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The Psychosocial Adjustment of Siblings of Children with Autism Spectrum Disorder in Taiwan and the United Kingdom:
Influence of BAP-Characteristics, Coping Styles, Social Support and Demographic Factors

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Doctor of Philosophy
The University of Edinburgh
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Declaration

This thesis has been composed by me and is entirely my own work. It has not been submitted for any other degree or professional qualification except as specified.

Hsiao-Wei Tsai 07/April/2016
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This PhD thesis would not have been possible without the guidance and the help of several individuals who in one way or another contributed and extended their valuable assistance in the preparation and completion of this research.

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My very great thanks go to my family, the reason that motivates me the most to conduct this research. I hope this research can further help families and siblings that have been through a journey similar to mine, and I sincerely hope this research can have some positive impact on the understanding of siblings’ adjustment.

This thesis is dedicated to my beloved family and friends, especially my dear uncle Daniel Huang who should have been here to share this joy with us.

Finally, well done! Joy!
Abstract

Having a child or sibling with an Autism Spectrum Disorder (ASD) may be a positive experience, but it influences every family member differently. The present thesis examined the psychosocial adjustment of typically developing (TD) siblings of children with ASD and the extent to which this is impacted by key demographic and psychological variables. In addition, the influence of variables more specific to the families of children with ASD were considered, such as the broader autism phenotype (BAP) in parents and siblings, and the severity of symptoms in the child with ASD. A cross-cultural perspective was also adopted, in order to compare the coping and adjustment processes of siblings of children with ASD within two different cultures - Taiwan and the United Kingdom (UK). A combination of the Double ABCX Model and the Diathesis-Stress Model was used to explore: the influence of BAP-related traits; the interaction between coping, stressors, and support resources; and how these variables influenced TD siblings’ adjustment outcome in the two locations. The research model was explored in two, interlinked studies using complimentary quantitative and qualitative methods.

The first study was a large-scale questionnaire study including 89 and 77 parent-TD sibling dyads, in Taiwan and the UK, respectively. The findings indicated that UK siblings evaluated themselves as having significantly more adjustment difficulties but also significantly higher prosocial behaviour than their Taiwanese counterparts. Furthermore, there were substantial differences in terms of the variables which predicted TD siblings’ adjustment outcome between the two countries. Taiwanese TD siblings’ adjustment was more related to children’s internal characteristics, while the UK TD siblings were influenced by both internal and external variables. The benefits of social support for adjustment were also evident in both countries. The discrepancies between parents and TD siblings’ reports could be interpreted as resulting from culturally-specific patterns in parent evaluation of child behaviours. The siblings’ level of BAP traits was also found to moderate the relation between ethnicity/culture and TD siblings’ self-report adjustment difficulties. If Taiwanese TD siblings were reported to have higher BAP level by their parents, they showed fewer adjustment difficulties than those with lower BAP level, whereas the opposite
pattern was found in UK siblings. This may indicate that for Taiwanese TD siblings’ BAP level had a negative impact on their ability to evaluate their adjustment difficulties.

Seven parent-TD sibling dyads from each country participated in the follow-up interview study. From thematic analysis of the data, a negative tone in the descriptions of the influence of ASD on the TD sibling was more evident in parents’ and TD siblings’ transcription in Taiwan, while a more balanced tone was apparent in the UK families. With the emphasis on involving their children in decisions about the child with ASD and providing age-appropriate information from the UK parents, it was speculated that UK siblings had a greater understanding of their parents’ stress. Various types of support service were mentioned in the UK, whereas the availability of social services and support was relatively limited in Taiwan, whether for parents or TD siblings.

Taken together, the findings from the two studies have important implications for clinical and educational settings. UK siblings’ adjustment could be enhanced through modelling the coping of parents, while Taiwanese siblings could benefit from increased social support from peers. Health professionals should be aware of the influence of the BAP level displayed in parents and TD siblings, which might change the way they experience stress and respond under pressure.

This thesis emphasised the importance of using TD siblings’ report in comparison with parents’ evaluation. Some potential relations, such as between BAP level and the coping style of parents and TD siblings remain unclear. With further development of self-report measurements, future research could replicate the present research design to clarify the influence of the variables discussed.
This study explored and discussed the similarities and differences in typically developing siblings’ (TD sibling) adjustment in Taiwan and the United Kingdom (UK). The majority of siblings in Taiwan and the UK were well adjusted based on their self-report in the questionnaires. This good adjustment was linked to having plenty of social support. Teaching and modelling positive coping strategies to TD siblings in the UK may support them in dealing with challenging situations, while Taiwanese siblings could benefit from increased social support. Health professionals should be aware of the behaviour and cognitive patterns displayed within the family, which might change the way they experience stress and respond under pressure.

Seven parent-TD sibling pairs from each country participated in the follow-up interview study. The influence of autism was more evident in parents’ and TD siblings’ interview in Taiwan, while both positive and negative views were apparent in the UK families. With the emphasis on involving their children in decisions about the child with autism and providing suitable information from the UK parents, it was possible that UK siblings had a greater understanding of their parents’ stress. Various types of support service were mentioned in the UK, whereas the availability of social services and support was relatively limited in Taiwan, whether for parents or TD siblings.

Despite its limitations, this study is one of only a few to explore the TD siblings’ adjustment by using both parents and children self-report and in both Chinese and Western culture settings, and thus makes a meaningful contribution to the literature on families of individuals with autism. Factors that were identified in the present studies as contributing to TD siblings’ adjustment are potentially important for health and educational professionals working with families of children with autism in the two cultural contexts.
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Chapter 1: Introduction

1.1 Introduction

What is it like to grow up with a brother or sister with a disability? Living with a child who has a disability might be a positive experience, but it can still pose significant financial, emotional and lifestyle challenges for a family. When a family has a child with a developmental disability, the relationships amongst family members might be different from those in families with typically developing children. In addition, the roles of family members and the function of the family may also be different. The strain on financial and emotional resources associated with raising a child with a disability may result in family conflicts which can affect the psychosocial adjustment of every member. Yet having a child with a disability could also be a positive experience that helps family members bond. Siblings of children with a disability also have been found to show more caring, warmth and positive characteristics. This thesis is concerned with how such factors may impact on siblings of children with disability, and focuses particularly on adjustment and coping in siblings of children with Autism Spectrum Disorders (ASD)\(^1\) in Taiwan and the United Kingdom (UK).

Leo Kanner (1943) in the paper ‘Autistic disturbances of affective contact’ first described eleven children with “monotonous repetitiousness and the resulting limitation in the variety of spontaneous activity” (p 246) and with several social deficits and unusual behaviours. The term ‘early infantile autism’ was first used in this journal paper, and much research has developed since that time. With the development diagnostic systems, the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) states that Autism Spectrum Disorders are diagnosed by persistent deficits in social communication and social interaction across multiple contexts, alongside restricted, repetitive patterns of behaviour, interests, or activities. Under the DSM-5 criteria,

\(^1\) The term ASD is used to represent autism spectrum disorders throughout the thesis, but when reviewing literature the terminology used by the authors is adopted.
individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later. Severity is based on the level of social communication impairments and restricted repetitive patterns of behaviour.

