many issues in their daily life which may force them to give up their original jobs. They always aim to enable their children to have better outcomes.

L: …and I worked for the number one mental health charity for a number of years, but due to my caring role and Thomas’s needs I had to stop working, because sometimes he had self-injurious behaviour and there were periods of great difficulty, to ensure that as a family we were able to come through those really difficult times. (L&P 1.29).

When in a group, parents compare their child with others that are present. This may be subconscious, but the result is often frustration and possibly a feeling of inadequacy or depression. A parents’ depression might put stress on their child unconsciously, and might further trigger the child’s negative emotions.

P: I can remember that we used to go to a baby and toddler group in the park, in a centre in the park. Tom was probably one of the oldest ones there, just under a year, something like that. So he was one of the first ones to walk, just because of his age, not because of anything else. All the other children, children who weren’t yet mobile, would be sat playing and I always thought that because Tom was on his feet that’s why he wasn’t, but then when the others all found their feet as well and you know they’d get new toys, they’d all be playing with the toys. Tom would be walking around the wall, like that (makes hand gesture like a mime), you know doing the boundaries of the wall. I actually eventually stopped going, because Tom didn’t get anything out of it and it just became a stressful situation. (L & P1.67).

Thomas is a bad sleeper, although when he was three; he slept like a new born baby. His parents attempted to make him sleep all night as they had work to do in the day time. Due to a lack of sleep they felt exhausted; this was made worse by having to constantly meet Thomas’s needs. If his needs are not being satisfied, his bad temper might result in his parents’ frustration and depression. In this kind of vicious circle, his parents might lose patience with their interaction with Thomas. On school holidays, Thomas and Edward mostly are looked after by their parents (except when they go to a camp). Because of this Larry and Patricia cannot find their own time to do their private things, they find this to be ‘very challenging’ (L&P 3.335).

L: We used to have to push him to sleep downstairs in a pushchair here and keep pushing him, keep pushing him, keep pushing him and eventually he’d drop off. (L & P1.68).

L: Because he’s so, so all encompassing, so all absorbing, he’s so demanding of you that you can’t actually see what’s going on, coz you’re that busy meeting to his needs, his needs, his needs, his needs, his needs, you know you’re just like on a treadmill really and you don’t really see what’s happening sometimes in that respect, or you get the op...You know you do have the time for reflection, but sometimes you’re that exhausted you know. You don’t sometimes get the time that maybe you do need. (L & P 2.46).

Larry and Patricia experiences are filled with conflicting and difficult emotions: love, loss, positivity, negativity, reflection, hope, confusion or uncertainty, satisfaction, and responsibility. Their attitude is that their life is filled with challenge, having two sons with autism, but they attempt to stay optimistic and prepare to face the challenges ahead. They are filled with concern and worry about the future of their children. They appreciate what they have and enjoy every moment, try to face the rearing issue and address it, and adjust their life and expectations to meet Thomas’s abilities. They think that their son’s future looks better than it did before.

L: our journey has been very enlightening, very positive in the main, the self-injurious behaviour isn’t positive whatever slant you put on that, but I guess if you can restrict somebody from doing that then that’s a positive outcome so that’s really the family dynamic. (L&P 1.29.5).

L: I think I can see the comparison between Thomas’s journey and our journey and how there are so many questions that are asked of yourself and that you ask of the child, but that once you do accept and acceptance is the real key in all that then you understand that there is a different way of making that journey and maybe a different destination, but once you are on it, it can be certainly more powerful and more meaningful than any other journey that you have made in your life. (L&P 2.92).

Thomas’s parent’s love is unconditional. Even in the face of the bleak prognosis given by medical staff that Thomas had autism, developmental delay, Severe Learning Difficulty (SLD), extreme anxiety disorder with obsessive compulsive presentation, no communication, and that he was proprioceptive. Of course, they still love him and hold a hope for him. They comment that ‘Thomas has put us in so many embarrassing situations in our lives… to be honest I don’t think he has any concept of how it is for the rest of us’ (L&P 3.164). For example, Thomas is ‘fiddling with his poo and stuff like that and social situations and melting down in public, or getting upset or stressed in public’ (L&P 3.165).

P: As he gets older, as he changes, I think he will always be autistic, but that’s not to say that he won’t progress as the communication system shows and he will get happier and have a happier future, sometimes we thought he would but it could be that other diagnoses will come into play as well. (L & P1.112.4).

Larry and Patricia have a hope that Thomas ‘will develop more and reduce his self-harm’ behaviour (L&P 3.315). They said that without accepting the elements of Thomas’s autism and learning disability, both Thomas and their expectation would fail. They have several criteria to gauge Thomas’s success, such as ‘remaining in the community’, ‘enjoying life’, ‘continuing to develop his communication systems’ (L&P 2.149), and lessening his self-harm behaviour. So far, Thomas has made much progress due to the commitment from all those individuals engaging with him.

His parents believe that Thomas, just like any other child, experiences emotion and they think that he is more capable than is apparent. In accordance with his teacher’s thoughts, they believe that the sensory environment affects his emotions. They also believe that his improved communications have also increased his ability to express his emotions. That is to say that his emotions have always been there, just not his ability to express them.

L: If you can get the conditions right, the sensory environment and all the other elements of it all. Learning can take place and emotions can be expressed as a part of that. It’s all part of that. If you get that right you get a full, just a far better experience for that child. You actually engage in that child. The child is engaging in meaningful activity and enjoying life as it should be, about enjoyment and enjoying a whole range of emotions that we all have and just because somebody’s autistic it doesn’t mean to say that they shouldn’t be able to experience those and that their world should be very closed and autistic in its own right. Autism I think shackles people anyway without people acting in an autistic way to shackle them even further. (L &P 1.261).

Thomas’s parents discern his emotions and feelings by his sounds and behaviour, but mostly they have difficulty deciphering them clearly, and might lack confidence in reacting with his emotions.

P: So I think we were probably about at that point then, weren’t we. He was just never...I was going to say he was never happy, but that’s not actually true. He was happy, but really... (L & P1.82).

Thomas and his brother, Edward, share a special relationship. They ‘are in different places on the spectrum, because Edward often voices what Thomas feels. They are set in different directions I guess. It is helpful in that respect really it enables you to capture things that sometimes you miss’ (L&P 2.163). Sometimes Larry and Patricia get a better understanding of Thomas through Edward as he is more able to express his thoughts in words.

Larry and Patricia feel somewhat neglected by the system. Luckily, they support each other when encountering the enormous challenges from bringing up Thomas which might result in the best outcome for Thomas’s emotionality. They would have liked to have more counselling for themselves. Patricia also thinks that some support programs should extend their service to children above three years-old, because a child may not have been diagnosed with autism by the time they are three.

L: I think sometimes, you know sometimes you need to explore your own wellbeing and your emotional wellbeing around it. Sometimes when you’re overwhelmed it would be nice to have the option just to... Patricia and I do that really well. We bounce off each other and that’s great, but I think at certain stages in the past when Thom was in a really dark place, I think when two people are experiencing that kind of intensity that we really were quite affected. The only way you could access any sort of provision would be to be treated for depression, or accessing a mental health worker, when really you just needed somebody to talk to, who understood your situation really, so that would have been really, really important I guess what I’m saying is that the services need to be mindful and more sensitive to parents needs really. I think they have training in lots of things. They have training with children, they have training with families, but they have no specific training with parents and that’s a big bloody gap. So that for me is an issue really. I have raised it actually, quite recently and it will be interesting to see if anything happens. As parents you just have to flounder really and then to pick up the blame. Regardless of how articulate you are and how battle hardened you are really, every carer feels guilty to different levels, to different degrees at different times and sometimes you do need, you know, some additional, you know someone to talk to really. (L&P 3.391).

Bringing up a child with autism means that parents have to fight many battles, some of which are with their children. When they encounter an issue relating to their sons, they will ‘raise them, address them and focus on them’ (L&P 3.369). Larry and Patricia believe that because they are well educated and articulate they have been able to get the best treatment and education for their children so far.

L: I think we’re able to get more of an holistic approach, because we make sure all the bits are joined up and if you weren’t articulate enough to, if you weren’t empowered enough to bring that about then sometimes you might end up getting a service that maybe....not be as satisfactory as you might want really, so that I think would be an example of our own empowerment really, being able to help Thomas in terms of his education. Also in terms of being a parent governor at school I think is very good insight in terms of how the school functions and how they do meet the needs of every child as it were. I guess making sure that as a parent you’re representing all the other parents as well and that when you’re talking about, you know, about their needs being met and they need to be met more fully and that the understanding of the parents and children is paramount, not just from their educational perspective, but seeing the bigger picture as well. (L&P 3.386).

After Thomas’s diagnosis was made, Larry and Patricia spent plenty of time researching autism, trying to understand it in order to use any medical resource they could get for him. They think that their responsibility is to be fully engaged with the whole process, get resources, find information, do research, and discuss with professionals. Larry said that it must be very difficult, almost impossible, for single parent families who have a child with autism.

L: Yes it’s a whole life. I mean we are both pretty knowledgeable about it as Patricia said. We have done lots of background reading anyway and I have done some work with autistic adults so I was aware of what the diagnosis meant and I think to be fair our own knowledge - and also there was training at Ryegate - so it’s about establishing and working out what works best for your child and how can you best meet his needs. (L&P 1.102).

Larry and Patricia told me that they have to reflect on every thought and incident and try to look at the pros and cons of all aspects, especially regarding Thomas’s sensory issues which affect his emotionality.

L: You see that that brings in....It’s very, very interesting about the hug. Is that for his benefit? Is that for your benefit? Is he giving? Is he taking? Or is it mutual? So, that’s very interesting, because that could be a way of showing affection or also... (too quiet to hear). (L&P 2.69).

L: He loves rice, because he likes the feel of it on his teeth, he absolutely loves boiled rice, which is really good. The only problem is that, because he’s such a sensory child, Thomas likes to eat outside. So there’s rice everywhere and you have to be mindful of vermin and stuff like that, so with him, there’s always a side issue with everything isn’t it, like medication there’s always a side effect and that’s one of the effects of Thomas eating outside. (L&P 2.40).

Thomas’s parents are satisfied with Thomas’s progress in learning and with his emotions. During our discussions they mentioned that Thomas is in a pretty good place nine out of ten times, and report that he is starting to interact with others, develop his turn-taking ability and to initiate communication (such as ‘making more sound verbally’, L&P 3.311). From the following statement, it is clear that Thomas’s language ability has a close relationship with his emotions which is supported by Dodd (2004)’s, Dowling (2000)’s, and Saarni (1999)’s statements.

P: For everybody… and now to think that it’s two years…You know a relatively short time really, and we’re now at the stage of communicating. He’s a lot happier because he’s able to show his emotions that way rather than his behaviour really so…(L&P 1.179).

#### **5.1.2.2 Siblings**

Thomas has two brothers. His older brother lives away from home and is studying at university. His younger brother, who has autism, is living with him. According to his parents, Edward’s emotional competences (such as empathy), oral language, and other abilities are better than Thomas’s. They told me ‘Thomas does take his lead from Edward and does show emotion around him, but as to how much, it all depends on what’s happening and what it’s about really and also where Thomas is at’ (L&P 3.120).

Thomas also learns to do things by mimicking his younger brother’s behaviour, particularly when he sees that Edward is having fun, however, he cannot stand Edward’s crying.

There is a certain amount of sibling rivalry between Thomas and Edward. This is demonstrated through aggressive behaviour that results from the parents’ pride in Edward. Thomas and Edward vie for their parents’ love and attention, or for the territory at home. Thomas expresses his jealousy by hitting and writing on Edward’s picture.

### 5.1.3 The Education System

Thomas ‘is by far the most challenging child that they have had at the school’ (L &P 2.109). ‘School made necessary amendments and changes’ (L &P 2.109) based on an occupational therapist’s suggestions concerning Thomas’s sensory awareness. Thomas has favourite people who are working with him in an intensive way, such as engaging him more, ‘meeting his needs fully’, and ‘understanding him better’ (L&P 3.251). ‘He finds them more fun to be around’ (L&P 3.252), or perhaps Thomas seeks acceptance from others.

Larry and Patricia said ‘what we have found as well is that the quality of the teaching and the ideas is changed and according sometimes to that age and the attitude of the teacher’ (L &P 1.168).

P: If your child’s probably not as severe as Tom, but still has a need, the irony is that your child will probably be mainstream in a class of thirty-odd children. No fault of the teacher or the TAs they can only do what they can with the resources that they’ve got so they are fighting fires really, so your child doesn’t get the best that they could. (L&P 1.97.2).

Being prepared to make changes and showing acceptance toward Thomas are the best means of working with him. Once Thomas likes educators (such as teachers, teacher assistants), he will behave well and learn better. Thinking on the other side, Thomas is doing well because he is always in an environment that caters to his wants. Would he have done as well had he been in an environment that only catered to his needs? He likes the staff who are ‘Thomas centred’ (L&P 3.251), this may be required to initiate communication with him, but in the social world he will not be the centre of attention.

Thomas’s parents found that some of the suggestions from his therapists and teachers do improve Thomas’s emotionality and learning progress. For example, his occupational therapist suggestion is addressing Thomas’s sensory issue first, and then his learning would progress. A teacher utilised the things that Thomas likes to develop a game which increases his interactions with others and develop his turn-taking ability.

Thomas’s parents think that Thomas’s learning experience is directly related to his teachers’ ability and what is presented. Educational context also plays a vital impact on his emotionality. For example, his school provides various activities to moderate Thomas’s tendency to want the same routine or schedule.

The reason why Thomas’s parents sent him to a special school is that at first they had tried putting Thomas in a nursery school, but he could not settle into the two and a half days a week routine which might have messed Thomas’s desire for expected schedules up. Now that he is full time, Thomas is well suited to the special school and he has made good progress since he has been there.

Thomas’s parents appreciate positive comments from his teachers. For example, Thomas can control his emotions and interact more with others than he did before, and is more capable than he appears.

During the course of my interviews Patricia and Larry mentioned that Thomas is in a pretty good place more than ten times, and reported that he is more receptive, starting to interact with others, developing his turn-taking ability, and initiates communication (such as ‘making more sound verbally’, L&P 3.311). Thomas is making progress possibly due to his teachers reacting to his choice with his favourites (certain songs) and encouraging him to join school activities and communicate with others. This progress is due to his teachers working hard, making his environment and sensory elements right, developing some curriculums by utilising his likes to motivate him to learn social interaction skills and communicate with others (such as turn-taking, throw-pick ball game, picture system). It shows that Thomas’s emotions and sensory issues do have a close relationship with his learning progress.

There are many professionals working intensively with Thomas. His parents think that it is vital to have the right resources to fully meet his needs and to support them. He has a consultant and an educational psychologist. Thomas uses pictures (photos; a picture board) to communicate with others rather than Picture Exchange Communication System (PECS) (because PECS did not work). He makes decisions and expresses himself by picking up a picture from a picture board or arranging the pictures (mostly they are about his needs and wants) on the board at school and at home. Thomas ‘takes more control of his life and shows more emotions’ by using the picture board (L&P 3.84). The picture board alleviates his anxiety by allowing him to know upcoming events, and communicate with others. However, there are some concerns about using the picture board, for example, his parents often have difficulty meeting his needs when he uses the picture board to say what he wants (like going to Blackpool at 5:00 at night or not going to school on school days). It is difficult to carry it on as it excludes ‘no’ and ‘not yet’ and they have not found a way to use it to say no. Thomas’s carers have to find suitable pictures for Thomas because he is better at real pictures than at symbols. During the course of my interviews, Thomas’s parents and teachers were attempting to make an advanced version of the picture board for him (a mix of pictures and symbols on the carry-on picture board) to express his needs and give him choices.

Larry and Patricia’s view of a good teacher is one that makes regular contact, develops the student-teacher relationship, has flexible boundaries, is more responsive to an individual’s needs (emotions), and gives their students some options, ‘engaging him more’(L&P 3.251), ‘meeting his needs fully’(L&P 3.251), and ‘understanding him better’(L&P 3.251).

The parent-teacher relationship is very important. The parents must form a cooperative relationship through meetings and appreciation.

### 5.1.4 The Medical System

A child with special needs requires special medical resources. Thomas’s parents ‘have multidisciplinary team meetings’ which gather all the professionals and agencies together and exchange ideas (L&P 3.407).

His parents and the professionals all benefit from the meetings and are able to make the best decisions for Thomas. Larry and Patricia feel super lucky about what they have gone through, and agree that ‘the quality of the professionals makes all the difference’ (L & P1.91, L&P 2.222).

The medical staff and professionals use Thomas as ‘an example of good practice and good team work (L&P 2.109). For Larry and Patricia it is more about ‘understanding challenging behaviour and understanding what lies behind challenging behaviour’(L&P 2.109), and giving Thomas ‘the right resources’ as well as ‘what he needs in a sensory way’ (L&P 2.109). In other words, Thomas’s parents hope that medical staff and professionals explore Thomas’s emotions and feelings behind his challenging behaviour, and then give him the right resources and consider his sensory issues. Thomas’s treatment approach ideally is Thomas-centred, and involves good communication and engagement with all parties. It also inextricably linked with his emotions and behaviour.

#### **5.1.4.1 Diagnosis**

It took Larry and Patricia a long time to get Thomas’s diagnosis. In the first instance they had to wait for an appointment, they found out later that there were staff issues that caused the delay and ‘nobody addressed [these] issues, or encouraged [Larry and Patricia] to face up to the [their own] issue’ (L & P1.79). It was much quicker for Edward because of Thomas’s diagnosis history.

Thomas was diagnosed at nearly 37 months. His diagnosis ‘was given in forty five minutes or something and that was it’ (L&P 1.92). Some individuals have two-day assessments. Larry and Patricia say that his diagnosis makes them very realistic in their expectations, and reflect about how ‘lucky’ they are that he has a diagnosis which is extreme! Larry and Patricia said that a diagnosis is ‘an anchor point’, it brings the resources and makes parents ‘know that’s what the future is likely to bring’ (L&P 1.100).

Larry and Patricia told me that it would be better to gather all the professional staff (such as speech and language therapist and psychologist) and lessen the assessment time, because the whole diagnosis process stresses children with autism considerably. Parents need to wait in a room whilst all clinic staff discuss the result. After diagnosing, they get a holistic diagnosis report.

Thomas’s diagnosis includes ‘severe autism’ (L&P 1.92, L&P 1.149), ‘development delay’ (L&P 1.150), ‘severe learning disability’ (L&P 1.93, L&P 1.151, L&P 3.313), ‘extremely self-directed’ (L&P 1.151), and ‘no communication’ (L&P 1.151). The diagnosis might be changed because he is still young. Thomas was assessed without an IQ test. Parents think that the clinical staff considered his emotions whilst they were assessing him, and his ‘diagnosis is correct’ although they ‘wish it wasn’t true’ (L&P 3.315).

They also comment on the impact of a medical diagnosis. The medical diagnosis makes resources more readily available, but for individuals on the higher functioning part of the spectrum it could affect their life in a negative manner.

Larry and Patricia were shocked and confused by the clinical staff when they were given the diagnosis. They think the whole process was too clinical (there was no couched approach or soft language) to help them understand there was no consideration of a patient’s emotions and feelings. They were unprepared to hear the results. All they could see was ‘global developmental delay’ with no explanation. The words from doctors are ‘very concrete’,’ very factual’, ‘very clinical and matter of fact’ (L & P1.152). For parents without an understanding of this type of condition and professional vocabulary, it would be even more traumatic. It might further affect their child’s emotionality.

Larry and Patricia are critical of the medical system, saying it is inflexible and not centred around the patient and their needs. They say that a child with special needs should not be kept waiting for clinical staff to see them. The staff have more flexibility than this type of patient. They also believe that the clinical staff should be more sensitive to the issue; they should not assess the child when there are too many distractions. They think that this affected the results of Thomas’s assessment. Meanwhile, Thomas’s parents admit that it is difficult to engage with Thomas and assess him.

L: [M]y biggest observation was that it was a medical diagnosis for a set of social behaviours and now I still find a bit difficult to reconcile really, even though all the professionals involved in a medical...have been fantastic, they undoubtedly have. Why do you have a medical diagnosis, because if it’s on your medical records. Then it will affect so many different things. In a positive way, you can get services if you aren’t functioning anywhere you need it. You may well be able to function perfectly fine, but with little or no intervention from anybody really then I’m sure in terms of employment or anything else, then I’m sure that it’s like a bit of an albatross around your neck really, so unfortunately it’s where you are on the spectrum. I don’t think the spectrum’s helpful. Another observation is that the spectrum is really unhelpful, because people that are really affected, you know that are doubly incontinent like Thomas and you’ve got at the higher functioning end, that have got degrees, de, de, de, that are functioning perfectly well in society, writing books de, de, de, da. How on earth can you chuck a label over that? You know, that broad amount of people. You can’t really. In my opinion, so I think I understand why they use the spectrum in terms of understanding it and how people are affected, but I just think it isn’t a positive way for diagnosing and placing people really. (L&P 3.379).

Finally a health visitor came to visit them and then things started to move in the right direction. Thomas’s medical resources include a speech and language therapist, doctor, clinic (doing development checks), Rygate neurological medical centre, the Child and Adolescent Mental Health Service (CAMHS team, address Thomas’s needs, give information and intensive interaction), consultant (observing at school, keep contact with parents, approachable), occupational therapist, and psychologists. Thomas’s parents appreciate these resources and support for bring up their children.

#### **5.1.4.2 Medication**

As Thomas grew bigger and stronger his parents worried that he might hurt himself seriously, so they considered using medication, such as Aripiprazole. Thomas ‘was put on medication because he has challenging self-injurious behaviour’ (L&P 1.104), Melatonin, Sertraline (an antidepressant), and seasonal-used hay fever medication.

The medication had side effects. It made Thomas gain weight and feel happy (possible side effect of Sertraline). In spite of its side effects, Aripiprazole helped the family start to work, improved the quality of their life and allowed the family to function.

L: [T]he Aripiprazole brought down his anxieties and brought him out from under the blankets, because his life was under a bunch of duvets and he was stuck in his bedroom and he couldn’t come out, or he’d be in the foot well of the car. As a family we couldn’t function and thankfully it enhanced Thomas’s quality of life. (L&P 1.109).

Does medication really work? Supposedly, the medication provides better life quality for patients and their family. However, in reality a patient has to be a guinea pig for a while, until the best medication is found.

P: I am sure you’re familiar with Melatonin, the irony that it only works if you’re tired which is a bit obvious I suppose, but you can sometimes see with Thomas he’s really tired and I don’t think he’s actually able to just actually shut down. You do need to go to sleep so, but sometimes we’ve laughed because we thought that he was tired and we’ve given him the Melatonin and the next minute he’s bouncing up and down and you think “I’d like some of that”. It has that effect. At the moment that’s all that he’s on isn’t it? (L&P 1.126).

#### **5.1.4.3 Many Faceted Approach**

Thomas uses a picture board to reduce his anxiety and for communication, for making decisions, and to have an expected time table. His parents use a wheel chair to ‘get him out actively in the community’ (L&P 2.63).

Thomas’s parents measure his progress in small steps with optimism and they consider how difficult it has been to reach the current status, which might reduce their stress and Thomas’s anxiety. For example, they said that Thomas is still very grumpy and self-injurious, ‘but it’s all about degrees and it enables him to function at this point in time in the community’ (L&P 1.109.8). After making Thomas’s sensory environment right, he has made huge progress.

#### **5.1.4.4 Suggestion or Feedback**

Patricia and Larry emphasised the following points:

They appreciated that the occupational therapist had a sensory assessment for Thomas, and agreed with her suggestion which was ‘until you get the environment right and all the other factors you can forget about learning’ (L&P 2.109).

The speech and language therapist told them ‘you know, you’ve got to remember you came in here with a lovely little boy and you’re still leaving with a lovely little boy, he may be different, but he’s still a lovely little boy’ (L&P 2.200). This is ‘a really lovely approach’ for parents (L&P 2.200).

They trust the speech and language therapist and a consultant because they are willing to observe Thomas at school and at home to understand his performance and abilities under every scenario. Additionally, they are willing to provide comfort and useful information for them. They also appreciate and trust the occupational therapist, because she has given them very useful ideas to educate Thomas. As for the other clinical staff, they question their abilities.

They believe that good doctors have these characteristics: they consider patients’ emotions, they co-operate with schools, keep contact with parents, are approachable, flexible, and -provide Information.

### 5.1.5 Policy

During the interviews with Larry and Patricia I had an opportunity to discuss how the existing policies supported them in working with their son Thomas and how these policies have impacted on Thomas’s (emotional) life.

Individuals with autism are affected by the way people respond to, or treat them in general. In this part of the paper, I will explain how labelling affects the emotional life of an individual with autism.

Larry and Patricia discussed the pros and cons of diagnosis. The advantage of getting a firm diagnosis is knowing what is wrong with their son, being able to research relevant information, getting resources, and making staff working in the special education field be in tune quickly. The medical diagnosis makes resources more readily available but sadly, the issue is how the medical system works. Autism is not a concrete illness or disorder. The disadvantage is dealing with it emotionally and practically.

For individuals from the high-functioning end of autism, labelling can become very negative in their academic, career, and social life. They are rejected because of this label, even though they may do a better job. Patricia said Thomas would not ‘be aware of the label’ (L&P 2.170). Does Patricia imply that Thomas will never become immersed in society? After several years, they can now start to imagine the future and face up to the reality of the diagnosis. They ‘do understand how easily labels are attached in terms of learning disability because again, it’s a medical diagnosis for a social behaviour really and the two models never fit comfortably, they don’t fit snugly’ (L&P 3.315).

They agree that ‘he fits the criteria, by virtue of the fact that his behaviour is self-harm and supports that argument really. You know if I felt there was any doubt about that we would query that. We really would, but he is as he is and we need to do the best for him that we can’ (L&P 3.315).

After discussion with Thomas’s parents, I understand their dilemma, their struggle and how the system works. Because of the difficulties of raising their sons, they receive carer’s allowance. I still wonder how our society and system could make some changes to make their life better and more meaningful. Longden (2013) suggests that professionals should find what happened to them rather than find what’s wrong with them. When we find what happened to them, we will accept them and attempt to find some strategies to work with their behaviour rather than think of them as abnormal or less able. Higashida (2013), a 13-year-old non-verbal boy with autism, said that he wants to make a contribution to society rather than to be thought of as worthless. I think it is time to change society’s attitude towards individuals with autism.

P: [O]n the one hand, it’s such a relief that you have a diagnosis, because now you can see what lies ahead of you. With that diagnosis comes the [medical, educational, and financial] resources as well, in terms of accessing special needs provision and of a greater quantity because of his needs. So as a family it eased a lot of the pressures, on the other side of that is, of course, facing up to the reality of the diagnosis as well and the impact of that goes down on everybody. (L&P 1.95).

L: [F]or somebody that I would say would be at the other end of the spectrum, who would possibly have characteristics of Asperger’s and that it didn’t necessarily affect their level of functioning, or anything of that nature, then I can see it being actually quite a negative label because you’ve managed to get through life academically, socially and overcome all the hurdles that have been in front of you and you’ve overcome all those so then to have a label attributed to you even though you’ve done that and you function at a level that a lot of people aren’t necessarily able to function at, intellectually anyway, why dump a label on them. And ironically perhaps some of the best insights that people have been able to get of autism subsequently, has been from people from the higher functioning end, because they will be able to describe their experiences. For us, because of how Thomas is, and Edward is, to actually access specialised education has been really important. For sure there’s going to come times in their lives when their education - not so much Thomas, but possibly Edward as he gets older and perhaps it’s not so apparent - then the label might be more challenging for him. I think like it’s a double edged sword really. (L&P 2.169).

### 5.1.6 Society, Community, Nation

Under this theme I identified two subthemes namely ‘societal pressure’ and ‘resources’ which will be discussed below.

#### **5.1.6.1 Societal Pressure**

When an individual with autism goes out to a public place, he/she normally is stared at by other people which adds pressure onto his parents or other family members. Thomas’s parents mention that ‘Thomas has put us in so many embarrassing situations in our lives… to be honest I don’t think he has any concept of how it is for the rest of us’ (L&P 3.164). For example, Thomas is ‘fiddling with his poo and stuff like that and social situations and melting down in public, or getting upset or stressed in public’ (L&P 3.165). Thomas’s parents wanted to say to those people ‘he’s not got two heads or whatever. That’s just how he is’ (L&P 2.142). They want their son to immerse and feel comfortable in public, so they enjoy going to places where many individuals with autism visit, such as the railway museum at York.

#### **5.1.6.2 Resources**

Larry and Patricia told me that if a community can accept that an individual with autism has emotions and feelings, no matter how severe their status, other people will attempt to find the requisite and positive communication approach to bridge the gap between them. This caused me to consider; is it all about public attitude towards an individual with autism? How do others think of individuals with autism? How do they look at them?

In line with this, Larry and Patricia believe that the media has ‘heightened the awareness’ of autism and portrays an image of autism that suggests that people with autism are all high functioning or savants (L&P 3.397). TV programs rarely show low functioning autism cases, perhaps because they would be too disturbing or because an individual with low-functioning autism cannot consent to being filmed. Larry said that he is more interested in the Autism Chronicle, a TV program which showed various individuals with autism who had challenging behaviour and were self-injurious, and showed the impact on the families at different stages, because this was ‘more Thomas- like’ (L&P 3.401). Patricia added that it was sad to hear about family issues involving autism only when there was a tragedy. Larry further added that the media should broadcast more positive examples of low-functioning autism including how to meet an individual’s needs, and sharing a broader range of knowledge as well as experience. Speaking of the film ‘Rain Man’, Larry made the following comment;

L: Fantastic film. Love it to bits. Yes it’s a brilliant film, but the reality is that when you live with it, at the shitty end, people don’t grasp it and you know you’re in the community and I’ve never seen another child with really challenging behaviour. Where are they all, you don’t see them in the community do you? They’re usually stashed away, so people don’t really see it. Yeh so that’s one of the down sides of it all. The other side is of course, is that it’s positive representation. Some people perhaps, get a bit of insight. (L&P 3.400).

Occasionally Thomas goes to some camps where he and his parents get some support from the staff working there. Of course, he meets a different set of people; this might be in the school holidays for instance. The camp staff always say that he has had positive experiences there.

Larry and Patricia go to some information seminars. For example, the Sheffield Autistic Society provides a class which leads typical-development people to experience how individuals with autism feel, in a sensory way. The Challenging Behaviour Foundation provides information in their newsletter aimed at individuals with very limited communication ability. The main mantra is ‘every behaviour has a function’ (L&P 2.145). ‘Children with challenging behaviour’ show their emotions in that way because they cannot convey their needs or thoughts to others and they feel frustrated (L&P 2.145).

I wonder about all of Thomas’s limitations, for example, does he need a wheel chair? I think he can walk but he prefers to be carried by other people or to use a wheelchair. Why? Perhaps Thomas feels loved under this scenario.

L: He doesn’t really walk. Thomas doesn’t use his legs very often when he’s out with us. If we - for example in the summer at Cleethorpes we had to carry him off the beach, didn’t we? And he will walk for about a few yards and sink to his knees. (L&P 2.21).

## 5.2 Balaravi

On January 30th 2012, I first interviewed Paavai concerning her son Balaravi. Paavai and her family are from India. At the time of our interview Paavai was around thirty years old and Balaravi was almost ten. Their family is a nuclear family. Due to her husband’s job and Balaravi’s situation, Paavai has ‘never thought of working full time’ (PB 2.132).

Balaravi has some key words in English and Bengali. Paavai’s husband has a master’s degree in computer science and ‘speaks six languages’ (PB 1.39). He works for a software company and has moved around the world many times because of his job. At present they all live together in Sheffield and have been in the UK for four and a half years. Previously they have lived in India, Canada and the USA with Balaravi who was first diagnosed with autism in the USA. They speak Bengali, and are immersed in Indian culture at home where Balaravi mostly talks in Bengali. Therefore, in the UK, Balaravi has to cope with two cultures (Indian culture at home, UK culture at school).

Paavai is a university graduate with a masters in biochemistry and two and a half years of a PhD, which she had to give up in order to look after her son and her ailing mother. Paavai has a very strong, sometimes difficult to understand, Indian accent, but moderately good English.

Paavai believes that she is more open-minded than her husband, who is bound by the confines of Indian society, because she went to a catholic missionary school. She works part time as a lunch supervisor and is studying a teaching assistant level 3 course. In order to give her son the best education, she is trying to be a teacher and will teach her son in the future.

All three interviews (January 30th 2012, June 29th 2012, and July 9th 2012) were conducted in their home. Due to Balaravi’s violent behaviour, Paavai has scars on her face and keeps her hair short.

Our interviews were conducted over a period of about a year, due to Paavai’s mother passing away from a long illness. During this time, Balaravi’s language ability improved from being almost non-verbal to using only a key word and then to a short sentence, which is associated with several key words, to express himself.

Peter was present during all three interviews to help with language interpretation.

### 5.2.1 Individual

Paavai seemed to have a normal pregnancy and labour. Then, when Balaravi was six months old, Paavai’s sister (a doctor) noticed that Balaravi was different in that he did not respond when she called him. For this observation she was rewarded by a severe telling off from Balaravi’s grandmother.

After he was six months old, his mother took him everywhere with her in spite of the difficulties that she experienced. She suspected there was a problem, because of his nonverbal and not typical development; he was always crying, cranky and insisting on doing the things he wanted like breaking and throwing things, banging his head, and sitting in her lap all the time.

Paavai said “when he was a baby he was not toilet trained. In the beginning, I guessed that his odd behaviour was caused by his isolation from his family when we were in US.” When Balaravi was around 2 years old, his grandfather dropped him on a hard surface and was blamed for his autism. However, Paavai defended her father as there was no evidence to confirm this, even after a CAT scan. The family moved to the USA and his parents put Balaravi in a play school for one year.

#### **5.2.1.1 Emotionality**

Paavai and Balaravi have a close relationship and he is very attached to her. Paavai explains this saying that she has been with him for at least 12 hours a day for the last six years. He asks for her and, at bed time, he wants no one but Paavai to read a story for him, hug him and sleep with him. If Paavai leaves when he falls asleep and he then wakes up, he will call her back.

Balaravi also attaches with his father now. When he was two years old, his father travelled internationally for business very often and once stayed in the USA for seven months. At that time, he showed that he missed his father by carrying his father’s photo with him and showing it to other relatives.

Balaravi became attached to his grandfather and thought his grandfather was his father since his father was absent for such a long time in his life. Apart from his family members, Balaravi also formed an attachment to his first teacher in Chicago.

Paavai finds complexity in Balaravi’s abilities, she tells me that they are irregular, but she cannot make a comparison with other children who have autism, because ‘every person is different’ (PB 3.141). Paavai also mentions that Balaravi shows his intelligence in one way by judging a person’s reaction before he does something that he knows is bad, or against the rules. Does this mean Balaravi can tell right and wrong and like to challenge an adult’s limits just like other typical-development children?

Based on Paavai’s background, she uses a neuroscience view to describe the emotions of her son:

Emotion is literally developed in the cerebellum, controlled by the hormones in the cerebellum and evidence has been found in regular. If you could make the lesions of the cerebellum of a guinea pig’s brain, or of a dog’s brain they do lack emotions even with the mouse we have seen that. I don’t know what the cerebellum structure in autistic children, but my son can read my emotions! (Said in a low powerful/ confidential voice) sometimes unexceptionally. (PB 1.93).

Paavai said that Balaravi is generally happy, and he has started to understand his emotions which are easy to read by his expressions. He still needs time to develop the emotions of jealousy and shame. Balaravi definitely recognises Paavai’s face, and appears to be very sensitive to her emotions, such as worry, sadness, and happiness. He can determine some basic emotions (happiness, sadness, and anger) from other individuals’ facial expressions and from emotion pictures. However, he still needs to understand emotional subtleties, such as the difference between being sad or depressed, tears of sadness or of joy, as well as a smile that hides sadness. Additionally, by utilising pictures, he needs to learn about pains such as headache, toothache and earache.

Paavai further mentions that she has utilised the story building cards (PECS) to teach Balaravi emotions and the concept of sequence for two years. Her approach seems to adopt Stafford (2000)’s concept of utilising visual clues to teach children with autism emotions. Balaravi can differentiate between an angry face and a disapproving face and can draw a happy face if you ask him to. I guess it is a trained result since Paavai has taught Balaravi to recognise and display emotions for 2 years. Interestingly, Paavai does not think he understands the subtleties of a smile, but he is sensitive to her feelings and knows when she is angry or upset and tries to comfort her. Paavai also thinks that Balaravi cannot tell the difference between disappointment and anger and is trying to teach Balaravi to express disappointment before he becomes angry. He is also able to put the cards in order to tell a story. Due to his obsession with scissors, these pictures are locked in drawers, away from his reach.