Over time, there have been some changes in the diagnosis system, and in the latest DSM-5 system, the terms used in the previous version - Autistic disorder, Asperger’s disorder, Childhood disintegrative disorder and PDD-NOS (pervasive developmental disorder not otherwise specified) are no longer used. Instead, they are all known as Autism Spectrum Disorder (ASD). Asperger’s syndrome is merged into the overall category of ASD in this edition. Asperger’s syndrome differs from the other ASDs as there is no general delay in cognitive development. In general, those who are diagnosed as having Asperger’s can still function independently even though their social skills are impaired in various aspects (Macintosh & Dissanayake, 2004; Szatmari, Archer, Fisman, Streiner, & Wilson, 1995).

The causes of ASD are unknown, but there is evidence of a genetic component (Bailey, Palferman, Heavey, & Le Couteur, 1998; Bolton et al., 1994; Connolly & Hakonarson, 2014). In the UK, it is estimated around 1.57% of children are diagnosed with ASD (Baron-Cohen et al., 2009), while in Taiwan is around 2.24% (Lai, Tseng, Hou, & Guo, 2012), the difference perhaps due to the differences in case-finding methods and the awareness of ASD conditions (Fombonne, 2009). Some people diagnosed with ASD require occasional support and can live relatively independent lives but about 50–70% of ASD cases also have intellectual disability that needs intensive specialist intervention or lifetime assistance (Matson & Shoemaker, 2009; Strømme & Diseth, 2000). The male-to-female sex ratio is about 4.3:1 (Fombonne, 2003).

Although challenging behaviour is not usually considered a core feature of ASD according to the DSM-5 diagnosis manual (American Psychiatric Association, 2013), challenging behaviour, such as self-injury, aggression, and noncompliance are frequently found amongst children who are diagnosed with ASD (Hattier, Matson, Belva, & Horovitz, 2011). The percentage of such challenging behaviour amongst children with ASD is relatively higher than is amongst those children with another diagnoses (Hattier, et al., 2011). Around 64.3% to 90% of children with ASD
exhibited challenging behaviour to some degree (Matson, Wilkins, & Macken, 2008; Murphy, Healy, & Leader, 2009). The frequency and intensity of challenging behaviour were also found to be positively related to the severity of ASD (Matson, et al., 2008).

ASD is a life-long disability, and stress within families across the life-cycle results from a variety of factors acting and interacting at the same time (Myers, Mackintosh, & Goin-Kochel, 2009). The nature of ASD means that the impact on family is likely to be complex, variable across different families, and likely to change over the life course.

Under different pressures, the experiences of parents and siblings, and the strategies they use to adjust to having a child with a disability in the family are largely different, as noted by professionals and mental health-care specialists (Gamble & McHale, 1989; Heiman, 2002). Typically developing siblings (TD siblings)\(^2\) adjustment to life in a family with a child with a disability is therefore a research topic in its own right. A substantial body of research has shown that siblings of disabled children are somewhat more susceptible to psychological maladjustment than those of healthy or typically developing children (Petalas et al., 2011; Ross & Cuskelly, 2006). Considering the importance of sibling relations for child development (Dunn, 1983; Lamb, 2014). If those working within health and education can provide TD siblings of disabled children with well-tailored support to adapt to family life, the function of the family might be improved and the potential psychosocial problems of the TD sibling might be reduced. Research in this field is crucial, as it has the potential to more precisely identify the types of support that contribute to the adjustment outcome of TD siblings from different cultures, potentially enabling support to be tailored and delivered more efficiently.

A crucial factor which may influence sibling adjustment is the influence of the culture. The design of this thesis involves cross-cultural comparison, which examines

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\(^2\) Unless specifically clarified, throughout the thesis the abbreviation ‘TD siblings’ refers to typically developing siblings of children with ASD. The abbreviation ‘ASD siblings’ refers to children with ASD.
the families of children with ASD in Taiwan and the UK. It will examine the factors that may influence TD siblings’ adjustment, such as coping, social support and stressful events. So far, the majority of research studies with families with a child with ASD have been selected from Western populations (Hastings & Petalas, 2014; Hesse, Danko, & Budd, 2013; Orsmond, Kuo, & Seltzer, 2009). Although there is some cross-cultural research on families with a disabled child, focusing in particular on parenting strategies (Blacher & McIntyre, 2006; Cho, Singer, & Brenner, 2000; Mcconkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008), research which directly compares the experiences of siblings of children with disabilities from Eastern and Western countries is relatively limited. Little progress has therefore been made in cross-cultural research on the experiences of the siblings of disabled children and on the cultural factors that shape their coping strategies. Furthermore, these studies did not explore whether TD siblings of children with ASD used different types of coping strategies and their adjustment from siblings of children with other disabilities. It could not be expected that the TD sibling of other disabilities to cope in a similar way to the TD siblings of children with ASD. Hence, this thesis explores how culture influences the process of family adjustment to having a child with ASD, and whether there are culturally-specific types of coping, social support, or demographic factors that may influence TD siblings’ adjustment outcome.

In this first chapter, parents’ experience of raising a child with ASD is briefly reviewed to provide an overview of the family dynamic and how it influences parental mental health and stress. Because parents play an important role in shaping TD siblings’ behaviour and adjustment, parental experience and parenting are reviewed first in this thesis. Then, sibling relationships amongst typically development children are introduced to provide background on what a generic relationship is like for the siblings. Followed by that, the main focuses of this thesis, TD siblings’ experience with children with ASD, is discussed.

1.2 Parents’ experience of raising a child with ASD

Parents’ experience of raising a child with ASD has been explored in many studies, focusing on issues such as the degree of stress, parental mental health, family
functioning and relationships, in order to understand their experience better. As recent studies have demonstrated, parents of children with ASD generally experience more anxiety, depression, stress, and strained spousal relationships than those of typical developing children (Ingersoll & Hambrick, 2011; Montes & Halterman, 2007) and those of children with other types of disabilities (Dabrowska & Pisula, 2010; Van Steijn, Oerlemans, Van Aken, Buitelaar, & Rommelse, 2014).

Parental stress has been one of the most frequently explored aspects in the research on families with an ASD child (Mcstay, Trembath, & Dissanayake, 2014; Plumb, 2011; Rao & Beidel, 2009). Parental experiences in handling their child's major difficulties, the challenge of family cohesion, the limit on family activities and the frequency of being stretched beyond their limits, might be expected to have an impact on parental stress. The stress often has a negative impact on parents’ mental health, particularly mothers, and leads to psychological distress such as anxiety, anger, and depression (Herring et al., 2006). It is important to note that most research mainly focuses on mothers’ perspectives and experience rather than on those of other members of the families (Bromley, Hare, Davison, & Emerson, 2004; Duarte, Bordin, Yazigi, & Mooney, 2005; Montes & Halterman, 2007; Tomanik, Harris, & Hawkins, 2004). This reflects the general social assumption that, although there are exceptions, the brunt of caring falls upon mothers, whilst fathers’ roles are likely to be more limited in relation to physical care or household tasks (Holmes & Carr, 1991). Nevertheless, this has been changing for the past decades, with more fathers involved in the child care, and treatment of their children with disability (Cabrera, Tamis-Lemonda, Bradley, Hofferth, & Lamb, 2000; Simmerman, 2001).