Paavai has this to say on Balaravi’s emotional states: Balaravi’s tantrums are due to severe anger. If he is having a tantrum, it might last for several days. When Balaravi is in physical pain, he shows it by having tantrums. The way Paavai deals with it is to bring him to see the doctor and attempt to find the cause of his pain. His tantrums take the form of breaking things, throwing things, screaming, biting Paavai, and scratching other people. Paavai gave this example of his tantrum and guesses his tantrum might be due to Balaravi misreading his parent’s facial expressions. My guess is that Balaravi detected his parents’ sorrow and exhibited his sorrow in an aggressive way to his parents;

Due to my Mom’s death and all these things and lot of tantrums my son went on...there was a huge tantrum in my house, the Easter break and after my Mom died we could not board the aeroplane to go to India, because son was really bad in the mall and he threw food on somebody’s head, screaming and broke all the cups and all the plates and all the flowers… it was a huge tantrum and I was not able to restrain… You see these scratches here so that he could scratch me. He took out flesh from me and then I was bleeding. (PB 2.36).

Balaravi is afraid of darkness, injections and going to live in a dirty place. Balaravi expresses his anger by making a grunting sound, making very obvious facial expressions, violent action, banging something, or by breaking, smashing or destroying things. For example, when he is angry, he will break or burn an object, attack Paavai, or put some paste on the sofa. It will take Paavai fifteen minutes to reason with him and calm him down or negotiate with Balaravi by promising to give him some plates to break when he gets angry.

He is anxious about interacting with others (except for Paavai), and he expresses his anxiety by peeling things, such as a branch. To address the issue, she sent him on trips and to shops, and he has started to talk to his teachers and his father.

Balaravi seems to be ‘happy most of the time’ (PB 1.193). He is happy when he works with soap. He expresses his happiness by smiling, or being talkative. He is not in the least embarrassed when he is breaking things or is chastised in public. When Balaravi was upset ‘he used to slap me or pull my hair, or beat me’ (PB 2.38).

Balaravi feels frustrated when he cannot make a thing he wants. To avoid him breaking or destroying their house, Paavai gave him a metal biscuit tin, and he can bang holes in it with a knife when he starts to become frustrated. Most of his worries are due to moving home so frequently. The way he shows his worries is repeatedly asking the same question.

Paavai gave me an example of Balaravi’s sense of humour. He is able to interpret humorous situations and find them funny as in this example;

A man was standing and other...you know the Nepali Watchmen the Ghurkhas they do in India a lot of watchmen. In Indian channel was coming. A man was standing and a watchman was coming and the watchman suddenly shows his hand that it is wet and he has not said anything about that dog, or anything else…but my son was laughing a lot and he is saying the dog has peed in his hand. (PB 1.99).

From Paavai’s statement, Balaravi has developed an obsession for bell peppers. If Balaravi lacked imagination, he would purely treat bell peppers as one kind of vegetable. Instead he gives them human characteristics almost like imaginary friends. He definitely shows his imagination ability in the following anecdote;

He will peel the skin off that one and he will put that capsicum in his bed and look at that capsicum and then sleep, so he draw a picture of a capsicum like a man, human being, you know, with a capsicum having an eye, capsicum having a nose, capsicum having a teeth and tongue, so I realised that he does think that those things are real and maybe it is talking to him, because his mental development may not be like a nine and a half year. He might be lagging behind with his imagination. Though he has having very restricted imagination you know that the child of the autism, so very restricted imagination about the soap, but sometimes I do see some other things as well. (PB 1.216).

Peeling is also how he relieves his stress. Since Balaravi was eight years old, he liked to peel everything he could peel, such as vegetables, his lips, their sofas and tables. His teacher in his Chicago school suggested not to resist this and instead suggested that they should find an acceptable way for him to do it, so Paavai bought twenty-five-cases of potatoes, and prepared a peeling area, soft peeler and a bucket for him. Balaravi is skilful at peeling and cutting vegetables now, and he helps Paavai to prepare meals. He learns how to make some dishes by watching cooking videos on YouTube. He is also good at peeling his soaps.

Paavai believes that Balaravi has social needs and is gregarious. Balaravi is a social boy. He is not shy. When he sees his peers, ‘he will try to talk’, ‘try to sit with another child and try to play’ with them. Therefore, he shows (not) the least shyness (PB 3.113). He wants to go and interact with his peers every day suggesting that he wants to have the company of children, however their circle of friends in the UK is very small.

Balaravi is sensitive toward other children’s predicaments. Paavai gives me an example of Balaravi’s empathy. She mentions that Balaravi cares every time a baby is crying, but he can’t distinguish between their sadness and pain. He guesses that the baby is hungry (physical needs), and needs to have milk.

One day my friend came… he had two daughters. They brought butterfly wings from shop. When they are going back home she forgot to take these butterfly wings. My son came with that and said “Mommy she will cry if she doesn’t get this one” So this is purely empathy. (PB 1.123).

Paavai told me that Balaravi shows sympathy. An example is when he heard the news of some children dying in South Africa and India, he started crying. Another example is that he was taught a song at school concerning a lost baby. He was crying after coming back from school and searched for a song called ‘I lost my baby’ on YouTube. Does he think a baby is lost because of a song, or because he hears about some babies dying?

Paavai said that he is still developing the emotions of hate or dislike. She thinks that surprise is bad for a child with autism, so they prepare before things occur to avoid surprise as much as possible. Paavai thinks that the ‘Hide and Seek game’ is one kind of surprise for Balaravi, and he laughs a lot when he is playing the game.

Balaravi can tell right from wrong in the movies and in daily life. He feels guilty for hurting his mother. After he has attacked her, he hugs her, apologises to her, or makes a cream (made of yogurt) and applies it to her wounds. Balaravi does get sad and he cries when he is sad.

The factors that affect his negative emotions are his poor communication ability, his anxiety, manufacturing videos, and physical pain, bad smells and negative things on television. He cannot express himself and engage in his peers’ conversations and releases his frustration by peeling some objects and showing his negative emotions; Also, Balaravi gets anxious when he enters a new environment and meets strangers, and he then misbehaves in public. Paavai has linked Balaravi’s frustration and challenging behaviour to manufacturing videos. I guess that it is because Balaravi cannot accomplish what he wants to achieve, the level showed in the video.

When in a small amount of pain Balaravi will make a big fuss, but when he is in a great deal of pain he goes quiet. Paavai thinks this may be neurological but does not want Balaravi to have to go through lots of tests.

Balaravi dislikes bad smells and negative things on television. Once he sees someone is crying, hitting, beating, or hears a loud noise on television, he will switch it off.

Paavai went on to describe some of Balaravi’s likings. Balaravi likes beautiful heroines and remembers their names. Other than that, he particularlylikes to play with soap. His teachers and his parents use soap to motivate him to learn or work and Paavai thinks playing with soap is ‘a sensation thing’ and makes him happy (PB 2.67). He likes to cut papers with scissors, such as pictures, enjoys watching the music channel and attempt to sing some songs. He has memorised whole songs in Bengali.

Paavai further mentioned that Balaravi loves swimming. Sometimes he behaves naughtily by spitting water onto someone. He likes being hugged; he particularly likes Paavai hugging him all the time even when he is sleeping.

#### **5.2.1.2 Behaviour**

Balaravi is able to do many things on his own, but he still needs Paavai’s help where he has limitations whether at school or at home. For example, ‘he is trained in toilet, but he cannot wipe’ (clean himself) after having a bowel movement (PB 2.154). However, she thinks he has the ability to do things, and he just relies on her very much.

She has decided to try a new experiment, by leaving Balaravi with competent carers when she returns to India for a while, in order to help Balaravi become more independent. I wonder if it might lead to more challenging behaviour since Paavai and Balaravi have a strong attachment between them.

Although he has poor safety awareness, Balaravi has developed the concept ‘of what could be harmful’ or painful and has started to fear ingestion and giving blood (PB 2.502). Despite this, Paavai needs to supervise Balaravi using a microwave because he likes to put all kinds of thing inside it. Consequently, ‘the microwave got busted two or three times’ (PB 1.2). After Balaravi’s father has been grocery shopping, he will open every bag, and check all the items. Paavai used the term ‘Experimental in mind’ to describe Balaravi’s dangerous behaviour of putting all kinds of thing inside the microwave (PB 1.2). She moved the microwave out of his reach to prevent further experiments. Paavai believes that Balaravi knows his mother is disapproving, but he has to be experimental anyway. He takes a while to understand that the parent is unhappy with his actions, but he does figure it out eventually. She further mentions that new things on TV or at school could trigger his experimentation. I wonder if this is an excuse for Balaravi’s dangerous behaviour or if Balaravi does it on purpose.

Paavai thinks Balaravi is a well-behaved boy. However, ‘sometimes when the thing doesn’t match’ (PB 1.20) or having ‘physical pain in him’ (PB 1.26), or not getting the things he wants, he becomes aggressive and shows tantrums. He has broken electronic devices (laptop, Blackberry), Paavai’s spectacles, he throws things, and has hurt his parents (especially Paavai). For example, Balaravi attacked, beat, and scratched his parents, and his father could not ‘go to work for a week’ (PB 1.20). Paavai considers the factors that affect his behaviour are lacking exact structure, communication ability, and mimicking peer’s behaviour. She further states that ‘it is not that his behaviour is bad. We are always told someone with autism has bad behaviour, but my son has let me know, through his behaviours, that he is uncomfortable in some situations’ (PB 1.20).

Balaravi mostly talks in Bengali. Paavai thinks his syntax is better in Bengali than English, therefore his school uses a Bengali teacher to assess him and they disagree with Paavai’s observations. Paavai also thinks that he has good language comprehension, understands everything his parents say and is able to translate many things in two languages (Bengali and English). He said his first word when he was around 4 years-old, and has some basic syntax now - normally three or four words. His oral language level is around two and half years old.

According to Paavai, due to his limited communication ability, he is able to express his basic needs (such as the name of food or a place), but unable to tell others of his feelings, have a chat, and describe what happened. Although he can speak 4-word sentences, Paavai still needs to interpret his words to other people because she understands him very well. Perhaps his challenging behaviour is his means of communication and a way of expressing his frustration due to his limited language ability.

Additionally, he takes other people’s words literally. He cannot understand the hidden meaning relating to social understanding, but Paavai believes that he has the concept of death. He seems to know his grandparents are dead.

When Balaravi was younger, he was a bad sleeper. He would suddenly wake up and cry loudly. To avoid disturbing their neighbours, Paavai slept with him in their car for four months in ‘minus twenty degrees in Chicago’ (PB 1.26). Recently, Balaravi developed a sleeping pattern. His sleep pattern is altered by the amount of tension or stress in his life (school). Sometimes he sleeps well for several months, and sometimes he gets up to play at night when he will cut his soaps, or do some drawings or something. Then he will fall asleep again. Paavai has to be awake while Balaravi is awake. Sometimes he gets hungry in the middle of the night, so she has to feed him.

He has bad teeth. His tooth ache affects his emotions, and he cannot express where his pain is and how painful it is. Paavai has found a paediatric dentist to fix his teeth. He will need major dental surgery and a general anaesthetic to fill his cavities and extract seven teeth.

Balaravi uses scissors to cut paper. Paavai related one scary incident. She used to have long hair and Balaravi would tear it out. Then one day he cut it all off with a pair of scissors when she was taking a nap ‘for maybe five minutes’ (PB 1.32). After this incident, she optimistically says that it helps her very much because he is unable to pull her hair again. From Paavai’s tone, she seemed to feel scared. Did their parent-child relationship become tense after the incident? Did Paavai change her attitude toward Balaravi?

Paavai told me that she thinks Balaravi is a very flexible boy, she can ask him to change activities when he is making his own soap. He has learned to accept the changes of new environments (houses, schools) and activities, because of his father moving around countries. Paavai says that she prepares him for a move by telling him that the house they are living in is not in good condition. Normally, he only needs a few days to settle down.

Paavai thinks that he gets upset because he is not able to get the specific type of soap that he wants when they move home. Balaravi is obsessed with soap. Balaravi likes to use a peeler or a knife to peel or write something on the specific soap, and reshape and personalise it.

Paavai told me that he has an excellent memory for roads, daily routines and routes, such as bin day, swimming pool opening day, specific goods at specific shops, and shop locations. He is also obsessed with Stop signs. Paavai believes that this is because the stop signs are octagonal and he was fascinated by them (PB 1.77). She believes that this is because he has a spatial and number mind. Paavai said that he would ‘shout whenever he saw a specific geometric shape that was in his mind and he was about to tell about it, or count the odd numbers without knowing any numbers when he used to cry at night, so probably some number disturbed him in sleep’ (PB 1.81).

When speaking of his learning progress Paavai commented that her son may make little progress, then suddenly he is able to make a connection and he leaps forward. Balaravi has learned PECS for four years since he was six years-old, and he is still learning. Paavai noticed that Balaravi is a visual learner, and she talked to his head teacher. The head teacher moved him from a more verbal structured class into a visual structured class immediately.

Paavai told me that Balaravi has an advanced reading ability without being taught. He started to read English words in books, newspapers and on billboards without knowing their meaning when he was 12 months old and ‘literally could even read a dictionary’ (PB 1.83) and ‘even he can read on the opposite side’ (PB 3.26) (when he is around 10 years old).

Paavai said that Balaravi is sensitive to subtle changes in loudness, and dislikes loud noises or people shouting. For example, if his parents raise their voices when they are arguing he will ask his father to go out. Paavai continued that he is not sensitive to light. Instead, he likes things to be brightly lit.

Paavai told me that her son is very good at solving advanced puzzles. At preschool, when he was just twelve months old, he could solve puzzles which a ten-year-old child could not solve. According to Paavai, Balaravi is able to think of and apply logic to a situation, when he went back to India for a holiday, his cousin who is two years younger than him tried several times to take his toy boat, so ‘he climbed and put that boat up on the armida’ out of reach of his cousin (PB 3.78).

Balaravi has extreme emotional reactions. Paavai said that when he is experiencing negative emotions, he often breaks and throws things, such as a knife. Apart from this, he reacts badly when his parents say ‘No’. To address this issue, his parents negotiate alternatives rather than say ‘No’.

Paavai said that Balaravi is also creative; he shows an ability to create solutions to problems. She told me of an incident when he made a healing cream for her after he had attacked her.

Paavai explained that Balaravi likes to be complimented on every little thing he does, but he hates other people criticising him. She said that she has to speak to doctors and therapists when he is at school, because Balaravi does not like it when people talk about him. Does this show that he has self-esteem or is self-conscious, or has other emotions in this incident?

According to Paavai, Balaravi has fine motor skills, such as painting and cutting and is comfortable using technology tools. He is able to find useful information (such as a roast chicken recipe), make power point presentations, manufacture videos, and watch Indian TV shows by typing keywords on the internet. However, he is unable to send an email to other people. He does have certain spelling and written English abilities, even though he has limited oral language. Due to Balaravi’s behaviour, Paavai finds it is very challenging to compare all new software for phones and tablets that she believes will be helpful for him, and to find the best software for him.

### 5.2.2 Family

Family stress affects the family in many ways especially for the family of a child with autism, including their relationships with family members and others. (Blacher, 1984; DeMyer and Goldberg, 1983). Under this theme I have identified four subthemes namely ‘mother’, ‘father’, ‘grandparents’, and ‘other family members or friends’ which I have discussed below.

#### **5.2.2.1 Mother**

Dunn and Kendrick (1982), Fisher and Goodley (2007), Moss (1991), Parker (2012), and Shu and Lung (2005) found that the mother is the main carer of children with autism. Paavai tells me she is positive as well as strong, and does not indulge in self-pity. Due to her background, she thinks that she is more open-minded than her husband, who is very traditional. She was educated by Catholic missionaries from the West and her father was a high school head teacher and a journalist who commented on social injustice. Paavai thinks that in contrast to her mother, she is very liberal and is often criticised, even by her husband, for not being strict enough with her son. Paavai maintains her independence and, although she considers some opinions from other people, such as her father and husband, she makes her own decisions. Paavai credits some of her strength to the hardships she has endured since Balaravi was born.

Due to Balaravi’s development condition, Paavai was forced to give up her PhD study and stays at home to look after him. Balaravi’s tantrums have caused considerable damage and his parents need to renovate the whole house. They have to keep things locked away to prevent them from being broken by Balaravi. His negative emotions have caused them excessive emotional and financial stress. Due to the societal pressure in India, the family have ostracised Paavai and Balaravi, because he is different.

Paavai was taking Balaravi on her lap and cooking meals because he wanted to stay on her lap all the time. It was also arduous to put him down and take him out of the home. She said that she could not even pick up the phone because he would break the phone or throw it away.

Additionally, to avoid disturbing her husband and neighbours, Paavai told me that she had to sleep with Balaravi in their car for five months in ‘minus twenty degrees in Chicago’ when he was three year-old. The changing point was Independence Day in the USA. Paavai ‘took him to see the fireworks and then when he got back. Suddenly he started entering the house and sleeping at night’ (PB 1.26).

‘Then Balaravi wanted me to take him in the lap rather than go to bed.’ After sleeping in the car, Paavai told me she slept on a sofa for three or four months, ‘just holding him in my lap and sitting’. Then finally he started to sleep on the bed, but Paavai ‘had adapted to sleeping in the sofa’ (PB 1.26).

According to Paavai, Balaravi is her priority and life-centre. She has spent half her life on him, and he has become attached to her very closely. She said that she has to concentrate on keeping her eyes on him while he is at home.

When I saw Paavai after a long break in our interview sessions she told me of yet another sacrifice that she had made, her mother passed away and, because she and her husband anticipated Balaravi’s potential bad behaviour on the aeroplane, she could not go and see her family in India for the mourning.

Balaravi is their only child, and Paavai told me that they adore him very much. She has dedicated her whole life to working with and bringing him up. She is studying to be a teacher so she can work with him when he goes to school. She told me that she spends all her time with him when he is at home. If the family went to India, Paavai said that, because they have maids to do all the chores, she would be able to concentrate on him even more.

Paavai explained that, because she has a big family in India, she has seen many relatives growing up. Therefore she noticed Balaravi’s not typical development during his first year and sought some advice from medical professionals (paediatricians, psychiatrists). The medical professionals in India just told her that Balaravi will speak when he is getting older. It is common for a child immersed in at least three languages at home.

In our interview Paavai said that, for Balaravi’s best benefit, she meets and discusses with professionals and parents of children with autism. She attempts to understand his needs at every stage and constantly prepares for them, exploring every possibility for Balaravi or for herself.

In another example, Paavai said that she wanted Balaravi to have a vaccine before going to India, but she realised that the vaccine is made using eggs, so she first determined that Balaravi was not allergic to eggs. Then she had to deal with his fear of injections and was not helped by the hospital staff. She said that ‘nobody in this world is going to understand him if I don’t’ (PB 1.151).

Additionally, she tries very hard to make Balaravi happy even though those around her disapprove of her parenting approach; she still stands at his side, and fights for him. Paavai uses an instance to illustrate her blindness to his difference where she fails to recognise her son in a photo to illustrate that working with children is totally consuming and that she sees her son as being the same as any other child.

Our grief, our sorrow, or our thing should impact the children so we should be happy with their things. If they are happy, we should be happy. They are sad we should be sad, but it’s not the opposite way. (PB 2.97).

From Paavai’s story, it appears that Balaravi is very devastating. She suffers a good deal of both physical and mental pain. She copes with the stress by doing yoga and meditation to help her through her difficulties. Paavai told me that she struggles with the idea that she is a bad mother because she is not bringing up her son in a traditional Indian manner. She also has struggled to teach Balaravi PECS and to understand emotions since he was six years old.

Paavai said that she attempts to do the best for her son. When she takes him to attend public activities, she worries that he might learn something bad from his misbehaving peers. Additionally, because Balaravi looks like any other 10 year-old boy without any visible and physical impairment, Paavai is afraid that people might misunderstand or mistreat him, and then cause emotional damage to him.

Paavai thinks that Balaravi can develop to a 10 year-old level. It might be due to the bleak diagnosis from doctors (autism ‘is a lifelong disability’, ‘may be able to lead a normal life with some support and all, but he may not advance’) (PB 1.138). Paavai confided that she is very concerned about Balaravi’s future and worries about his ability to be independent and that she even thinks of Balaravi’s future marriage. She said that she thinks if Balaravi can communicate with others and behave well, then he will be able to ‘live happily and peacefully at home’ (PB 1.151).

Regarding emotions and feelings, Paavai explained that she thinks about why people raise their voices when they get angry. She said that she believes it is out of frustration from an inability to communicate, just as with autism, when people fail to make the other party understand them they become angry and frustrated.

Paavai also explained that she has little use for IQ, she believes that everyone is unique and that the measurement of a person’s IQ is irrelevant. Paavai does not want to test Balaravi’s IQ, because she does not think it will help in any way.

Paavai told me that sometimes she is confused about what causes Balaravi’s negative emotions and is uncertain about how to define his emotional cycle of surprise, curiosity, shyness and jealousy. In terms of deciphering Balaravi’s behaviour, she said it takes her a long time to find out what caused his negative emotions and what the hidden meaning behind his misbehaviour is.

Paavai told me that she chose Balaravi’s school in the UK based on four criteria. Firstly, the abilities of the children are compatible with him. Secondly, the school was in walking distance (because she cannot drive a car in the UK, her husband always works abroad, and she knows nobody in Sheffield). Thirdly, the school has sufficient professional staff and resources for Balaravi and finally, Paavai keeps Balaravi ‘working with a special educator all the time’ (PB 2.27).

#### **5.2.2.2 Father**

When talking of her husband, Paavai said that he ‘is a very God abiding and God fearing and worshipping person’ (PB 1.52). Both he and Paavai are Hindus, and ‘believe in a previous life and the after-life’ (reincarnation) (PB 1.52). In terms of his attitude towards Balaravi, Paavai said that her husband refuses to accept his diagnosis of autism, but he does his duty to support his family financially. In contrast to this, Paavai prefers not to ask why she is burdened, but rather to work on the problem and make it better.

Paavai said that she suspected Balaravi was different and sought professional advice, and then accepted him with his autism. She had a huge argument with her husband whom she claims is still in the denial stage. She told me that he refused to meet professionals, and always believes that Paavai is wrong and that upbringing is the cause of Balaravi’s ‘misbehaviour’. Even after getting the same diagnosis (pervasive development disorder, PDD) and after two assessments from different medical settings, he still refuses to accept it.

In our second interview, Paavai told me that her husband and family now say that they accept that Balaravi is autistic, but she doubts their statement. She believes that her husband still has high hopes for Balaravi’s future. Meanwhile, she thinks that she needs to explore Balaravi’s strengths outside of his academic performance and help him to achieve a better life.

Paavai told me that she and her husband expected Balaravi to have good academic performance (such as going to Oxford University) before he was born. Now, they are unsure about their son’s future and ‘definitely cannot expect him to develop like a regular child’ (PB 3.141).

#### **5.2.2.3 Grandparents**

When Paavai’s sister suspected that Balaravi was different, Paavai told me that her mother lost control and told her sister to keep her mouth closed.

Paavai said that when Balaravi was two years old, his grandfather had a close relationship with him. He even confused his grandfather with his father. Paavai recounted that due to the Indian culture, she and Balaravi were ostracised by their family, because Balaravi was diagnosed with autism, and they were the shame of her family.

Now the grandparents and grandson have little interaction with each other. Paavai said that amongst her family members, her father was the only one who attempted to research autism in order to understand his grandson more.

Under these circumstances, Paavai has no mental support from her family, and must have a huge amount of stress on her shoulders. It may be the reason for Balaravi’s aggressive behaviour or his behaviour may be the cause of her stress.

#### **5.2.2.4 Other family members or friends**

Paavai told me that her family in India is a big family and that there are ‘many psychiatrists and psychologists in the family’ (PB 1.26). She said that her sister was the first to notice Balaravi’s unusual development when he was 6 months old.

She told me that she does have some relatives who are scattered over the UK. They only meet each other on some special occasions. Paavai tells us her family has difficulty accepting Balaravi and some believe that he is mentally ill. She said that they will only accept him under the condition that he is well-behaved. Paavai said that she doubts that her family members say what they think which is that they accept Balaravi has autism.

### 5.2.3 The Educational System

Paavai told me that she believes that different schools in the USA and UK all see something different in Balaravi. They all said that Balaravi is different, and hard to be understood, but she cannot understand ‘what is different in him’ (PB 1.153). Every time he changes school, educators need to spend at least 6 months to understand him. UK schools ‘are quieter than the USA school’ (PB 1.153). She said that Balaravi enjoys his school life in the UK.

Following his diagnosis, Paavai and her husband put Balaravi in a school. Paavai said that she appreciates the school and is still in contact with the teachers there because they attempted to explain the concept of autism to her husband.

According to Paavai, Balaravi’s first educational experience was in America when he was three years old. She said that some professionals gave her good parenting suggestions and that she thinks that they are good at giving advice, but poor at handling Balaravi. They concealed Balaravi’s different behaviour and misled her and her husband. Instead, they asked Paavai and her husband to extend his school time so that they could charge more tuition fees. She said that Balaravi was devastating and almost got lost at that school. Additionally, they threatened to have her son taken away by the authorities if she told other people what she thought.

Paavai said that at special school Balaravi’s ex-teachers combined his parents’ information into his annual report which includes some set-up targets (IEP). According to P-scales (the assessment level of special education), his academic achievement in literacy was P7 and in mathematics was P3.

She told me that she believed that Balaravi learned violent behaviour from his peers, and showed it at home. She said that at first, she and her husband thought that he was being bad. Then they found out that he could not tell right from wrong. She went on to say that he attempted to tell his parents ‘that he is uncomfortable in some situations’ by representing his peer’s behaviour at home.

Paavai told me that she thinks a good rated and structured school, which is structured to work with children with autism, would be better able to help Balaravi. She said that her son prefers established routines that he has accepted. Paavai told me that she noticed that Balaravi is a visual learner, and felt stressed in studying in the verbal structured class (because he wet his pants at night). She said that she talked to his head teacher. The head teacher moved him from a more verbal structured class into a visual structured class immediately, and his situation improved.

Paavai said that parents are not always the experts. They see only their own children’s problems. On the other hand, teachers see many children, and have a bigger window to look at student’s needs, so sometimes they might be wrong. For Balaravi’s benefit, she said that she should contribute her observations to his teachers by writing notes, and his teachers would then have the right to choose which information they want to adopt.

Paavai said that she questions whether a regular school has enough resources for Balaravi, considering their holistic approach. Even a mother of another child with physical problems could not fully understand how to take care of Balaravi, because each child’s behaviour is different.

Paavai told me that Balaravi sometimes uses typing on a computer, writing on papers, or some pictures to express himself or make known his needs. Therefore, a computer, pens and papers, and PECS are his communication tools.

Paavai said that she believes that Balaravi has come a long way from being very autistic. He has become continent and is able to perform basic ablutions such as tooth-brushing, going to the toilet, and bathing. He has made some progress in understanding what his parents are saying and what might be harmful. She told me that Balaravi has got a ‘certificate for making a beautiful butterfly’ and a certificate for achieving 100% of his IEP and that he is also learning some safety practice at school.

Paavai told me that she thinks he can do many things, but when he is with her he expects her to do them, so she is a barrier to his progress. Paavai told me that during the course of our interviews, Balaravi has made some progress in oral language and expressing his emotions. Now she thinks that it might be better not to cater to his autism. Instead, it is better to make him accept the world as it is.

Paavai told me that she has accessed all kinds of resources starting with a social worker in the USA, an educational psychologist who visited their home and made an assessment of Balaravi, and said that Balaravi ‘is going to be another Temple Grandin’ (PB 1.168). She told me that Balaravi had a great deal of speech therapy when he was younger and now has a good vocabulary (his ability is ‘near to the regular child of this age’) (PB 1.183), but he has poor syntax. The school will evaluate him for further help with his speech.

Paavai said that she has attempted to find available resources for Balaravi. She made contact with the special educational needs educator in India by Skype to discuss how to improve his abilities. She told me that a social worker in a Chicago school told her that ‘God has thought that you could have that patience to raise this kind of child and that’s why he has given him to you. So with all due respect to the Lord’ (PB 1.54). She wants to be happy.

This kind of statement (attitude) makes her feel better. She said that a psychologist suggested that Paavai gives him bubble wrap to relieve his anger. Paavai said that it is partly working but ‘it is very hard to catch him just when he is getting angry and it is not even possible that, when he is getting angry, I would run with those in my hand and search for that’ (PB 1.202).

Paavai said that she was troubled by Balaravi’s continuously peeling when he was eight year-old. His teacher in a Chicago school suggested that she should not resist Balaravi’s desire to peel. Instead, she should find an acceptable way to do it because peeling is a way of relieving his stress.

Paavai said that she believes that the characteristics of a good teacher include giving useful advice, forming good relationships (communication) with parents (if Balaravi is happy and growing, this option is the least priority), listening to his parents’ thoughts and input into teaching, being friendly and warm, keeping Balaravi happy and making him grow.

The school system has struggled to place Balaravi in the correct spot. At special schools, his teachers placed him according to his ability rather than his chronological age. His current school has placed him in year six for three years since he was four. Paavai says she thinks that the school has not correctly placed Balaravi, because his classmates have much better abilities than him. She feels that he should be in year 5, yet she is satisfied with the current school’s arrangement. ‘The educational psychologist, the principal officer, the head teacher, the deputy head’, and Paavai had a big meeting to discuss whether to transfer Balaravi from one school to another. Paavai said that she believes that it is important that the professional staff and the parents work together to enhance the abilities of a child with autism.

### 5.2.4 The Medical System

Paavai told me that she thinks the quality of Indian doctors is inconsistent, and it depends on which institution you go to in India. She thinks that the quality of American doctors is more stable and better than in India. Paavai said that she sought some help from psychiatrists or psychologists in India. The first doctor said that Balaravi’s bad behaviour is caused by her bad parenting. The second Indian doctor gave Balaravi a diagnosis of autism.

Paavai told me she got a flyer from an organisation for children with special needs in Chicago.She asked for advice from her friend who is a doctor from Romania and lived next door to her. Her friend encouraged her to contact the organisation. She did it and then took Balaravi there for assessment by a team of clinical psychologists and therapists. He was diagnosed with Pervasive developmental disorder (PDD) and autism at three years-old. Paavai said that her husband refused to accept the result, so they went to a private hospital to get a second opinion. After assessing Balaravi for around five hours, a doctor at the hospital said that Balaravi is autistic. She said that her husband was still in denial. The doctor offered a bleak diagnosis which was ‘is a lifelong disability’ and ‘he may be able to lead a normal life with some support and all, but he may not advance’ (PB 1.138). In spite of the doctor’s gloomy prediction, Paavai told me that she keeps hope because ‘nothing is impossible’ even with some limitations (PB 1.145).

Balaravi has not been reassessed since he was three years old. Paavai said that Balaravi was diagnosed at around 42 months old in the USA. To get an assessment and to protect Balaravi, his parents had to use private psychologists, private psychiatrists, and private paediatricians. Paavai told me she also went to see a psychiatrist to find out more about her son.

Paavai says she has had plenty of help from therapists and that she is currently exploring the idea of picture cards and an i-pad to help with communication. She said that Balaravi had 90 minutes of speech and language therapy every week and they tried many different techniques with him in the USA. In addition, he had weekly occupational therapy and physiotherapy.

When he first started special school in the UK, his parents asked for medication because his behaviour was so challenging. Although they asked for medicine to help him, the school staff said that ‘we are not going to sedate this child with medicine. It is a purely behavioural issue. We will support you in any other way’ (PB 1.171). She told me that they provided a more structured curriculum for Balaravi but in the end, Balaravi’s behaviour was adjusted with medication.

Paavai said that the doctors and a psychologist at a UK neurological centre give Paavai encouragement by saying that Balaravi ‘is equal to the other children’ (PB 1.161).

Paavai says that she doubts the professional ability of some doctors in India. She believes that the characteristics of a good doctor are giving useful advice, and utilising a good teaching strategy.

### 5.2.5 Society, Community, or Nation

Paavai told me that she believes that there is a low instance of mental health problems in India, because everyone is so happy. She thinks this is due to Indian philosophy. According to Paavai, her family belongs to a high caste in Indian society; they are very wealthy and have many maids to serve them. Her relatives are all well-educated and are doctors or officers in the military.

#### **5.2.5.1 Cultural View toward Children with Autism**

Paavai told me that she believes that ‘no one should be disrespectful of anybody’ with autism (PB2.204). In our first interview, Paavai said that, in India, there was no provision for children with autism. It is hard to be the parent of a child with autism because Indian people do not consider it a disorder. Instead, they blame the parents of the child with autism for being a bad parent. Without mental and physical support, it is understandable how much hardship parents and children with autism encounter in daily life. This extract from her testimony illustrates some of what Paavai has had to endure.

[I]n India there was no such awareness about the autistic children. They do think that these are just spoiled brats, because of their behaviours and the parents are not doing good parenting or somebody else to blame or some scapegoat, but nobody wants to address the main reason why the child is different and being different in a country of one billion is not very expected. The government don’t care about them. They do care about the physical disabilities, but you cannot see it. It is a disability without Band-Aids and wheelchair, it is much more complicated to make people understand that OK, if he is looking like this but, he is having a problem. I don’t know how much it is in Taiwan, but still now in India, the people do struggle to get the government to do any legislation to include autism in a disability. That’s why parliament is yet debating on that. (PB 1.16).

Even people say to me ‘People can train an elephant…they can train monkey. You are a failure, you are a bad mother so you are spoiling your son’. (PB 2.17.1).

Six months later (in our second and third interviews), she told me that Indian people are starting to have an awareness of autism in their society. They have built some institutions for individuals with autism and autism research and they train special educational needs teachers.

#### **5.2.5.2 On a Child in India**

Paavai believes that parents in India are too demanding of their children. Therefore, both parents and children are under a huge amount of stress from Indian society. I believe that this extract from her testimony is very relevant:

Still the parents are very free here (the UK). They give a lot of independence to their children. In India…Oh God. A child is born… he is just an insurance policy for the parents I see that. Honest. It is not your child…how can you say that you are so bad. That’s why your child is like that you are not buying insurance policy and all your things what you have not done Oh God the poor child… if you can imagine the weight of the bag he carries to the school even one year old. It’s really horrible. So many children commit suicide. My neighbour he stood second in the bold… his father asked him “Why didn’t you stand scoring 98%? The first.” Everybody wants their children to be first, then who is going to be last. (PB 1.354).

#### **5.2.5.3 Neighbour’s Reaction**

Neighbours’ reactions affect Paavai very much. She feels stressed, hurt and helpless especially as she needs to handle Balaravi’s emotions, behaviour, and daily trivia by herself most of the time. Paavai tells me of an incident when she was at a mall in the USA as it was closing. Balaravi had a tantrum and was screaming back and forth. Some people called the police because they thought she was abusing Balaravi. When the police came and found a bleeding Paavai, she explained what had happened and asked for help. The police suggested that she take Balaravi to see a doctor. Then she told me that later, in the UK, her neighbour was not understanding of Balaravi’s behaviour, because he looks normal. What appeared to be discrimination was perhaps only ignorance.

#### **5.2.5.4 Societal Pressure**

Paavai mentioned an incident about her sister, who is an experienced doctor, who noticed Balaravi was different (when he was six-months old), Paavai’s mother was defensive of her grandson and hoping not to suffer the social embarrassment of having a child who does not conform to the standard, so Paavai’s sister ‘kept her mouth shut’ (PB 2.19). Paavai told me that at the time she thought that she was a bad mother because she was not bringing up her son in a traditional manner according to Indian traditions.

According to Paavai, autism has had a major influence on her life and family, Balaravi’s diagnosis caused them to be ostracised from their family in India, and caused some disagreements between her and her husband due to societal pressure. Additionally, the family is socially isolated because of Balaravi’s behaviour. In spite of the traditions of her culture, Paavai maintains her independence. Although she considers the opinions of her father and husband she makes her own decisions. Paavai credits some of her strength to the hardships she has endured since Balaravi was born.

P:…so I have gone through a very very difficult phase when my son was one and half till five years, even with my family. They told me not to go to my own house like, you know, because the other children are talking and my son is not, so they will be feeling shameful. I didn’t go there for more than six years. I didn’t see my parents for more than six years. (PB 2.17.2).

To find out what caused Balaravi’s unusual development, Paavai and her husband brought Balaravi to see doctors in the USA and India. After assessing Balaravi, the first doctor in India said that Balaravi’s bad behaviour was caused by her bad parenting which was the stereotype in India. She was furious and said to the doctor:

If you cannot help, don’t put mothers in a position, in a place like India, where the society is always after blaming women. Don’t do this kind of mistake again. If you don’t know, go and study! And don’t sit in your clinic, but don’t create more trouble for mothers! (PB 3.34).

#### **5.2.5.5 Resource**

Paavai told me that she was given hope by other parents of children with autism in The Sunrise Programme group. She found some of their techniques quite useful in developing his communication ability and growing his understanding. Unfortunately, their techniques make his behaviour worse and further affected other family members’ lives. At some point they were no longer helpful to Balaravi. Paavai told me that the CEO of the organisation (Raun Kaufman) saw Balaravi and wrote ‘I think you have many potential and you will do many things’ in a nursery rhymes book. From Paavai’s statement, I seem to hear her heart cry out for approval of her observation that Balaravi is capable of doing many things and that she is a good mother.

Paavai said that to meet Balaravi’s social needs, she brought him to swing and play in children’s entertainment centres, or to attend county activities for children with special needs. Meanwhile, she worries that he might learn something bad from misbehaved peers.