The experience of having a child with ASD is not always negative. A wide range of positive changes and transformational outcomes have also been reported by parents of children with ASD. For example, a recent qualitative online survey of 493 parents of children with ASDs found that around 39% of parental experiences can be categorised as having a mixed tone (elements of both negative and positive feeling) in relation to the impact of the diagnosis of the child for the parents, or the families as a whole (Myers, et al., 2009). Positive themes include enriched spiritual and married life, ability to appreciate simple pleasures, a willingness to learn to slow
down the pace, positive family adjustment and support and positive impacts on siblings. The negative themes included exhaustion, marital/couple strain, negative work experiences and siblings being neglected, embarrassed, or hurt. These experiences might relate to various factors, such as demographic variables (i.e. number of children, gender, socio economic status) and psychological variables (i.e. social support, coping strategies and severity of children on the spectrum). These variables are reviewed and discussed in more detail in Chapter 3, in which the factors contributing to parental adjustment and coping are reviewed in detail, with the aim of better understanding how this relates to the experience of siblings. In summation, parental experience of having a child with ASD, despite the stress and negative influence on their mental health, still includes positive experiences, as identified in the qualitative studies.

The next section considers the experiences of siblings of children with ASD, the central focus of this thesis, first reviewing general evidence for the importance of the sibling relationship and then focusing on the sibling relationships when a child has ASD.

1.3 Sibling relationships

The idea that sibling social interaction plays a special part in the development of an individual’s social and moral understanding is of considerable interest (Boer & Dunn, 1992; Dunn, 1988). Several studies indicate that the quality of sibling relationship is associated with children’s social development and psychological well-being (Lamb, 2014; Pike, Coldwell, & Dunn, 2005). However, such development is not necessarily achieved through solely positive sibling interaction: Brody (1998) claimed that it is the balance of prosocial and conflicted interactions in the sibling relationship that can create experiences that are most likely to help children’s social, cognitive, and psychosocial development.

In ‘typical’ families, siblings are the most regular playmates available to each other (Dunn, 1983). Siblings learn from, and imitate each another through daily interactions and activities. Such social interaction within the family helps children to acquire social skills, emotional adjustment and provides them opportunities to
distinguish the self from the other (Lamb, 2014). Through the interaction with siblings, children can therefore develop their specific styles of interacting with others and understand different contexts, and they can subsequently apply these skills to other similar social contexts. This is the first stage of how typically developing individuals learn to adjust to society. However, in some cases, the normative social process may be influenced by children’s disability, such as ASD. Further literature regarding this will be discussed in the next section.

Sibling rivalry also plays an important role in the sibling research literature. The term ‘rivalry’ here refers to a competitive spirit, jealousy or resentment between siblings (Shaffer, 1999). It often starts as soon as the younger brother or sister is born. This rivalry can sometimes continue throughout the preschool and school years, with older siblings often becoming more domineering and aggressive parties while younger ones are more compliant. Older siblings also initiate positions of authority (i.e. being models and directing younger siblings how to respond in different social contexts) and responsibility (i.e. caretaking roles when parents are occupied), while younger siblings imitate their model siblings and learn various values, knowledge and socially acceptable behaviour from them (Cicirelli, 1994; Lamb & Sutton-Smith, 1982).

The relationship of siblings is not static, but changes with life stages. In conjunction with the results from other studies, Buhrmester and Furman (1990) surveyed sibling relationships during middle childhood to adolescence. They found that with advancing age, especially during the adolescence, less companionship, intimacy, and affection are experienced between siblings. Along with the development of children’s abilities, sibling relationships may change. Relationships between typically developing siblings were found to become more egalitarian and less asymmetrical during the adolescent years (Shaffer, 1999). During this period, the older siblings display significantly less nurturance and are less dominant toward their younger siblings, whilst the younger ones require less supervision and guidance from the older ones. As children grow older, the sibling relationship also becomes less intensive (Boer & Dunn, 1992).
Many of these issues identified in TD sibling research, such as relationship changes with age, might reasonably be expected to be seen in families with a child with ASD. In the next section, sibling relationships when a child has ASD and the factors which influence their relationships are briefly reviewed.

1.4 Sibling relationships when a child has ASD

When one of the siblings has a ASD within a family, sibling relationship may not develop in the typical way (Knott, Lewis, & Williams, 2007). Knott, Lewis and Williams (1995) compared the sibling interaction between the siblings and children with ASD, with interactions between siblings and children with Down syndrome. A poorer quality of interaction between siblings was found in the families with a child with ASD. Similar findings have also been indicated in Kaminsky and Dewey’s (2001) research, which investigated sibling relationships between children with ASD, Down syndrome and typically developing children and their siblings aged between 8 and 18 years. The findings indicated that siblings of children with ASD experienced less intimacy and were less likely to show prosocial behaviour and nurturance than the other two comparison groups, while the siblings of children with Down syndrome, on the contrary, were found to experience more closeness and intimacy to their diagnosed siblings. Therefore, children with ASD are less likely to initiate interactions with their TD siblings, which can have an adverse effect on their relationship.

Having a sibling with ASD may be stressful for the TD sibling relationship. Roeyes and Mycke (1995) compared 8-15 year old TD siblings of children with ASD with siblings of children with an intellectual disability, and those without disabled siblings, on their experience and sources of stress. Participants were matched for age, gender (both diagnosed children and the siblings), birth order and age difference. All the siblings filled in questionnaires regarding their relationships with their diagnosed siblings and stressors. Siblings of children with ASD also responded to their knowledge of ASD symptoms. The three groups were basically similar in their ratings of the frequency of stressors associated with their siblings, but the type of stressful events was different in the groups. Children without a disabled sibling reported more verbal aggressive interaction than those with a sibling with intellectual
disability, while children with a sibling with ASD reported experiencing more abnormal and upsetting behaviour than the siblings of children with intellectual disability. From the results of this study, it is clear that it is important to study siblings of children with ASD, rather than studying mixed groups of siblings of children with a variety of disabilities, because the experiences are, to some extent, unique and varied within the group of siblings of children with ASD.

Sibling relationships do not occur in a vacuum, and are likely to be influenced by parents and parenting. One such important factor is differential parenting which refers to siblings within the family experiencing parents’ differential treatment. If the TD siblings were dissatisfied with differential parenting, the quality of the sibling relationship may be compromised (Rivers & Stoneman, 2008). It has been suggested that it is usually not the extent of parental preferential treatment that affects siblings, but rather how they perceive and understand the reasons for differential parenting (Mchale, Updegraff, Jackson-Newsom, Tucker, & Crouter, 2000).

Another factor that may influence sibling relationships is maternal stress. In the early research of Rivers and Stoneman (2003), 50 families of children with ASD participated in a self-report questionnaire study. Information was gained from one of the parents and a TD sibling. The investigation found the quality of siblings’ relationship was negatively affected by parenting stress, and the higher the stress reported by parents, the lower the siblings’ satisfaction with the sibling relationship. These findings were consistent with other research that showed parenting stress would have unfavourable influence on the sibling relationship (Stocker & Youngblade, 1999).

Previous studies have also investigated the roles and responsibilities of TD siblings, and whether these are associated with parental demands and higher expectations due to a compensatory mechanism. Barak-Levy, et al. (2010) found TD siblings participated in extracurricular activities at a significantly lower level compared to children without an ASD sibling. Along with parental expectations, these TD siblings also felt a personal pressure to offer assistance within their homes. As suggested by Barak-Levy, et al. (2010), TD siblings’ feelings of obligation to be responsible and helpful at home may be explained as a special adjustment for these siblings, in which
they put others’ welfare above their own needs. A consistent conclusion of these reports is that TD siblings experience a sense of duty and foresee a taking over of caregiving responsibilities in adulthood (Tozer & Atkin, 2015; Tozer, Atkin, & Wenham, 2013).

Nevertheless, siblings can still benefit from positive interactions with children with ASD. For example, whether from parents’ reports or TD siblings’ self-reports, research has found that despite the limitations of children with ASD in social interaction, positive relationships with their TD siblings were still found and were characterized by less conflict and competitiveness than those of typically developing children (Kaminsky & Dewey, 2001; Knott, et al., 1995; Rivers & Stoneman, 2003). Most interview-based studies found siblings of children with ASD reported they appreciated their ASD siblings’ unique achievements and had gained positive feedback and learnt from their siblings (Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey, & Reilly, 2009a). From the research reviewed above, it is clear that it is important to explore positive, as well as negative, outcomes in sibling research. This might point the way to how families can nurture positive outcomes for siblings.

In Chinese culture, sibling relationships have clear hierarchy, with younger siblings expected to obey and respect their elder siblings (Cicirelli, 1994). It is assumed that if there is a child with disability in the family, this hierarchical relationship may be reversed or replaced, for younger siblings to shoulder the role of older siblings or vice versa (Tseng, Kawabata, & Gau, 2011). Typically developing siblings in a Chinese family need to learn how to meet their parents’ expectations and find a balance between their own wishes and those of their parents. The emotional contradictions involved in both the obligation to take care of their sibling and the need to strive for independence, and how this influences Chinese siblings has not been fully explored, and further research is required to provide more detailed understanding.

The majority of research, whether qualitative or quantitative has similar suggestions: if age-appropriate information and support are provided, TD siblings can benefit from better sibling relationship (Mchale, Sloan, & Simeonsson, 1986; Roeyers & Mycke, 1995). However, what is unclear is whether this information and support
needs to be tailored for children in different cultures and the details of the support provided.

1.5 Limitations of sibling research to date

Generally, previous studies have shown variable findings with regard to the level of impact on the TD siblings in terms of adjustment outcome, sibling relationships and self-concept. The mixed results in the previous literature may be due to lack of sufficient comparative groups, small research samples, lack of control of various demographic variables and inappropriate methods to investigate the research hypothesis (Hodapp, Glidden, & Kaiser, 2005; Stoneman, 2005). With the specific focus on siblings of children with disabilities, Hodapp et al. (2005) reviewed previous research and proposed a number of methodological challenges evident in this field. Firstly, is the issue of research design and participants. Hodapp et al. (2005) point out that it is quite common for research into families of children with disabilities, to have a sample size of around 20 to 50 cases per group. Due to the prevalence of the ASD, it is also a challenge to recruit a reasonably sized group of participants in the family of children with ASD research. This limits in-depth analysis of variables. Thus, it becomes difficult to draw strong conclusions. Furthermore, as Zwaigenbaum et al. (2007) suggested, various variables, such as demographic variables and factors already identified, relating with adjustment outcome, need to be considered along with outcome measures. These variables have been found to in some ways mediate or moderate the outcome measures (Breslau, 1982; Hodapp, et al., 2005; Macks & Reeve, 2007). Moreover, families that participate in the research are often volunteers from service agencies or clinically referred samples. It is believed that the families that seek professional support will be different compared to those less involved families, particularly in relation to the level of support they will experience, which in turn will be related to the family functioning (Hastings, 2003a; Meyer, Ingersoll, & Hambrick, 2011). Together, these methodological issues mean that research in this field may lack the statistical power to identify key relations or may involve potentially unrepresentative samples.

Secondly, Hodapp et al. (2005) stated that some research designs do not have a control group and some use mixed disabilities as contrast reference, or use normative
data. As multi-diagnostic control groups are often not differentiated with diagnostic categories, this may cause difficulties in identifying some significant behaviour of siblings’ adjustment. Since each disability may have a unique impact on each family, different adjustment strategies might be found from family to family with a child with different disabilities or associated symptoms. Therefore, focusing on only one disability, or using a single disability control group in the studies, might offer sufficient evidence to explain the different strategies each family takes (Cuskelly, 1999).

Thirdly, Hodapp, et al (2005) also raised the outcome measurement issue. Over-reliance on parental reporting is a common problem in this area. Research often used parents’ reports as reference to evaluate TD sibling’s adjustment. It is often not clear how TD siblings view themselves and whether this is consistent with their adult informant’s observations. It is possible that different informants have different views of how appropriate or well-adjusted their behaviours are. Hence, if research could include TD siblings’ self-report, it could provide more practical information for the interventions (Hastings & Petalas, 2014).

Similar suggestions were also addressed by Cuskelly (1999), who suggested that some measurement instruments may be more sensitive to differences between groups than others, or more focused on the particular challenges of the sibling group. Moreover, Hodapp, et al. (2005) also suggested balancing views between negative and positive aspects while choosing the measurement outcome required. The majority of the research focuses on the adverse outcomes of having siblings with disability, and relatively less research emphasises positive outcomes. As well as researching the difficulties that children with disability and their families may encounter, it is important to identify the positives of raising a child with a disability, in order to offer even more constructive guidelines for helping these families and their children to adjust better in the future.

Another issue Hodapp, et al. (2005) pointed out is the influence of the disability, especially those linked with a epigenetic factor. For example, it has been suggested that first-order relatives of children with an ASD, including parents and siblings, are at an increased risk for displaying ASD-related traits (Ingersoll & Hambrick, 2011;
Scheeren & Stauder, 2008). This ‘broader autism phenotype’ (BAP) is a sub-clinical set of personality traits in social, cognitive, and behavioural patterns sometimes found in the immediate family (parents and siblings) of children with ASD (Bailey, et al., 1998; Bolton, et al., 1994; Mohammadi & Zarafshan, 2014; Petalas, et al., 2011; Sucksmith, Roth, & Hoekstra, 2011). These related traits may make TD siblings or parents more vulnerable to feelings of anger, frustration and rejection (Constantino et al., 2006; Yoder, Stone, Walden, & Malesa, 2009). Recent research on the BAP emphasizes that epigenetic vulnerability may interact with environmental stress to influence TD sibling and parents’ adjustment outcome and well-being (Orsmond & Seltzer, 2009; Petalas, et al., 2011). Thus, when collecting data from the parents and the TD siblings of children with ASD, the BAP-related traits need to be taken into consideration.