## 5.3 Harry

### 5.3.1 Something About Taiwan

In Taiwan, The Department of Education has made special education available for all people who have learning difficulties. Additionally, they recognise children who are gifted with exceptional skills such as maths, science, arts, or sports. More and more schools are providing inclusive education, catering for children who have difficulties as well as exceptional talents allowing them to immerse in the mainstream of education. ‘In school year 2011-2012, about 7,000 students attended such schools’ (Taiwan Ministry of Foreign Affairs, 2013).

The regulations in Taiwan that relate to individuals with special needs are there to provide basic services. They cover personal assessments, hiring of professional staff, curriculum, educational principles, transportation, special equipment, benefits, and so on (see Appendix 3).  The diagnosis usually happens in the child’s early years and at this point they become deeply involved in the medical system. Infants or young children with autism frequently accept early intervention in the hospitals and institutions (Chen et al., 2010).

Many hospitals in Taiwan now have day-care centres for preschool children with special needs. For example, the National Taiwan University Hospital focuses on developing children’s basic skills, such as eating, toilet training, imitating, following simple instructions, getting used to group life and sitting nicely and quietly in class. Children with autism are mostly accepted into the day-care centre by the time they are 2 years old. The emphasis is on cooperation between doctors and parents and showing parents how to work with their child. Thus parents participate in the whole treatment.

Clinical staff and parents develop the child’s communication and social interaction abilities together through various activities. When the child with autism has attained a certain ability level, he or she will be transferred into either a special class or a mainstream class. Clinical staff will follow the child’s progress in other institutions for at least 6 months. Due to the prevalence of autism, most children with autism have to wait on a list for at least six months (National Taiwan University Hospital, 2013).

### 5.3.2 Introduction

The first interview with Catherine and John concerning their son Harry was on April 15th 2012. Harry was around 7 years old at that time. Catherine and John are both university graduates. Catherine is around 38 years old and John is around 40 years old. She is of Taiwan origin, but has dual nationality between Canada and Taiwan. Catherine speaks Mandarin and English. John is of Philippine origin and speaks Filipino and English. Because of this, their children are strongest in English.

Both parents work in the IT industry. John works from home and his employer, who is based in the USA, has allowed him to work from home in Taiwan and now in Canada too as they intend to move and settle in Toronto within the next month.

Catherine and John have two children Harry and Elizabeth. Catherine started to write a diary from when she first became pregnant. Elizabeth is almost four and can speak both Mandarin and English fluently, happily switching between both languages. Elizabeth is not diagnosed with autism but is registered with special needs in Taiwan. She is quite bright and enjoys a good relationship with her brother.

Harry started at kindergarten when he was 2 years old. He was assessed and diagnosed as being autistic at age 3. (Later, when he was six, the diagnosis was changed to severe autism.) After the diagnosis, Harry was entered into the hospital’s intensive day-care program as well as with private tutors (a psychiatrist, speech and a language therapist, and a student tutor) who were to work with him at home until he was 5 years old. He later attended special education kindergarten class and then went on to special education grade 1 class at 6 years old. They have a full time carer for their son. The carer also helps with housework and cooking.

Peter, the interpreter, was present only during the first interview, which was partially conducted in English.

### 5.3.3 Individual

Every child with autism is unique, and every family of a child with autism is unique. It is hardly surprising; therefore, that parents of children newly diagnosed with autism panic, trying to find a definition that fits their child. Teaching children with autism is a challenge and their parents have to learn as they go along, through trial and error.

After recalling Harry’s early development, it was evident that he had some unique behaviour implying autism, but his parents did not recognise this, not only because they were new parents, but they were focussed on his lack of verbal development. When Harry was 2 years old, he was still non-verbal, and liked to be hugged as he was sleeping. Catherine described the following occasion;

I remembered that he didn’t react when we called him. We thought he had hearing problem. But when John came home around 6p.m. He can hear papa was using a key to open the door on ground floor immediately (they live on floor 5). (C&J 1.371).

Catherine had early stage uterus contractions in her 7-month pregnancy, and was hospitalized during the last two months of pregnancy for her tocolysis and was treated with anti-contraction medication or labour repressants. During this period, she was ordered to stay in bed all the time, and John burned the candle at both ends between his office and hospital. The whole labour period was normal.

Harry was breast-fed until he was 25 months old, and developed a close relationship with his mother. Before Harry was diagnosed, Catherine followed textbooks when looking after him, but she found that he did not react in the way the books said he should. She became confused and doubted her sanity and her child-rearing ability; her confidence was seriously undermined. After Harry’s diagnosis, she began to learn how to bring up a child with autism.

#### **5.3.3.1 Emotionality**

Catherine thinks that Harry has emotions and these affect his learning. (While he has a bad mood, he cannot learn anything.) Catherine said that ‘once when his emotions more stable, he is actually being more understood and more patience to change us to different things’ (C&J 1.17).

Harry somehow is like a robot with feelings. He doesn’t know how to show his feelings. Whenever he feels something, he would just sit next to me, or try to sit on my lap so I could hold him. He would also take me by the window and want to sit quietly with me, looking down on the streets. (Diary 1/Nov/2012).

Playing ‘tickling and peekaboo’ (Diary 18/Oct/2012), mimicking other people’s actions (drawing, doing exercise), playing musical games, holding other individuals’ hands are some of Harry’s ways of social interaction. If you ask Harry to let go of your hand, he will have a negative emotional reaction.

Catherine believes Harry has a close relationship (bonding) with family members (parents, grandparents, nanny, sister). He is just weak at expressing his emotions and feelings. In daily life, Harry likes to snuggle with Catherine especially when he is tired or sleepy. Additionally, he also has an attachment to his ex-teachers. Catherine gave this illustration: Harry’s three ex-teachers (who were teaching Harry around 4 years ago) visited his home before they departed for Canada. After a couple of hours of parent-teacher chatting, Harry suddenly hugged his main teacher tightly.

After a 3-week separation from his father, Harry missed him very much, and had the following reaction when he saw him:

When Harry, following his morning routines, opened my bedroom door after he woke up, he saw daddy. He would usually climb to my side of bed and cuddle with me. But, not today. He bypassed and ran to daddy’s side, and start holding daddy’s face to kiss him. The boys stayed in bed for quite a while. (Diary 22/Nov/2012).

Even though Harry likes sweets very much, he is still willing to share candy with Elizabeth. Harry can recognise familiar faces. For instance, family members (such as parents, grandparents, auntie, sister, cousin), and teachers. Catherine can tell this ability by whether he looks at the person, sits next to the person, or hugs him or her.

His parents can tell Harry’s emotions by facial expressions, gestures, and sounds. The best way of detecting his emotions is through his gestures and facial expressions (innate or basic expressions). Catherine said that Harry released his negative emotions on her when he was young. As he is getting older, Harry’s emotions are mostly stable. Harry ‘likes being close to somebody. It makes him feel safe’ (C&J 1.733). Once Harry’s negative emotions are evoked by not getting the things he wants, Catherine keeps him company and counts numbers with him until he calms down. Catherine directs his attention to acceptable activities. As for John, the way he comforts Harry is to hug him and let him sit on his lap.

We discussed Harry’s emotions; he expresses his happiness by laughing, screaming, bouncing, and jumping on the sofa. It is not always clear why he is happy, but he is definitely happy when he finishes a 300-piece jigsaw puzzle by himself. His tantrums are mostly caused by hunger, being scolded or being separated from his parents. Harry shows his tantrum by throwing things and screaming. Catherine thinks that Harry lacks the ability of empathy. His anger is shown by his refusal to do things he is asked. Instead he whines, or stamps his foot. This is mostly caused by not getting the thing he wants (such as an i-pad).

Harry is easily distracted from his negative emotions by giving him other objects. He shows his anger is grabbing a person’s upper arm tightly. If you say ‘it is painful’, he will pat your head to say he is sorry. Disdain is mostly caused by his sister (Elizabeth) bothering him. Harry expresses his disdain by moving his eyes right or left and then looking down with a turned down mouth.

Being scolded by his parents or being given a ‘time out’ (punishment) is what mostly makes him angry or cross. Being scolded sometimes makes him scared. Harry shows he is cross by bouncing himself and shows he is scared by crying.

Harry’s parents can tell when he is sad from his cries. When Harry is sad, his parents comfort him by holding him and massaging his head which can help put him in a better mood. Catherine doubts that Harry’s emotional outbursts have anything to do with his sensory issue.

Catherine thinks that Harry does not feel sympathy, and she is teaching him how to become sympathetic (say sorry and pat the person’s head). Harry still needs to be reminded to show sympathy. One exception was when Harry stepped on Catherine’s feet, she shouted in pain and Harry spontaneously patted Catherine’s head to show he was sorry. However, I wonder if Harry’s reaction is evoked by a feeling of sympathy or just a conditioned response (Pavlovian’s concept: Classical conditioning), or he may have been shocked by Catherine’s loud cry.

When Harry was younger, he expressed his anxiety by biting his fingers. As he has become older and more stable, his anxiety has subsided. Harry becomes anxious when walking past a dental clinic. He will hold his parent’s hand tightly and run past as quickly as possible, or try to find another route. He shows his excitement by bouncing and laughing and generally running around.

Harry’s emotions are affected by language, Harry is non-verbal; therefore, he uses sounds, gestures, and movements to show his intention. Unfortunately, most people cannot understand him, and they scold him for his socially unacceptable behaviour. John thinks that ‘after Harry started (expressing himself by technology tools), he is able to express himself. He’s not as frustrated as before’ (C&J 1.428); actually, ‘he is more stable’ (C&J 1.449).

Hunger also affects his emotional state. Harry is a picky eater, and he has an eating schedule. He likes to eat the same food at home or in the same restaurants. If Harry does not like the food, he will refuse to eat it. His parents have difficulty in finding food and restaurants that he will like when they go out; therefore, sweets (candies, cookies, and chocolate) become an alternative option. Unfortunately, Harry cannot express his hunger and sweets cannot stop him from feeling hungry, so he usually ends up having a tantrum, consequently Catherine and John do not enjoy taking him to new places to eat.

He does not like waiting. He is easily distracted, and has limited patience when waiting. After waiting for a short while, Harry will be inclined to leave and his father will have to keep dragging him back to the queue.

Of course when he is not well he has a very short temper. Also, hot weather makes Harry have a bad temper, because he has atopic eczema, which makes his whole body very itchy. He prefers the temperature to be around 23°C. After a-week long experiment, Catherine found that Harry wakes up three hours earlier if the room temperature is set to 24°C instead of 23°C. Catherine jokingly said that Harry’s life is built on money, such as treatment and electricity fees. His mood is altered by sleepiness. When Harry is tired it is easy to evoke his negative emotions. Harry cannot stand shrill noises in the subway and pneumatic drill sounds in construction areas. Changes in humidity also affect Harry’s emotions.

Harry does have different jobs for different people; for example, Mommy is for doing some things and Daddy is for others. His way of seeking his parents’ attention is by sitting on their lap, or by hovering around the person he wants to interact with.

Harry likes sweets (chocolate, cookies, and candies) and is good at finding hidden sweets. All his carers are amazed by this gift. Sweets are a motivational tool that can be used to persuade him to do things like problem-solving and waiting, they can be used as a temporary hunger-stopper, and as a reward for him.

He likes to play in water. The way he plays in water is by spinning in the pool and continuously jumping into and stepping out of the pool smiling, so his parents have registered him in a swimming class.

Harry likes to eat fruit, such as pineapple, grapes, and pomelos. Fruit can be used as a motivational tool as well. When Harry was younger, he had little interest in Thomas the Tank Engine. As he has grown, his preferences have changed. Now, when he visits a toy shop he always wants to see these wooden trains. Catherine thinks he is too old to play with Thomas toy trains.

In Taiwan, Harry likes to travel in their own car, on the MRT (Taipei Underground Railway), and by taxi. In Canada, Harry prefers to take the bus rather than take the subway.

Harry likes to do puzzles row by row, and seems to remember the allocation of each puzzle. He even made a thanksgiving book, and wrote ‘I am thankful for puzzles’ on the last page (Diary 5/Oct/2012).

He likes to sit on his parent’s lap and do some activities. It is also his way of attention-seeking.

Harry loves to play computer (games), i-phone, and i-pad. His parents even said that Harry is addicted to this, because he can play all day long. Only technology tools make him sit down for a while. He likes soft material for example he spontaneously went to a student’s sleeping bag and lay inside it in class.

When Harry is given advanced schedule warning, he can compose himself into a new routine or new environment. Harry’s parents think that he can feel their emotions, but he is unable to express it.

#### **5.3.3.2 Behaviour**

Catherine thinks Harry is easily distracted, because he has a low insistence level and a low fixation level. Harry becomes anxious when his close adults leave him with other people. Harry is a picky eater; he has strong preference for a limited range of foods. Only Harry’s school teachers and nanny can make him try different kinds of food. The nanny has to feed him though. He prefers fruits, sweets, ice cream, and crispy chicken skin, and ‘it is hard for him to try new food’ (Diary 31/July/2012).

Following a therapist’s advice, Harry’s parents decided to control his sweets consumption. To conquer his bad eating habits, they first forced Harry to try new food by slapping him. Harry suffered a bad a nightmare that night, and Catherine realised that she had taken a wrong step. Then Catherine told his nanny to give him nothing but main meals.

At the same time Harry’s carers also developed a strategy to give him his favourite food to go with the food he dislikes. Catherine said that ‘gives him a little something that he likes, such as some gummy bears, so he is willing to take a small bite. After a few more bites with gummy bears, if he likes the new food, he would not hesitate anymore. If he doesn’t like the new food, we will let it go’ (Diary 31/July/2012). Catherine concluded that ‘after all, we all have something we don’t like’ (Diary 31/July/2012).After trying these approaches, Harry now has a wider taste in food.

Harry has an excellent memory for roads, songs, and affairs. Sometimes, he may suddenly become cross because he remembers bad experiences, such as seeing a dentist, or his parents breaking their promises.

As he has been getting older, Harry has started to have preferences and make his own decisions. In terms of food, he likes to eat fruit, chicken skin, and sweets. If he dislikes the food, he will shake his head and refuse to eat it.

In terms of music, he likes strings (violins, string quartets, string instruments), but dislikes orchestra pieces, such as Swan Lake. Catherine noticed Harry’s music preference when they took taxi rides, because some taxi drivers would play classical music. Since then, his parents have tried to figure out Harry’s other musical preferences.

In terms of clothing, Harry refuses to wear certain clothes or new items. This may be due to sensory issues.

According to Catherine, Harry’s bad moods are produced by his not getting what he wants every time, lately they have reduced because of his parents consistent control, which appears to lower his fixation. Harry has some compulsions, for example he likes to walk along a line, to play puzzles row by row, and to have a specific routine.

Harry has the concept of schedule. If the schedule changes, Harry will be upset. Even if Harry sticks to a routine a lot, he still needs some reminders and advance notice to do school activities from his teachers.

Harry is a bad sleeper, he tends to wake up very early, and disturb his parent’s sleep (around 4 o’clock in the morning). He often has a seriously grumpy mood after sleeping, this may be due to his not having enough sleep; sometimes his parents use his favourite food to lessen his grumpy mood.

Catherine thinks that Harry’s biggest problem is communication impairment, and she attempts to tackle this issue. Due to Harry’s nonverbal and limited communication abilities, his parents are uncertain about what is in his mind. They have tried PECS, sign language, drawing, and App software. In the end, they have found that App software is the best approach for Harry’s communication issues. He uses ‘I want…’ to express his needs by using technology devices (i-phone & computer) or letter blocks at 7 year-old. Even though Harry can type several words to express his basic needs, his parents think they ‘need to teach him more words, so that he can put them together, but he knows that this is a good method of communication’ (C&J 1.433).

Catherine thinks that Harry’s sensory issues are mild, and he is not afraid to be hugged or touched. Harry is sensitive to sound, humidity, and weather. The way Harry deals with these things is to ask someone to massage his head (around his ears) to release his stress. Additionally, he likes mild pressure on his body, such as hugging, and wrapping himself with a thick blanket, even in summer. Harry’s therapist thinks that liking to touch the ground with his hands and to put his hands into his mouth is his way of meeting his sensory needs. Harry also likes to wear headphones. Catherine suspects that Harry’s emotional outbursts might have a close relationship with his sensory issues.

Harry is simple and direct in his expression. He knows certain rules (such as getting permission before leaving the room), but cannot understand more complex or hidden social rules (such as turn-taking). This implies that he can control his behaviour. However, he stepped into a neighbour’s house when he played Trick or Treat at Halloween. He is impatient, Harry cannot postpone his needs even if he is requested to wait, especially where food is concerned and public transport.

Harry does generalise his life experiences such as a birthday or a camping break through doll play. He has a fear of new things, Harry dislikes entering a new environment, or routine. If Harry is made to try new things, or new routines, he always loses his temper easily, and his parents are always intensely nervous. Harry’s reactions make his parents want to give up trying new things or routines, and only do things he is familiar with.

On the positive side, Catherine has learned many things from several-years of trying. She understands that Harry is unhappy about routine-changing, needs more time to adjust himself and that his parents need to put themselves into Harry’s shoes and attempt to reduce his anxiety of new things, giving him more time to wait and calm down. In terms of encountering a new scenario, Harry would react to it clumsily.

Harry is a slow learner. Catherine believes that he ‘is able to learn’ (C&J 2.284), and will show what he has learned as long as those working with him keep inputting knowledge and encourage him by repeatedly practising new skills. Harry’s Taiwanese ex-teacher told Catherine that a child with special needs is like a container for liquid. Parents and teachers need to continually input knowledge and skills (water) until he shows his limitations (overflowing). However, Catherine is unsure how much input Harry can manage (a cup, a drain, or an ocean). Harry does not easily co-operate.

Catherine registered Harry in a swimming class (in Taiwan) because he likes to play in water. After one-hour of trying, the tutor found it was very difficult to teach him how to swim because he only did what he wanted to do. Therefore, Catherine has set a goal for the swimming class which is for Harry to follow his swimming tutor’s instructions.

It is also very difficult to take Harry to see doctors and especially dentists. Clinical staff need to tie him up on the bed or restrict him in the X-ray room. Harry does like to be hugged. He likes to be hugged by Catherine or other family members when he is in bed, when he is upset, or just because he wants a hug.

Harry feels comfortable using technology tools such as a computer, an i-phone, or an i-pad. This may be due to both parents working in IT industries, and that technology devices for them are just like air in daily life. They even send messages to each other while they are in the same house. The devices become a motivation to learn how to spell words and for the use of PECS, as well as a basic communication tool.

Catherine wrote an app for the i-phone for Harry, and now Harry can type words in the i-phone to express himself, such as ice cream, MRT, bird, tree, train, cookies, candies, and a computer. The i-phone can be used as a distraction tool. Playing on an i-phone can distract Harry during dental treatment, waiting for a bus or when eating new food.

Technology devices (such as an i-phone) can also be a babysitter. If his parents feel unwell or are busy, they let him play on a computer without restraint.

The i-phone also acts as a social connection bridge between Harry and those who work with him. Harry can type his needs using an i-phone, and interact with his sister by sharing an i-pad. He has better typing ability than hand-writing. Unfortunately, there are some disadvantages from playing with technology tools, these include concern that it may affect his eyesight and he tends to rub his penis. If Harry plays with a computer without constraint, he will lightly rub his penis. Catherine suspects that the computer stimulates part of his brain. Once he stops playing he seeks the same pleasure by lightly rubbing his penis. Harry’s carer has suggested that he cut down his computer time, replacing this with other learning activities and to teach him to restrict his penis play to a private space, like his own room. Harry has taken to rubbing his penis in the last three years. At first, it started when he was sleepy. He lay prone on the bed and rubbed his penis with a bedding sheet. His parents asked him to lie down when they saw him doing it. Now they ask him to do it in private after taking a doctor’s advice. They have found that the frequency of doing it decreases if they cut down his computer time and when Harry feels exhausted after school.

Harry dislikes unexpected things, because he is unaware of what is going on around him. It is better to give him some advance notice of what will happen next, and then he can prepare himself mentally to deal with it. However, advanced notice will be in vain if he goes against what is planned.

Harry had eight decayed teeth which caused him pain. Catherine took him to see a dentist, but due to Harry’s special situation, the dentists needed to use specific equipment and approach to treat him. Following this, Catherine decided to take Harry for annual check-ups and she hopes that good experiences will replace painful ones.

Harry is a visual learner, but his listening and speaking skills are seriously delayed. His parents noticed that Harry ‘learned the alphabet on his own’ (C&J 2.284).

Counting numbers calms him down and makes him more patient when waiting, or during activities. Catherine thinks that counting calms him because it brings a sense of order. Unfortunately he lost interest in counting when he was at elementary school, because the teachers made him repeatedly write the numbers down.

When Harry was around five years old he used to spin around a lot. Catherine said that ‘it’s hard for Harry to sit down’ (C&J 1.254). However, when he is playing on a computer, i-phone, or i-pad, ‘he can sit down for a while’ (C&J 1.256). Harry is also ‘not really into reading’ (C&J 1.252). When Catherine is reading Elizabeth a bedtime story, Harry ‘will just be popping around. Catherine is sure that he is listening’ (C&J 1.252).

Harry’s teachers and parents have found that he can postpone his needs which means he has the ability of emotional regulation. For example, Catherine noticed that Harry can wait for another person’s TV programme to finish, then choose his favourite programme, or he stops eating grapes until the course ends. His parents need to give him instructions all the time. Harry’s primary teacher wrote one account in the contact book which describes his following some simple instructions and postponing his need to eat his favourite fruit. However, he played some tricks and behaved accordingly. He seems to consistently challenge the limits of other family members, teachers, and clinicians. Additionally, he knows whom he can take advantage of and whom he needs to obey. For example, he may ask for permission to go to the toilet, but actually will leave the room and toddle around the house. Another example is that Harry eats various kind of food by himself at school, but at home he has to be fed and of course Harry is much naughtier when he is in his grandparent’s home.

Catherine wonders whether Harry’s memory system might not develop or connect totally. If this is so, he may need more time to deal with information processing.

Harry enjoys the company of other children. If they are playing, he wants to be with them even if he just observes. He likes to watch other children’s actions (if he is interested in that activity), and attempt to imitate their movement, such as playing on a swing, rolling, chasing and running. However, he is weak at imitating other people’s facial expressions. Due to his poor oral language ability, Harry uses facial expressions, pointing, sounds (such as ‘ma ma’), pictures, shaking or nodding his head, dragging adults to the place, crying and raging, gently controlling other persons’ movements, and some objects (such as chairs) to help him get the thing he wants. He always knows where his parents hide the sweets (while Harry was not present) and climbs on a shelf or on a chair to get sweets (cookies) from the shelves without asking for help.

### 5.3.4 Family

In accordance with Bronfenbrenner (1979)’s theory, relatives and friends (social networking) provide some needed help, information, and resources for persons directly interacting with Harry (such as his parents). These are second-order social networks. In this section, five subthemes namely ‘parents’, ‘sibling’, ‘grandparents’, ‘other family members or friends’, and ‘network’ will be discussed.

#### **5.3.4.1 Parents**

According to some researchers, the quality of the husband-wife relationship affects the quality of the parent-child relationship and child performance (Bronfenbrenner, 1995; Crockenberg & Smith, 1982; Moss, 1967; Moss & Robson, 1968; Robson, Pedersen, & Moss, 1969). Catherine and John have similar family values. They work hard bringing up their children and are a back-up for each other. Since Harry’s diagnosis, John has been willing to spend a large proportion of their income on Harry’s treatment, and he has worked hard caring for Harry. On the other hand, Catherine believes that it is unwise to spend all their savings and income on Harry, because Elizabeth is just as important in the family, and it will be a long-term fight against autism.

Catherine and John struggle to balance their financial situation and Harry’s treatment. Since Catherine, John, and the nanny all communicate with each other in English, English is the predominant language spoken in the home. Mandarin and Filipino are also spoken secondarily.

Harry’s parents work together to bring up their children. Without his father’s effort, it would be arduous for his mother to raise their children alone especially having a child with special needs. In Taiwan, the grandparents have an enormous influence on upbringing, and tend to blame the mother for having a child with special needs. Harry’s father supports his wife and they work together to conquer the grandparents prejudice.

Whilst they were living in Taiwan, both Catherine and John had jobs, and they found it very tiring to look after Harry. Based on their personalities and circumstance, John was the main carer (this has changed following their move to Canada). His role in Taiwan was to discipline their children, keep company with them, play with them and take them to treatment and class. He spent more time with the children than Catherine, because he works at home. Sometimes, John hopes Catherine will be able to spend more time with the children. On the other hand, Catherine believes that she is not so good at playing with the children and needs more time to learn how to deal with their behaviour. Catherine believes that she is better at playing the non-disciplinarian role. Catherine was in charge of contacting with locals, reading bedtime stories, building the network, scheduling (trips, and education), and coping with daily trivia, because John only speaks English and Filipino. Catherine’s role resonates with Altiere and Kluge (2009)’s statement in which mothers found more support from friends and family than did fathers.

It is Catherine’s belief that raising a child is not only the mother’s responsibility, but also the father’s. She questions why other Taiwanese only think highly of John’s effort and take hers for granted? Why should she quit her job and take full responsibility for her children’s’ education? She feels lucky that she and John have a tacit agreement of their nurturing role based on their personalities.

Catherine and John faced and accepted the diagnosis of autism very quickly. Without the more commonly experienced denial phase. Catherine was pregnant at the time of Harry’s diagnosis. Catherine had to look after herself and make the best decisions for Harry and her soon to be born baby.

When discussing the stress that she experiences, Catherine told me that she thinks that their anxieties reduce when Harry goes to school. Their stresses come from working to deadlines, nurturing two children and their financial situation. When Harry is at home, he needs to be watched all the time, and they have no time to finish their projects which usually have tight deadlines. Due to this, they have no money to pay for Harry’s treatment and run their family. Under these circumstances, having their own time for work and an occasional break is vital for carers.

Harry’s parents decided to move to Canada because his English ability is better than his Mandarin. Additionally Catherine and the children are Canadian citizens and have some relatives there. In Canada they will have more space for the children to run around. Catherine and John have had to conquer their fear of the unknown, giving up their jobs, friends, network, family members in Taiwan, and starting a new life in Canada. This kind of parents’ fear of the unknown might affect Harry and his younger sister’s emotional status.

After moving to Canada, Catherine and her husband need to adjust to a new environment, cope with daily trivia, and deal with their children’s educational and medical issues.

Perhaps sub-consciously parents of a child with special needs will experience envy when they see their child’s peers make progress. This will cause a degree of stress as they want their child to be able to make the same amount of progress. Catherine has attended some parent groups both in Taiwan and in Canada. In Taiwan Catherine disliked attending the parent groups for several reasons. She found the groups to be filled with a negative atmosphere due to a strong victim mind-set and there were arguments, and parental comparison. She felt pressure from other parents. Some of the other mothers suggested strongly that Catherine should be a strict mother, and push Harry to learn more.

In the end Catherine succumbed to the pressure from the other parents, and attempted to enforce their higher expectations on Harry. She gave up because of the effect it was having on Harry, resulting in emotional outbursts. Additionally she was afraid that the advice from the other parents was unprofessional and potentially damaging. The parents in these groups would push their child to study in mainstream classes without concern for the child’s ability. The groups in Taiwan are held on weekends, and mostly they expect the parents to attend every week.

Catherine and John occasionally need to go to Elizabeth’s social activities, and they need to rest on weekends when they are both exhausted from work. Catherine is enjoying the Canadian parenting sessions, called ‘Triple P’. In the group, parents discuss how to take care of themselves, how to cope with their child’s slow learning progress, what their realistic expectations should be, and so on. She has shared her thoughts and experiences in the parent group, and the therapists there thanked her for her valuable input.

At the end of the sessions, she reflected that ‘there are various kind of personalities in a group. Diverse approaches arise due to mothers with diverse personalities who are interacting with children with diverse temperaments’. The people Catherine admires most in the group are two leaders, ‘because they used their own way to lead us to discuss different depth levels and subjects. During discussion, a cluster of strangers gradually broke silence, got familiar with each other, and further shared the darkness and the mild light in their lives’ (Diary 24/Aug/2012)

**Parental Reflection:**

Catherine reflects that she has the theory and idea of upbringing, but lacks the ability to put it into practice. She appreciates Harry giving her the chance to taste the fruit of her hard work. For example, Catherine has spent a great deal of time, made a huge amount of effort, and conquered many obstacles arising from Harry’s autism. Therefore, she appreciates every little bit of Harry’s progress, because it is a big achievement for her.

Catherine has learnt to face and address the difficulties encountered in daily life from nurturing Harry. She admits that her temper is not always perfect, and that it has greatly affected her relationships. She also admits that she needs to spend more time teaching Harry, but she lacks the confidence to do this formally and prefers to take him out rather than engaging in one-to-one teaching. After having two children and encountering lots of unexpected things, Catherine has started to modify and smooth her temper. Two years after Harry’s diagnosis, Catherine started to feel cool and composed enough to talk about Harry’s autism in public.

After watching Temple Grandin’s speech on Ted.com and seeing Harry spinning at 3:00a.m., Catherine came to the realization that Harry will never be like others. Once she had done this she understood that it does not matter if it takes 30 years, she and her husband will continue to work with him to master the fundamental needs of life, like toilet training, speaking, and reasonable behaviour. Catherine knows ‘that he is special, I am not going to deny that he has some problems and he will always have problems regardless of his autism or not. To me what is more important is that we want to provide what he needs’ (C&J 1.912), and she is ‘not expecting less of him. There are still things that she believes he can accomplish, but it’s hard to see what he will become as an adult’ (C&J 1.926).

Different systems have different viewpoints: clinical staff make subjective judgments based on their professional training perhaps without considering a child’s temperament. On the other hand, teachers are concerned with every child’s temperament and apply suitable teaching approaches. Parents should understand that every professional has his or her own idea, but in the end they need to make the final decisions for their child.

**Example Rather than Precept:**

Catherine reflected that parents should speak and act cautiously in front of their children at all times because example is better than precept. For example, parents should avoid fighting with each other in front of their children. Catherine also reflected that John and Harry have similar tempers, and often end up in ‘conflict each other’, so Catherine gets involved before ‘their relationship becomes tense’ (C&J 1.346).

Even before Harry’s diagnosis Catherine knew she would have a unique family because she married a Filipino (which is very rare and against some of society’s hidden rules in Taiwan). She expected that she would face their child’s language issue (getting confused between Mandarin and English). However, they were unexpectedly forced to face another challenge—Harry’s autism. Meanwhile, she felt that she had disappointed her parents by marrying a Filipino, therefore how could she ask Harry to meet her expectations.

Catherine is grateful that Harry is lucky in that he has good teachers and a good environment and wonders if it is necessary to constantly push him towards their expectations; perhaps it would be better to just let him go through life at his own pace. Of course his parents give Harry all the resources that they can. Catherine thinks that the choice of educational settings (mainstream class or resource class) should be based on a child’s abilities rather than the parents’ preference.

Every child is unique. When teaching or raising a child we should adopt appropriate strategies rather than applying the same standard to them all. It is rare to hear the following statement from a parent; ‘Education is not only about school, it is a whole thing. Like, you know, there is something school can give to him, something a family can provide to him’ (C&J 1.847). For Catherine, learning takes many forms and should not be limited to educational settings. Everything in daily life offers a chance for Harry to learn. Most parents rely on schools to educate their children rather than take the responsibility of educating them themselves.

Catherine thinks that teaching non-verbal young children typing to express themselves is very questionable, because written language ability is beyond their chronological age. She worries that this kind of performance is forced on parents and might have some mental health issues. A child is a child, even if they are gifted or autistic. If a 7 year-old child showed a 20-year-old written language ability, Catherine would worry about his mental status and emotions.

Catherine also reflects that being a parent is a very tiring role, and their mental status is always up-down. She has to be focussed and set a good example with her own conduct. She finally realised what it was like for her own parents.

After they moved to Canada for Harry’s good, she reflected that ‘I guess, I am so used to getting ready for disasters around Harry that I sometimes forget that he’s also just a kid’ (Diary 7/Dec/2012).

After Harry’s diagnosis, Catherine and John were confused. Catherine’s friends suggested that she seek religious support. At that moment, Catherine was willing to try any means of improving Harry’s situation. She went to see a Buddhist Monk who suggested that she try chanting. The suggestion was her salvation; it switched her and her husband’s mental status from guilt to acceptance. Buddhist Bibles tell her that causality is unimportant. The most important thing is to face and address the issue.

She noticed that Harry can learn a new concept in two days, or follow new instructions if he is interested in learning. She reflected that motivation is very essential for Harry’s learning. After briefly discussing Harry’s communication issues with his teacher, Catherine wrote down the following;

I have been wanting to know what Harry thinks for so long that the only solution that I can think of is to help him to find a way to talk. But I overlooked the fact that he’s been “talking”. He smiles and laughs at things that he likes. He drags me around and points at things that he wants. He pats on my head when I say, “ouch”. He gives me the TV remote when he wants to watch cartoons on Netflix. He even points at the cartoon that he wants to watch. And, do I really want to limit his ways of communication? I am sure PECS work great. I am sure typing is fine. But when we communicate, don’t we use more than one method? Perhaps, I should just keep on trying. Drawing, writing, singing, talking. One of these days, Harry would pick his tool and let me know. (Diary 23/Oct/2012).

After several-year attempting to teach Harry to accept new things, Catherine has made the following conclusions: She understands that Harry does not like change in his routine and needs more time to adjust himself and in order to reduce Harry’s anxiety, she and John would have to put themselves in Harry’s shoes, attempt to reduce Harry’s anxiety over new things, and take more time to wait for him to calm down. From a mother’s point of view, she feels that she is not good at being a strict mother, her son’s happiness should be the priority of her life.

Sometimes I wonder that his world is pretty simple, in fact, we are the ones who are complicated sort of feeling (her son is making ioioio sound). Yep, so I am not so anxious. I want my son to be happy. Whatever! (laughs). (C & J 1.84).

Also after attempting to push Harry to learn, Catherine found that she cannot be a strict mother. Therefore, she negotiated a compromise with her husband regarding Harry’s upbringing.

For me, I might find an excuse not to adopt other moms’ suggestions, and use my way to treat him. Later, I asked my husband to play a bad guy, because I only can be a nice guy. So I let papa to be a bad guy. (C & J 1.10).

Having a child with special needs forced Catherine to modify her views concerning child behaviour. She began to appreciate what she has right now and look at things on the bright side.

Frankly speaking, I am an impatient person. However, after several-years working with Harry, I have developed lots of patience. Elizabeth (Harry’s younger sister) enjoys the fruit of Harry’s labour. The reason is that Harry needs to spend more time on learning typical-development child’s easy missions. Therefore, I turn to appreciate Elizabeth’s naughty behaviour, and learn something from it. (Diary 4/Sep/2012).

It is not only the child with autism, but also his family members who must live with this condition. In the parents’ eyes, he is their dearest child who just happens to have some special needs.

Catherine is aware that a parent’s emotions and a child’s emotions are inextricably linked, especially with respect to negative emotions. For example, when parents feel stressed, their children are also under stress. To be specific, when his parents feel unwell, Harry’s behaviour becomes more difficult to tolerate. Therefore, it is difficult to judge which is the cause and which the effect. Catherine reflects that her bad temper might be caused by sleepless nights and her ailing physical condition. On the other hand, his parents have more patience with Harry when they get enough sleep. In addition, Catherine thinks that going to work is like a break for them, and makes them appreciate the time they spend together more, because of the better parent-child time and improved relationship.

When Harry was diagnosed, it was around the time of Elizabeth’s birth. Catherine and John knew they had to spend a large amount of time on Harry to facilitate his development. Meanwhile, they worried that Elizabeth might feel ignored by her parents. They hope that Elizabeth will consider this and forgive their inadequacies and understand that they love both her and her brother deeply. They ‘do their best to take care of both children’s emotions and development’ (C&J 1.304, Diary 24/May/2010).

When his mother attempts to make a decision for Harry, she always has a dilemma, and struggles between Harry making progress and being hard to control. For example, his parents attempted to find the balancing point between discipline and encouraging communication. They want Harry to express himself. However, they dislike Harry’s addiction to technology tools and the sweets which he always requests. An example is his parent’s struggle between Harry’s using an i-phone to learn and the effect on his eyesight. How to find the balancing point becomes a challenge for his parents. Meanwhile, they have difficulty deciding how to teach Harry and how to balance the two competing ideas, such as in the child-development approach or the autistic teaching approach, maintaining a flexible standard (depending on the scenario) or being consistent.

Additionally, she cares about Harry’s emotional needs and attempts to let Harry have a chance to develop independence. At the same time, she worries about his health and safety.

Catherine also faces the parenting dilemma of how to teach both children simultaneously. For example, parents generally dislike their children to eat sweets, but they allow Harry to have sweets to motivate him to communicate with others. Elizabeth has to wait until Harry gets a sweet first, and then she can get one. In Elizabeth’s mind, she must question why Harry is privileged to get the thing he wants just by asking for it, but she cannot?

Apparently after smashing the i-phone, Harry actually tried to tell his teacher that something was wrong. Typical dilemma for mommy: should we punish him for breaking the phone or reward him for trying to communicate?

Catherine thinks that Harry is still young and not up to complex things. She respects that everyone has his own way and style to spend his life, because every child has his own character and temperament. His personality is shaped by his own innate factors as well as his environment. Parents have to adjust themselves to address their child’s development issues. Generally speaking, a child’s will is always against their parent’s will.

They feel lucky about what they have. Catherine and John are affected by Harry’s screaming and yelling when they take him out. His misbehaviour in public tends to trigger his father’s temper and John becomes impatient. Because of this he tends to stay at home rather than go out.

Catherine takes the opposite view that more individuals are understanding and accepting of autism nowadays, and that she should take Harry out frequently to develop his social skills through reminding him to consider other individuals’ feelings under certain circumstances.

So, with regard to taking Harry out, John prefers to stay at home with Harry based on his own personality whereas, Catherine - after considering her own mental status, energy, health risks, and so on - is willing to take Harry out to new environments as often as she can to develop his social skills by presenting him with varied situations. When Harry was around 7 years old, he became more willing to explore new environments for a short period of time.

**Parental Uncertainty:**

His parents are unsure about Harry’s frequent requests to leave a place. Is it because he is unwell or because he wants to escape from a restrictive situation? Further, Catherine is uncertain about his unstable urinating performance. Sometimes he spreads his urine everywhere; sometimes he does it neatly. Additionally, they are unsure how to correctly decipher Harry’s emotional behaviour and needs, because Harry has few facial expressions and limited communication ability.

Harry’s parents are unsure about his ability to recognise emotions in other individuals. He might feel it but he is unable to express it. However, he definitely knows that his parents love him deeply and he recognises family members’ faces. Harry’s parents are also uncertain of his emotional need to build relationships with his peers.

Catherine is confident that she knows her child’s every trick. She said ‘mother knows everything. It’s scary’ (C&J 1.567). Catherine also thinks she has a better understanding and ability to handle Harry’s emotions than does her husband, because a mother has an innate intuition concerning her child. In her opinion, Harry is similar to other children. Actually, he is essentially a child. Therefore, she has ‘a hard time trying to decide if his behaviour is because he is special or because he is a child’ (C&J 1.909).

Sometimes, I wonder whether make up a lot of stories about his emotions or not. He does have some subtle facial expressions. His facial expressions, quite frankly, other people rarely notice. Perhaps it’s mother’s intuition. Sometimes, I wonder that do I add lots of imagination on his emotions and feelings. Sometimes, I think that I get it right. Interestingly, I think that I understand my son’s emotions and feelings better than my husband. Somehow, my husband cannot figure out why my son’s behaviour is like that. Sometimes, I can tell that he is angry. Most time, the reason of his anger is tiredness and then he becomes grumpy. At that time, I will tell my husband to leave him alone. But his father cannot understand why his son suddenly became like that. I think that it is the difference between Father and Mother. It cannot be helped that this is a natural instinct. (C&J 1.537).

Parental love is unconditional. No matter how serious the symptoms their child has and how unexpected the future waiting for them is, parents still love him deeply. Catherine thinks that ‘at certain point, both children are actually spoiled’ (C&J 1.306, C&J 1.308). Rearing a child with autism is a very arduous task, especially since children with autism rarely show emotions and feelings towards their parents. Therefore, the parents feel unloved and unneeded by their child. Even a small asked-for reaction can satisfy a parent’s mental needs. For example, one morning, Catherine said to Harry ‘You know I love you a lot, right?’, and Harry nodded. For Catherine, ‘that’s good enough’ (Diary 12/Sep/2012).

During the whole nurturing process, being positive is essential for them. For example, when Harry stole candies from his parents, they think it is good because Harry knows how to find food by himself. At Harry’s sixth birthday, Catherine was thankful to have Harry, because his being special makes her realise how big the Universe is, how many possibilities they have, how much love they have, and how their life is getting better. When a doctor reported to Catherine that Harry’s IQ is located in mild mental retardation area (in his annual medical report), she still felt good because Harry had made a little progress compared with the result from last year. She thought that it shows Harry has the ability to learn.

Once Harry’s negative emotions are evoked by not getting the things he wants; Catherine keeps him company and counts numbers with him. As soon as he calms down, Catherine distracts his attention to acceptable activities. As for John, the way he comforts Harry is to hug him and let him sit on his lap.

Parents need an integrated programme of professional knowledge to reduce their bewilderment. If they had a step-by-step parenting guide, the parents would reduce the time exploring options and making mistakes. After Harry’s diagnosis of autism, his parents were anxious and panicked about his future. During the parenting process, Catherine worried whether their approach met Harry’s on-going developmental needs.

Additionally, she is concerned about the impact on their children of the conflicts and different parenting ideas between her and John. Now Harry’s abilities have improved, they are still afraid that they might disregard some important development.

When Harry goes out, he needs at least two carers to hold his hands all the time because he might lose control and then have a serious accident (such as running into a car). His parents need the courage to take Harry out step by step. Meanwhile, Harry needs to develop the ability of following his carer’s instructions.

His parents are uncertain and worry about Harry’s future because of his limited abilities (such as poor emotional regulation). John’s idea is to save a large amount of money for Harry to provide against a rainy day. Catherine is calm about Harry’s slow learning progress. Instead, she is worried that he might regress. Before they departed for Canada, Catherine worried about special education resources in Canada since she has no experience of Canadian special education.

Catherine thinks that it is a parent’s responsibility to have reasonable expectations for their child. She hopes that Harry will develop proper behaviour, self-care ability, interests, good values, moral standards, his own ideas, independence, respect, humbleness, and politeness. Once Harry has oral language, she hopes that Harry will be able to discuss his own ideas with her. They hope that Elizabeth will help to look after Harry when she is an adult. However, they know that this expectation for Elizabeth is unfair. More specifically, She hopes that Harry will attain the independent abilities of a 20-year-old by the time he is 30-year-old (such as self-care capability). Other abilities, like academic ability or professional skills, are the least essential.

As for John, he wishes for Harry to ‘grow up normal’ (C&J 2.265), ‘go to normal school, graduate, (and) get a job’ (C&J 2.267). However, John also thinks ‘the worst case is that we need to make lots of money so that before we leave, you know, he will have some money and then you know we can find people who will take care of him’ (C&J 2.271). Harry’s parents will provide any resource they can and they will respect any decision he makes, either working with a group or alone, as long as he can survive in society.

When Harry was around three years old, his grandfather asked Catherine whether she would send Harry to a special school. Being a parent, Catherine was shocked by the idea because she was avoiding having Harry study in special classes. Now, due to Harry’s foundational abilities (non-verbal, self-care abilities) and specific learning style, Catherine started to accept the thought that a special class was the best option for Harry. Harry learns better in a one-to-one tutoring situation rather than in big-class (factory) teaching.

After hearing that Harry’s classmate at his day-care centre (hospital) had moved to a preschool special class, John pushed Catherine to enquire about more details from the school. Catherine felt anxious and scared about upcoming challenges because they had endured a great deal of disappointment, pain, and trepidation. Challenges seemed never ending for them. After visiting the school and talking with the teachers, she decided that Harry would study at the school in the morning, and accept treatment at the hospital in the afternoon.

Speaking of studying at an elementary school, Harry was allocated to a special class based on his foundational abilities. Considering that Harry’s English ability is better than his Mandarin ability, Catherine decided to move to Canada for Harry’s good.

Having a child with autism intensifies the parents’ relationship, alters their sleep pattern, brings family members closer together, and is one reason that the family social circle narrows (partly because of the parents’ personalities and partly because of having a child with autism). Or perhaps the reason is as Baxter (1989) mentions that the parents of a child with special needs prefer to take their child to a close and familiar group rather than to an unfamiliar group.

#### **5.3.4.2 Sibling**

Harry has a good relationship with his younger sister Elizabeth (C&J 3.250). When Elizabeth was around 1 year-old, she started to be talkative and have more facial expressions. She enjoyed being in the spotlight. Therefore, she attracted attention from Harry to her. The situation was such a huge relief for both the parents and Harry. Harry and Elizabeth have a mutual effect on each other. For example, when Harry is screaming, Elizabeth resonates with some odd noises.

He tolerated Elizabeth stealing his toys away, held Elizabeth’s hands, and waited his turn to sit on Catherine’s lap. Meanwhile, Elizabeth was willing to be a helper looking after Harry, tried to teach him how to speak, and have social interaction with him such as telling stories to him, playing with him, and asking him to lift her up, ‘even in a very bossy way’ (Diary 21/June/ 2013).

However, sometimes Harry cannot stand Elizabeth’s noise and behaviour. He chooses to cover her mouth or surrender the activity that he likes in order to escape from her. Harry often mimics Elizabeth’s behaviour and joins in her games such as bicycle riding, doing exercise, or playing on a swing. Interestingly, Catherine pointed out the language ability difference between Harry and Elizabeth is when Harry ‘remains so quiet, this girl cannot stop talking’ (Diary 22/October/2012).

Elizabeth likes to be centre stage, and diverts other people’s attention away from Harry’s condition and so relieves Catherine’s stress. Catherine reflected that ‘being the second born, [Elizabeth] always wants to be the first. She’s the “first half” while her brother is the “second half”’ (Diary 5/November/2012).

Elizabeth and Harry compete for their parents’ hugs or attention, especially when they are sleepy. Once Elizabeth gets Catherine’s attention, Harry will have some negative reactions, such as screaming or refusing to go to school.

#### **5.3.4.3 Grandparents**

Grandparents deeply love (indulge) their grandchildren and they are willing to give them everything they want. His grandmother helped Catherine to look after Harry when he was a baby. Their relationship shows in a different way. For example, when grandpa visited them, the children totally ignored him and played by themselves. Then, when grandpa stood by the door and was leaving, Harry started to cry.

Grandparents give parents financial support and human resource support. Grandmother gives Catherine a hand when she feels stressed or needs her help to look after the children. Catherine thinks that she is spoiled by her mother, and she feels guilty about that. However, they occasionally have disagreements about child-rearing. The grandparents complain that the parents are too strict with their grandson. The parents think that discipline makes Harry’s life easier because it helps him adjust himself accordingly in various situations.

#### **5.3.4.4** **Other Family Members or Friends**

Catherine and John’s support network (both in Taiwan and in Canada) is indispensable because rearing a child with autism needs plenty of support. Individuals working with a child with autism need a break occasionally or need others to assist them. It is pretty vital to build a network for the child with autism, and discuss teaching ideas and expectations with each person involved. In the beginning, Catherine built the network alone without John’s support. Gradually, John understood the importance of building a network for Harry. Catherine and John’s support network includes a 24-hour nanny, tutors, friends and relatives who understand their situation and are willing to step in and provide company (playmates), needed items, and human resources for them when they are needed. Before moving to Canada, Catherine was confident in her ability to build a new network there for Harry.

Usually, the nanny, father and mother construct a triangular network to cooperate and work better with the children. If one of them finds it too much, the other two can take over and continue with the child’s upbringing. Additionally, having a break occasionally is pretty essential for the carers of the child with autism.

Nanny’s main tasks are doing housework, keeping the children company and assisting to take the children out. Nanny is the most objective among all when dealing with Harry’s behaviour because she is the one who was hired to take care of the children.

Mother’s main task is finding all resources for the family, coping with affairs from the outside world, and scheduling activities. His father’s main task is to earn money, and keep company with (teaching) the children. Once one of them leaves, the other two feel stressed about the unbalanced situation. Catherine reflected that Harry’s tutor (Taiwan) integrated the therapist’s suggestions and applied them to Harry. On Saturdays, Catherine and John synchronised with therapists and checked the progress at home and at the hospital.

An auntie, who was an administrator of a specialist school in the USA, suspected Harry’s development was slow and suggested that Catherine send Harry to a specialist school.

Parents without a network, which is the case for most mothers of children with autism in Taiwan, lose the right to be sick, and their lives become unbalanced. Even if their child’s abilities have improved as a result of regular intensive treatment; they are still the victims of sinking emotions and depression.

### 5.3.5 The Educational System

Catherine thinks that the Taiwanese education system is scary because educators take both parents demands and children’s needs into consideration in regular education. These mostly conflict with each other and there are severe budget-cuts. The scariest part is that parents overrule teachers in professional decisions, and show them no respect. The best way is to find what is in the students’ best interests through parent-teacher cooperation.

In terms of special education, this might be acceptable because parents and teachers all focus on the children’s needs and enjoy better cooperative relationships. In Taiwan, Harry’s carers had to try very hard to drag Harry to school especially after weekends or holidays. Catherine was anxious about this situation because she worried that Harry might escape from their control and have a car accident. Catherine guessed that it was because Harry needed to do homework and attend more static classes.

Speaking about Canadian education, Catherine said that ‘everyone in Canada has a right to be educated’. The only thing she needs to do is communicate with school staff, be a cooperative parent and she will get any help Harry needs. Catherine expects that Canadian teachers can evoke Harry’s attempts at communication. In Taiwan and Canada, Harry has been allocated to special classes. After applying to Harry’s school in Canada, Catherine made a comment that the Canadian educational system is slower working than the Taiwanese system.

Due to Harry’s communication issues and other delayed development, he was allocated to a resource class. In a resource class at elementary school, teachers mainly teach students self-care abilities. Parents were told by school administrators that once Harry attends a special class, it becomes more and more difficult to move to a mainstream class. The ratio of the students to teachers was 2: 1 in Harry’s class in Taiwan. Teachers told Catherine that Harry was stable, but weak at mathematical concepts. Parents find out many details of what happened in class through a Teacher-parent Contact Book. At class, teachers used a reward system (by giving him a piece of puzzle) to motivate Harry. Unfortunately, Harry was always very good at finding hidden puzzles in class which tormented his teachers.

When Harry was 2 years old, Catherine and John sent him to a mainstream kindergarten, and found a teacher who was willing to teach him. At first, everything was ok until the teacher became pregnant, so they moved Harry into the medical system (treatment, day-care centre).

Catherine and John have spent a great deal of time exploring ways to help with communication and have found the following useful tools for Harry:

1. PECS: John and Catherine bought a whole set of PECS for Harry which was suggested by teachers, however, they found ‘it was too troublesome’ because they ‘have to carry it all the time’ (C&J 1.437).

2. I-phone: Catherine and John found a way to communicate (typing on an i-phone) with Harry by themselves. John installed an app in an i-phone, and accidently found out that Harry can spell (English), so Catherine wrote an i-phone app specifically for Harry. This has two modes—text and picture. Harry can use an i-phone to practise his spelling (English) and express his needs. Catherine still attempts to improve the software in order to meet more of Harry’s needs.

Due to their success in modifying their phones into Harry’s communication tool, teachers asked for the software they are using. Catherine cannot help them due to the following: firstly, one is that the software is for personal use only; secondly, every child is unique, and the software needs to be personalised for each child; and, finally, the child needs a certain spelling ability and to continue learning new words.

Harry’s progress is unpredictable and slow; sometimes he progresses quickly, sometimes slowly and sometimes he regresses. The landmark in his learning progress is communicating with others via the i-phone.

The only thing they can do is keep teaching, supervising him, and waiting for him to mature. Often his parents and teachers notice Harry’s progress by accident. For example, his teachers noticed that he can spell by writing a brand name in class. In addition, his parents noticed that he can spell by playing a computer game.

When Harry graduated from kindergarten, he had learnt to eat new food, and to try new clothing. A Taiwanese elementary teacher also reported some improvements in Harry’s physical training, such as repeated ball-bouncing. His parents follow Harry’s progress through his Teacher-Parent Contact Book, IEP meetings, and discussions in the family. His mother is proud of his being more independent, he goes to his class from the school gate by himself, tidies his own bag, goes to the toilet, takes a shower, is more stable and is more patient when waiting by counting numbers.

Catherine told me that she was very happy that in Canada, they provide a school bus service for children as this makes her life much easier.

According to Catherine, the characteristics of a good teacher are being friendly, open-minded, should educate the whole family to deal with the treatment issue, know how to communicate with and monitor the parents of a child with special needs, be able to handle every child’s situation and behaviour by being responsive to individual needs, and keeping regular contact with the parents about what is going on at school.

Catherine and John told me that they enjoy a good parent/teacher relationship. They trust and appreciate Harry’s teachers in Taiwan. They kept track of Harry’s progress by discussing it with teachers at pick-up time, through the Teacher-Parent Contact Book, meetings, and educational reports. They had several meetings to discuss Harry’s learning situation, and built a relationship via meetings.

Teachers in Canada think that Harry’s strength is his memory, and his weakness is logical reasoning and thinking. Sometimes, discussion with Harry’s teachers provokes some reflections from Catherine.

They told Catherine that Harry needs to learn to tolerate frustrations more and more as he gets older in small steps. His parents should let him go and attempt to not over-protect him.

Teachers at his elementary school told his parents that Harry was keen to look after a dog doctor (a dog that is trained to work with patients) when it visited his class. During the dog doctor’s visit, Harry was willing to follow the teacher’s instructions to get the opportunity of looking after the dog.

His teachers encouraged his parents to bring Harry to attend social activities to improve Harry’s social skills. The teachers take the children with special needs and their parents on weekend trips.

### 5.3.6 The Medical System

In Taiwan, the medical system is very convenient. Harry got his rough diagnosis report in several weeks. Whereas in Canada, Catherine has spent 5 months looking for a paediatrician for both her children and her requests have been refused by many doctors. She felt stressed and thought the efficiency of the medical system was low (long waiting time), and said that ‘I do miss the medical system in Taiwan. It is far more efficient!’ (Diary 25/Oct/2012).

At first, Catherine registered Harry for a speech and language therapy assessment session. At that session, the physician immediately referred Harry to the department that was in charge of early intervention, and then Harry got his first rough diagnosis report of autism in a few weeks when he was around 3 years old. When a young doctor was assessing Harry at this first diagnosis, the doctor was careless and let Catherine catch sight of the diagnosis on his computer screen. When she asked the doctor about this, he answered directly that Harry had typical autistic behaviour. This was very negligent in terms of patient-doctor ethics.

Before attending Harry’s diagnosis result meeting, about 2 weeks later, Catherine and John had read all available information relating to autism, and adjusted themselves to face the issue. As they were due to have their new baby, Elizabeth, Catherine and John were forced to be strong, practical, and tackle all the encountered issues. Catherine thinks that Harry’s doctors and therapists evaluate every child’s conditions (mental, physical, and language ability) when they are assessing him. They are also concerned with the parents’ emotions when they tell them the medical results. Additionally, they write obscure reports.

Catherine is unconcerned whether the diagnosis result represents Harry’s real abilities. If the result underestimates Harry’s abilities, it just shows how a stranger sees Harry, or that his ability is not stable. Catherine understands that a stranger’s view of Harry is different from those of the individuals working with him.

In terms of treatment arrangements, Catherine and John grab any chance they can get even if it is at short notice. Once they put Harry into these therapy sessions, they find a schedule that suits them. In Taiwan, parents need to accompany children with special needs to any treatment. Catherine and John found mutually acceptable times to take Harry to attend treatment. John complained that this was an unfair arrangement, and Catherine felt guilty about not handling Harry properly. In retrospect, Catherine realised that the first two years of treatment was mostly wasted trying to reach an agreement about Harry’s upbringing, expectations, and because of their attitudes. Then, they finally had the energy to face and address Harry’s development issues.

The resources Catherine and John have accessed for Harry are Daycare Centre, speech & language therapy, paediatrician, doctor, developmental paediatrician, nurse, psychologist, social worker, occupational therapist, and dentist. Harry uses an App on an i-phone which makes it a communication media tool for non-verbal children.

Catherine told me some of the feedback and advice that she has been given by clinical staff in Taiwan:

1. Catherine does not need to be so anxious to push Harry because every parent treats their child differently.

2. It is vital to find a balancing point between the main carer and other family members. Time will prove that once everyone’s emotions are stable, the life and treatment of the child with special needs can be steady for a long time.

3. A child with special needs will not become a heavy burden for his family members if parents, teachers, and professionals can train the child with special needs to take care of himself and find something he has an interest in.

4. Catherine felt offended when an occupational therapist blamed her for delaying Harry’s precious treatment without asking her about his history first.

5. After helping Catherine cope with Harry’s emotional outbursts and discussing what was going on around Harry for several weeks (due to Catherine’s long working hours and being stricter toward Harry). A therapist told Catherine that Harry might react strongly to the recent changes and then said ‘if Harry makes progress without your pushing, why are you asking for trouble?’ (Diary 1/Jul/2010).

6. It is necessary to take care of her family (their mental status, financial stress, human resource, medical resource, educational resource, social welfare resource, and so on) first, and then you can look after the child for longer. Catherine appreciated the suggestion very much, because it was a very practical suggestion for them.

7. Teaching only one main point is taught at a time. For example, when parents focus on developing their child’s communication ability, then they need to put it into priority, and take other areas as inferior.

8. Teachers in his day-care centre suggested that his parents do toilet training when Harry was 4 years old. During the toilet training, John showed Harry how to use the facility. Luckily, he stopped using nappies quite early, but he only defecates at home. He is unstable in his urinating performance and emotions during the training. Sometimes he spreads his urine everywhere; sometimes he does it neatly. Catherine is uncertain about how serious this unstable performance is.

In Taiwan, parents and clinical professionals have good, close cooperative relationships. Harry’s doctors illustrate medical results with the consideration of the child image they are building. Even though sometimes Catherine wants to cancel the treatment sessions due to Harry’s emotional outbursts, the therapists still are willing to go to their home and help them deal with the situation. The characteristics of good doctors are giving positive feedback and being supportive.

Catherine told me that, when considering the pros and cons of the Taiwan medical system, she thinks that Harry needs a complete network (programme together with a therapist or a case worker who would be in charge of all the related information, and scheduled treatment, Harry’s individual educational (treatment) plan, and who would contact relevant staff. Even though the Taiwan medical system is very convenient, it lacks functional integrity, has severe clinical staff shortages, and lacks proper training of how to inform parents. Taiwanese parents stagger along the medical treatment route.

### 5.3.7 Policy

Elyn Saks (2012) in a TED Talk said ‘portray [people with mental illness] sympathetically, and portray them in all the richness and depth of their experience as people, and not as diagnoses’, and I totally agree with that. When doctors suspected Harry’s behaviour as autism, Catherine started to register Harry into speech and language therapy sessions and read any information available concerning autism. After reading through this, she realised that she was not the only variable in Harry’s autism. She learned to be a parent by hands on experience.

I asked Catherine’s opinion about her child being labelled. She said that she struggled to accept it at first. However, she found that accepting the label not only to helped Harry to get social welfare and resources, but also to release her mental and emotional stress in public (because society has a certain understanding of autism). From her point of view, the most important thing was to get the best benefit and resources for her son. She does not compare her son’s ability with other children. She focuses on her son’s own progress rather than pushing him into serious academic competition with peers in Taiwan.

My thought is; I am not sure about what my son really needs. Does what I want equal the thing he wants? Did I give him the thing he wants? I struggled as to whether I should put him into a special class or not. Even a teacher told me that it is late to make the decision of my son studying in the special class. My attitude is that I am not sure whether the thing is good or bad, because the only thing I can do is evaluate our current resources and make the best decision. From the beginning I have tried to find the best resources for him. From the outset he has been at a disadvantage and the only thing we can do is do our best to find any resource he needs. It is not the symptoms and how serious they are. Whether they be profound, severe, moderate, these are only the measurement standard of dysfunction level. I care more about how much progress he made between last year and this (inter-comparison). You know, comparisons are onerous. Comparing is competition’s twin. Comparing yourself to others is nothing but bad news. You cannot compete with a gifted person and win. So what is the point in competing with other people? (C&J 1.496).

Even though Catherine does not mind the labelling, she often doubts that he has autism especially when Harry is in good condition. The most important issue for her is whether autism is an obstacle to his development. If yes, she will attempt to conquer it with Harry.

#### **5.3.7.1 Welfare**

After diagnosis, parents can choose to apply for a Disability Manual or not. Catherine and John decided to apply for one, and used the Disability Manual to apply for a 24-hour nanny from overseas. Harry is the holder of a Disability manual. According to Taiwanese regulations, the holder of a Disability Manual (severe level) can apply to employ a nanny from overseas (mostly they come from the Philippines or Vietnam).

### 5.3.8 Society, Community, Nation

Under this theme I identified two subthemes namely ‘cultural view’ and ‘societal pressure’ which are discussed below.

#### **5.3.8.1 Cultural View**

Every culture has its own set of values, and its own way to deal with things. Everything per se is neutral, and human beings endow things with meanings. Take Harry’s birthday as an example. An individual with autism cannot understand the complex meanings hidden in the social rituals. Therefore, he is cool and remote about the social rituals.

Before leaving for Canada, Catherine mentioned that she is ‘used to the fast pace in Taipei, and just expects everything to be done like yesterday and the later on’ (C&J 1.845). However, in Canada, it takes a longer time to run a procedure, and she needs to adjust herself to it.

Cultural view toward children with autism: when Catherine told other people that Harry has autism, she found that 9 out of 10 would say ‘he must have some gifts’. Then she had no idea how to follow on the conservation. She jokingly said that Harry’s gift was picking onion mince from a bowl of rice. She thinks that not every child with autism has gifts, the maximum he or she has is luck. She heard that many parents, who have a child with autism, break down under the huge stress from their relatives or society.

Thanks to media dissemination in the last three years, the Taiwanese have a certain understanding of autism, and it gives Catherine some relief to be able to say that Harry has autism or to deal with Harry in public because people now have a higher tolerance for Harry.

Canadians have a more positive attitude toward individuals with autism, readily accepting them, showing them respect and respecting their privacy. For example, Canadian clinical staff are willing to spend more time explaining the procedure and treatment of children with special needs to their families. Catherine thinks it might be due to the campaign of understanding autism. When Catherine had an interview with social workers in Canada, she suddenly realised that she and her husband were seen to abuse Harry. From the Canadian point of view, as it was too much to ask Harry to write down what he wants at home.

Catherine enhanced Harry’s life experiences by utilising any community resource available both in Taiwan and in Canada (some of these involved exchanged volunteering tasks), such museums, Autism Treatment Network, POND research on autism, swimming class, soccer class, respite programs, rock climbing events, and camp. When his mother was uncertain what happened to Harry in the camp, her doubts arose.

After Christmas, Harry went to Geneva Centre’s winter camp for two days. The first day, he didn’t want to go into the building. Mommy sent out stressed call email to other Triple P moms. It wasn’t the first time that Harry showed signs not wanting to go to Geneva Centre. I was getting worried that he doesn’t like the activities there. And I don’t know what they do there exactly. All the “positive comments”, such as, “He has a good day” doesn’t really tell me anything. And, I don’t believe in “good days”. No one can have a good day every time. It’s just not normal. It’s too positive. (Diary 8/Jan/2013).

#### **5.3.8.2 Societal Pressure**

In Taiwan, in the parent group in the hospital, other mothers suggested strongly that Catherine should be a strict mother, and push Harry to learn more. Catherine felt the pressure from other parents, and used other parents’ strategies on Harry. In the end, Catherine gave it up because of Harry’s emotional outbursts. From this incident, we can see that there is an emotional interaction relationship between parents and children.

Catherine thought “why on earth did I abuse Harry by choosing to meet other people’s expectations instead of following my intuition”? At a certain level, Catherine thinks that she is Harry’s supporter, and always provides a cosy atmosphere and cheers him up when he needs her. Taiwanese society also puts more stress on the mother instead of the father if they have a child with special needs. They expect the mother to quit her job and take full responsibility for the child’s upbringing. Catherine thought that it was unfair to her.

Catherine also mentions an occasion that illustrates how parents compare their child’s performance with others. One of Harry’s classmate’s parents saw Harry’s progress in walking into the class from the school gate by himself. At first, he questioned Catherine’s way of upbringing. Then he was persuaded to let his child go with Harry and let them walk together to class. Catherine concluded that ‘parents do have some sort of pressure against each other’ (C&J 1.518).

## 5.4 Han

### 5.4.1 Family Background

Interviews: 15/April/2012; 22/April/2012; 5/May/2012

My first interview with Ya (Han’s mother) was on April 15th 2012. Both Ya and her husband are graduates with masters degrees. Ya works with gifted children as a teacher in a special elementary school and her husband works in IT. They have two children, a boy and a girl. Their son, Han was diagnosed with autism when he was two and a half.

Due to placenta previa, Han was born by caesarean. At first he was looked after during the day by a babysitter and later by his grandparents until he was 20 months old. From this point on his mother was his full time carer. The doctors at the hospital (2011/05/25, National Taiwan University Hospital medical report) made the following comments: 1. understand mother’s angry tone; 2. selective attention; 3. diagnosis is mild autism. Mother denies that he is autistic; 4. the CDIIT cognition score is smaller than 54, percentile rank is smaller than 1, and it is equal to a baby of 6.9- months cognition ability; 5. non-verbal. The CDIIT language score is lower than 54, percentile rank is smaller than 1, is equal to a baby of 12.8-months language ability; 6. the CDIIT motor score is lower than 54, percentile rank is below 1, equal to a baby of 14.3-months motor ability; 7. the CDIIT social score is lower than 54, percentile rank is below 1, equal to a baby of 10.3-months social ability; 8. the CDIIT Self-care score is lower than 72, percentile rank is below 3, equal to a baby of 20.3-months Self-care ability; 9. short eye contact; 10. the sleep brain wave inspection has the local anomaly electric discharge.

The doctors commented that his physiological age was 41-months (2012/06/06, National Taiwan University Hospital medical report); 1. diagnosis is autism; 2. short eye contact; 3. poor social-interaction skills; 4. need assistant in self-care district; 5. distraction; 6. like to take MRT (this is Taiwan’s equivalent to the London transport underground system); 7. high activity levels; 8. expresses his needs through his gestures; 9. MABC2 scores show the child's motor abilities are delayed; 10. zero to six-year-old child development control table shows his language and communication is at a 16-month old ability, social is at 24-month old ability, motor social is at 40-month old ability, Consciousness and cognitive capability is at 29-month old ability; 11. Bayley-III scores show his cognitive ability in 25-months old, and language ability in 15-months old; 12. severe separation anxiety.

After reading the following portion of my research you may assume that Ya is a self-centred, non-caring mother. However, please consider the culture in Taiwan before making this assessment. Ya is very self-deprecating and would consider it impolite to extol any of her virtues with any emphasis. It is clear to see that she blames herself for Han’s issues and feels frustration at her inability to help him even though she is a professional who helps gifted children every day in her work.

### 5.4.2 Individual

Regarding the intelligence of children with autism, Ya has this to say about her son Han. He has not shown any higher intelligent behaviour or action so far, but he showed some unique behaviour when he was a toddler. At first, Han did not respond when she called his name, so she suspected that he might have a hearing impairment. However Ya noticed that Han could detect subtle sounds (such as the twirling sound of using a key to open a door on the ground floor when they live on the floor 4). Secondly, Han did not reject his mother playing with him, but he played with toys in his own way. Thirdly, Han cannot use a straw to drink. Finally, Han is non-verbal and Ya has suspected this since he was 20 months old. She tried to improve it, but unfortunately, her efforts have been in vain.

When discussing Han’s history Ya told me that she had been writing her thesis for her master’s degree while she was pregnant and she wonders if the high pressure of this might have been the cause of Han’s autism, and she blames herself for that. Due to Ya having placenta previa, Han was born around 39 weeks into the pregnancy by caesarean section. After he was born, Han had jaundice (or icterus) and lived in incubator for a while.

#### **5.4.2.1 Emotionality**

Han shows little facial expression, but is able to display his different emotions accordingly. His more obvious facial expressions are negative, especially when Han is being scolded. Han does not react to other individuals’ emotions.

Ya said that anger is Han’s most obvious emotion. He feels angry when he is scolded by her, or if he cannot get the things that he wants (such as CDs, food, a longer ride on the MRT, not going out with his parents, or if his toys are taken by his baby sister). In addition, hot weather and being tired or hungry, are triggers for Han’s anger.

Han shows his anger by biting an object, or biting himself to the point of bleeding (mostly biting his own hands), head-banging (on the wall and on the floor), yelling, throwing some objects (such as a chair), and laying on the floor, crying and kicking. Ya stops him from showing his anger in an inappropriate way by slapping or scolding him, and has noted the ways he has developed to release his anger.

At around Han’s third year, he started to yell ‘A’ shortly to release his anger. At that time, Ya thought that his behaviour was acceptable, so she did not slap and scold him.

Ya told me that Han’s happiness is triggered by interesting computer games, tickling games, being praised, learning new tricks, and playing with water and bubbles. When Han was younger he showed his happiness by hitting his head on the wall or the floor. Now, he shows his happiness by smiling with a laughing or ‘lelele’ sound, or by spinning, hugging or kissing.

In our interview, Ya told me that Han’s excitement is evoked by an unexpected surprise (such as his mother showing up at a school trip or his father coming home). When Han was excited, he would run around, hugging and kissing, and biting a stuffed toy, especially on its nose.

Ya described Han’s cry as silent and short which might be caused by his hypotonicity. Ya has difficulty deciphering his emotions from his facial expressions. Mostly, she can tell his emotions from his behaviour and facial expressions (PL 1.652). In terms of sadness, she has determined that he exhibits two kinds of sadness: feeling wronged, and not making himself understood. If Han feels wronged, he will cry with tears in his eyes, otherwise he has a flatter or perplexed facial expression, because he cannot figure out what he has done wrong.

Ya explained that Han easily irritates her, because he cannot follow her instructions (because of his poor communication ability). Every time she loses her temper, she will slap and scold him. Han shrank once during the interview when Ya raised her hand up. Han also shows the emotion of fear when he is in a new environment.

Ya explained that when Han does something wrong (such as, mess up his play room), he will either run away or try to clean the mess as soon as possible if he sees Ya.

Ya described Han’s anxiety as mostly being evoked by separation from his parents. He will cry and struggle to escape from the arms of someone who is holding him when they leave.

In my third interview with Ya (Han was around 30-months to 36-months old, PL 3.28), Ya said that Han showed empathy toward his younger sister whilst her nose was being cleaned or if she fell down, and his way of expressing it was by laughing and running toward his sister. Ya explained that he did this, because Han generalised his reading experience into daily life. She thought that his ability to empathise was limited. Ya said that Han falls short with regard to sympathy even though he has a certain level of empathy. Han only shows empathy toward others when they appear to be ill and not for their feelings. Ya told me that she believes that sympathy is a higher level of emotion than empathy and that sympathy is an emotion which is felt, without expecting to get any reward, by someone who hopes that another person will have a good or better life (in the field of psychology, ‘sympathy’ is what you feel for a person, and ‘empathy’ is what you feel with a person. Simply put, empathy is a more complex ability than sympathy). Han is willing to share food with others, but does not reach her standard of sympathy. It was difficult for Han to learn emotions by observing others, so she was teaching Han how to show basic sympathy.

Ya observed that Han exhibits some mildly jealous behaviour, but sometimes she was unsure exactly how to classify his emotion. For example, Han hit his young sister’s head with a toy without any reason, or when Ya was playing with his sister, he would go to join their activity immediately. However, if he is playing with Ya and his younger sister comes to join them, he will choose to give up or leave.

Ya believes that Han loves his parents deeply. He will also become attached to certain people after being with them for a period of time (such as his main teacher or grandparents). Han can recognise Ya’s face and his father’s face. She told me that if we put him among all the people he is attached to, he will definitely run to his parents.

Ya said that there are many factors affecting Han’s emotions: communication or language, hot weather, tiredness, hunger, not getting the thing he wants, illness, his toys being stolen by his sister, music (children’s songs make him stable), sweets (chocolate, Taiwanese caramel custard puddings), and his parents’ emotions. Ya said that she believes that Han’s outbursts are due to not knowing his own physical limits. He does not know when to take a rest, when to eat, and how to follow instructions.

Ya told me that, due to Han’s behaviour, she is concerned that he has limited social interaction with others (outside of his parents and main teachers). In the beginning, Ya always kept company with Han while he was getting treatment in day-care centres and rehabilitation clinics. Then Ya gradually withdraw herself from the classes. After several separations, Han stopped crying and learned more from his therapists. Then, Ya sent Han to a development centre (whole-day course, 7:00am-6:00pm). After several days of crying, Han gradually accepted being separated from his parents. In the third interview, Ya mentioned that Han can study with peers and teachers without her being there, so she attempted to leave Han with his grandparents for longer periods.

When Han wants attention, he will bring a book to his parents, and wait for them to read it for him, or he will want Ya’s company no matter how busy she is. However, if he focuses on playing with a toy and his parents or sister try to join in, he will just shut them out or leave his toy. Ya observed that if Han is concentrating on a toy he will not invite or allow his parents to become involved, but at other times he will pester Ya to get him the thing that he wants.

When Han made babbling sounds and played with his tongue, Ya would imitate his behaviour and attempt to interact with him. His parents taught him some interactive children’s songs such as ‘Head and shoulders knees and toes’ and ‘Peek-a-boo’ and some tickling games. At first they would have to help him make the correct movements, then after he was 3 years old he started to join in without assistance.

Ya explained that Han assigns different individuals to different jobs. He has a better relationship with his father than his mother (even though she is his main carer), This may be because when he is with his father, he can get sweets, play games, have hugs, and do forbidden activities (from his mother’s point of view). Han’s mother gives him regular meals, reads to him and does some learning activities.