Lastly, Hodapp and colleagues (2005) addressed the importance of cultural issues. How does culture influence the way in which people interpret disability and how they construct their ways of coping? This is important to consider how families with a disabled child are differently supported within different cultures. Additionally, since the majority of the measurements, such as coping and adjustment scale, are established upon values within Western cultures, translated items might have different meanings in the contexts of non-Western cultures. Not only might items get lost in translation, but the concepts themselves might not be appropriate within other cultures. Therefore, whether these questions are being interpreted appropriately by the participants from different cultural backgrounds should be carefully considered. Nevertheless, it is not necessarily the case that researchers must develop entirely different research themes for those from different cultural backgrounds. With similarities and differences in mind, research under a general framework can clarify some significant but different points of view between cultures (Dmitrieva, Chen, Greenberger, & Gil-Rivas, 2004), particularly if these methodological issues are taken into consideration.

In conclusion, as discussed above, the study of siblings of individuals with ASD is still an area requiring further research to clarify the factors that contribute to their adjustment outcome. There are potential benefits for conducting this type of research.
Health professionals and family workers can target the factors that influence TD siblings’ adjustment in the early stages, which might lead to a decrease in the need for social-welfare or intervention. Several limitations and suggestions in relation to research design, participant recruitment, choice of the measurement construct and cultural influence have been discussed in this chapter. Another important factor, which is also emphasised in the present research, is the epigenetic (BAP) level and environmental influences on the TD sibling. In Chapter 3, these epigenetic, environmental stressors and influence of cultures are further discussed.

1.6 This thesis

There are nine chapters in total in this thesis. The first chapter provided an overview, looking at parents’ and siblings’ relationships in the typically developing family and then specifically focused on the siblings of children with ASD. The limitations and the suggestions addressed by the previous research in the families of children with ASD were also discussed. Chapter 2 looks at the cultural context of the present research, including demographic information, family composition and dominant philosophy in Taiwan and the UK. The prevalent attitudes toward disability and views on the causation of disability are also discussed. Chapter 3 looks at TD siblings’ adjustment and coping, based on previous Eastern and Western research. Several factors including demographic and psychological factors are discussed. The model adopted for the present research is also presented, along with a brief review of other research models used in family research.

There are two interlinked studies in this thesis. Chapter 4 explains the general methodology approach first and then focuses on the questionnaire study. The results of the questionnaire data are presented in Chapters 5 and 6, with the former focused on the comparison between Taiwan and the UK, and the latter the variables which predicted TD siblings’ adjustment outcome between the two countries. The results of the first questionnaire study are discussed in Chapter 7, along with the issues that arose from the analyses, which leads to the questions that need to be clarified in the interview study presented in Chapter 8. In this chapter, the approach to analyze the transcriptions is then introduced. Several themes are identified from both countries and are reported side by side to provide a contrast between Taiwan and the UK.
families. The last chapter pulls together the findings from questionnaire and interview studies to discuss the results from the two countries. The limitations and suggestions for the future research are also presented in Chapter 9.
Chapter 2: Cultural Context (Taiwan and the UK)

According to the *Oxford dictionary of English* (2010), a ‘culture’ refers to the customs, attitudes, and social behaviour of a particular group of people or a society. It could also be a set of values that people believe in, or traditions that people follow; therefore, a culture is like the foundation of a society that influences the ways people understand a situation and act. In this sense, people live being influenced by such collective attitudes and behavioural characteristics of their society on a number of different levels.

Apart from the general definitions, there are many different definitions of culture from descriptive, historical, normative, psychological, and structural to epigenetic perspectives. Psychological definitions, which are applied in this thesis, focus on a variety of psychological features (e.g. coping patterns, learning and habits) and how the process of learning these features are a result of the collective customs in a particular group (Berry, Poortinga, Breugelmans, Chasiotis, & Sam, 2011).

Triandis (1996) first proposed the term ‘culture syndrome’ to describe networks of associated features that are prevalent throughout a culture, such as shared attitudes, beliefs, norms, role definitions and values that are organised around a theme. Triandis (1996) also stated that culture syndrome is not unitary, but more multifaceted, according to individuals’ social status and what is relevant to them. Some philosophical traditions and values in a society might not have a direct influence on individuals, but instead an indirect effect by provoking certain beliefs and cognitive appraisals that are more likely to come to mind than they would to others from different cultural backgrounds (Oyserman & Sorensen, 2009). In line with Triandis (1996), a culture can be studied through the analyses of both cultural and individual differences. Therefore, this research mainly explores how the dominant philosophy of the culture influenced peoples’ behaviour, but still considers the individual differences of the research participants. This is especially important for studying the
cases in countries with an ethnically diverse population such as the United Kingdom (UK) or countries with a controversial socio-political status such as Taiwan³.

Rather than covering Eastern culture in a broad sense, this research is focused only on the Chinese cultural context, with a specific focus on Taiwan. The main reason is that I have a Chinese Taiwanese background. There are other reasons why Taiwan has been chosen to represent Chinese culture in the present research. Due to the one-child policy in the People’s Republic of China, the family structure and interactions between family members, especially the parent-child relationship, have been changed significantly (Short, Fengying, Siyuan, & Mingliang, 2001), and the policy means that sibling relationships cannot be readily examined in this country. China’s two special administrative regions - Hong Kong and Macau - have also been excluded since these were the colonies of the British and the Portuguese Empires respectively for a long time, and these two regions are very influenced by the Western cultures in many aspects of daily life, making it more difficult to explore Eastern cultural influences on family and disability.

Although Taiwan was colonised by the Netherlands and Spain and was under Japanese colonial rule for over 50 years until 1945, compared to Hong Kong and Macau, Taiwan still follows most of Han Chinese culture and lifestyles even if Japan’s colonial legacy has shaped some of the customs and mannerisms of the Taiwanese (Brown, 2004). Even though China and Taiwan both have similar features of Chinese values, such as the Confucian ethics, research has found differences in the patterns of parental roles, family relationships and rural-urban development, and different policy context (Ho, 1989). Disability family research findings from China must therefore be interpreted cautiously with regard to the extent to which it reflects the experience of Taiwanese families.

³ Although Taiwan declared itself to be an independent sovereign nation at the end of Chinese civil war, the mainland Chinese government still considers Taiwan to be the territory of the People’s Republic of China. Despite the political differences between Taiwan and mainland China, Taiwanese people still view themselves culturally as Chinese. For simplicity, the word “Chinese” is used in this thesis to refer to Taiwan not only ethnically but also culturally.
Lying off the south eastern coast of mainland Asia, Taiwan is officially known as the Republic of China (ROC). The Republic of China government claimed sovereignty over Taiwan and independence from China in 1949. According to the Taiwanese government report (Council for Economic Planning and Development, 2013), the total land area in Taiwan is about 14,400 square miles and the population is estimated at around 23 million, making it a densely populated country. About 98% of Taiwan's population is of Han Chinese ethnicity and the majority of Taiwanese are adherents of a combination of the moral teachings of Confucianism, Buddhism, and Taoism. About 2.8% of the population are foreign immigrants to Taiwan, including Vietnamese, Indonesian and Japanese (National Immigration Agency, 2015). It therefore offers a relatively simple Chinese cultural background.