Ya said that Han’s likes are constantly changing. He used to like specific colours (such as red or other dark colours), water, bubbles, soft rice, and bananas. Now he tends to prefer sweets (Taiwanese caramel custard puddings, cookies), electronic tablets, hard brushes (for example, using a floor brush, or a toilet brush to rub himself), biting things (such as a tooth brush, or a spoon), Velcro, drawing, and Mass Rapid Transit (The MRT, is like the underground in London). Ya wonders if some of the things he likes might be due to Han’s hypersensitivity or to his self-stimulation.

Ya said that she believes that Han can detect the emotion of others by their voice and volume (mostly negative emotions), but he cannot tell from their facial expressions.

#### **5.4.2.2 Behaviour**

In terms of Han’s oral language development, Ya said that she patiently waited while Han slowly learned to speak. Han had around 3 key words when I conducted the interviews with Ya, ‘ma ma’ ‘ba ba’ and ‘bao bao’ (Mandarin for Mother, Father and Baby respectively). Han’s oral language ability is unstable. If Han uses certain key words such as ‘ba ba’, ‘bao bao’ (father, baby) frequently, the words will be remembered for a period of time. Nevertheless, for the most part, Han has motives for the sounds that he makes. Normally, Han will be silent all the time. She thinks that it is only when he has a desire to speak, that he will utter some repeated sounds. For example, during an assessment at a new venue, he was separated from his mother for a short while. When she returned, as soon as he saw her he immediately called out for his mother ‘ma ma’.

Ya told me that Han learns things very slowly and she must constantly reinforce and make him practise what he has learned repeatedly. Otherwise, he will forget the skill or ability very soon.

Ya thinks that Han’s insecurity is mainly the result of separation from his parents when he was around 12 months old, and that this has been further exacerbated by his emotional disturbance.

According to Ya, Han has been able to ask for a hug since he was 2 years old. He does this by reaching forward with his arms towards his parents while making the sound ‘bao bao’ (baby/hug).

In his earlier years, Han did not react or show any feelings when praised by his parents, even though, Ya told me, she would praise and compliment on him all the time. During the course of our interviews, Ya noticed that Han had started to react to her positive actions (such as reading and playing), and he would smile when he was being praised.

Ya said that Han’s negative emotions only last a short time, usually two to three minutes. Only on one occasion did they last longer, perhaps for thirty minutes. He is easily distracted from his discomfort by a toy, an electronic tablet, a TV program, or some unrelated activity.

Han would only accept a specific brand and type of pacifier (dummy) when he was a baby, Ya said, Han likes to touch hispid objects, such as Velcro, or a stiff brush. He dislikes having his upper gum touched when brushing his teeth and his mother has to remove the labels from his clothing, because they irritate him.

Ya told me that Han enjoys playing games on a tablet, or a mobile. When a character in a game, for example a bear, makes a sound it will make him laugh.

According to Ya’s story, Han likes the lights on the subway and high-speed train, Han will quietly concentrate on the lights and scrolling text marquees. She said that she believes that Han’s self-stimulated behaviour might be due to his sensory issues.

During our interviews, Ya said that she thinks that it is essential for her to enhance Han’s ability to care about other individuals and to build relationships with others. Most of the time, Han plays alone and does not have close friends. Nevertheless, he can recognise his classmates and teachers. When Han was new to the school environment, he would adhere to a specific teacher and ask for hugs.

Compared with other children with autism, Ya thinks that Han is flexible in his routine or schedule as long as he has a favourite thing to do. Ya felt relieved about this, but she is worried that Han might have severe fixation issues when he grows up.

Han makes eye contact with others. Ya illustrates this with two examples; In photographs he is often looking into the lens, also when I arrived for the interviews he looked at me for at least thirty seconds.

Ya said that Han will get his way by insistently dragging an adult to the place he wants, or he will go to specific places, for example he will go to the kitchen if he is hungry. He will use objects such as a chair, to get to the thing he wants, or make an ‘a a a’ sounds to indicate he wants something.

### 5.4.3 Family

Under this theme I have identified four subthemes namely ‘parents’, ‘sibling’, ‘grandparents’, and ‘network’ which will be discussed below.

#### **5.4.3.1 Parents**

Ya said that she is Han’s main carer. Her husband is willing to assist her and accept Han regardless of any diagnosis. Ya is frustrated because Han does not meet her expectations and standards. Her reaction has been to scold and slap Han when he does something wrong. Even though she is a special educational needs teacher for gifted children, Ya says that she lacks the confidence required to bring up her children.

Ya keeps records to track Han’s progress. From Ya’s point of view, playing with toys and doing some learning activities which she chooses for him is better than watching TV at home. She has encountered many dilemmas in her daily life. Ya says she has had to make many decisions based on which consequence is more acceptable.

Each parent has a different family background with a different set of values. For example, Ya says she will attempt to save money by comparing prices and shopping wisely, whereas her husband prefers to make extra money by playing the stock market. She says that between the two of them Han’s father is the more patient at home, but less tolerant in public. If Han misbehaves in public his father will blame Ya for not teaching him well. Ya is much more severe in her treatment of Han and will scold him badly for his misbehaviour. Han’s father trusts in Ya’s ability to bring up Han, because she is a teacher. Ya told me that she gave some reading material on autism to her husband (information-giver), and her husband was willing to try to understand autism more to help their son (information receiver). According to Ya, her husband’s main role is to play with Han and, because he treats Han like a typically developing child, Han likes his father very much.

During the pregnancy, both parents expected a healthy, beautiful, smart baby to be born, so when they heard the professional’s diagnosis, they were in denial. Ya told me that she cannot accept Han’s behaviour even though she knows he has autism. The first medical report says ‘Mother cannot accept her child is autistic’ (25/05/2011, National Taiwan University Hospital medical report). Ya explained that she doubted the diagnosis, because Han makes eye contact with other individuals and he can recognise family members. In addition, he has separation anxiety and demands to be hugged by his parents. Ya believes that Han’s symptoms are more indicative of Specific Language Impairment (SLI).

Ya told me that raising a child with autism is challenging, stressful and very demanding. It can damage your health and is very costly. As Han was growing, Ya tried to get whatever help she could and tried many different types of treatment, some of them less conventional. At one point she turned to religion and became frustrated and angry when she was told that Han was born to torment her and test her through her whole life. After reading some of the stories I gave her (sharing material for parents), she said that she likes the concept of the ‘Dragging a snail for a stroll’ story. She prefers to think that Han needs someone to accompany and understand him rather than thinking of him as a burden sent to torture her life.

Ya told me that in some areas she felt that parents would compare their children especially in the parent groups. Ya attended some parent groups. She compared the difference between a group in a hospital and one in a private educational organisation, and noticed that parents in the hospital group tended to accept who their child is and parents in the private educational organisation group tended to push their child’s limit to meet their expectations.

When comparing the emotional competences of her two children, Ya said that she thinks that her daughter is weak at emotional control and emotional reactions and is a more difficult child than Han. If they are not told who has autism, she thinks that someone might guess her daughter is the one with the diagnosis because she is stubborn and cannot stop crying by any means, whereas Han is more flexible in this aspect.

Ya told me about her personal attitude; she said that her anger is evoked by her frustration and Han’s inability to learn. She told me she attempted to escape the reality of having a son with autism even though she has a great body of knowledge of teaching children with special needs, she avoided interacting directly with Han and making educational tools. Instead, Ya attempted to buy many toys (for educational purposes) and find highly rated professionals for Han, and scheduled his time very tightly.

Ya said that she felt guilty teaching Han because she was spending little time teaching him and most of the time being impatient with him. She found she was venting her anger and frustration on him even though she knew that this was not the right way to treat him. In addition, she knows many educational strategies and methods, but she rarely employed them. To reduce her guilt, she sent him to a development centre and says she is now happy to see his progress.

According to Ya, her husband treated Han like a typically developing child and was unsure why Han behaved the way he did. Ya thinks that she can understand Han better than others, but sometimes she still struggles with what Han really wants, how to interpret his behaviour, how he sees the world, or how to classify his emotions.

Ya worries about finding a communication approach for Han. She is also concerned about his emotions in daily life.

Ya’s expectations are raised, she says, by Han being happy to learn, and that he likes to go to school. She believes that Han’s ability to survive and be independent in the world is very important. Cognitive ability and oral language development are the least of her expectations. Even so, she still has hope that one day Han will speak. Ya thinks that her expectations are high for Han because she expects Han to behave well and follow her rules. For example, keep the eating area clean when he is eating, or tidy his own toys after playing. When Han has done something wrong, and then attempts to put things right, Ya says she will scold and reason him out of inappropriate behaviour.

Ya says she thinks of herself as an ambivalent person. As Han has grown she has had very complicated feelings towards him. She attempted to keep calm by finding some excuses for him, and she admits that she was extremely shocked by Han’s diagnosis of autism. At the time of our interviews, she told me that she still could not believe that he has autism. Ya told me that she is patient about his language development , but she still asks every teacher to check him and say whether they think he will learn to speak or not.

Ya understands that his learning progress is slow, but she loses her temper when she tries to teach him something. At times she has felt like she wanted to give him away, but in the end he is still her dearest baby and she wants him to grow and have better and more abilities. At the same time she thinks that as his abilities grow he will become more and more difficult to manage.

Of course as an experienced SEN Teacher Ya is familiar with many different approaches and strategies, but she does not have the heart to use them with Han. For example, she does not want to use behaviourism with Han for the following reasons; firstly, it is a bit like training a dog. Secondly, she cannot stand Han’s suffering from waiting (especially when Han is hungry and thirsty). Finally, it is crucial to find a balance point of training between Han and his baby sister (they have different level ability and age). In addition, Ya prefers to do house work and make albums and records for Han rather than to play with him because she is impatient, does not know how to play with a baby and dislikes tidying Han’s mess even though she has collected many books and toys for him. This kind of ambivalence makes Ya panic and struggle between what she should do and what she really wants to do.

Ya says she is the main carer, and Han’s father is willing to assist her and accept Han no matter what kind of diagnosis he has. When Han was a toddler, Ya loved him deeply and looked after him very carefully and gently with positive expressions. To expand his life experiences and group activities, Ya and her husband brought Han to visit many places and registered him in some extra educational institutes. Unfortunately, Han’s behaviour (such as running around the class and playing alone) added to Ya’s frustration. After thinking, she said with hesitation that he made some progress.

When Han was around 18 months old, his baby face started to fade and Ya began to scold and slap him when he misbehaved. Ya and her husband have different ways of coping with Han’s behaviour. If Han clamours in public, Ya will scold him. On the contrary, Han’s father will hold Han in his arms and leave the scene. Then, normally Han soon calms down.

In terms of educational attitude, his father is more active in engaging with Han. Ya accepted the fact that Han learns things slowly, and wants him to learn things in a comfortable way. However, if Han makes a mistake which Ya cares about, Ya will scold him severely.

**Parental Reflection:**

1. Motivation: Ya thought that it is important for Han to have communication motivation. As Han’s motor skills develop, he can get things he wants without asking for help which might slow his language development.

2. Herself: Ya applied for a two-year Parental Leave so she could care for Han. At the end of the leave, she thought that she had spent more time disciplining Han, and is unsuitable to teach Han by herself. The reason why she thinks Han is better to be taught by other professionals is that she is an SEN teacher for gifted children, not for children with autism and her area of expertise is teaching primary age children, not under 6-year-olds. She believes that theory and practice are quite different and she had no experience teaching nursery age children before teaching Han. She cannot handle young children with severe autism and finally, it seems that children learn less from their parents, and she feels super disappointed, panic and stressed when she finds that Han did not make any progress after a day’s instruction.

Ya thinks that she is too selfish and that she always put her needs in the first place (for example, she prefers to do exercise rather than making PECS for Han even though she knows PECS is good to facilitate Han’s communication ability). Apart from this, she realises that she has poor emotional management even though she knows how to deal with it, but she cannot stop releasing her anger on Han (saying is one thing and doing is another matter).

When Ya recalled her childhood experiences, she remembers having had difficulties developing relationships with her peers. Therefore, her old experiences shaped her personality of minding her own business and vice versa. She was not keen to have children, but under the circumstances (she was accidentally pregnant; her parents-in-law were eager to have grandchildren; respect every life even an embryo), she decided to have children.

3. Han’s emotion: From Ya’s point of view, emotional abilities consist of other abilities, such as cognitive and observational abilities. Ya reflected that she might oppress Han too much because she focused on developing Han’s routines and good behaviour without considering his temperament. Ya admitted that it is hard to assess Han’s emotions in two hours at a hospital because most of the time he plays alone quietly. She only picked up some of his emotions after several days of scrutinising his subtle behaviour even though she is the closest person to him. Han’s emotions and feelings last a very short time and he is easily distracted. His emotions are simpler and more direct compared with his parent’s (adult’s) emotions. Ya cannot explain why her emotions are complex and affected by various factors.

4. Han’s temperament: Ya reflected that Han is still curious about the world and does the things he wants to do, even though she implements rules and releases her temper on him so often.

5. The idea of raising a child: After Han was born, Ya raised Han by following textbooks and loved him dearly until Han’s young sister was born. She explained that her attitude changed towards Han, because Han’s lovely baby face (features) changed into more adult-like features.

After Han’s diagnosis, she explored and modified her child-raising ways with some autism-specific strategies. Ya thought that even if Han is autistic; some parts of him are still like other typical-development children. She wants to raise him without strategies that are exclusively autism-specific, and she wants to find a balanced educational approach between teaching a typical-development child and a child with autism.

Unlike other parents in the parent group, Ya does not always follow Han’s demands in the hospital. She believes discipline is very important for raising a child and that every child is unique. Even if Han has a diagnosis of autism, she still thinks that she can teach him how to control his emotions by suppressing him when he is difficult. Nevertheless, she pays less attention to developing Han’s language and cognitive ability. Ya believes that she is still in the ‘learn to be a parent’ period, and attempts to find a suitable and peaceful approach between herself and Han. She hopes that they might have a close parent-child relationship in the future.

She is a strict mother and thinks that she should teach Han to follow social norms rather than developing his cognitive and language development abilities. Meanwhile, she is willing to let Han explore the world, and learn something from the natural consequence of his behaviour.

Ya understands and accepts that everyone has his or her own characteristics and personality. If Han’s behaviour affects Ya’s daily life, she will be angry at him. If not, she will let him do anything he wants. If Han behaves badly, Ya will slap and scold him. However, due to Han’s poor language ability, Ya admitted that he might not understand why Ya was so angry, and that she needs to find a better way to make him understand that his behaviour is inappropriate.

She told me that she wants others to understand that it is hard to raise a child with autism, and she has to overcome many issues. Ya also admitted that she has different gender expectations from her children. She thinks that a boy is naughty and worth slapping and scolding, whereas, her daughter always fawns on her mother when she does something wrong, so she feels bad about punishing her. In terms of Han’s future, Ya focuses on what is right for him and what he needs at this moment, because Han is still only young (30 months old) and will change.

6. Autism: Ya thinks autism is a series of unusual behaviours rather than a disorder. She tries to understand Han’s view of the world, and hopes that she will reduce her emotional reactions towards Han’s behaviour through understanding. Ya thinks that the communication ability of an individual with autism has been improved, because they can express themselves through using computers. She also knew about typical autistic behaviour and checked whether Han exhibited this.

7. Reciprocal emotional influence: A family is like a unit; members inside this unit inevitably affect each other. Ya thought that Han treated his family like a tool (such as asking for cookies) when he was 30 months old. About a year after our first interview I spoke to Ya again. Han was around 42 months old at that time. She told me that Han had started to show his emotions and develop some social interactions (such as hugs and kisses) with his parents.

As a result of our interviews Ya told me that she continued to keep notes on her observations of Han’s behaviour. She told me that Han continued to enjoy exploring the world, and that she is the main instigator of Han’s negative emotions. Ya also made the following observation to illustrate the reciprocal emotional influences at home:

Han’s bad mood seems to be triggered by mine. My emotional management is really bad. I do want Han to be happy and pleasant every day, but he seems so naughty and makes lots of trouble. I also know that slapping and scolding does not work, I often think myself as a mental case. My husband tells me that I will become calm if I think of my behaviour as being like a bully towards our vulnerable child. On the other hand, I ask my husband to recall that when he was losing money in the stock market, he lost his control and was angry at the children. My point is that a child’s feelings and emotions are simple; in contrast, an adult’s are complex. (Diary 3/May/2012).

8. Combined effects of medical, educational, and family aspects: Ya thought that clinical staff, educators, and parents have diverse views towards treating an individual with autism. However, the parents of children with autism must consider every aspect, so she listens to every opinion or suggestion, and then makes final decisions for Han. She does not want to change other individuals’ thoughts on the matter, because she wants to hear different voices from diverse systems.

9. Parental needs: Ya hoped that the government would provide more transport service and longer term caring provisions for the working parents of children with special needs.

Educational decision: During the interview process, Ya faced the dilemma of choosing between a development centre and a special class as a school for Han. She evaluated every aspect (such as financial implications, peer ability and age, facilities available, teacher-student ratio, teacher quality, attendance times, the length of holidays, necessary adjustment, inclusion, transport, and the course) of these two educational settings. Ya even considered bringing Han to her work place but she worried that she would not be able to concentrate on work due to worrying about his health and safety. In the end, she decided to send Han to a special class.

Home-based intervention: There are many devices and toys for sensory integration and educational purposes at their home. Ya and her husband use a sensory brush to rub Han’s body at bedtime. This intervention makes Han have better sleep quality.

Autism’s influence on family life and social circle: Ya disagrees that having a child with autism diminishes her social circle. She thinks having a dependent child does. For reasons of health and safety, Ya and her husband choose places to go where there are fewer people. Once they decide to take Han out, they know the trip is for Han, not for themselves. Going out with Han is very exhausting because they have to keep their eyes on him all the time and avoid evoking his negative emotions. Because of this, they prefer to go out with family members rather than friends. When unexpected things occur, family members have a higher tolerance and are willing to help them.

#### **5.4.3.2 Sibling**

When Han’s young sister was a new-born baby, Ya encouraged Han to touch, comfort her, hug her, and hold her hand, and Han enjoyed it. Many interactions between Han and his baby sister are shown in family picture albums, such as of him comforting her. She liked to play with him (such as grabbing Han’s toys and putting her whole weight on him).

Now instead of playing with her, Han always runs away from her. When Han and his baby sister are in public, their parents always ask her to socialise with other people in order to distract their attention from Han. Ya thinks that Han learns by imitating his young sister’s behaviour and reactions in daily life, even though he takes longer to learn.

Han has mild sibling competition with his young sister. When Han’s baby sister was born, he started to have regression. For example, he needed his parents to feed him even though he can eat and drink by himself. Ya believes that he sought his parents’ attention because they were busy looking after his baby sister. When Ya played with Han, Han’s young sister would hold Ya’s hand and want Ya to play with her, and to leave Han to play alone. Ya thought Han’s baby sister showed jealousy towards Han. During the three interviews, Han and his sister both were competing for Ya’s attention.

#### **5.4.3.3 Grandparents**

Before Han was diagnosed, he stayed with his grandparents several times, once was for a period of six months. After his diagnosis, Han only stayed with grandparents for few hours at a time, because Ya was afraid to trouble his grandparents.

Han’s grandparents have respect for Ya’s educational abilities, because she is a teacher. Even so, they still have some disagreements. Once a disagreement occurs, Ya thinks that whoever was his main carer at that time should make the final decision. If someone criticizes her approach, she will say ‘ok, you teach him’ or ‘ok, Han can stay with you since you do better than me’. Normally, the grandparents will keep their mouths shut, because they know how difficult it is to work with Han. When Ya is in need, her parents always support her both mentally and physically. For example, the grandparents help to look after both children when they need a break.

If other family members (except the grandparents) question her teaching approaches, she will ask that person to teach Han for an hour, and then if he or she is successful to tell her how to teach him. Grandparents and other family members all know that it is difficult to work with Han. Therefore, no one blames Ya for taking breaks occasionally.

#### **5.4.3.4 Network**

Ya’s network consists of a nanny and some family members or friends. Ya’s 24-hour nanny (since he was 20 months old) thinks that Han is normal. Ya’s relatives who provide this support are her sisters-in-law who are SEN teachers as well. Ya doubted the diagnosis of autism, because her sisters-in-law did not suspect Han’s different development either. Her friends include mainstream class teachers, SEN teachers, doctors, and speech-language therapists. When she suspected Han’s different development, she asked for their opinions and suggestions. After discussion, they suggested that Ya should bring Han to a hospital and accept some assessments. One of Ya’s friends said that Han might have selective attention disorder.

### 5.4.4 The Educational System

When considering herself as a parent, Ya told me that she thinks that Han’s teachers do a better job than her. This is because Han started to make more progress after he began attending classes at around 3 years old. He became more settled and started to utter some words such as ‘bao bao’ (Mandarin for baby or hug).

It became apparent that he was happier than before and would sit down and play with Ya and her husband. In addition, she explained, school education accelerated Han’s learning progress via long one-to-one sessions and through interaction with his peers. Ya said that she believes that Han learnt better from his teachers than he did from her. Meanwhile, she trusts his teachers to improve his abilities through teaching and play. Due to Han’s long school days, Ya thinks that his teachers understand Han better than she does.

Ya told me that she thinks that Han has made some considerable progress since he has been at school. Every time he learns a new skill; he will play it or show it to Ya, so she sees the things he has learned. Ya related some of things he has learned, these include; sitting at a desk, playing with blocks for more than 1 minute, taking off his shoes and socks and putting them into a shoe box, and he is willing to take the school bus without a struggle. Ya may feel happy about Han’s progress and consequently, Han might be proud of himself.

During our interviews, Ya gave a recent example of his progress: At one bath time Han grabbed a toilet brush and put it inside his bath. Then he was holding a tooth brush and a towel in each hand. Ya became very angry and took the toilet brush away and started to scold Han severely. Han passed her one of the towels and she threw it away with anger and continued to scold him. After a few seconds Han gave her the tooth brush. Suddenly, Ya realised that Han had not reacted to her anger by crying and screaming, as he had before, but had adopted a new approach, attempting to find out what it was that she was angry about. Since Han likes to play with hard brushes, Ya assumed that he has a sensory issue. For Han’s good, Ya and her husband utilise a sensory brush to rub Han’s body at bedtime.

Ya said that a teacher in his day-care centre observed that emotions between Ya and Han are interdependent. If Ya feels upset or pettish, Han’s behaviour in class will be hard to control. On the other hand, if Ya does not slap or scold him at home, Han will feel happier and learn better in class.

Ya told me that the parent-teacher relationship is maintained through a Teacher-Parent Contact Book, which is used to pass notes on the child’s recent activity between the parents and teachers. Ya was worried about asking the teachers too many questions, because she knew they were busy and she did not want to anger, or annoy them. She said that she believed that Han would further develop some abilities as a result of the SEN teachers work. However, I am uncertain as to whether she trusted professionals or just wanted to pass the responsibility of educating Han to them!

### 5.4.5 The Medical System

Ya told me that Han was diagnosed with autism when he was 30 months old. Mostly, doctors take two hours to assess a child at the hospital. When Han was assessed the first time, the hospital arranged for a whole team to assess him at the same time (transdisciplinary evaluation model). The team consisted of a speech & language therapist, occupational therapist, physiotherapist, psychologist, and so on. During the first assessment, Han avoided eye contact, played on his own, and was non-verbal.

At his second assessment (one year later), they assessed Han separately, although it was the same group of professionals. Ya told me that her reaction to the first assessment was that they had not taken enough time and that they had underestimated Han’s abilities. She did not take the diagnosis seriously. Like most parents she considered that the diagnosis is only a tool to access resources. Ya pointed out that Han’s behaviour while meeting with a doctor was different from the way it was at home. Because Ya doubted the doctor’s diagnosis, the doctor wrote that Han’s mother did not understand autism in the medical report. Ya told me that she thought that there was a better way of assessing Han’s real abilities using his therapists, because these therapists had taught Han for a while and he was comfortable with them.

Following the diagnosis, Ya told me, she actively arranged Han’s treatment and interventions. In the beginning, Ya tried to find any available resource (including psychologists, doctors, a day-care centre for children with autism as well as a rehabilitation clinic), and created a tight schedule for Han. Ya felt exhausted. Then she found Han a development centre for delayed development children, and finally she felt as though her burden was reduced.

Ya told me that, in the hospital, there is a day-care centre which provides training programmes for preschool-age children with autism and their families. In the programme, parents need to participate in the whole session. Ya thought that Han behaved worse in the day-care centre because he knew that Ya had to treat him nicely there. Ya also mentioned that Han had negative emotions and severe head-banging behaviour there, and the situation infuriated her.

Han was diagnosed in the Department of Physical Medicine and Rehabilitation. Ya said that the doctor mentioned her doubts about the diagnosis and commented that this was disadvantageous to the functioning of the family in his report.

Ya described how Han studied in a development centre for about a year. The development centre provides transport, therapists, and a curriculum. Han was taken to the centre at around 7:00 a.m., and them taken back home at around 5:00 p.m. In the centre, the staff scheduled some therapy for him according to his needs.

I asked Ya about medication and she told me that a doctor suggested that Han should take medication for his hyperactivity. Being Han’s mother, Ya surfed the internet and found that the medication is for children with autism who are more than 6 years old, so she refused the doctor’s suggestion. Ya thought that medication would be the last approach after having applied structural teaching (educational approaches).

Ya made three observations relating to medical issues during our meetings:

Firstly, therapists should cooperate and communicate with each other to find the best way to educate Han as a whole. Ya asked why the Taiwanese government divided the treatment and interventions into smaller categories (such as physiotherapy, occupational therapy, and speech & language therapy) since all therapists did the same thing and use the same play toys with Han. It totally wastes the government’s money and parents’ time. She suggested that the government should train professional staff who have the ability to integrate all the treatment into one development curriculum, especially for young children with special needs.

Secondly, she found that the parents of children with autism think that the motor and fine skills of their children are far more developed those of typical-development children in a kindergarten because parents of children with autism emphasise the importance of self-care skills such as tying shoelaces, running, climbing and coordination and yet their children are the ones getting physiotherapy and occupational therapy.

Finally, she believes that the treatment and intervention for an individual with autism should focus on the core issues of autism. For example, human understanding and care for others, especially their family.

I agree with Ya because of my experience in Taipei. Early childhood educators think of the child as a whole, and tend to teach them daily life skills. They give the child a whole-life experience by utilising all their senses. As an example take teaching the concept of food. Teachers tend to give the children real food to touch, smell, taste, hear, and to see. At the same time the children get some practise of table manners, food history, or how to make food. Whereas, older children learn things separately by subject such as mathematics, history, chemistry, art and so on, I believe that most children with special needs have difficulty in generalising and therefore, the treatment and intervention should be by integrated education.

With regard to parent-doctor relationships, Ya told me that she has doubts about the doctors’ diagnoses. She explained her reasons for this: Han makes eye contact with other individuals; he recognises his family members; he has separation anxiety, and he demands hugs from his parents. In Ya’s opinion, Han’s issues are more indicative of language difficulties.

### 5.4.6 Policy

Ya told me that she thinks that the label of autism is a means of getting welfare for Han, but in her eyes Han with labelling is just as dear to her as he is without it. According to the regulations in Taiwan, after getting a diagnosis from selected hospitals, parents can apply for a disability manual for their child. Han is holding a disability manual. Out of all the welfare services, Ya prefers to have transport (Fu-kang Bus) to take her and her two young children between home and school, but in the end, she does not use the service.

### 5.4.7 Society, Community, Nation

Many Taiwanese can understand and accept individuals with autism now more than before, and show more empathy toward the family of an individual with autism. However, when they are in public and Han makes ‘iiooyy’ sounds, Ya becomes upset by the expression in the faces of others and she is sorrowful even though she knows that they do not understand autism. If Han’s baby sister is nearby, she will ask her to behave like an ambassador to relieve the tense situation.

# Chapter 6 Critique and Discussion

This chapter outlines the responses to the research question which are highlighted in chapter 1. I have drawn from my study and recommendations that are based on the data provided by parents which is followed by a summary of the important conclusions. Chapter 5 presented the primary data generated from the study and in this chapter the key parental narratives emerging from the data will be discussed in light of the existing literature, as outlined in chapter 2. This research focused on the emotions of young children with autism. Rather than scrutinise infants, I sought to explore the views of parents in order to see how mothers and fathers understand and interpret their children’s needs.

Due to the richness of the data gathered from participants, a variety of themes and subthemes emerged suggesting that emotional responses arise in different ways, for example from interaction with individuals, family, school, hospital, or from other social contexts. I found that areas of emotion interact with each other. It was difficult to connect all the systems, or to arrive at an analysis which provided just one major concept. Many dilemmas have presented during the final preparation of this thesis. The decision had to be taken as to whether all the themes should be addressed together or whether to select the most individually meaningful. Some themes may have arisen from my personal bias, background, knowledge, or other preferences (Haynes, 2006; Reinharz, 1992; Roberts, 1990; Stanley and Wise, 1993).

Having analysed my research data, I would like to reflect on and discuss my methodology, followed by a discussion of the parental narratives in order to answer my research questions. It is as if the child’s emotionality (whilst there in the parental narratives) is constantly being lost – almost overwhelmed by the practical considerations of family, policy, resources, and so on.

## 6.1 On my research

Before embarking on a critical discussion of the data I would like to remind the reader of issues which define my positionality in this research. Prior to embarking on my doctoral studies, I worked for over 13 years with children who have autism. During that time I found many ‘hard to reach’ children who were intelligent and teachable. As their teacher I created a comfortable environment with regular learning schedules and clear discipline. A typical example among my students was a 6 year-old who, in spite of having no verbal language, could operate a computer, surf the internet and send email to others without help. In addition to this he acquired basic arithmetical skills when he studied in my preschool special education class. However, he was diagnosed with severe autism and a low IQ by the child psychologist who dealt with his case. Because of his non-verbal, odd behaviour, many teachers considered that he was low functioning and initially rejected him for study in mainstream classes. After he achieved excellent academic scores in his first tests they relented and with their acceptance he went on to do quite well.

During the time that I have been writing up this thesis, I did some volunteer and supply teaching assistant (TA) work in several specialist schools; mainly working with age 4 to post 16 students with autism. Recalling the difficulties I faced in my own childhood, being a foreigner in the UK and as a former SEN teacher in Taiwan working now in British schools, I have reflected on these issues.

Firstly, in my early childhood, I was considered to be mentally retarded or autistic when I had language, social and learning issues. I still recall some of my feelings and emotions of some incidents (such as feeling frustrated and discriminated against as well as sometimes being content) even though teachers and relatives said that I behaved like a puppet with no feelings, and with no reaction to the outer world. Due to my experiences, I realise that individuals with subtle facial expressions and limited oral language will still have feelings and emotions, and it is critical to understand their emotions.

Secondly, for me, emotionality is hard to measure by electric devices because it is dynamic, complex, interactive, individual and cultural, except for some basic emotions such as happiness, sadness, and anger. Talking with the parents of children with special needs gave me richer data on their children’s emotions than I would have obtained using ‘function Magnetic Resonance Imaging’ (fMRI).

Thirdly, even though I understand what other teachers and teaching assistants say, they seem to have difficulty understanding my English (possibly because of my accent). In addition, some students seem to enjoy correcting my English pronunciation; I would often feel frustrated in expressing my feelings, emotions and thoughts. From my personal feelings and experiences I think that a verbally-limited student with autism might have similar experiences and feelings to me.

Fourthly, being a supply TA, I would often be expected to go to new schools and meet unfamiliar staff and students without any chance to prepare. I would feel nervous and uneasy most of the time. My personal experience leads me to believe that children with autism will probably feel the same when they encounter a new or unexpected environment or a new person.

Fifthly, I would often have difficulties understanding other people's behaviour, what they said, or why they would make their decisions. I also had difficulty understanding how to react to other people’s behaviour, because of my different cultural background or my temperaments/idiosyncrasies/behaviour. I suspect individuals with autism might be similarly confused about the intention or social rules from unfamiliar persons.

Finally, I hold different views from clinical professionals due to my different background. I attempt to understand my students’ fundamental abilities and so design suitable courses for them rather than to ‘cure’ or label them.

During my research, there were many unexpected and accidental occurrences which challenged my comfort zone, such as passing the Ethical Review as well as finding participants. While interviewing the participants, I felt nervous about how to make them feel at ease and stimulate the conversation flow. I often felt an empathy with the children in my research and found myself recalling my own childhood experiences. During the data analysis I was concerned about under or over interpreting the data and whether or not to include my observations. I worked hard to maintain a neutral position. Cultural issues and translation into English were also areas that caused me concern.

Due to the small scale of my research, the findings cannot be generalised to the population as a whole. My research has caused me to think deeply about many issues, in particular questions such as: What methodology would be the best to use to achieve the most meaningful results? Should my research position be remote from the participant or involved with them? What would be the best hypothesis for me to develop? To what extent is culture an issue?

In the end I made what I believe to be the best compromise, always considering that the core of my research has been to explore the notion of emotionality in the lives of children with autism.

Finding participants was a long and arduous journey. It took one and half years to find participants who were positive and willing to share their stories. During the period that I was working as an SEN teacher I encountered many parents of children with autism; most were child-centred and struggling with the issues related to bringing up children with special needs. These parents generally felt helpless, with little optimism, and it is my wish that the positive experiences provided by my study will help them and bring hope for the future.

In terms of translation from Mandarin into English, the quality of the data may be dependent on my fluency in Mandarin and English. My first thought is that the accuracy of the translation is very important. This translation is very difficult as the two languages take completely different forms. Mandarin has a limited vocabulary relating to feelings and emotions, but can describe some concepts that I cannot find accurate English words for. On reflection I have decided that I should analyse the data in my native Mandarin and then translate the result. I have been concerned about my interpretation of words, facial expressions and body language, especially those of my UK participants. English is not my first language and I am unfamiliar with British and Indian culture, so I have been concerned about how to interpret the facial expressions and body language of my participants correctly. While interviewing these parents many questions arose; Did I provoke their reactions on the topic? Did they tell me their real thoughts? Did I react appropriately? Were my questions emotionally hurtful? Had I used another method, would I have obtained more reliable information and would the interviews have gone more smoothly? In addition, could I analyse the data well, with compassion and empathy, considering my own lack of social interaction ability?

My research supervisor reassured me by telling me that it is good to have these concerns, because it shows that my research involves complexity, reflexivity, and critique.

Considering this, I focused on the participant’s context rather than their gestures and facial expressions. Following my discussions with my supervisor, I realised that I would have to find a transcription model that would cater for my personal limitations and the purpose of this research.

Originally, my long-term objective was to develop a programme for individuals with autism, which centred on emotion. I expected that the results of this study would assist me in developing a template to increase teacher and parent understanding, enhancing the relationships which they develop with the child who has autism. As time passed, I began to realise that this task would be too difficult. Every child is unique and diverse cultures have different ideas on correct education and treatment. The outcome of the resulting programme would be inconsistent, as the backgrounds of the implementers would be diverse in culture, views and prejudices, experience, ethnicity, religion, politics, predilections, and gender. Thus, I came to the conclusion that I should attempt to find basic principles for individuals who are working with children who have autism, to include specific consideration of their emotions. In addition my reflections might prompt the rethinking of existing concepts, policies, practices, and systems. In view of this, I have recorded all my thoughts in the hope that they would be of value.

A notable contrast of attitudes was shown in that; UK participants tend to think of autism as a neurodevelopmental disorder, whereas Taiwan participants tend to think of autism as a label to get resources and information. All participants focus on addressing the issues concerning their child in daily life.

The following section presents a discussion of the main parental narratives of the study. The main parental narratives drawn from each of the four stories will be discussed concurrently.

## 6.2 Response to my research question

*What factors affect the emotional lives of children with autism and their families?*

In order to answer this question my research study has engaged the narrative of parents. These data I used not to provide the definite answer, but to explore the subject and also to challenge the prevailing belief that young people with autism are in some way emotionally deficient. The evidence from the parents’ accounts is that they believe their children do possess emotional lives.

Interpreting the parents’ narrative, utilising Bronfenbrenner’s concept in my study, I believe that the best way to answer my research question is to present the children’s existing emotionality, and then determine which factors affect this emotionality.

**6.2.1 The emotionality of young children with autism**

Human emotions and feelings are evoked from outer stimuli causing reactions in the internal milieu and viscera (Blaylock, 2010; Damasio, 1994, 2000, 2003, 2010; Goleman, 1996; Grossberg, 2014). Similiarly, Zahn-Waxler et al. (2009) found that emotions, particularly stress-related, triggered pro-social behaviour and measurable physiological changes such as changes in heart rate and skin conductance. Dodd (2004) asserts that an individual’s emotionality is a subjective experience.

It is worth noting that an individual’s emotional life is affected by natural (body, temperament) and nurtural (culture, relationships with adults and peers, family environment) influences (Hyson, 2004), especially our culture, shapes how we perceive, react to, and interpret emotions and feelings. Even cultures play an important role in shaping an individual’s emotionality, Grusec (2011) still believes that parenting has more influence on the development of a child’s moral values and social usages by providing guidance and interaction in parent-child and group relationships in all cultures.

My study has established that the parents of non-verbal children with autism feel that their children do have emotional competence and emotions, such as having negative (anger, upset, jealous, fear, disgust, anxiety, frustration, and embarrassment) and positive emotions (happiness, pride, content, excitement), seeking attention from parents, recognising parents’ emotions and feelings (Thomas, Balaravi), empathy (Thomas, Balaravi), having relationships with close family members (parents and siblings) and teachers, behaving accordingly, and showing preferences (Thomas). My parental narratives resonate with Alvarez (1992), Bogdashina (2006), Dafydd (2010), Grandin (2008), Higashida (2013), Sacks (1985), and Williams (1992, 1996)’s statements that individuals with autism have various emotions, imagination and sense of humour which are shown differently from typical-development individuals. Similarly, Harris (1989, p.213) argues that ‘children with autism feel and express emotion, but they have difficulty in making sense of other individuals’ emotions’. Furthermore, Weeks and Hobson (1987)’s finding might provide the answer -- children with autism have a tendency to notice people’s features rather than their facial expressions. On the contrary, my parental narratives contradict the American Psychiatric Association (2013), Dodd (2004), Grayson (2006), Kubicek (1980), and Osterling and Dawson (1994)’s findings in which young children with autism lack emotions--have no basic understanding of empathy, no facial expression, no emotional interaction, and no emotional recognition. However, I agree with Chen and Liu (2010)’s Taiwanese research findings in which 8-12 year-old children with high-function autism (HFA) took longer to react and were less accurate on emotional discrimination and had a poor ability to express emotional intonations.

Even though all the participants in this study acknowledge that their children with autism do have emotions and feelings, Paavai, Catherine, and Ya believe that they need to teach their children how to recognise emotions and how to react to another person’s emotions to be socially-accepted. Interestingly, these three parents are all of Asian origin. Are they coincidentally believers that emotions are shaped by nurture? Or do their immersed cultures gradually influence their view of emotional development? Hadwin et al. (1996), Shore et al. (2006), and Swettenham (1996) also believe that children with autism can be taught how to recognise self-emotional states through pretend play production, understanding emotion, and understanding belief/false belief. The common result they had is that they found children with autism have difficulties generalising the laboratory learning into their daily lives which might have resulted in the researchers’ disregarding the existing emotions of children with autism and imposing the researchers’ view of how emotions should display in children. Even though Stafford (2000) claimed that he had success in teaching basic emotions to a non-verbal, low functioning child with autism by utilising photographs. The same doubts that I have are raised by MacLure et al. (2008) and Williams (2013) -- whether children display their real emotions or the adult-expected ones.

The expressions of children with autism almost always appear to be negative. Saarni (1999) and Yirmiya, Kasari, Sigman, and Mundy (1989) support my parental narratives. This might be because their caregivers tend to observe their negative emotions rather than their positive ones. Thomas’s parents note that it is rare for him to exhibit stable or moderate emotions. Individuals with autism, even though they may have limited spoken language and a bizarre manner or behaviour, do have emotions, empathy, a sense of humour, imagination, and a certain degree of intelligence. This view is consistent with Williams’s (1996) own experiences which refute some of the common myths about autism. To demonstrate that non-verbal children with autism have the ability to play imaginatively, Paavai (UK2 participant) told me that her son drew pictures of red peppers and added a mouth and hands to them and he talked to the red peppers as well.

He will peel the skin off that one and he will put that capsicum in his bed and look at that capsicum and then sleep, so he draw a picture of a capsicum like a man, human being, you know, with a capsicum having an eye, capsicum having a nose, capsicum having a teeth and tongue, so I realised that he does think that those things are real and maybe it is talking to him. (PB 1.216).

Paavai’s observations of her son add to the body of knowledge surrounding imaginative play by children with autism which is contrary to Barnbaum (2008), Baron-Cohen (1995), Gopnik et al. (2000), and Siegel’s (1998) belief, that children with autism lack ‘Theory of Mind’. This is further explained by Klein’s (1963) theory, that for example Balaravi might not get enough attention or social interaction; therefore, he would generate an imaginary friend to satisfy his needs for having company or a friend. Continuing in this vein, the narratives of individuals with autism contradict the conclusions drawn by many researchers (e.g. Baron-Cohen, 1987; Lewis & Boucher, 1988; Wing et al., 1977) who believe that a child with autism has limits in creative representational play, especially in spontaneous play. Williams (1996, p.12) says some individuals with autism do have ‘empathy, emotions, a sense of pain, a sense of humour, imagination, interest and curiosity’. Sacks (1985) also illustrates some drawing activities of his patient with autism showing an imagination and a sense of humour. Similarly, Alvarez (1992) noted that one of her patients with autism did have imagination. When he said ‘I’d like to fly up there in a plane - in a spaceship… I’d like to fly to Spain… and France’ (ibid. p.218). Balaravi has emotions, empathy, a sense of humour, imagination, interests and curiosity, based on Paavai’s account which resonates with Higashida (2013) and Williams (1996)’s descriptions in their autobiographies. This research suggests that young children with autism and without oral language do have rich and complex emotional capabilities even though they have fewer social-emotional abilities, which is in line with some other research findings (Atkinson, 2009; Baron-Cohen, 1995; Baron-Cohen et al., 1993; Baron-Cohen et al., 2000; Begeer et al., 2008; Erbas et al., 2013; Harms et al., 2010; Hubert et al., 2007; Mclntosh et al., 2006; Philip et al., 2010). Both of the children in the UK have a sense of humour which is also mentioned in Rankin (2000) and Sacks (1985)’s records. The Taiwan participants barely mention humour. This might be due to the younger age of the Taiwanese children as well as cultural differences. Regarding the desire to make friends, only Paavai mentioned that Balaravi felt lonely and longed to make friends, in the interviews which are supported by Rankin (2000)’s diary content of working with her son with autism. Only Balaravi expressed a desire to make friends in my research this might be due to his being an only child in the family and having no sibling’s company.

Considering their development history, Larry and Patricia noted that Thomas had digestive problems and Han had jaundice (or icterus). Neither of the other two children in my study have had any serious health issues. The mothers of the UK participants had normal pregnancies and both Taiwanese participants needed extra care during their pregnancies (Catherine had early stage uterus contractions in her 7-month pregnancy, and was hospitalised during the last two-months of pregnancy for her tocolysis and was treated with anti-contraction medication or labour suppressants. And Ya had placenta praevia, Han was born around 39-week into the pregnancy by caesarean section). Only Thomas had a sibling with autism. There is no sign as to the cause of autism in my research, which is supported by Timimi et al. (2011)’s statement. The parents first suspected that there was something unusual in different ways. For Thomas it was his flapping and that he was non-verbal; Harry was non-verbal; Balaravi was not responding to his name; and Han was non-verbal, not responding to his name, having a strange way of playing with his toys, and unable to suck his feeding bottle properly.

Regarding sleeping patterns, Thomas and Balaravi had serious sleeping difficulties which caused a great deal of stress to their parents. The parents reported that the best way to deal with the sleeping issue was to stay in the car and drive them around. The parents’ reports agree with some researchers’ (Cotton and Richdale, 2006; Kodak and Piazza, 2008; Liu et al., 2006; Research Autism, 2009; Richdale and Prior, 1995; Schreck and Mulick, 2000; Schreck, Mulick, and Smith, 2004) findings that the sleeping patterns issue is common in children with autism.

A memorable moment from Paavai’s interviews was concerning Balaravi’s sensitivity to his mother’s emotions. Reacting to her depressed mood, he surfed the internet and found a yogi whom he believed could help her. To do this he would have had to type key words into a search engine and then interpret the results. Yet, he has very limited verbal ability (PB 1.93.4).

P: [M]y son can read my emotions! (Said in a low powerful/confidential voice). Sometimes unexceptionally. For example one day I was cooking and was thinking that “It looks like I am feeling a little bit too bad today” so I had to do more meditation. I was just thinking. I [did not] utter a single word, or I was not looking at him. He [did not] see my face. (Returns to normal speaking). You know what he did? He straight away went to the internet. He went to the Google. He found out the name of the yogi…you know in India. Who spreads all the yoga and meditation, Ramded, he found out his video in Youtube and pulled my hand. “Mommy” and showed his picture there. (PB 1.93.4).

Another example is Thomas who seems to perceive other people’s attitude and to know who is in charge in a group immediately, without any clue.

L: That time he took her (Aida) to the door, Patricia’s auntie, and she doesn’t give off very good vibes at all. She’s very domineering… and she came and Thomas took her straight to the door. Oh I’d so like to do that. So I think he can read people and he can perceive people, but what’s really interesting to know is they always seem to know who’s the boss, or who’s in charge, or where the power lies …Who’s in charge, who’s the gaffer or he always seems to understand the hierarchy for whatever reason. (L&P 2.123).

From the above two examples, a question is raised: How can we explain Thomas and Balaravi’s capability if they lack ‘Theory of Mind’ or the ability to perceive other’s emotions and attitudes?

Among the four children in my research, there are some common behaviour - poor communication, finicky eating habits, sensory issues, slow learning, and fixation. This common behaviour might partly meet Herbert (2003)’s autistic features which are intelligence difficulties, speech and language difficulties, stimulus over-selectivity, self-stimulatory behaviour, as well as self-injurious behaviour, however according to DSM-V, individuals with autism have restricted repetitive behaviour, interests, and activities. They also have difficulties in social communication and social interaction (American Psychiatric Association, 2013). Can we judge that a child has autism or not from this common behaviour in my research? If not, why were they diagnosed with autism?

From the parents’ narratives, each child with autism is very unique; it would be difficult to build one model to describe all four of the children in this study. As indicated in the examples above, each one of the four children presented different characteristics.

In terms of deciphering children’s emotions and feelings, all the parents in the study distinguished or interpreted their children’s emotions and feelings through their sounds, gestures and facial expressions, but it was still challenging for them to classify their children’s emotions correctly. Rankin (2000) has the same reflections in her diary. Here is an example in my research; Catherine told me that she has ‘a hard time trying to decide if [her child’s] behaviour is because he is special, or because he is a child’ (C&J 1.909).

He does have some subtle facial expressions. His facial expressions, quite frankly, other people rarely notice. Perhaps it’s mother’s intuition. Sometimes, I wonder that do I add lots of imagination on his emotions and feelings. Sometimes, I think that I get it right. Interestingly, I think that I understand my son’s emotions and feelings better than my husband. Somehow, my husband cannot figure out why my son’s behaviour is like that. Sometimes, I can tell that he is angry. (C&J 1.537).

Regarding positive emotionality, the children expressed themselves differently. For example, Thomas’s parents think that he shows his happiness and pride through his facial expressions. He sometimes shows his pride to them by demonstrating new learned skills. He shows his excitement mostly by ‘jumping up and down’ (L&P 3.30). Balaravi’s mother (Paavai) said the way Balaravi shows his sympathy by crying for a lost baby and dying children. Balaravi shows his empathy by imaging other people’s emotional reactions. Harry expresses his happiness by laughing, screaming, bouncing, running around, and jumping on the sofa. Han shows his happiness by smiling and laughing or by making a ‘lelele’ sound, or by spinning, hugging or kissing.

Regarding negative emotionality, again, children expressed themselves in diverse ways. For instance, Thomas shows his anger by banging, hitting, slamming doors, and by falling to his knees. He shows his jealousy by fighting for his parents’ attention. Balaravi’s mother (Paavai) said that Balaravi shows his anger through a tantrum, or by making a grunting sound, making very obvious facial expressions, breaking things, throwing things, screaming, biting Paavai, and scratching other people. Balaravi exhibits his guilt by hugging, apology, or putting medicine on the wounds he has inflicted. Harry shows his tantrum by throwing things and screaming. Harry expresses his anxiety by biting his fingers, holding his parent’s hand tightly and running past the scenario as quickly as possible. Han shows his anger by biting an object, or biting himself to the point of bleeding (mostly biting his own hands), head-banging (on the wall and on the floor), yelling, throwing some objects (such as a chair), and laying on the floor, crying and kicking.

Regarding motivation, 3 out of 4 participants in my research mentioned that their children need motivators. Durden (2007), Goleman (1996), Grandin and Scariano (1986), Hyson (2004), Nutbrown (1999), and Williams (1996) assert that motivation is essential for children’s development (such as cognitive and emotions) and achievement. For example, Thomas sometimes needs to be motivated and his motivation is affected by his mood. Harry needs sweets, fruits, and technology devices as his motivators to drive him to learn and to communicate. Han needs motivation to communicate with others. It is evident that finding the motivation of individuals with autism is challenging for people working with them but is essential to their lives.

Given that these children are non-verbal, they tend to express themselves in extreme ways. Parents have got to get used to interpreting the ways through which their children express themselves for effective communication. From the study, parents indicated that this was not always an easy task highlighting that it was easier to notice negative emotionality compared to positive emotionality. This might resonate with Mundy’s (1989) finding that children with autism express more negative emotions rather than positive emotions.

**6.2.2 Factors affecting children’s emotional life**

The parental narratives in this study indicate that the common variables affecting children’s emotional life are language ability, physical discomfort (hunger, pains, illness, sleepiness, and tiredness), waiting, environmental factors (noise, pollen, daylight or seasons, humidity, heat, medication) and their parent’s emotions as mentioned by the Taiwanese participants. Bronfenbrenner (1979), Cole et al. (2004), Eisenberg and Morris (2002), Goldsmith and Davidson (2004), Morris et al. (2007), Parke (1994), and Walden and Smith (1997) indicate that an individual’s disposition, neurophysiology, cognitive development, and the interaction between a child and external milieus (such as organisations, policy and culture) play essential roles in shaping an individual’s emotionality. The accounts of the behaviour of the children in my research resonate with several research papers (Baker and Cantwell, 1982, 1987a, b; Beitchman et al., 1986, 1989a, b; Cantwell et al., 1989; Rutter and Casaer, 1991; Rutter and Mawhood, 1991) which have found limited language ability usually has a close relationship with behavioural, social, and emotional difficulties.

Does cognitive ability affect emotional ability? Compared with children who have autism, children with Down’s syndrome have a lower cognitive ability, but have rich social needs and effective connection. Some high-functioning children with autism (high IQ), in common with children with Down’s syndrome, cannot build spontaneous relationships with others. They are good at rational induction rather than relationship-building.

Goodman (1991) denotes that psychological delay is not the same as neurological delay, nor is psychological deviance the same as neurological deviance. Some of the participants in my research indicate that their son lost his social interactions and oral language around age two. Is the regression of social interest, social awareness, and language ability, which was mentioned by Goodman (1991, p.25), due to a shift in neural substrate?

In my research, according to Thomas’s parents’ account, his emotions are affected by his limited language ability, hunger, pollen, hypersensitivity, medication, daylight or seasons, unpredictability, noise, and waiting. Hypersensitivity is one of the factors that trigger Thomas’s negative emotions. The other three children in the research are not as hypersensitive as Thomas.

L: [H]ay fever affects him and really bogs him down, too much daylight, the really long days from seven in the morning till ten at night and if you’re very difficult to engage and you have very little activities that engage you, then with a really long day its enormously difficult and that’s when he gets most affected, but in the winter days there is less light, it’s a lot easier for him, because of the daylight. It’s dark, he doesn’t get up too early, it’s dark of an evening so he settles better. He settles better when it’s dark, so that’s how Thomas knows the difference between night and day of course. The trouble-some days are incredibly long. (L&P 1.187.2).

The learning process of a hypersensitive child with autism is hampered by the flood of sensory information (such as sound, light, images, taste and smell) which is present every second of their daily life (American Psychiatric Association, 2000; Billington, 2000, 2006; Gadia and Tuchman, 2003; Kaufman, 2010; Kern, 2002). For example, both Taiwanese participants in my study mention that their children are sensitive to subtle sound even though they do not react to their names being called. Ya mentioned that Han could detect the twirling sound of using a key to open a door on the ground floor when they live on the 4th floor, and Catherine remembered that Harry can hear that John ‘was using a key to open the door on ground floor immediately (they live on the 5th floor)’ (C&J 1.371). I am unsure about Gomes et al. (2004)’s unclearly explained research findings which indicate that auditory behaviour is not associated to hypersensitivity of the auditory pathways, but rather to difficulties in the upper processing at the level of the cerebral cortex (such as the limbic system). For me, how to tackle the sensory issue in daily life is the most important task.

Williams (1996) mentions that hypersensitivity affects her emotions and daily life. In this study, Thomas and Han’s parents suspect that hypersensitivity affects their child’s emotions and feelings, and makes him have bigger negative reactions because he is overwhelmed by sensory stimuli. Billington (2000, 2006), Carlisle’s (2007), Kaufman (2010), and Kern (2002) provide a suggestion—reducing sensorial stimuli in the environment. Thomas’s learning started to progress after tackling his hypersensitivity issue, which was suggested by his occupational therapist. According to Macnamara (1972) language is learned from our intentions. Children form a relationship between what they hear and the meaning conveyed by the exchange. If we accept this to be the case, how can we expect a child with autism, who is overwhelmed by sensory stimulus, to distinguish the main object or details of pointed direction? For example, if a person says ‘listen, a bird is singing’, the child with autism might hear other sounds, such as cars honking, or people’s laughter at the same time, and then misunderstand the person’s point. This could result in unexpected behaviour, or confusion.

In addition to the above factors affecting a child’s emotions, some outer milieu (family, the educational system, the medical system, policy and society) might need to be considered (Bronfenbrenner, 1974; Cross and Huang, 2012; Denzin, 1984; Ecclestone and Hayes, 2009; Lazarus, 1991, 2001; Lazarus and Folkman, 1984; Seyfert, 2012; Winograd, 2003).

**Family**

‘The most “contagious” models for the child are likely to be those who are the major sources of support and control in his environment; namely, his parents, playmates, and older children and adults who play a prominent role in his everyday life’ (Bronfenbrenner, 1974, p.133). For all children the family unit is important. Inside a family, children learn how to build relationships with others, how to see and interact with the world, how to gain support from their family members (especially their parents), how to mimic those in their immediate surroundings, and how to handle negative emotions (Howe et al., 1999). Morris et al. (2007) review current literature relating to the relationships between a child’s emotion regulation and their family. They conclude that a child’s emotion regulation has been learnt through observation, social referencing, and modelling, and it is also affected by parental emotion-coaching, parents’ reactions to emotions, parental encouragement to control emotions and perceived control over emotions, teaching about emotion regulation strategies, niche-picking, parental characteristics, parenting style, attachment, expressivity, and marital relationship in the family. My parental narratives concerning parents and their difficulties of understanding their son’s emotions clearly, support Saarni (1999)’s findings. Furthermore, parents of children with autism undergo huge psychological distress (Paynter et al., 2013). Bronfenbrenner (1979) illustrates that effective parenting is affected by role demands, stresses, and supports originating from other surroundings. Parents evaluate their function abilities, the view of their children, job flexibility, child care arrangement, emergency helpers (friends, relatives, and neighbours), social and health services, and neighbourhood safety. The availability of supportive settings is, in succession, presenting their existence and frequency of a function in a given culture or subculture. The adoption of public policies and practices that create additional settings and societal roles conducive to family life can enhance its frequency.

Meanwhile, the quality of the husband-wife relationship is a considerable predictor of the quality of the parent-child relationship and the resulting child development/outcomes (Bronfenbrenner, 1995; Crockenberg & Smith, 1982; Moss, 1967; Moss & Robson, 1968; Robson, Pedersen, & Moss, 1969). In my research, except for Paavai, the families have cooperative relationships between the husbands and wives—having shared duties and consistent child-rearing approaches. For example, Catherine and John always exchange and discuss their strategies of interacting with Harry. When John lost his temper with Harry’s tantrum, Catherine took charge of the situation, reinterpreted the hidden meaning of Harry’s tantrum and then calmed Harry down which might be conducive toward Harry having a more stable emotionality.

A traditional scenario is that a mother should be responsible for upbringing, and many societies take the mother’s efforts for granted. Therefore, the mother needs to leave her employment and is responsible for the child’s inappropriate behaviour or bad academic performance. Dunn and Kendrick (1982), Fisher and Goodley (2007), Moss (1991), Parker (2012), and Shu and Lung (2005) found that mothers are the main caregivers in most cases. However, Parker (2012) suggests that the father should share the burden of looking after a child with special needs, a situation revealed in my study. One of my Taiwan participants, Catherine mentioned and questioned this unfair situation in her diary (Diary 2/Dec/2010). In half of the families that participated in my research the father (Larry and John) is the main caregiver of their son. Consider that according to Freud’s theory and previous research findings (Beets and Foley, 2008; Cabrera et al., 2000; Fagan and Iglesias, 1999; Koestner, Franz, and Weinberger, 1990; McBride, Schoppe-Sullivan, and Ho, 2005; Ninio and Rinott, 1988) a boy is more likely to imitate his father’s behaviour rather than his mother’s, and will benefit from his father’s involvement (role model), in socio-emotional, physical activity, cognitive, academic aspects, and so on. Consider also that a survey in England indicates that the ratio of males to females with autism is 9:1 (Brugha et al., 2009).

All the parents in my study told me that they did the best for their sons. Interestingly, both of the Taiwan participants showed an attitude of being ‘good-enough parents’ (which partly matches the notion of Winnicott’s book ‘The Ordinary Devoted Mother and her Baby’ published in 1949. Parents do their best for their children, meanwhile, they still have their own time and hobbies) rather than being ‘perfect parents or A+ parents’.

The perfect parent or A+ parent is a common phenomenon in Taiwan. The centre of a perfect mother’s life is her child. She sacrifices and devotes herself to child-rearing or to her other family members, and is, herself, the lowest priority of all of her family members. A perfect mother is inclined to ascribe her child’s achievement to luck; by contrast, she will blame herself or be blamed for her child’s illness, bad behaviour or poor academic achievement.

The ‘good-enough parents’ may be a result of both parents having to earn enough money for their family to enjoy a minimum lifestyle (since the social welfare system in Taiwan is not as excellent as it is in the UK) and to pay for other support resources (such as a 24-hour nanny). Fortunately, the Taiwanese parents (particularly Catherine and Ya) in the study have their parents and parents-in-law to help them to look after their children temporarily and give them some financial support. In addition to this, their relatives and friends also provide some help, with such useful resources as job-searching, and house-finding which resonates Altiere and Kluge (2009)’s finding-- mothers found more support from friends and family than did fathers. Except for some financial and physical support, even though grandparents may not interact with their grandchild directly, they may influence the parents’ child-rearing approach which affects how the child is treated or expected by their parents (Bronfenbrenner, 1979).

In terms of parental attitudes toward their child, the Taiwanese participants (mothers) reflected that while they attempted to control their own tempers, there were times when they actually lost control, because their sons drove them crazy. Both participants knew that they should manage their temper, because they knew that their sons did not mean to irritate them and they were aware that the parent’s and child’s emotions were reciprocal which resonates with Reay (2000)’s observation of mother-child mutual relationships of emotionality and Bronfenbrenner (1979)’s Ecological system. From Bronfenbrenner (1979)’s viewpoint, different settings can have an effect on one another. If an individual is not getting the emotional support they need from their family at home, it can negatively affect their performance at school, which in turn can negatively affect how their teachers and peers interact with them. Unless broken, this becomes a vicious cycle of in which individual family members can feel unsupported. However, the UK participants completely overlooked parent-child reciprocal emotional influence. This might be an indication of cultural differences.

Raising a child with autism is considered to be an onerous task (Ann, 2009; Divan et al., 2012; Neely et al., 2012). The parents of children with autism experience a significant amount of stress and depression (Divan et al., 2012; Neely et al., 2012; Paynter et al., 2013). They encounter substantial issues; assessment-arrangement (Ann, 2009; Neely et al., 2012), social withdrawal in the beginning and social reintegration later (Ann, 2009; Divan et al., 2012; Neely et al., 2012), acquiring the required skills and knowledge to cope with their child’s difficulties (Paynter et al., 2013), accessing any social support, social networking and the health care system (Ann, 2009; Divan et al., 2012; Neely et al., 2012; Parker, 2012; Paynter et al., 2013), and gaining professional awareness of their family’s huge economic and emotional burden (Blacher, 1984; DeMyer and Goldberg, 1983; Divan et al., 2012; Neely et al., 2012; Timimi et al., 2011). Similarly, Thierry and Watkins (2006) filmed ‘Autism Every Day’ to explore the parenting experience of working with children with autism. Parents in the film mentioned that parents’ exhaustion, as well as stress from other parents, schools, and financial situations. Sometimes the parents would consider suicide with the child due to the unbearable stress. Sadly, lacking social safety nets and support networks outweighs the stress coming from the child per se.

The irregular sleeping pattern, toileting, and challenging behaviour of children with autism are some of the parents’ stressors (Blacher, 1984). In my research, Thomas and Balaravi’s parents have undergone all of these stresses with optimism. Harry and Han’s parents also have experienced this except for the challenging behaviour; nevertheless, Harry’s parents hold a positive perceptive of Harry’s progress. On the other hand, Han’s parents were adjusting themselves and attempted to find the right means to cope with it.

Considering parent groups, the Taiwanese participants dislike attending parent groups because they hate comparison among parents and the negative atmosphere in the groups, even though Shu and Lung (2005, p.51) believe that parents of children with autism can benefit from an organisation ‘for self‐exploration and sharing ideas and experiences’ rather than for releasing their negative thoughts.

Parents in this research (see Chapter 5) mentioned these five issues:

(1) It was hard to find suitable day-care options for children with autism. This often forced one parent to leave their employment in order to look after their child and take them for treatment. Of course this situation imposed a financial burden.

(2) The parents were torn between their child with autism and their other children and family members.

(3) The parents worried about their child's future.

(4) Due to their child’s normal appearance and inappropriate behaviour, the parents felt judged by society. This may lead to the parents of a child with autism preferring to take their child to a close and familiar group rather than to an unfamiliar group (Baxter, 1989).

(5) Parents of children with autism had to make many sacrifices. They encountered many barriers and hardships, and they hoped that the medical and educational system would work together to give them the guidance they needed and desired.

My parental narratives resonate with Ann’s (2009) research findings which also identified the five issues discussed above.

Concerning siblings, Thomas, Harry and Han’s emotions and behaviour are affected by their young siblings and they fight for their parent’s attention with their siblings. They also mimic their younger siblings’ behaviour, particularly when they think that their siblings are having fun. The relationship between Thomas and his young brother is competitive for academic success and parental attention. Harry has a good relationship with his younger sister Elizabeth. She helps to look after him, plays with him and teaches him how to speak. Meanwhile, he mimics her behaviour and joins her games. Han had a better relationship with his younger sister when she was a toddler.

**The educational system**

A student’s emotionality has a close and interactional relationship with adults (such as teachers), peers and academic performance, and cultural/educational values (Birch & Ladd, 1997; Ecclestone and Hayes, 2009; Gumora and Arsenio, 2002; Pianta, 1999; Raver, 2002). Raver (2002) believes that emotional understanding can positively affect social behaviour and school performance. Individuals who cannot regulate their emotions and/or feel as if their emotions are not understood or supported can begin to display disruptive behaviour in school, spending less time focusing on tasks and receiving less individual instruction and less feedback (Raver, 2002). Reflecting on Raver (2002)’s statements, teachers should treat children with autism as human beings with emotions. The purpose of education is to prepare children for the ever-changing world and develop their ability to survive in it. In the case of children with autism, an effort is made to prepare them as much as possible for autonomy, unfortunately this is not always possible (2011, February 10, research diary).

Educators would like to think that they always take the best course of action for the children in their care, unfortunately life is seldom perfect and in my experience there have been occasions when an assessment has not been completely accurate, or the teaching method chosen was not the best. When making decisions concerning the children in my classes I always tried to bear this in mind and considered, with my colleagues, all possible alternatives (2011, February 10, research diary).

When first meeting someone, most individuals immediately make judgements about the person, which are based on their appearance, their job, the way they speak, their social status and ethnicity. They will then decide how to talk to the person and how to behave. This form of reaction is called socialising, or more recently profiling, which is shaped by social norms or stereotyping. It makes people do things efficiently. Socialising makes individuals ignore the human inside. They do not see other people as humans, but as categorised goods. Common classification criteria like gender, ethnicity (skin colour) and social-economic status are used in surveys. For example, the police may treat a black person as a criminal and treat a Muslim as a terrorist (2013, March 20, research diary).

As an educator, ideally, I think it is vital to explore a student’s strengths in depth, and not to focus on their weakness before trying to develop those strengths. Teachers get used to ticking the boxes on a checklist and filing it. They know students by their number and reports, and do not have the time or interest to know the students themselves. This is not the purpose of education. Many teachers argue that they do not have enough time to explore deeply every individual’s strengths, because of the standards that are imposed by the system (2013, March 20, research diary).

A school is not a factory production line, and teachers do not expect to manufacture the same products or robots, because society needs various kinds of citizens to run it and do various kinds of jobs. Respecting and accepting the differences between individuals is essential for a healthy society.

All the participants believed that resource classes are better for their child than mainstream classes because the staff in specialist schools provide more resources, pay more attention to their child, and in the case of Harry’s parents, think that they also have better parent-teacher cooperation. My parental narratives are contrary to those of Barnard, Prior, and Potter (2000)’s research result in which most parents of children with autism are satisfied with the service in primary mainstream classes in the UK. The different results might be affected by children’s abilities, parents’ expectations, local educational systems and resources and local medical systems/resources. Also Chen (2007)’s research in Taiwan indicates a vital issue which teachers’ professional teaching strategies and acceptance toward children with autism affect how other children react to the children with autism.

It is essential that all the professionals, such as therapists and educational psychologists, work together in the best interests of children with autism in the educational setting. Thomas’s parents said that he made more progress in an intensive, ‘Thomas-centred’ learning environment, especially when he had good relationships with the educators.

In terms of utilising PECS, Thomas’s parents (UK1), Balaravi’s mother (UK2), and Harry’s parents (Taiwan 1) prefer to use other alternative communication tools rather than PECS because it is inconvenient for them.

All the participants in my research believe that a good parent-teacher relationship is very important. The parents and teachers can acquire information and learn some strategies from each other. The Taiwanese participants told me that information is passed between the parents and teachers through Teacher-Parent Contact Books. Catherine further states that the characteristics of a good teacher are being friendly, open-minded, should educate the whole family to deal with the treatment issue, know how to communicate with and monitor the parents of a child with special needs, be able to handle every child’s situation and behaviour by being responsive to individual needs, and keeping regular contact with the parents about what is going on at school. Similarly, Balaravi’s mother told me that that the characteristics of a good teacher include giving useful advice, making her son happy and helping him progress in a friendly and warm atmosphere.

**The medical system**

The diagnosis of autism is overused, questionable, and sometimes misused (Alarcon, 2009; American Psychiatric Association; Boucher, 2009; Timimi et al., 2011), however, it cannot be denied that solid diagnosis (labelling) gives parents of a child with autism an explanation for their child’s behaviour, gives them relief, allows them to access resources, prepare a plan to move forward, and might further help other parents at the same situation later (Fleischmann, 2004, 2005; Midence and O’neill, 1999; Moore, 2008). All of the parents in my research told me that they think the diagnosis is very important for them, even though they have encountered, are encountering and will continue to encounter some unfriendly treatment in their daily lives. Without the diagnosis, they could not provide their children with the support and resources they need. With regard to the diagnosis, parents in my research put little emphasis on the medical results (medical reports and Intelligence Quotient tests) due to its credibility affected by the test environment, staff and children’s cultural background, children’s conditions (Suzuki and Aronson, 2005). Besides, Siegel (1989), Suzuki and Aronson (2005), and Wolman (2008) question the validity of Intelligence Quotient (IQ) tests. Alarcon (2009), Dawson et al. (2007), and Suzuki and Aronson (2005) caution us some IQ test-related issues, such as cultural variables, family relative data, ‘pathogenic and pathoplastic factors’, ‘explanatory models’, and children’s strengths and weakness. Meanwhile, IQ test cannot define learning abilities and predict our future achievement (Gardner, 1983; Goleman, 1996; Siegel, 1989).

Additionally, the parents in my research are aware of the impact of the diagnosis (labelling), but they chose to neglect it at this stage because tackling the current resource issues is more vital than future disempowerment which is alerted by Ecclestone (2004).

According to Chamak et al. (2011), 63 % of parents are unhappy with the way the diagnosis is presented. Rosenberg (2007, p.50) cautions about ‘the arbitrary and constructed quality of psychiatric diagnoses, yet we have never been more dependent on them than now’. Doctors should be cautious about employing psychiatric labels and classificatory systems due to the criteria of establishing the validity of psychiatric diagnosis, classificatory principles or the definition of symptoms are questionable (Kendell and Jablensky, 2003; Zigler and Phillips, 1961). Dyck, Piek, and Patrick (2011, p.2704)’s research ‘results imply that there are no natural boundaries between disorders or between disorders and normality’ after investigating typical-development children and some non-typical-development children. Verghese (2011) argues that while medical staff are examining or assessing their patients, they should utilise their senses to probe deeper into their patients’ physical and mental states rather than turn their patients into statistics. Gillman et al. (2000), Hodge (2005), and Shyu et al. (2010) contend that clinicians should carefully consider the influence of a diagnosis on a child and his/her family and only make it when it is necessary for accessing resources. Mallett and Runswick-Cole (2012) caution that the dangers of the autism label might lead people to the diagnosis rather than the understanding of an individual with autism. In the same vein, Hodge (2005) believes that support/resources should be dependent on the child’s needs rather than the diagnostic label. Thomas and Balaravi’s parents complained that even after they went to see their doctor it took a long time and many referrals before a diagnosis was made. Harry and Han’s parents think that the Taiwanese medical system is convenient, but medical staff lack the awareness of patient confidentiality and lack cooperation with each other; therefore the parents of children with autism need to schedule all treatment and intervention for their children and to be an agent of each resource. From my participants’ narrative, parents are keen to gain as many resources as they can for their children which resonates with Tsai et al. (2008) and partly resonates with Hsieh (2007)’s findings. Tsai et al. (2008) indicate that parents of children with special needs play ‘integrating nurturer–trainer roles’ in Taiwan. Parents manage to ascertain effective treatment, developing training and nurturing competencies, negotiating roles, and adjusting expectations. Parents also undergo these processes: trying it all, going along, insisting on training, and facilitating the child's strengths. The mothers who facilitated the child’s strengths were better at integrating the nurturer–trainer roles, experienced better role preparedness, less strain, and positive emotional reactions. Hsieh (2007) thinks that parents take their child’s fundamental abilities, parent’s active and positive attitude, professional knowledge and the exchange of information relating to the outcome into consideration when selecting resources for intervention.

All parents in the research agreed that there was difficulty assessing their children. All participants mentioned that once the diagnosis was made there was little support, or guidance offered to them by the doctor, as also discussed by Ann (2009). Thomas’s parents believe that the UK medical system is inflexible and not centred on the patients’ needs. Balaravi’s mother complained that in India there is little awareness of autism amongst doctors and gave this example: She told me about an occasion when she had taken her son to a doctor in India whose diagnosis was that “He is just a very naughty boy!” and told her that her son’s bad behaviour was the result of her bad parenting.

Considering treatment, Williams (1996), who has autism, challenges the existing medical concepts and treatment of autism, in particular ABA, ‘hug therapy’ (ibid, p.55) and eye contact training. This type of treatment may be extremely distressing, and could amount to a form of torture, for individuals with autism who may be hypersensitive, or cannot stand direct eye contact (ibid.) even if Applied Behavioural Analysis (ABA, or Behavioural Therapy) is widely applied and recognised as a safe and effective treatment for autism so far. Lovaas (1987) demonstrates that applying intensive Behavioural Therapy on young children with autism can improve their intellectual functioning. However the study failed to consider the emotional life of these children. For Ya, applying Behavioural Therapy at home not only affects children with autism, but also people working with them. For example, Ya does not want to apply behavioural therapy on Han even though she has SEN training background. The reason is that she felt like training a dog, and she cannot stand Han’s suffering from waiting (especially when Han is hungry and thirsty). Besides, it is crucial to find a balance point of training between Han and his baby sister (they have different levels of ability and age).

Considering the triangular relationships (the child, the parents and the therapists), it is necessary to have trusting relationships between all the parties to achieve satisfactory progress and all the sessions should connect with the social world to give the child the basic skills they need for daily life. Hodge and Runswick-Cole (2008, p.645) indicate that the essential characteristics of good partnerships are ‘open-mindedness, free-thinking and a willingness to take on board new perspective’. In my research, Thomas’s parents think good doctors have these characteristics: they consider the patients’ emotions, co-operate with schools, keep contact with parents, and are approachable, flexible, and provide information. Balaravi’s mother states that the characteristics include giving useful advice, and utilising a good teaching strategy. As for Harry’s mother, she thinks that the characteristics are giving positive feedback and being supportive.