The UK was used in the present study as the Western population, again primarily for pragmatic reasons. The United Kingdom of Great Britain and Northern Ireland, is commonly known as the United Kingdom (UK) or Britain. The UK consists of four countries: England, Scotland, Wales, and Northern Ireland (Prime Minister's Office, 2003). Ethnic diversity varies across the UK, including White British (86%), Asian (7.5%), Black/African/Caribbean/Black British (3.4%), multiple ethnic groups (2.2%) and other ethnic group (1%) (Office for National Statistics, 2012a). Furthermore, around 11.3% of the total population are immigrants, for example from Poland, the Caribbean and the Indian subcontinent. The UK therefore has greater diversity within the culture than Taiwan.

The influences of culture are extensive. In the cases of families with a child with disabilities, it can affect the ways that families seek help, approach treatments and resources, the parental coping patterns and the ways of raising children (Holroyd, 2003; Ravindran & Myers, 2011). In the following section, the research literature on Chinese and British family values in general are firstly reviewed as these are likely to play an important role in the life of families with a child with ASD. The discussion is then narrowed down to examine research on families of children with ASD in Western and Chinese culture specifically.
2.1 Family composition and family values in British and Chinese societies

The constitution of ethnicity and family structure have changed massively across the UK over the recent years (Office for National Statistics, 2014b). The 2014 Census report showed that around 60% of families with dependent children in the UK consisted of married couples, or couples in a civil partnership, followed by 25% being lone parent families and 15% were opposite sex cohabiting couple families. Amongst these families, about 46% of UK families had one child, 40% had two children and about 14% had more than three children in the family. The average number of dependent children in the married couple was 1.8 (Office for National Statistics, 2012b). Around 1.1% of households were multi-family households, which also included members who were unrelated or related in some way.

In the Taiwan government’s report (National Statistics, 2002), the core family type - married or civil partner couple family with dependent children - was around 63%, while the lone parent family rate was 6%, less than half that of the UK. The number of parents cohabiting with partners was also lower than in the UK. As for the number of children, nearly half of the families had two children. The average number of children in a family was 2.3, which was higher than the UK. Around 14% of families also lived with their elders or extended family members and this was also much higher than the UK families.

Family values have changed since 1830, and in the twentieth-century British family values and parenting became a recurrent theme of public policy, with neo-liberal policies emphasising family, community, and personal responsibility (Gillies, 2005). Although respect for parents is seen as important, Western family values tend to focus on the autonomy of the child more than Eastern values (Triandis, 2001; Wise & Da Silva, 2007).

The traditional Chinese family is deeply rooted in Confucian and Buddhist values, which emphasise filial piety, familial responsibilities and interdependence (Ho, 1996). Parents teach their children to take responsibility for caring for family members, and to obey and respect their parents so that family harmony can be
maintained (Holroyd, 2003). Traditionally, children are viewed as the possession of parents. In this regard, a high degree of parental intervention on children’s options, such as education or career, is common (Chao & Tseng, 2002; Chen & Uttal, 1988; Wang & Chang, 2010). Sometimes issues as tiny as daily life or as big as marriage are decided by parents (Riley, 1994). Chinese parents would also expect their children to look after and support them in later life in order to ‘repay’ them for their sacrifices and caring (Chao, 1994). Phinney and her colleagues (2000) also found evidence that Chinese parents have stronger expectations of their children’s obligations within the family than do their Western counterparts. Obedience and respect for parental instruction were seen as the performance of filial piety (‘孝顺’) and a key virtue in Chinese culture (Ho, 1996). The process of modernisation and industrialisation has been modifying and eroding the dominance of these values in the Chinese family nowadays, and filial piety is no longer a static concept (Whyte, 2004). However, although the younger generation may not adhere to this core value as much as the previous generations, filial piety is still highly valued and regarded to be fundamental within the society in general (Lin, Zhang, & Harwood, 2004).

Research has shown that there is also a similar hierarchy within Chinese sibling relationships, where younger siblings are taught to obey and respect the older ones, and the older ones are taught to be role models for the younger siblings, and would act like their parents (Cicirelli, 1994). This hierarchy maintains the balance of Chinese family dynamics.

Another asymmetric relation in the Chinese families can be found in the relationship between genders. Traditionally, males dominate social relationships and are the main decision makers within families. Chinese fathers are responsible for economic support and moral instruction. Training children to follow a moral code, on the other hand, is seen as the mother’s responsibility; therefore, she is usually the one who gives up work in order to take care of the children (Chao & Tseng, 2002).

As a famous Chinese saying goes, ‘Children are like white paper’, which means that children are naturally good before being tainted by their environments. Therefore, if
a child displays challenging behaviour or maladjustment, Chinese society would blame his/her parents for being unable to teach their child to follow the norms (Holroyd, 2003; Mak & Kwok, 2010).

Nevertheless, family structures and values have been changing over the past few decades in response to the rapidly changed social and economic milieu. Chinese families, therefore, have been experiencing a shift from the traditional familism toward adapting western lifestyles and social norms due to modernisation and globalisation (Croll, 2006; Faure & Fang, 2008). Despite these changes, composition and values in the Chinese family still cannot be seen as identical to Western families.

2.2 Parenting style

The issue of parenting style is briefly reviewed here. Whilst it is not directly examined within this thesis, parenting style influences the way parents interact with their children and the parent-child relationship, which in turn may impact on the sibling relationship, and is therefore of relevance in understanding how cultural factors shape family relationships. One dominant Western theory of parenting styles is based on Baumrind’s (1971) four child-rearing practices which examine each individual parent’s combination of restrictiveness and nurturance. The four parenting styles are authoritative parenting, authoritarian parenting, permissive parenting and neglectful parenting. Authoritative parenting is high on restrictiveness and nurturance; authoritarian parenting is high on restrictiveness but low on nurturance; permissive parenting is low on restrictiveness, high on nurturance, while neglectful parenting is low on restrictiveness as well as nurturance. Much of the research on Western population has focused on how different parenting practices influence children’s development of character and competence (Eisenberg & Valiente, 2002; Shucksmith, Hendry, & Glendinning, 1995). Among the four parenting styles, authoritative parenting has been suggested to be optimal and found to be the most common in Western society (Baumrind & Thompson, 2002), and has been found helpful in developing socially mature behaviour and for high academic achievements of children (Deković & Janssens, 1992; Steinberg, Dornbusch, & Brown, 1992).
The influence of the culture can also shape parenting approaches. For example, in order to attain the moral goals in the Chinese cultural context, the major task for Chinese parents is to train their offspring to follow the moral codes and to be obedient. In such a case, harsh discipline may be used. The elderly would also advise the next generation on the best manner of raising their offspring. Generally, authoritarian has been shown to be the most common parenting style in Chinese society (Chao & Tseng, 2002).

Chao (1995) compared Chinese and European American parenting, and she found that the parenting of Chinese mothers of TD children greatly emphasises the individual’s relations with others. This reflects Chinese cultural emphasis on the close networks between people. In contrast, the European American mothers would show more emotional expression and support to help the child towards independence.