According to Goodley and Lawthom (2006), parents tend to use primary educational methods rather than medication on their children with autism for them to adjust to the ‘social world’. In this study, three out of my four research participants were offered medication for their children by their doctor. Only half of them use medication (both the UK participants), this may be because their children are older and have severe behaviour issues, and to ‘help to control the stress they experience on a daily basis’ (Boucher, 1996, p.89). Before talking about medication, I would like to give an account of my own recent experience. During my writing-up period, I started to suffer serious pain in my right wrist. I could not sleep, and had difficulty performing even some very simple tasks. My GP and physio-therapist could do nothing except to offer a strong dose pain killer (Naproxen). After taking this medication, the pain in my wrist was dramatically reduced and my muscles felt relaxed, but I started to have some pain in my digestive system and felt depressed (useless) all the time. Two months later, my wrist felt much better and almost like normal, so I stopped taking the medication. After 2 days I began to feel positive and my digestive system felt back to normal, but the pain returned to my wrist. I was presented with a choice, do I accept the pain in my wrist and risk it becoming worse, or do I go back to the stomach pain and depression. My experience reminds me that medication may not be a catholicon and sometimes one has to weigh the side effects. When a doctor prescribes medication for a child with autism, they may not always consider the potential side effects and perhaps we should ask ourselves “who is this medication for?” Teachers require the medication for the child to enhance good class management. Parents want the medication for their child because they desire a more peaceful life. Consider that it is the child who will suffer the side effects. The child’s silence does not indicate their acceptance, because they cannot speak out and tell you.

**Policy**

Comparing the social welfare systems in the UK and in Taiwan, the UK system is significantly better. The parents of children with special needs in the UK and Taiwan must take their children to a hospital to get a diagnosis, so that they can access some useful resources. For example, in the UK, a health visitor arranges related therapists and treatment for the child with special needs whereas in Taiwan the parents have to find all the relevant information, contact people and schedule meetings by themselves, even though both governments do provide allowances and resources for parents who have children with special needs.

In terms of labelling, I feel harassed by the anchoring effect, (the tendency of a person to accept the first piece of information on a subject as a reference which then gives a bias which is hard to shift). Due to the influence of the media, the public has some typical images of autism—disabled, low IQ, unusual behaviour, no emotions, and so on. Once this image is rooted in a person’s mind it is very difficult to change their view. Meanwhile, Kirschner (2013), Timimi (2014, p.1), Timimi et al. (2011, p.286) claim that autism is a difference, not a disorder, and the label ‘should be abolished’. The reasons are that the concept of autism is embedded in socio-cultural and political frameworks (Kirschner, 2013; Timimi et al., 2011; Timimi, 2014); increasing stigma (Kirschner, 2013; Timimi, 2014); ‘the legitimacy of the diagnosis’ of autism is questionable; and the label of autism is unscientific and unhelpful for finding suitable treatment and may harm the sense of self, identity, and cosmology of individuals with autism (Timimi, 2014; Timimi et al., 2011). Additionally, the label of autism is wide-ranging and every individual with autism is unique, and we cannot overlap one person’s behaviour onto another (Billington, 2006a). Even though the parents in my research were initially shocked and in denial, they now have a positive outlook for their son’s future. They all mentioned that without the firm diagnosis, they could not have received the financial, medical and educational support that they desperately needed. My participants’ statements resonate with Timimi et al.’s (2011, p.293) words ‘autism has become a “ticket” for specific services, creating a two-tier system for help and support among this group of obviously disabled young people’. However, the question is whether our system forces the parents of children with autism to accept the diagnoses? Do the children really benefit from this support or intervention or does it result in them being marginalised by our society? Are they inferior to other typical-development children? Do they really need to be dependent on other people? Do they really have deficits, or lack some abilities? What are the strengths of autism? If we accept the need for diagnosis, what would be the best age for assessment and diagnosis? (Is 2-years-old too early? Is 5-years-old too late?)

Therefore instead of looking at what capacities they lack and try to cure them, it is better to find what they have and help them to become immersed into society (Billington, 2006a). Billington (2013) further mentions that children are more vulnerable in the adult system because adults dominate the whole educational and governmental systems. Parents and teachers may be far more frightened than the ‘naughty’ children themselves.

**Society, community, nation**

Legitimately and morally, individuals with autism have the same rights as typical-development individuals. This is evident from ‘The Convention on the Rights of Persons with Disabilities’ (CRPD) (The World Health Organization, 2011) and Foucault’s ideology. However some people who emphasise genetic and neuropathological factors fail to recognise this and think of individuals with autism as lesser beings who have something wrong with them. The attitude towards autism may have a negative affect because an individual’s emotionality consciously and unconsciously interacts with the individual’s mind, culture and society. The laws, norms, and values of a society affect directly and jointly into organisations and individuals in daily life. ‘Individuals are connected to society through the emotions they experience’ (Denzin, 2009, p.24). It is partly because of our emotionality and empathy that society exists. Concern and interest in others form ‘sociality and moral conscience’ (Denzin, 2009, p.243). In this section, cultural differences, neighbour’s reactions, and societal pressure will be discussed.

**On cultural differences**

I moved to The UK from the Far East in 2009 to start this research. There are, as you might expect, many things about life in Sheffield that are different from life in Taipei/Kaohsiung. Here I list some that I have observed that I believe to be relevant:

First, it is common in Asian societies for individuals to put the needs of the community over the needs of the individual. In this respect Asians prefer to listen rather than to speak, whereas in Western culture the rights and freedom of the individual take priority. Also Westerners appear eager to express their own thoughts and pay less attention to the views of others.

Second, when Asian parents educate their children, they tend to use the ‘you are not good enough’ mode to enhance their children’s abilities, especially in the academic domain. In the West, parents use the ‘well done’ mode to encourage a child’s development.

Third, most Asians prefer to have male children. This results in high expectations for male children as they are to become the breadwinners of the family.

Academic achievement is highly prized amongst Asians, as it is believed that good qualifications will lead to a better lifestyle. On the other hand, Western culture demands diversity and believes in the development of personal interests (Flynn, 1991; Goleman, 1996).

Since the reader is probably from a university background, they may not agree with my assessment; however, in communities which are more representative of the general populace, a university education may not be considered as a given in the UK, especially amongst males. In many UK communities a muscular body may be more appreciated than intelligence. For many young men, being a footballer may be considered an ideal career (in part, perhaps, because it is so well paid).

Finally, Asian cultures dictate respect for older members of the community and it is expected that the young will support the older members of their family, this is not so apparent in the West.

All of this is significant when considering the disposition of the parents who form part of my research. Before interviewing parents of children with autism in the UK and Taiwan, I wanted to find common ground between children with autism. However, collected data is so difficult, complex and messy to analyse. For example, the children’s ages are different. In the UK, the ages of the two children are about ten years old. In Taiwan, the ages are 3 and 7. Another difference, as mentioned previously on page 177 and 178, is the many nouns used to express feelings and emotions in English and their subtle differences which are understood by the participants, whereas Mandarin has fewer words than English in the field of emotions and feelings. Cultural issues make collected data hard to analyse and compare. Armstrong (1999, p.63) points out that, ‘cultures do not all share common values and concerns and, to make things even more complicated, different communities within the same country may themselves hold values which are fundamentally opposed’. Armstrong also points out that it is difficult, but necessary to step outside of our own cultural belief system when making ‘cross-cultural enquiry’. Further, Armstrong (1999) and Timimi et al. (2011) have the same idea that the model of disability may be shaped by our social, economic, or cultural norm rather than an individual’s difficulties. ‘The right to an adequate quality of life should be a basic human right. This is an issue for the so-called “advanced” countries where many people do not have this right, as well as in poorer parts of the world’ (Armstrong, 1999, p.86).

Apart from the above, since arriving in the UK to study in Sheffield, I have encountered a considerable amount of non-physical abuse, insults, frightening behaviour and often just been ignored. Some of my friends from overseas have been physically attacked, having eggs thrown at them, even on the university campus. This racist bullying and marginalisation induces me to ponder the plight of the person with autism and others with special needs. Being part of a minority does not mean that our status or abilities are any lower than the majority. We are told ‘When in Rome, do as the Romans do’ yet it seems, we are always placed somewhere below the Romans!

Individuals in Confucius-influenced societies are familiar with two proverbs; ‘the principle of teaching without prejudicial discrimination’ (有教無類) and ‘the principle of adaptation to individual differences in learning environments’ (因材施教). According to these principles, no student is un-teachable. A teacher needs to find every student’s temperaments and idiosyncrasies to tailor an individual’s instruction to meet their learning needs. A label is the least solution for addressing a student’s needs. Conversely, acceptance is the best solution to improve a student’s learning.

Cultural issues seem to affect my research significantly, presenting a huge challenge when it comes to analysis. ‘The type of education and care we offer young children will inevitably reflect the values and beliefs that are held by society and reflected by the government of the day’ (Dowling, 2000, p.xiii). Culture plays a very important role in our daily life. It unconsciously shapes our values, sets up standards, helps to classify things into many groups, and makes quick decisions and judgments. People in diverse cultures see the same thing differently, and react to it in diverse ways. Based on this, is autism a universally agreed disorder or is it more a classification defined by high social-economic class, white psychologists in America?

Many individuals with autism said that autism does not define who an individual with autism is. He or she might have autism, but they like or enjoy things as other typical-development people do. They like or enjoy these things not because they are autistic, but because they are themselves. Just because they have autism and it is currently a part of them, it does not define them as a person. For them, autism is merely considered as a collection of behaviours.

In this study, except for Balaravi’s mother, Paavai, who is from India, the parents all believe that the public has an awareness of autism, and that individuals with autism are accepted more now than before.

In human society, human beings develop a set of categories (norms) to run their society easily. The ‘norms provide the background for the immediate detection of anomalies’ (Kahneman, 2011, p.74). Blame and justice are based on the norms, and associate like twins. Human beings tend to find someone, some organisations, or some objects to blame when bad things happen because they want to seek justice. For example, when someone falls to the ground, his/her first reaction usually is to blame the bumpy road or bad weather, while someone else might blame him/her for being imprudent. Other people might blame the bad city design and bad government. Very few will say that it is my fault and sorry to scare you. In the case of autism, initially the parents are blamed. The biological and neurological factors are blamed later. Why do we not think of an individual with autism as a person with different behaviour from us and appreciate their differences rather than put a label on them and marginalise them? When people are considered disabled, they become a burden for us because we have a low opinion of them and low expectations for them (Derbyshire, 2013). Since our culture affects us unconsciously and tremendously in an immersive way, we should consider seriously how our culture views an individual with autism. Outsiders normally hint at the parents’ mistake for having a child with special needs. Parents of a child with special needs suffer huge pressures, such as financial, relationship, societal, child-rearing, and so on. From my viewpoint, parents are not the ones to be blamed, because a relationship is built on both or multiple sides. Society and community should take responsibility as well.

**Societal pressure**

Thierry and Watkins (2006) filmed ‘Autism Every Day’ to present the stress of parents of children with autism in the society. In this film, the parents mention that other parents are intolerant of their children’s behaviour, often criticise and judge them as not controlling their children properly. All the parents in this study also told me that they feel pressure from their societies. For example, Balaravi’s parents are under pressure, because of the expectations in Indian culture, such as being diagnosed, having a poor academic performance, and unique behaviour. Paavai (Balaravi’s mother) belongs to the upper hierarchy in India, even so, she still encounters hardship. Societal/cultural pressure has made Paavai’s family as a whole, ostracise her and her child, because he is different and therefore brings them shame, or embarrassment. Harry’s parents cannot stand the pressure from other parents with special needs children, because they like to compare their child’s achievements and abilities with other children. Thomas and Han’s parents felt uncomfortable in the public gaze when their children were behaving differently.

**Neighbour’s reaction**

Among all the participants, only Paavai told me about a neighbour’s reaction. Paavai told me that to avoid disturbing her neighbours, she had to sleep with Balaravi in their car for five months in ‘minus twenty degrees in Chicago’ when he was three year-old (PB 1.26). At one point while the family was in USA, their neighbour called the police because they suspected that child abuse was happening in the home. In the end, the police understood what had happened and suggested that she should see a doctor. She still felt being discriminated against and attempted to minimise the disturbance of her neighbours in both the USA and the UK.

As discussed above, a number of variables affect non-verbal children with autism’s emotionality. The next chapter presents the main conclusions drawn from my study including recommendations for further study.

## 6.3 Conclusions and Implications

This section presents a summary of the important conclusions drawn from my study. My conclusions are framed in terms of the areas corresponding to the main research questions. Furthermore, this section contains recommendations based on the parental narratives of my study.

My purpose in this study has been to explore the importance of emotions, often neglected in considering children with autism. As individuals with autism express themselves differently from others and their feelings are hidden from unfamiliar people, I have looked to those closest to them, their parents, to explore this issue. In this study, I have presented a view of the perceptions of emotion in an individual with autism. Judging from the evidence of the parents’ narratives in my research, young children with autism do have emotions, experience both negative and positive emotions and they do have relationships with close family members (parents and siblings) and teachers, with whom they behave accordingly. In fact, there is evidence to suggest that they have richer emotions than has previously been allowed for through diagnosis using the DSM. For me, understanding the emotional lives of children with autism will lead the world to recognise them as being social in different ways. In order to do this, we must first reach into their worlds which are inherently emotional.

For this study I interviewed parents of young children with autism, two in the UK study who were around 9 years old and two in the Taiwan study who were 3 and 7 year-old. Even if they were typically developing children I could not compare their emotional competence at different ages. Therefore, I chose to illustrate their emotional competences rather than to compare them.

In the following section, I summarise some conclusions drawn from my study relating to the following aspects; Individual, Family, The educational system, The medical system, Policy, and Society.

## 6.3.1 The individual and emotionality

The complexity of autism is clear to see from the parent narratives. Like all children, children with autism are unique, however only certain elements of their autism are similar. Each child has their own set of characteristics. Two out of four children with autism in my research are comfortable to use technological tools to do the things they want. The two children from the UK both exhibit challenging behaviour. Should we accept that children with autism have rich emotional lives and such behaviour may now be considered, not as discrete phenomena, but interwoven with their emotionality, as such, while their challenging behaviour may be because they are older, it may be due to frustration, for example, in their inability to express their thoughts and feelings. The more they try to express themselves the more frustrated they become, which in their cases resulted in the challenging behaviour. It is reasonable to conclude from the parents’ narrative that their children do have emotional competence, negative and positive emotions and, for the UK children, a sense of humour. This may be simply because they are older, or it could be a cultural difference. I found that all four of the children enjoy relationships (attachment) with close family members (parents and siblings) and teachers, behave accordingly, and have preferences. In the fact, they have richer emotions than were attributed by clinical staff who subscribe to the DSM diagnosis criteria. For all four children the people in their life have specific roles to fill, usually as drivers, cooks, and teachers.

## 6.3.2 Family and emotionality

One factor across the different cultures of the parents whom I interviewed is the sacrifices that these parents are prepared to make out of love for their child. As in many situations, it is better to fight together than to fight alone. Family members have to work hard together to cope with the daily stress of autism.

From the parent accounts, having a sibling affects the development of a child with autism. A child with autism might develop faster if they have siblings. Parent’s expectations are that their child will become independent in society (take care of himself and find a job). When asked, all the parents said that their wish is that their child will be able to manage on their own, be able to take care of themselves and even find employment.

It was noted that, unlike their counterparts in the UK, the participants in Taiwan related that there is reciprocity between a parent’s and a child’s emotions.

## 6.3.3 The educational system and emotionality

From the parent narrative, good parent-teacher relationships are very necessary for children with autism. Parents and teachers have to work together and outside the family, teachers are the closest to the children and they play one of the most significant roles in progressing the child’s development.

The voices of the parents of children with autism should be considered extremely important as they understand their child’s strengths and difficulties better than anyone.

## 6.3.4 The medical system and emotionality

A firm diagnosis is crucial for parents while they are working with a child with autism, because it will allow them to gain access to resources for their children.

Doctors and their teams should help the parents find the resources they need. The medical system should be sensitive to the needs of families of children with autism. From the beginning they should be working with the parents to make sure that they can take advantage of all the available resources.

## 6.3.5 Policy and emotionality

As stated already, a firm diagnosis is immensely important for the parents of a child with autism as this will allow them access to the necessary resources for their child.

The welfare support offered in the UK and Canada is the best of the four countries experienced by my participants, closely followed by Taiwan; at this stage India seems to be a way behind.

## 6.3.6 Society and emotionality

The participants from Indian and Taiwanese background reported that religion or a belief can play an important role supporting a family who has a child with autism.

Societal acceptance will reduce the stress on the family of a child with autism, which can be achieved by educating the public about autism. The contrast between the West and the East is apparent, although for different reasons. In India, for example, the family may feel shame at having a child who is considered unusual whereas in Taiwan the pressure is for children to perform well academically and to behave well in public.

I think that every individual with autism is unique, and that doctors over-use the term when diagnosing children. I would like to see the autism label revised and moved away from mental illness and reconfigured to allow access to resources. While interviewing participants, I suggested some ideas of de-labelling. However all the participants told me that they were unconcerned about the label of autism because it allows them to access the resources they need for their child. This can be especially important since they cannot work in regular employment when they are busying looking after their children. Sadly, it may become a more serious issue later in their children’s lives. My supervisor, Professor Tom Billington, suggested that I might find ways to approach teachers, parents and professionals, to lead them to go beyond the label, and see the real person inside a child with autism.

In summary, emotions and feelings are affected by individuals and external milieu. Emotion is complex, interactive and integrated with the individual, their families, schools, hospitals, policies and societies. If we are to understand the emotional lives of these children, then all of these factors need to be considered. For me, understanding the emotional lives of children who have autism will help us to inspire them to step into the social world. In order to do this, we must first reach into their world. The parental narratives in this study challenge the view of the predominantly medical perceptive in which individuals with autism lack or have little emotional competence and emotions. Three novel incidents mentioned by the parents in my study are: Thomas’s parents illustrate that Thomas can perceive other people’ attitude toward him and know who is in charge in a group immediately (L&P 2.123): Balaravi can sense his mother’s emotions even though she did not make any sound or show any facial expression (PB1.93): The Taiwanese participants noticed parent-child emotional reciprocity which contradicts the autism diagnosis criteria in DSM-V [‘deficits in social-emotional reciprocity’ (American Psychiatric Association, 2013, p.50)].

## 6.3.7 Implications

As a result of my research I have some suggestions for medical and educational practitioners, further research, and policy-makers.

### 6.3.7.1 Suggestions for practitioners

Parents would like schools to have a proactive approach providing regular feedback and parent participation in dealing with their child’s needs, such as offering understanding, giving positive feedback to them, and reporting their child’s progress. Based on the parent narrative in my research and my own experiences, young children with autism do possess emotionality. It is suggested that teachers in class not only utilise suitable teaching strategies but also explore the emotions of children with autism.

While medical professionals must take a largely objective view of autism there should be more empathy on the part of medical staff who should give consideration to the parent’s and children’s emotions and stresses.

In terms of the social welfare system, parents hope to have case workers who are warm and friendly, maintain regular contact with them, help them with follow up from other domains, introducing resource and treatment to them, and assist parents in understanding all related information pertaining to their child (such as history, diagnosis, and treatment).

### 6.3.7.2 Suggestions for further research

It is hoped that this study will stimulate further research in this field. I offer some suggestions for future research based on my perceived limitations of this study:

1. As my research was a small-scale, qualitative study, it cannot be generalised into the larger population. It might be more revealing if future research explored the narratives of the parents, teachers and the children themselves over a longer period.

2. An expanded comparison between the perceptions of autism in different cultures.

### 6.3.7.3 Suggestions for policy-makers

1. Build an integrated parenting programme that will help parents of a newly diagnosed child with autism cope with the news and gain access to all the help that they need. In the course of our meetings, Catherine, a Taiwan participant, mentioned that this is an area that would make a tremendous difference to parents.

2. Design a training course for parents of newly-diagnosed children with autism which focuses on meeting the parents’ needs and to help alleviate their guilt.

3. Build cross-departmental cooperative mechanisms: Education for children with special educational needs will inevitably involve the medical system, the welfare system and the educational system. These three domains should work together toward the benefit of the child with special needs.

4. Not only parent groups but also government needs to advocate that individuals with special needs are able to contribute their strength to society. It is every citizen’s duty to think positively of them and find a suitable working place for them. For example, the temperaments/idiosyncrasies of ‘aloneness’ are better suited to the information technology industry rather than in the customer service industry.

5. Most individuals with autism dislike having their routine disrupted. For example, long holidays make them uneasy, and they need time to adjust their biological clock and routine. This is why they behave worse in the beginning of a semester. Perhaps schools can modify the gap between each semester, so that they might perform better.

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**Appendices**

**Appendix 1**

**DSM-IV and DSM-V diagnostic criteria for autism**

**DSM-IV diagnostic criteria for autism (American Psychiatric Association, 2000, p. 75)**

“A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairments in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairment in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, non-functional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder.”

**DSM-V diagnostic criteria for Autism (American Psychiatric Association, 2013, pp.50-51)**

“**Autism Spectrum Disorder**

*Specify* if: Associated with a known medical or genetic condition or environmental factor; Associated with another neurodevelopmental, mental, or behavioural disorder

Specify current severity for Criterion A and Criterion B: Requiring very substantial support, Requiring substantial support, Requiring support

*Specify* if: With or without accompanying intellectual impairment, With or without accompanying language impairment, With catatonia” (p. xiv).

“Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history.

 1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal

 social approach and failure of normal back-and-forth conversation; to reduced

 sharing of interests, emotions, or affect; to failure to initiate or respond to social

 interactions.

1. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
2. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

 *Specify* current severity:

 **Severity is based on social communication impairments and restricted,**

 **repetitive patterns of behaviour.**

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history:

 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g.,

 simple motor stereotypies, lining up toys or flipping objects, echolalia,

 idiosyncratic phrases).

 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of

 verbal or nonverbal behaviour (e.g., extreme distress at small changes,

 difficulties with transitions, rigid thinking patterns, greeting rituals, need to take

 same route or eat same food every day).

1. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
2. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

 **Severity is based on social communication impairments and restricted,**

 **repetitive patterns of behaviour.**

C. Symptoms must be present in the early developmental period (but may not become

 fully manifest until social demands exceed limited capacities, or may be masked by

 learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other

 important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual

 developmental disorder) or global developmental delay. Intellectual disability and

 autism spectrum disorder frequently co-occur; to make comorbid diagnoses of

 autism spectrum disorder and intellectual disability, social communication should

 be below that expected for general developmental level.

**Note**: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder” (pp.50-51).

**Appendix 2**

**Comparing the systems related to preschool children with Autism**

Table 1.

Comparing the systems related to preschool children with Autism (Child Welfare Bureau, Ministry of the Interior, 2009; Department of Health, Executive Yuan, 2002; Department of Special Education, National Taiwan Normal University, 2010; Ministry of Education, 2004; Wu, 2009)

|  |  |  |  |
| --- | --- | --- | --- |
|  | Education system | Social welfare system | Medical system |
| Administrative Department | Ministry of Education | Child Welfare Bureau, Ministry of the Interior | Department of Health, Executive Yuan |
| Acts and regulations | The Act of Special Education; The Enforcement Rules to the Act of Special Education. | Protection & Rehabilitation Division; CBI Work Report; The Regulations Governing Qualifications and Training of Professional Staff of Child and Juvenile Welfare Institutes; Protection laws of the handicapped rights | The assessment work method for the handicapped  |
| Professional staff | Special education teachers | Social workers | Child Psychiatrist, Psychologists, Physical Therapists, Speech-language Therapist , Occupational Therapists |

**Appendix 3**

**Taiwanese regulations relating to young children with special needs.**

|  |  |
| --- | --- |
| The name of regulation | Announced date |
| The Special Education Act | 2013.01.23 |
| Enforcement Rules of the Special Education Act | 2012.11.26 |
| 身心障礙及資賦優異學生鑑定辦法 | 2012.9.28 |
| 特殊教育課程教材教法及評量方式實施辦法 | 2000.12.31 |
| 特殊教育相關專業人員及助理人員遴用辦法 | 1999.06.29 |
| 身心障礙教育專業團隊設置與實施辦法 | 1999.01.27 |
| 特殊教育支援服務與專業團隊設置及實施辦法 | 2013.08.01 |
| 各級學校聘任特殊專才者協助教學辦法 | 2012.07.24 |
| 特殊教育學校設立變更停辦合併及人員編制標準 | 2012.05.31 |
| 高級中等以下學校特殊教育班班級及專責單位設置與人員進用辦法 | 2012.09.14 |
| 各級主管教育行政機關提供普通學校輔導特殊教育學生支援服務辦法 | 1999.08.10 |
| 高級中等以下學校身心障礙學生就讀普通班之教學原則及輔導辦法 | 2011.05.16 |
| 身心障礙學生教育輔助器材及相關支持服務辦法 | 2012.07.10 |
| 身心障礙學生無法自行上下學交通服務實施辦法 | 2012.08.09 |
| 特殊教育學生申訴服務辦法 | 2011.02.08 |
| 高級中等以下學校辦理特殊教育方案及補助獎勵辦法 | 2012.06.29 |
| 原住民與身心障礙者及低收入戶參與非正規教育課程補助辦法 | 2011.07.05 |
| 就讀私立幼稚園托兒所社會福利機構之身心障礙幼兒及招收單位獎補助辦法 | 2000.11.02 |
| 身心障礙者權益保障法 | 2011.06.29 |
| 身心障礙者權益保障法施行細則 | 2012.07.03 |
| 身心障礙者鑑定作業辦法 | 2012.06.18 |
| 身心障礙福利機構設施及人員配置標準 | 2012.10.17 |
| 身心障礙者搭乘國內公民營公共交通工具優待實施辦法 | 2008.02.04 |

**Appendix 4**

**Comparing the assessment or diagnosis related to preschool children with Autism** (Wu, 2009; Ko, 2005)

|  |  |  |  |
| --- | --- | --- | --- |
| SystemMeans | Education system | Social welfare system | Medical system |
| Assessment/Diagnosis | Behavioural Rating Scale for Children with Autism (Chang et al., 2001); Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R); Developmental Scale for Children with Autism; Vineland Adaptive Behavior Scales. | N/A | The Diagnostic and Statistical Manual (DSM-IV); the International Classification of Disease (ICD-10); A questionnaire on early development and physical and behavioural symptoms thought to be typical of autism; Baylely Infant Scales of Mental Development(2nd edition); Leiter International Performance Scale-Revised; Wechsler Intelligence Scale for Children-III; Wechsler Preschool and Primary Scale of Intelligence- revised. |

**Appendix 5**

**Comparing diverse treatment and intervention programs and approaches**

Table 3.

Comparing diverse treatment and intervention programs and approaches (Taipei association for autism’s parents, **2009; Wu, 2009;** Yapko, 2003)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| FoundationIntervention | School-based | Clinic-based | Home-based | Significant evidence |
| Applied Behavior Analysis (ABA) | **√** | **√** | **√** | **√** |
| **Occupational Therapy and/or Sensory Integration Therapy** |  | **√** |  | **√** |
| **Play therapies** |  | **√** |  |  |
| **Art therapy** |  | **√** |  |  |
| **Music therapy** |  | **√** |  | **√** |
| Structured teaching | **√** |  |  | **√** |
| Acupuncture |  | **√** |  |  |
| Speech-Language Therapy |  | **√** |  | **√** |
| Physical Therapy |  | **√** |  | **√** |
| Vitamins, diet and supplements |  |  | **√** |  |
| Medications |  | **√** |  |  |
| Animal Assisted Therapies |  |  | **√** |  |
| Picture Exchange Communication System | **√** |  | **√** | **√** |
| Pivotal Response Training | **√** |  | **√** | **√** |

**Appendix 6**

**Therapies in Taiwan (Wu, 2009)**

**Occupational Therapy (OT) is a form of treatment that focuses on the skills necessary for an individual’s daily life. It usually includes addressing three different areas: self-care, sensory motor and fine motor skills. Self-care skills include basic skills such as eating and dressing. The fine motor skills addressed in OT range from the basic skills necessary for self-care to more complex skills, such as writing. Sensory motor skills address the vestibular system (associated with balance), the tactile system (touch) and the proprioceptive system (involved in knowing one’s body position in space). Sensory Integration Therapy** is based on the idea that the body receives information through various senses and people with motor and sensory impairments have difficulty processing that information accurately. Disturbances in touch, movement, and balance are often addressed with **Sensory Integration. These are referred to as tactile,** proprioceptive **and vestibular problems respectively** (Taipei Association for Autism’s parents, **2009;** Yapko, 2003)**.**

**Play therapies** are based on the psychogenic theory of a psychological treatment. Therapists guide children, who cannot speak and understand words, to use physical function to express their thoughts in terms of play. In the course of the game, children can communicate through dolls or objects and learn interpersonal social skills, develop social resilience. The purpose of play therapy is to develop a child's self-healing ability, and express their inner feelings **(**Taipei Association for Autism’s parents, **2009).**

**Art therapy** mainly helps autistic children to enhance their communication skills, increase self-esteem, develop social relationships, and facilitate sensory integration **(**Taipei Association for Autism’s parents, **2009; Yapok, 2003).**

**Music** **Therapy** provides a way of communication for children with autism. It is flexible, and always starts with the child’s response to being given an instrument. Music therapy can be applied in groups or for individual treatment. The goal of Music Therapy is not to teach autistic children how to play or make music. Rather, it is to expand a child’s behavioural repertoire, increase social and communication skills. It will enhance motor control, increase feelings of self-worth, and increase participation in constructive activities **(Howat, 1996; Yapok, 2003).** Liao (2003) describes that Orff Music Therapy helps children with special needs to experience and explore their abilities of multiple perception such as hearing, touching and sight. Improving self confidence and satisfaction and via the learning process of musical healing activities to increase the chance and willingness of social interaction. Orff Music Therapy is readily accepted by the public and when combined with school music education can enable the course to have the function of music therapy.

**The TEACCH (Structured Teaching-Treatment and Education of Autistic and Related Communication-Related Handicapped Children) program** is a highly structured program that includes specific classroom methods, involvement of community agencies and support services for families (Yapko, 2003). The framework for TEACCH emphasizes development of learning through the use of visual prompts or cues in an environment that capitalizes on the visual processing strengths of children with autism. Four major components of structured teaching are; physical organization, schedules, work systems, and task organization **(**Lee, 2005; Schopler et al., 1995; Taipei Association for Autism’s parents, **2009).** Within each component, consideration is given to the child’s developmental levels and individual needs. TEACCH is recognized as one of the most valid treatment programs for children with autism today. In Taiwan, several studies were conducted at pre-school level to explore the effectiveness of TEACCH. These studies all illustrate that TEACCH can facilitate young autistic children’s cognitive abilities, such as numerical concepts (Lin, 2005; Nee, 1999; Wang & Zuang, 1998).

**Acupuncture** is a kind of traditional Chinese medicine (**Yapok, 2003**). It is a common treatment applied to young children with autism in Taiwan. However, I was unable to find any evidence to support it.

**Speech-Language Therapy** is a form of treatment used either to eliminate or to help compensate for delays and deficits in communication (Yapko, 2003).

**Physical Therapy (PT)** specializes in developing strength, coordination and movement in the large muscle groups of the body. Physical therapists work on improving gross motor skills through structured and repetitive physical activities including exercise (Yapko, 2003).

**Diet** The effectiveness of vitamins, supplements and diet, or a combination of the three is considered controversial. When people refer to a diet for children with autism, they are usually referring to the gluten and casein free diets. Gluten and casein are proteins. When parents provide nutritional supplements to autistic children, they tend to choose vitamin B6 and magnesium, vitamin B12, vitamin C, vitamin A, vitamin E, zinc, and cod liver oil (Yapko, 2003).

**Medication:** There are no medications designed to either treat or cure autism. The medications commonly used are for symptom management only. Studies on the use of drugs for autistic children are increasing, but most of the drugs have not yet been approved specifically for the autism population. To take medications to alleviate various symptoms or not is a decision between individuals and their physicians (Yapko, 2003)

**Animal Therapy:** Animals can benefit the development of psychical and social interaction in autistic children. Dogs, horses, and dolphins can be co-therapists (**Yapok, 2003**). Lin (2009) discovers that Animal Assisted Therapy (AAT) can help autistic children consider themselves as individuals who are loved, unique, and important. During the caring process, self-fulfilment and self-values of autistic children will incubate.

**The Picture Exchange Communication System (PECS)** involves using pictures to communicate. By beginning with simple, single words and then building to phrases and sentences and eventually more complex communication, the individual can effectively communicate without voice. The emphasis is on helping an individual to develop the skills for initiating communication with other people (**Yapok, 2003**).

**Pivotal Response Training (PRT)** is considered a behavioural treatment based upon applied behaviour analysis principles. This approach also uses discrete trials to modify their behaviour, but its emphasis is more child-centred and the rewards are based on a natural contingency (**Yapok, 2003**). Chung (2003) finds pivotal response training can enhance symbolic play behaviour, symbolic ideas spontaneously and spontaneous language skills.

**Appendix 7 Ethical Review Form**

**University of Sheffield School of Education**

**RESEARCH ETHICS APPLICATION FORM**

**Complete this form if** you are planning to carry out research in the School of Education which will not involve the NHS but which will involve people participating in research either directly (e.g. interviews, questionnaires) and/or indirectly (e.g. people permitting access to data).

**Documents to enclose with this form, where appropriate:**

This form should be accompanied, where appropriate, by an Information Sheet/Covering Letter/Written Script which informs the prospective participants about the a proposed research, and/or by a Consent Form.

Guidance on how to complete this form is at: <http://www.shef.ac.uk/content/1/c6/11/43/27/Application%20Guide.pdf>

**Once you have completed this research ethics application form in full, and other documents where appropriate email it to the:**

**Either**

Ethics Administrator if you are a member of staff.

**Or**

Secretary for your programme/course if you are a student.

**NOTE**

* Staff and Post Graduate Research (EdDII/PhD) requires 3 reviewers
* Undergraduate and Taught Post Graduate requires 1 reviewer – **low risk**
* Undergraduate and Taught Post Graduate requires 2 reviewers – **high risk**

I am a member of staff and consider this research to be (according to University definitions)

 **low risk 🞏**

 **high risk 🞏**

I am a student and consider this research to be (according to University definitions):

 **low risk 🞏**

 **high risk ✓**

\*Note: For the purposes of Ethical Review the University Research Ethics Committee considers all research with ‘vulnerable people’ to be ‘high risk’ (eg children under 18 years of age).

**University of Sheffield School of Education**

**RESEARCH ETHICS APPLICATION FORM**

**COVER SHEET**

|  |
| --- |
| **I confirm that in my judgment, due to the project’s nature, the use of a method to inform prospective participants about the project****(eg ‘Information Sheet’/’Covering Letter’/’Pre-Written Script’?:** |
| **Is relevant** | **Is not relevant** |
| **✓**(if relevant then this should be enclosed) |  |

|  |
| --- |
| **I confirm that in my judgment, due to the project’s nature, the use of a** **‘Consent Form’:** |
| **Is relevant** | **Is not relevant** |
| **✓**(if relevant then this should be enclosed) |  |

|  |
| --- |
| **Is this a ‘generic “en bloc” application****(ie does it cover more than one project that is sufficiently similar)** |
| **Yes** | **No** |
|  | **✓** |

I am a member of staff

**✓**

I am a PhD/EdD student

I am a Master’s student

I am an Undergraduate student

I am a PGCE student

The submission of this ethics application has been agreed

**✓**

by my supervisor

Supervisor’s signature/name and date of agreement

.........................................................................................................................................................................

**✓**

I have enclosed a signed copy of Part B

**University of Sheffield School of Education**

**RESEARCH ETHICS APPLICATION FORM**

**PART A**

**A1. Title of Research Project**

*Learning from experience: parent narratives concerning the emotional lives of preschool children with autism and without language.*

**A2. Applicant (normally the Principal Investigator, in the case of staff-led research projects, or the student in the case of supervised research projects):**

Title: Ms First Name/Initials: Hui-Fen Last Name: Wu

Post: PhD Student Department: Educational Studies

Email: taes3140@hotmail.com Telephone: 07552717793

**A.2.1. Is this a student project?**

 If yes, please provide the Supervisor’s contact details:

 Professor Tom Billington, School of Education. Department of educational Studies, 388 Glossop Rd, S10 2JA.