Although childrearing goals might be shared universally, the expression and parental motivation can differ from one cultural context to another. Chao (1994), therefore, argued that the authoritarian parenting style has different implications in the Chinese context, as it shows parents’ concern and care for their children. The children under authoritarian parenting in Chinese families have been found to have better academic achievement, while the opposite outcome has been shown in Western adolescents (Steinberg, et al., 1992). Accordingly, when comparing any aspects of family life, it would be misleading if sociocultural context is not taken into account. The brief review in this section focuses on typically developing families. The next two sections show how disability is viewed within different culture contexts and how these attitudes might influence the way families cope with the situations and support seeking behaviours.

2.3 Attitudes towards disability

The ways people interact with other members of the society have been inevitably shaped by the cultural milieu. Social perception towards disability can therefore influence policy making, approach of medical treatment and diagnosis of symptoms.
(Brodsky, 1983). Ingstad and Whyte (1995) indicated that recent Western cultural discourse on disability has shown the desirability of equality and feeling of sameness or similarity. Advocating individual’s rights and equality is one of the main principles of social policy in the West.

Within the Chinese culture context, Confucianism produces a set of obligations that underpins the society (Holroyd, 2003). Having a child with a disability is considered to be disgraceful. Therefore, family relationships are very likely to be affected. As one of the most popular religions among Chinese society, Buddhism also plays a significant role in forming the social values. From a Buddhist point of view, everything has a cause and an effect. The philosophy of Buddhism suggests that there is a cycle of suffering and rebirth for each being, and this is known as ‘transmigration’. A life is not just limited to the life in which one exists now, as it continues processing to the next life. After death, the life will move on to another form based on the good and bad things we have done in the current life. What we have done in this life will decide the fate of future existences. This process is defined as ‘Karma’. In Karma, it is believed that the previous existence produces ‘seeds’ which come to fruition in this life or in a later transmigration (Ghosh & Magana, 2009; Keown, 1996). Hence, feeling guilty and responsible for their children’s disability is heightened in the Chinese culture.

Such cultural beliefs might have influenced the attitudes of parents when having a child with disability. Therefore, people who believe in Buddhism may explain the birth of a disabled child as their karma or punishment (Huang, Fried, & Hsu, 2009; Liu, 2004). The attitudes of parents of children with disabilities in Chinese society have been shown to be negative (Huang, Rubin, & Zhang, 1998). Such negative attitudes might also influence their willingness to seek support and the decisions on choosing coping strategies to solve problems. Hence, the beliefs about the cause of disability may have consequences for action and treatment approach (Dale, Jahoda, & Knott, 2006; Mandell & Novak, 2005; Mercer, Creighton, Holden, & Lewis, 2006).
The influence of beliefs about aetiology on subsequent outcome is also seen in Western cultures, although those beliefs may differ. Whether from the attribution of the cause of the disability or attitude toward the disability, this brief discussion provided an overview of the variation between cultures in viewing the disability.

2.4 Social support systems in UK and Taiwan

The social support services available for a child with a disability also impact on family experience and the willingness to seek support. In the first part of this section, the concept of formal and informal sources of social support is introduced and legislation surrounding the support systems in Taiwan and the UK are also presented. The second part of this section discusses support seeking behaviour in Chinese and the Western cultures.

Social support, both formal and informal, has been found to be beneficial to a person’s well-being (Cohen & Wills, 1985) and this is also true of families of children with ASD (Hastings, 2003a; Lin, Orsmond, Coster, & Cohn, 2011). The sources of formal support include parent groups, social clubs, and day care centres, while informal support comes from spouses, immediate and extended family, friends, neighbours, and other parents of children with special needs. These sources of support can be helpful for an individual when dealing with adverse or stressful events.

According to UK Children’s Act (2004), the social services available for families with a disabled child include day care for children with a disability, child minding, financial help for persons with parental responsibility for disabled children and provision of accommodation to rent 4. Furthermore, legislative details differ depending on country. Similar legislation in Scotland also commits to equality for disabled people and emphasises support and protection for children and their families 5. Furthermore, numerous UK charities which have been set up to support families with disabled children (e.g. National Autistic Society /Scottish Autism).

4 http://www.legislation.gov.uk/ukpga/2004/31/contents
5 http://www.gov.scot/Publications/2004/10/20066/44710
In Taiwan the Child Welfare Act, which was revised in 1993, proclaims the importance of early interventions for children with special needs, and the need for professionals to understand the different needs of each family from psychological, social and medical perspectives. Children with a disability are issued a disability card, and with this card they may access social services and medical treatment more easily. For example, there is specifically funded support for TD siblings like free breakfasts and discounted public transportation. Parent associations and welfare foundations also provide formal and informal support for a family with a special-needs child. Nevertheless, this type of charity/group support is not as extensive in Taiwan as in the UK.

Research found that Chinese parents with a disabled child tend to avoid seeking support in the early stages (Holroyd, 2003). They may seek some formal support such as advice from professionals, but seek informal support relatively less in the early years. In addition to differences in the availability of support services in the West and the East, the concepts of support may have different implications in Chinese and UK families. Chinese families think family issues need to remain within the family and thus tend to resolve problems in their own way (Hsu, Chen, Wang, & Sun, 2008). Hence, extended families play a more important role in providing informal support than friends or others for Chinese families (Pearson & Chan, 1993). With the literature reviewed earlier, the feeling of guilt and criticism may make families resistant to seeking out the services of a professional. Not revealing their need of emotional support and keeping a distance from others would limit their access to the service provided. Families with a disabled child in Chinese culture not only face the challenge of the lack of sufficient services but also the need to confront the cultural stereotype of disability. The worry of being stigmatized for having a child with disability can deter families from seeking support (Chiu, Yang, Wong, Li, & Li, 2013; Mak & Kwok, 2010), something which may in turn impact on the experience of siblings.

As for Western parents, Douma, Dekker, and Koot (2006) surveyed the reason why Dutch parents refrained from seeking support, and found that – in contrast to the type of reasons given by Chinese families, as outlined above – in Western families this
was because of parents having evaluated the problems as being temporary or not so serious, or not knowing where resources were available. Furthermore, parent and child characteristics play a role in parents’ decision to seek social support. In the review of the seeking support behaviour of parents of children with ASD, Boyd (2002) found that it is cognitive limitations and behaviour problems of children that lead mothers to pursue social support. If parents are under greater stress, they are also more prone to pursue social support.

As reviewed above, there seems to be cultural difference in availability of social support, perceptions of this support, and motivations for choosing to seek or not seek support. Even within a single country there can be great variation. In a survey of support service utilisation for children and adolescents with intellectual disability in London, Durà-Vilà and Hodes (2009) found there were significant differences between the ethnic groups, with South Asian having a lower service uptake than White British parents. The researchers also found a perception of stigma with service access between the ethnic groups. Similar cultural difference was also found in other cross-cultural research (Shin, 2002). Nevertheless, worrying about being stigmatized is still a concern for parents of children with disability seeking support in Western cultures (Gray, 1993) but it seems to be a stronger influence for Chinese parents.

In terms of the support for TD siblings themselves, only in the past two decades was the importance of support for siblings/carers formally recognised in the Carers (Recognition and Services) Act 1995\(^6\) in the UK. Since then, more support groups have been developed to help siblings of children with special needs, such as leisure activities for TD siblings, charity run help-lines and support groups. For example, a sibling support program (Sibshops), designed to address young siblings’ need for peer support and information has been used as a model for supporting siblings in many Western countries (Conway & Meyer, 2008). In recent years, the development

\(^{6}\) http://www.legislation.gov.uk/ukpga/1995/12/contents
of the support group has become more specific to the disability, due to the diversity of the symptoms and behavioral disturbances of the child\(^7\).