**A2.2. Other key investigators/co-applicants (within/outside University), where applicable:**

 Please list all (add more rows if necessary)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Title | Full Name | Post | Responsibilityin project | Organisation | Department |
|  |  |  |  |  |  |

**A3. Proposed Project Duration:**

 Start date: *November 2011* End date: *January 2013*

**A4. Mark ‘X’ in one or more of the following boxes if your research:**

|  |  |
| --- | --- |
|  | Involves children or young people aged under 18 years |
|  | Involves only identifiable personal data with no direct contact with participants |
|  | Involves only anonymised or aggregated data |
|  | Involves prisoners or others in custodial care (eg young offenders) |
|  | Involves adults with mental incapacity or mental illness |
| **X** | Has the primary aim of being educational (eg student research, a project necessary for a postgraduate degree or diploma, MA, PhD or EdD) |

**University of Sheffield School of Education**

**RESEARCH ETHICS APPLICATION FORM**

**A5. Briefly summarise the project’s aims, objectives and methodology?**

(this must be in language comprehensible to a lay person)

*Aim of the Project:*

*To develop an understanding of the emotional lives of young children with autism who do not yet speak.*

*Research Objectives:*

* *To provide an opportunity for parents of young children with autism to talk about their child’s emotions;*
* *To explore how the children express emotion and how the parents interpret and understand these emotions.*
* *To assess the usefulness of emotion as a conceptual tool that professionals should use in the assessment of young children with autism and without language.*

*This research is based on the premise that the ways in which we speak about children will affect the ways in which we construct ideas about them (Billington, McNally and McNally, 2000)*

*David Brooks (2011) says that ‘people learn from people they love.’ In our attempt to separate reason and emotion we have arrived at ‘a shallow view of human nature’. He explains that we can easily talk about material things, but have difficulty discussing our emotions and goes on to say that humans are social, not rational animals and as such emotions are the foundation of our reason.*

*The study will include a detailed review of literature relating to the emotional lives of children with autism. Happé (1994) has argued that to be useful, psychological theory must address both positive as well as the negative aspects of autism. Many researchers subscribe to the belief that people with autism experience emotion, but they may just express their feelings in a different way, for example, Harris (1989:213) who illustrates that “one of the key symptoms of autism is an inability to enter into affective contact with other people. Children with autism feel and express emotion, but they have difficulty in making sense of other people’s emotions. One possible explanation for that difficulty is that they lack some basic perceptual mechanism that allows the normal child an immediate apprehension of other people’s emotional states from their mode of expression—from the gestures, tone of voice and facial expression that they display.” and “the available evidence suggests that autistic children fail to achieve this insight into the capacities of other people…. Even though autistic children can engage in simple object-based pretend play when prompted to do so, they have particular difficulties with this more complex make-believe or pretend mode. As a result, their appreciation of other people’s desires, beliefs and emotions is restricted (ibid: 214).” Another researcher, Dale (1992:192), explains that “…sometimes one has to go ‘inside’ and to examine one’s own emotional response before one can understand what is being communicated.”This is supported by Williams (1992:176-177) who writes “Not mad, not stupid, not fairies, not aliens, just people trapped by invisible crippled emotional responses. At the same time, it would be misleading to think that such people do not feel.” This is illustrated by Alvarez (1992:46-47) when talking about a client whom she studied between the ages of 7 and 17 she says “He did, however, manage to feel he occasionally attained to this desirable inside place himself. One of his ways of doing this was to lie on the couch, with his cheek on the pillow and his eyes gazing into mine, as though he felt he was right inside me. When this state was not achieved, however, a veritable avalanche of feeling was pouring from him, which by now the parents were unable to contain. His fears, his distress and anguish over any separation, from them or me, his sexual mischievousness with women friends of theirs, were overflowing even his parents’ tolerant boundaries, and could certainly not be contained in once-a-month treatment.” Perhaps Bogdashina (2006:87), who studied her PhD at Sheffield Hallam University, sums it up “People with autism may not show emotions in a traditional way, but this does not mean that they have no emotions. In fact, they show their emotions with a greater intensity. People with autism do have problems recognizing emotions…, but they do not lack them”.*

*In consideration of this, I will be focusing on the human aspect of the child rather than the deficits of autism. Parents spend the most amount of time with their children, and they potentially understand them better and more deeply than anyone else. They are also in a position to have a greater impact on the child’s education and well-being than anyone else. For this reason, this research will be focused on providing opportunities for the parents to explore different, perhaps more constructive ways of talking about their child with autism. Therefore, it is my intention to use parent narrative as analysis material to explore the hypothesis that young children with autism do have emotions even though they may be non-verbal. I will also draw on my own childhood and working experiences. My view has been established from a personal and working experience of autism. As someone who was regarded autistic in my early years, yet went on to become a teacher and then a doctorial research student, I prefer to listen to the parents rather than the child’s teachers or doctors.*

*In this research, I will continually ask myself the following five questions while conducting research and working with children:*

1. *‘How do we speak of children?*
2. *How do we speak with children?*
3. *How do we write of children?*
4. *How do we listen to children?*
5. *How do we listen to ourselves?’ (Billington, 2006:8)*

***Methodology:***

*This research project will be carried out with the parents of four children with autism, two of whom will be living in the UK and two in Taiwan. A narrative research methodology will be adopted and I will use a three-stage process detailed by Billington (2008) to collect data. This will take the form of three-one hour sessions with each of the parent pairs. The interviews will be recorded by audio-tape and will be transcribed at a later date. Atkinson (1998) comments that a person telling their own story in an interview will give more information than could be gained from other research methods.*

***Three-stage approach:***

*‘Use open-ended not closed questions, the more open the better’ (Hollway and Jefferson, 2000). I will attempt to create a comfortable environment to help the participants express their thoughts.*

*At the first interview,**I will describe my research and ask the participants to complete a consent form. At this point ‘narrative time’ begins from the first contact with parents. It is also the start of my record and data collection. I will then ask them to tell me the story of their child’s life so far in particular focusing on any area relating to emotion. During this part of the interview I will use prompts to try and draw information relating to the child’s emotions, for example are they able to tell when their child is happy or sad or if they are angry or afraid and if so how can they tell. How do they respond to their child’s feelings and what is the result of this response? During this first session the parents will be encouraged to talk freely with only guidance prompts from me to test behavioural accounts. The hypothesis being that parents might focus on diagnosis, behaviour and resources. I will ask the parents if they have any material or assessments of their child, made by professionals and if so would they bring them to our next meeting. Then at the end of the first session I will give each participant a diary and ask them to make notes about their observations of their child’s emotions and feelings before our next meeting.*

*During the second interview, I will discuss the observations that the parents have made in their diary and further detail relating to their interpretation of their child’s emotions. Then I will share some transcripts of evidence from people with autism. If they have any material relating to previous assessment (for example, teachers and doctors), I will discuss these with them in detail and make notes. Based on their responses I will ask them to make further specific types of observation looking for particular detail in order to obtain more relevant information.*

Between sessions 2 and 3, I will review these records taken with a view to further discussions with the participants in session 3.

*At the final stage, I will discuss relevant details from the records that I previously copied. I will discuss the observations that the parents have made in their diary and ask them if their observations have changed following our previous meetings. I will ask for their diary so that I can consider their notes along with my transcription of their narrative. Of course I will thank them for their participation and assure them that I will be sending a copy of the transcription for their approval.*

***Use of an interpreter:***

*As English is not my first language, while interviewing UK participants, I will utilize the services of an English speaking interpreter to help me with the precise meaning of the language used in the interviews and my transcription of the narrative. I feel this is important in order to reduce the possibility of misinterpreting any nuance of the vernacular. Personal research diaries will be kept by myself and my interpreter. The diaries will be included in the analysis with the interview transcriptions.*

*Some researchers think that the role of an interpreter is translation; they are a cultural broker, as well as cultural consultant (for example, Raval, 2003). Some researchers think that translators change written text into other languages and interpreters change spoken languages into other spoken language (Jones and Boyle, 2011; RIC International, 2007). I think ‘interpreter’ is the correct term for my application. Considering that English is not my first language, there is a strong probability that I will misunderstand the interviewee as I am not completely familiar with the local dialect and colloquialisms. Similarly, as I have a strong accent it is possible that the interviewee will not completely understand what I am saying. For these reasons I will utilise a native English speaker to help me with language issues in the UK portion of my research. This will include help with a verbatim transcription of any tape recordings of interviews in Britain. After the interviews, I will send a transcript to the interviewees and ask them to check the contents. The detailed terms of reference for the use of the interpreter are in the form of a contract with the interpreter (please see attached).*

**Selection of an interpreter:**

*I have chosen Robyn Smith who is my partner of 24 months as my interpreter. Robyn is most familiar with my accent and English talking style as well as the type of thinking logic that I use. I have also chosen to use Robyn as I lack confidence when speaking with people that I do not know in a language that I am not completely comfortable with. That is to say I am able to overcome my fear of interacting with unfamiliar people; however, this is made harder for me when I cannot completely understand them. Robyn’s presence will make this a lot easier.*

*Robyn is a retired businessman who was born in the south of England. He speaks international English and has lived in the Sheffield area for over 6 years. During this time he has acquired a reasonable understanding of the Yorkshire dialects. Prior to the research my supervisor and I will explain to the interpreter the goals of my study, the interviewing procedures that will be utilised and the role of the interpreter. In addition, I will ask that the interpreter maintain the participants’ confidentiality, convey the context accuracy, and hold a non-judgemental attitude (Raval, 2003).*

*The use of an interpreter is commonplace when there are language issues, for example the South Yorkshire Police have a list of interpreters to call on for aide in cases where they want to be absolutely sure that a suspect is fully aware of their rights. Groark, et al., (2011) in ‘Understanding the experiences and emotional needs of unaccompanied asylum-seeking adolescents in the UK’ employed two interpreters to solve different linguistic usages between researchers and participants.*

*I will ask my supervisor to help me address cultural and linguistic issues as I ‘may be unable to understand the cultural nuances of the second language spoken if that language was learned outside the culture’ (Lange, 2002:414) and I also consider cultural competence as an important part in my research.*

*In Taiwan, I will conduct and transcribe the interviews by myself. Because I have lived in the UK for over two years, my cultural concepts have broadened beyond those that I held in Taiwan, so during the coding and analysis process, I will utilise member checking (for example, participants or educational professors) to address this cultural issue. Only the results of the research will be translated from Mandarin into English.*

*The research will be carried out in accordance with the research ethics guidelines from the University of Sheffield as will be explained in the relevant sections of this application form.*

***REFERENCE:***

Alvarez, A. (1992) *Live company: psychoanalytic psychotherapy with autistic, borderline, deprived and abused children*. London: Routledge.

Atkinson, R. (1998) *The life story interview.* London: Sage.

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RIC International (2007). *Interpreting vs. translation.* Retrieved from http://www.ricintl.com.

Williams, D. (1992) *Nobody Nowhere*. London: Doubleday.

**A6. What is the potential for physical and/or psychological harm / distress to participants?**

*There is no potential for physical harm. My research will involve interviews with parents. I am experienced at interviewing the parents of children with autism in a professional capacity (14 years). On some occasions they may be overcome with emotion. I would expect that this would be most likely in a case where the child has recently been diagnosed; however this research will involve parents whose children were diagnosed some time ago. I am able to empathise, both on a personal and professional level and can offer some comfort. Both my interpreter and I are of a calm nature and we will strive to obviate this possibility, however should either of us perceive that a participant is becoming distressed we will stop the interview and allow them to recover. In the event that the participant decides not to answer some questions we will give them the opportunity to stop the interview or just pass on the questions. The children will not be present during the interviews to further reduce the possibility of any harm. All the interviews will be conducted in as sensitive manner as possible.*

**A7. Does your research raise any issues of personal safety for you or other researchers involved in the project and, if yes, explain how these issues will be managed?** (Especially if taking place outside working hours or off University premises.)

  *No*

**A8. How will the potential participants in the project be (i) identified, (ii) approached and (iii) recruited?**

*i) Parents of children with autism who are known to be willing to be interviewed will be approached. Possible sources are; Sheffield Autistic Society, National Autistic Society (NAS), Kaohsiung Autism Association.*

*ii) I will contact the parents of children with autism. Then, I will discuss my research ideas with them.*

*iii) Recruitment of parents of children with autism will be on a voluntary basis.*

**A9. Will informed consent be obtained from the participants?**

**✓**

 **Yes**

 **No**

 **If informed consent is not to be obtained please explain why.** Further guidance is at <http://www.shef.ac.uk/ris/other/gov-ethics/researchethics/policy-notes/consent>

Only under exceptional circumstances are studies without informed consent permitted. Students should consult their tutors.

**A.9.1 How do you plan to obtain informed consent? (i.e. the proposed process?):**

*I will use informed consent forms for individuals or group of participants.*

 *I will explain the details of the research to the parents and seek their consent.*

**A.10 How will you ensure appropriate protection and well-being of participants?**

*My interviews may be conducted at the parents’ homes; however, I will adhere to the ethical considerations for protection of participants’ dignity. Confidentiality will be strictly observed. No real names of participants will be publicised in any part of the research.*

**A.11 What measures will be put in place to ensure confidentiality of personal data, where appropriate?**

*Pseudonyms will be assigned to participants as indicated in question 10.*

**A.12 Will financial / in kind payments (other than reasonable expenses and compensation for time) be offered to participants?** (Indicate how much and on what basis this has been decided.)

 **Yes**

 **No**

**✓**

**A.13 Will the research involve the production of recorded or photographic media such as audio and/or video recordings or photographs?**

**✓**

 **Yes**

 **No**

**A.13.1** This question is only applicable if you are planning to produce recorded or visual media:

**How will you ensure that there is a clear agreement with participants as to how these recorded media or photographs may be stored, used and (if appropriate) destroyed?**

*Recording will only be carried out with participants’ written consent and assurance will be given to participants that no third party other than the project supervisor and examiner will have access to recorded data without the participant’s agreement. Any data recording media used to gather information will be destroyed after completion of the study.*

**University of Sheffield School of Education**

**RESEARCH ETHICS APPLICATION FORM**

**PART B - THE SIGNED DECLARATION**

I confirm my responsibility to deliver the research project in accordance with the University of Sheffield’s policies and procedures, which include the University’s *‘Financial Regulations’, ‘Good research Practice Standards’* and the *‘Ethics Policy for Research Involving Human Participants, Data and Tissue’* (Ethics Policy) and, where externally funded, with the terms and conditions of the research funder.

**In signing this research ethics application I am confirming that:**

1. The above-named project will abide by the University’s Ethics Policy for Research Involving Human Participants, Data and Tissue’: <http://www.shef.ac.uk/ris/other/gov-ethics/researchethics/index.html>

2. The above-named project will abide by the University’s ‘Good Research Practice Standards’: <http://www.shef.ac.uk/ris/other/gov-ethics/researchethics/general-principles/homepage.html>

3. The research ethics application form for the above-named project is accurate to the best of my knowledge and belief.

4. There is no potential material interest that may, or may appear to, impair the independence and objectivity of researchers conducting this project.

5. Subject to the research being approved, I undertake to adhere to the project protocol without unagreed deviation and to comply with any conditions set out in the letter from the University ethics reviewers notifying me of this.

6. I undertake to inform the ethics reviewers of significant changes to the protocol (by contacting my supervisor or the Ethics Administrator as appropriate

7. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data, including the need to register when necessary with the appropriate Data Protection Officer (within the University the Data Protection Officer is based in CICS).

8. I understand that the project, including research records and data, may be subject to inspection for audit purposes, if required in future.

9. I understand that personal data about me as a researcher in this form will be held by those involved in the ethics review procedure (e.g. the Ethics Administrator and/or ethics reviewers/supervisors) and that this will be managed according to Data Protection Act principles.

10. If this is an application for a ‘generic’/’en block’ project all the individual projects that fit under the generic project are compatible with this application.

11. I will inform the Chair of Ethics Review Panel if prospective participants make a complaint about the above-named project.

**Signature of student (student application): Hui-Fen, Wu**

**Signature of staff (staff application):**

**Date:** 17th October, 2011

**Email the completed application form to the course/programme secretary**

**For staff projects contact the Ethics Secretary, Colleen Woodward**

**Email:** c.woodward@sheffield.ac.uk **for details of how to submit**

**Appendix 8 Interview questions**

For my research I will conduct interviews with parents of the children I have selected using the criteria that I have described, such as being diagnosed as autism with nonverbal. So that I am able to concentrate on the collection of information I will record each interview and only make a limited number of notes during the interviews. Prior to the interviews I will inform the interviewees of the details of my research and explain why I want their narrative.

At the beginning of each interview I will ask the interviewee for written permission to conduct and record the interview. I will explain that all the information will be held in strictest confidence and handled in accordance with the University of Sheffield’s standards for ethical research.

At the beginning of each recording I will state the date and time and ask for the interviewee’s name and address and the name age, sex and address of the child we will be discussing. I will explain that they will have the opportunity to review a transcript of the recording and approve its use in my research.

In the first interview I will describe my research and ask the participants to complete a consent form. At this point ‘narrative time’ begins from the first contact with parents. It is also the start of my record and data collection.

I will ask the parents to tell me about the home background; Are both parents present? What is their occupation? Are there any siblings? If so, what are their ages and disposition? Once I have determined the overview, I will ask questions that relate directly to the child. Starting with the child’s history and point of diagnoses, I will attempt to build a picture of their persona and how their autism is manifested. Once I feel that I have a general picture of the child and their context I will ask questions that relate specifically to the child’s emotions and emotional states. During this part of the interview I will use prompts to try and draw information relating to the child’s emotions, for example are they able to tell when their child is happy or sad or if they are angry or afraid and if so how? How do they respond to their child’s feelings and what is the result of this response? During this first session the parents will be encouraged to talk freely with only guidance prompts from me to test behavioural accounts. The hypothesis is that parents might focus on diagnosis, behaviour and resources. I will ask the parents if they have any material or assessments of their child made by professionals and if so would they bring them to our next meeting. Then at the end of the first session I will give each participant a diary and ask them to make notes about their observations of their child’s emotions and feelings before our next meeting. During this interview I will begin the three stage approach with stage 1 questions;

1. How do you know if \_\_\_\_\_\_ (I will use the child’s name where I show a blank here) has learned or made progress?
2. Do you believe that\_\_\_\_\_ feels emotion?
3. Does \_\_\_\_\_ express their emotions
4. How do you know when they are experiencing an emotion
5. What does \_\_\_\_\_ do to express their feelings For example, do they give hugs, kisses, cry or sob, laugh or smile?
6. When\_\_\_\_\_ is distressed how do they show it and how do they manage distress?
7. When \_\_\_\_\_ experiences pleasure how is it expressed and how do they manage it?
8. How about guilt or shame? Or pride or jealousy, or any other more complex emotions?
9. Have you noticed a progression the way \_\_\_\_\_ expresses their feelings?
10. Does \_\_\_\_\_show empathy for their piers or siblings? For example, if another child is sad do they comfort them, or if someone else is hurt do they give them a hug?

**Stage 2**

At this stage I will discuss the observations that the parents have made in their diary and further detail relating to their interpretation of their child’s emotions. Then I will share some transcripts of evidence from people with autism. I will discuss the material that I have presented to them and evoke their reaction to it. Based on their responses I will ask them to make further specific types of observation looking for particular detail in order to obtain more relevant information.

 If they have any material relating to previous assessment (for example, teachers and doctors), I will discuss this with them in detail and arrange to take copies. I will ask their opinions on the assessments and how they have been affected by them.

During the stage 2 interview I will focus on answers to the following questions;

1. What is your opinion of the material I have presented to you, does it give you hope or despair?
2. Has recording \_\_\_\_\_’s emotions brought anything to light?
3. Do you have any new comments the emotional ability of \_\_\_\_\_\_?
4. What is your opinion of the professional assessments that have been made?
5. What are your reasons for thinking this?

**Stage 3**

I will begin with an overview of the ground we have covered so far and tell them what I am hoping to accomplish during this last interview.

Then I will discuss the observations that the parents have made in their diary and ask them if their observations have changed following our previous meetings.

I will ask them about their thoughts on their child’s emotions and feelings, in particular the way the parents see the child’s expression of emotion.

Following this I will discuss their feelings about the professional assessments and ask for the diary that I gave them, so that I can use their written comments along with my transcriptions of the narrative.

During the stage 3 interview I will focus on answers to the following questions;

1. Have you had any further thoughts on the material I presented to you at our last meeting?
2. Now that we have read your comments that you made in your diary, what are your thoughts about \_\_\_\_\_’s emotions and feelings?
3. Why have your comments changed (if they have)?
4. Is there anything else you would like to add about \_\_\_\_\_?
5. Do you have any further comments on the professional assessments?
6. Are there any resources that you think would be helpful, but that have not been offered to you?
7. What are your views on this three-stage approach?
8. Has it been at all useful?

I will then sum up the three sessions and ask for any further input, closing with a thank you for their participation.

**Appendix 9**

**Sharing material for parents—stage 2**

**~~ Dragging a snail for a stroll ~~**

One day God gave me a task

He asked me to take a snail for a stroll

Of course I couldn’t walk too quickly

In spite of the snail’s best effort he could only move forward very, very slowly

I urged him, I fooled him, I cajoled him …

The snail looked up at me most apologetically

He seemed to say “I am doing my very best”

I pulled him, I dragged him, I tugged him. I even tried to kick him

The poor snail got hurt

He was sweating, panting, crawling forward and forward...

He was very unhappy, and my heart went out to him

It was really strange

Why would God ask me to take a snail for a stroll?

”Oh! God! Why?” I cried

No answer came

”Alas! Maybe God has abdicated!”

All right! Let it go now! Since God has given up there is nothing I can do

So I just let the snail crawl forward while I sulked along behind him

Then gradually I noticed the fragrance of flowers

I never realised that there was a garden near here

I felt the night breeze gently touch my skin

Wait! I could hear birds singing and insects chirping

I looked up and the sky was filled with twinkling stars

How is it that I never noticed this before?

It was at that moment that I realised I had it all wrong

God had asked the snail to take me for a stroll

Reference: Wen-Lian Chang (2001) Dragging a snail for a stroll. Taipei: Campus Books.(Translated by Hui-Fen Wu)

A girl with autism and who is non-verbal, expresses her feelings by using a computer. She typed that “It feels like my legs are on fire, and over a million ants are crawling up my arms …… it is hard to be autistic, because no one understands me. People just look at me and assume that I am dumb because I can’t talk or act differently than them. ….. If I can tell people one thing about autism, it would be that I do not want to be this way but I am. So do not be mad, be understanding.”

Reference: <http://www.youtube.com/watch?v=TIoShV8EhO8>

The parents of a boy with autism believe that “The definition of success ... should be letting him have a steady life. We do not know how he feels, because he cannot describe his feelings or emotions. He does have feelings and emotions; he pays attention to your facial expressions and tries to detect your feelings. His emotions are exquisite, but he cannot express them. If you credit him with emotion you will understand his frustration, fear and anger and not just think that he is a bad boy through his actions. If you think of him as a person with various feelings and emotions and try getting along with him, you will find that he is just trying to communicate with you, but in a different way.”

This director said that “Try to imagine if I cannot find any method of expression to communicate with other people, how many misunderstandings I will encounter from other people and how many frustrations I will suffer. I will start to doubt that I am the person who I think that I am. We use our own standards to interpret the behaviour of others.”

Reference: <http://movie-yahoo.087creative.com/autism/video1.php>(Translated by Hui-Fen Wu)

 “People with autism take another path, and this path may be different from the one with which we are familiar. Because of this their behaviour causes us to become afraid just as they are afraid. Possibly we consider that we have some autistic traits ourselves as part of our personalities. Perhaps we should consider people with autism as mentors for learning the meaning of being human rather than people who should be changed and treated. Then we might get used to autism, and not be afraid any more. They, like each of us, have unique personalities, and have some autistic traits blended inside our personality blocks. An outsider might look at the Earth and say “Here is a world populated by 6.8Billion people each one is different.”

Reference: <http://movie-yahoo.087creative.com/autism/video4.php> (Translated by Hui-Fen Wu)

**Appendix 10**

**給家長的閱讀資料—第二階段**

**牽一隻蝸牛去散步**

上帝給我一個任務，
叫我牽一隻蝸牛去散步。
我不能走太快，
蝸牛已經盡力爬，為何總是那麼一點點？

我催他，我唬他，我責備他，
蝸牛用抱歉的眼光看著我，
彷彿說：「人家已經盡力了嘛！」
我拉他，我扯他，甚至想踢他，
蝸牛受了傷，牠留著汗，喘著氣，往前爬‧‧‧。
真奇怪，上帝為什麼要我牽一之蝸牛去散步呢？
「上帝啊！為什麼？」
天上一片安靜。
「唉！也許上帝抓蝸牛去了！」
好吧！鬆手了！反正上帝不管了，我還管什麼？
讓蝸牛往前爬，我在後面生悶氣。

咦！我聞到花香，原來這裡還有這個花園，
我感受到微風，
原來夜裡的微風這麼溫柔。
慢著！我聽到鳥叫，我聽到蟲鳴，
我看到滿天的星斗多亮麗！
咦！我以前怎麼沒有這般細膩的體會？
我忽然想起來了，莫非我錯了？
是上帝叫一隻蝸牛牽我去散步。

張文亮(2001) 牽一隻蝸牛去散步. 台北:校園書房.

一位無口語能力的自閉症兒童利用電腦打出語句來表達她的想法及需求 “我覺得我的腳像被火燒著一樣, 我的手臂像有千萬隻螞蟻在爬一樣 …… 身為自閉兒是很辛苦的, 因為沒有人了解我 , 人們只是看著我, 認定我是傻子, 因為我不會講話, 我的行為跟他們也不一樣 ….. 如果我能告訴人們有關自閉症的一件事情, 那就是我也不想要這樣, 但是**我就是我,** 所以不要生氣, 請多了解我.”

出處: <http://www.youtube.com/watch?v=TIoShV8EhO8>

這位自閉症孩子的家長認為 : ┌成功的定義…應該是讓他很平穩的生活才重要 我們不知道 因為他不會敘述這種感覺 所以他是有情感的 他也在注意你的感覺 他也要順你的感覺 看你的表情 他的想法其實很細膩 只是他不會表達 把他當作是有感情的 有七情六慾的一個人 那你來跟他相處 你就不會覺得他是一個麻煩製造者 反而會覺得他是可以跟你溝通的 只是用不同方式來溝通 ┘

看到這位孩子 導演有感而發的說 : ┌試著想像 如果我沒有找到任何可以溝通表達的方法 我會遭受到多少的誤解 多強烈的挫敗 我所認為的我 到底還存不存在 我們只是用自己的想法去理解他 ┘

出處: http://movie-yahoo.087creative.com/autism/video1.php

 “自閉症者 他們是透過另一個路徑 在看待這個世界 這個路徑或許和我們所熟悉的不同 所以我們也會不習慣 也會害怕 就像他們一樣 但有沒有一種可能 如果我們將自閉特質 也視為人格特質的一項 將自閉症視為我們從中學習身為人類意義的老師 而不是將這些特質視為一定要被改變 且應該要治療的‘疾病’ 或許我們也會慢慢習慣 不再害怕 就像我們每個人也都有自己的獨特性格 而有些自閉特質 不也參雜在我們的個性積木裡 放大來看 他們和我們一樣 不過是全球68億個截然不同的人當中的一個”

出處: <http://movie-yahoo.087creative.com/autism/video4.php>

**Appendix 11**

**Participant Information Document**

**1. Research Project Title:**

*Learning from experience: parent narratives concerning the emotional lives of pre-school children with autism and without language.*

2. **Invitation**

*You are being invited to take part in a research project. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for considering participating in this research.*

3. **What is the project’s purpose?**

*This study is being undertaken in partial fulfilment of the requirements for a PhD course I am doing with the University of Sheffield. This means that the findings of the study will be used solely for academic purposes. I am interested in understanding the emotions of preschool autistic children by talking to their parents. The project will be conducted between November 2011 and January 2013.*

*4.* **Why have I been chosen?**

*The parents of children with autism and without language that are known to be willing to share and recall their views of their child’s early years have been approached to participate in this project. Participation in this study is entirely voluntary.*

5. **Do I have to take part?**

Participation is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form). You can still withdraw at any time without it affecting any benefits, or services that you may be entitled to in any way. You do not have to give a reason.

6. **What will happen to me if I take part?**

*I am interested in your views and these will be sought through three one-hour interviews, which with your consent will be recorded. I will be accompanied by a colleague who will assist with the interview and transcription. My colleague’s role is to help with any language issues as my spoken English is not yet perfect. Whilst the whole project will be for three years, these interviews will be conducted over a short period of about a month. Any audio and/or video recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. Your details will be kept confidential.*

*The schedule for my meetings with you will be negotiated with you in advance. You will not incur any travelling expenses as I will be visiting you at your location.*

7. **What do I have to do?**

*I will talk with you and ask you to keep a diary of your observations of your child’s emotions and how they express them. In particular how you know what they are feeling at any time. If you have any material relating to your child’s emotions and feelings, please bring it to the interview, so that we may discuss it.*

8.**What are the possible disadvantages and risks of taking part?**

*There are no risks or disadvantages. I will be asking for your time to take part in the interviews.*

9. **What are the possible benefits of taking part?**

Whilst there may be no immediate benefit for those people participating in the project, it is hoped that this work will make a significant contribution to the development of knowledge on the emotions of young children with autism. This information will be important to educators who work with young children with autism.

10. **What happens if the research study stops earlier than expected?**

*If this is the case, the reason(s) will be explained to the participant.*

11. **What if something goes wrong?**

*If there is concern about any aspect of this project it should be addressed in the first instance to the PhD student, or to the Head of the research degrees programme Professor Tom Billington, Department of Educational Studies*

12. **Will my taking part in this project be kept confidential?**

*All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publications.*

13. **What will happen to the results of the research project?**

*The research results will be published during the last year of study and participants will be informed in due course how they can obtain a copy of the publication.*

14. **Who is organising and funding the research?**

*The research is being funded by the researcher herself.*

15. **Who has ethically reviewed the project?**

*This project has been ethically approved via the Department of Educational Studies’ ethics review procedure.*

16. **Contact for further information**

*Professor Tom Billington, School of Education, Department of Educational studies, 388 Glossop Rd, S10 2JA. Email:t.billington@sheffield.ac.uk*

*Each participant will receive a copy of the information sheet and a copy of the signed and dated participant consent form.*

*Thank you for considering participating in this small scale study.*

**Will I be recorded, and how will the recorded media be used?**

*The audio and/or video recordings of your activities made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.*

**Appendix 12**

#### Participant Consent Form

|  |
| --- |
| **Title of Project: *Learning from experience: A thematic analysis of parent narratives concerning the emotional lives of young children with autism and without language.*****Name of Researcher: Hui-Fen, Wu** **Please initial box**1. I confirm that I have read and understand the information sheet/letter(delete as applicable) dated *[insert date]* for the above project and have hadthe opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdrawat any time without giving any reason. *Insert contact number here of leadresearcher/member of research team (as appropriate).*
3. I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have accessto my anonymised responses.
4. I agree to take part in the above research project.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Name of Participant Date Signature(*or legal representative*)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Name of person taking consent Date Signature(*if different from lead researcher*)*To be signed and dated in presence of the participant*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Lead Researcher Date Signature*To be signed and dated in presence of the participant*Copies:*Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project’s main record (e.g. a site file), which must be kept in a secure location.*  |

Date: Name of Applicant:

**Appendix 13**

**研究參與者資訊文件**

1.研究題目:

從經驗中學習: 從家長角度探討無語言能力自閉症幼兒的情緒能力。

2.邀請:

我誠摯邀請你參與我的研究。在決定參與前，讓你了解如何進行研究及你需要做些甚麼是非常重要的。請花些時間仔細閱讀下列資訊，或與他人討論和決定你是否要參與。假如有任何疑慮或想要更多資訊，歡迎來問我。非常謝謝您考慮參與此研究。

3.研究目的:

這份研究目的是完成雪菲爾大學博士學位。這意味著此份研究結果僅供研究用途。 研究目的在於透過訪談父母(若雙方都能接受訪談更佳)來了解十歲以下無口語能力自閉症兒的情緒能力。這份研究開始於民國一百年十一月，預估於民國一百零二年一月結束。

4.為什麼選擇我?

本研究徵求十歲以下無口語能力的自閉症孩子的家長願意分享和回溯其孩子早期的情緒能力。家長須完全自願參與此研究。

5.我一定要參與嗎?

完全是自願參與的。假如你決定參與研究，研究者會請你在研究參與者資訊文件及同意書上簽名。假如你隨時想退出，你不需給予研究者任何理由。

6.假如我參與這份研究 甚麼將會發生?

我非常想了解你對你孩子情緒能力的看法。這研究牽涉到三次錄音訪談，預計於一個月內完成。任何錄音資料只供研究分析和會議解說用。若有其他用途會先徵求你的書面同意，非研究相關人員無法看到或聽到這些原始紀錄。你的任何個人資料會在保密的原則下做些更動。研究者會事先跟你討論適合的訪談時間。我會到你指定的地點去會面，你不需負擔任何交通花費。

7.我必須做些甚麼?

研究者會訪談並要求你留著一本日記本去紀錄孩子的情緒反應及他如何表達他的情緒。特別是你如何知道孩子的感覺及情緒。假如你有任何有關孩子情緒反應的紀錄，麻煩帶至我們的訪談處，然後我們可以討論這些紀錄文件。

8.參與研究有甚麼潛在的缺點或傷害嗎?

沒有任何潛在的缺點或傷害。我只會需要你花時間接受訪談和寫日記。

9.參與研究可能獲得的好處?

或許對參與者來說沒有立即地得到好處。但對未來的教育相關人員在了解自閉症幼兒的情緒能力上會有所助益。

10.假如研究提早結束了?

假如真的發生了，研究者會跟參與者說明原因。

11.假如事情出錯了?

假如對研究相關部分有所考量，請第一時間跟研究者反應或是跟教育研究系指導教授Tom Billington反應。

12. 我參與研究的任何記錄會被保密嗎?

你的所有相關資訊將會給予保密。你不會在任何出版品或報告中被指認出來。

13. 如何運用研究結果?

此份研究結果將會在博士課程的最後一年出版，參與者將會被通知並得到一份出版品。

14.誰負責組織和資助此研究?

研究者自費做研究。

15.誰負責審視此研究的倫理部分?

此份研究已經通過雪菲爾大學教育研究系的研究倫理審核過程。

16.若要進一步資訊，可與我的教授聯絡:

教授 Tom Billington, 教育研究系, 388 Glossop Rd, S10 2JA. 電子郵件帳號:t.billington@sheffield.ac.uk

任何參與者將會收到一份資訊文件和研究同意書的副本。

謝謝您考慮參與此份小規模的研究。

我會被錄下來嗎? 被錄下來的資料會被如何應用?

研究期間，你活動的影音紀錄只會被用在資料分析和研討會發表說明時使用。若有其他用途會先徵求你的書面同意，且非研究相關人士無法看到或聽到你的影音紀錄。

**Appendix 14**

**A letter for Taiwanese participants**

親愛的家長， 您好：

 我是英國Sheffield 大學教育系的博士研究生，目前正進行「從經驗中學習*: 從家長角度探討學前無語言能力自閉症幼兒的情緒能力*」的研究。

 教育的目的在培養孩子適應未來的社會，其中孩子的情緒能力佔有重要的地位。然而，自閉症常被冠上情緒異常或沒有情緒能力的標籤，因此研究者假設： 自閉症幼兒有情緒能力，只是受其他因素影響導致未能彰顯出來。本研究的重心，旨在透過家長對孩子的觀察，發掘尚未有語言能力的學前自閉症幼兒之情緒能力，期盼能獲得您的協助，並感謝您的辛勞。

壹**、**研究對象：家中有三至六歲診斷為自閉症且沒有口語能力的幼兒家長

貳、研究方法與程序**：**本研究施測方式與施測地點詳細說明如下：

一、研究者與受訪者進行三次訪談，每次時間約莫一小時。在三次訪談之間，研究者需請父母紀錄下幼兒情緒相關反應或父母本身的省思，以及與自閉症幼兒情緒相關的紀錄。

二、考量受訪者的便利，研究者將選於受訪者方便的地方訪談 (例如:受訪者家中)。

**参、受試者權益**

    首先，您無須負擔任何費用，針對受試者個人隱私保護事宜如下：

一、研究代碼將代表您與孩子的身分，不會顯示姓名等個人基本資料。

二、本研究在訪談的過程中所提供的資料僅運用在學術研究，個人基本資料是堅守保密原則，絕不對外洩露。

三、本研究完成之後，會將研究相關資料與研究報告書寄予家長提供參考！

**有了您的參與俾能幫助更多自閉症的孩子！**

指導教授：Tom Billington 博士, Sheffield 大學

英國Sheffield 大學博士研究生 吳惠芬 敬上

聯絡方式：taes3140@hotmail.com

**研究同意書**

|  |
| --- |
| **論文名稱:** 從經驗中學習*: 從家 長角度探討無語言能力自閉症幼兒的情緒能力***研究者姓名: 吳惠芬** **請在格子內打勾**1. 我確認已了解研究相關資訊.並有機會詢問研究相關問題
2. 我了解我是志願參與的 而且隨時可退出研究計畫

不需要給予研究者任何理由1. 我了解我的資料將會在分析前被匿名 我同意此

研究團隊的任何一員可使用匿名後的資料. 1. 我同意參與此項研究計畫.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_參與者姓名 日期 簽名\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ 研究者姓名 日期 簽名*在參與者面前簽名和寫上日期*副本:一旦這份文件已經被參與者簽署‚每一方應收到一份已簽署並註明日期的參與者同意書，文件和任何其他書面資料需提供給參與者。一個已經簽名的同意書副本‚需註明日期應放置在該研究計畫的記錄中，該項紀錄必須存放在一個妥善保管的位置。 |

日期: 參與者姓名:

1. pseudonym used [↑](#footnote-ref-1)
2. Catherine and John are pseudonyms for two of my research participants in Taiwan. [↑](#footnote-ref-2)
3. For headings 5.1.1 through to 5.1.6 refer to Figure 2. [↑](#footnote-ref-3)
4. The code at the end of each excerpt refers to the initials of the first name of each participant’s pseudonym. The number refers to the text place in the transcript. [↑](#footnote-ref-4)