Unfortunately, there is relatively limited support available for TD siblings in Taiwan. I have worked in hospitals and related organizations for child and adolescent children with special needs for 5 years, and it has always been a regret to find that the support for TD siblings is underdeveloped and inadequately addressed. There is one foundation, set up in 2002, which focuses especially on families of children with special needs, providing workshops, support groups and leisure activities for the TD siblings in a limited region. Except for that, only irregular activities are held for the TD siblings depending on the resources available in different organizations.

Whether for support systems or for help-seeking behaviour, differences between Western and the Chinese society are found. Formal support is more readily available in the West and there is more inclination to seek help. In the present research, social support for TD siblings was a key focus and there was exploration of the different sources of formal/informal support available and the importance of this support for the TD siblings surveyed in the questionnaire and in the interview study.

Unlike parents, there is no research identified that discusses whether cultural values influence TD siblings’ help-seeking behaviour. The interview study aimed to provide some insight into these. More detail regarding the impact of support for TD siblings is discussed in Section 3.3.2 and Section 8.3.5.

2.5 Summary and implications for the thesis

In this chapter, how parents endorse the prescribed cultural values and adhere to the social norms when bringing up their children was reviewed. In the case of raising children with a disability, parents’ attitudes can also be influenced by the social perceptions towards the disability. The overview of the support system in Taiwan and the UK also highlights differences in terms of the availability of support services

and how cultural values might influence the support-seeking behaviours of parents, and perhaps also siblings, of children with a disability.

Nevertheless, such cultural specificities in relation to a family’s outcomes and coping styles are rarely taken into primary consideration in studies of families with a child with a disability. Most studies focus mainly on Euro-American cultural contexts, and are limited only to cases within one country (Hodapp, et al., 2005). Not much research has been done in comparing the experiences of families with children with disability in Eastern and Western countries, and even less research has explored the TD siblings’ experiences between two different countries. Thus, this research seeks to fill the gap by investigating cases in both a Chinese population and a Western population. In the following chapter, the literature on siblings’ psychological adjustment, the influence of demographic factors, psychological variables, coping strategies, and social support for siblings of children with a disability in Chinese and Western contexts will be reviewed and compared respectively. The implications of those findings to the present study of siblings of children with ASD from a comparative point of view will then be discussed.
Chapter 3: Sibling Adjustment and Coping – Evidence from Eastern and Western Research

Although the literature on the significant impact on parents when raising a child with ASD, such as social adjustment, coping strategies and stress, has been largely documented (Deepika, 2011; Hall & Graff, 2011; Mak, Ho, & Law, 2007), there are relatively few studies focusing on the impact on siblings. During the period 1993 to 2015, there were around 33 published articles focusing on the siblings of children with ASD that examined their social, emotional, and behavioural adjustment, and these yielded mixed results (Meadan, Stoner, & Angell, 2010; Smith & Elder, 2010). The discrepancy in findings may be due to the conceptual and methodological issues that have already been addressed in Section 1.5, including the challenges in recruiting enough participants. Although limited, there is also some Chinese language research literature regarding siblings of children with ASD, which focuses on sibling relationships, the need for supporting siblings, and on the issues of sibling behavioural problems and adjustment (Gau et al., 2010a; McCabe & Barnes, 2012).

This chapter begins by reviewing previous research into the influence of demographic and psychological variables on siblings’ adjustment within different cultural contexts, as introduced in Section 1.5. Coping strategies among parents and siblings of children with ASD is a significant focus in this thesis. In particular, the coping strategies used by different family members such as parents and siblings, and why coping strategies among those with different cultural backgrounds (i.e. Taiwan and the UK) might be different and how this happens will be discussed. Following this, an outline of the research study and research models is provided.

Due to the limited number of studies conducted in Chinese populations, Western research was used as the main structure for this review and if available, Chinese research was added. Those topics which involved stronger cultural factors, such as psychological variables included both Western and Chinese literatures to provide a clear sense of cultural influence.
3.1 Research on sibling adjustment

The bulk of research into adjustment of siblings of children with ASD seems to be guided by the belief that having a sibling with ASD makes a child vulnerable to psychological maladjustment. Meadan, Stoner, and Angell (2010) reviewed 12 articles published between 1997 and 2008, and concluded that the negative effects of having siblings with ASD included: lower levels of prosocial behaviour, behaviour problems (both internal and external behaviour) and socialisation skills, while positive effects included positive self-concept and good social competence. Findings from the studies to date are not entirely consistent, which may be due, in part, to the limitations of the research as discussed in Section 1.5. It is also important to point out that these studies have found a range of outcomes for siblings, with some siblings experiencing difficulties (though often at sub-clinical levels), while others are not necessarily susceptible to adjustment difficulties.

Relatively less research has been done in the comparison of ASD siblings’ adjustment in different cultural settings. For example, Gau, et al. (2010a), examined the relationship between children with ASD’s behavioural problems, parenting styles and the possible influence on TD siblings in Taiwan, but their research did not further explore which coping strategies employed by family members were associated with better adjustment and whether coping strategies differed from Western populations. Their findings, however, indicated that, as shown in some Western research, siblings of children with ASD were more likely to have emotional/behavioural problems compared to siblings of typically developing children in Taiwan, although the authors did not further discuss what might contribute to or predict TD siblings’ behavioural problems. There is only one Chinese research study into families with a child with ASD which used a Western comparison group, but it focused on mothers of children with ASD in Taiwan (Lin, et al., 2011).

As is the case with research into families with children with special needs more broadly (Lloyd & Hastings, 2008), ASD family research has moved away from looking simply at whether families experience positive or negative outcomes, to looking at which demographic and psychological variables might explain outcome,
via mediation or moderation. ‘Mediation’ can be used to explain the relationship between an independent variable and a dependent variable (Baron & Kenny, 1986). It refers to the degree to which the pathway from an independent variable to a dependent variable goes through a third explanatory variable. To give a specific example, it is now broadly supported by the literature that parents of children with ASD who use more active/positive or problem-focused coping strategies are less likely to have parental distress and more likely to cope well. Here the coping variables have been shown to mediate the relationship between stressor and parental outcome (Abbeduto et al., 2004; Hastings et al., 2005; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). On the other hand, a ‘moderator’ is a variable that influences the direction and/or strength of the relation between an independent variable and a dependent variable (Baron & Kenny, 1986). For example, Hastings and Brown (2002) found that if the children with ASD had a high level of behavioural problems, fathers with high self-efficacy reported less anxiety than those with low self-efficacy. Here, father’s self-efficacy served as a moderator between the children’s behavioural problems and fathers’ anxiety. In the following sections, the possible relationship between variables and the extent of the influence on sibling adjustment is discussed in more detail.

3.2 Influence of demographic factors

Demographic variables have been examined to establish whether they place siblings of children with ASD at greater risk for social, emotional, and scholastic difficulties. These variables include family factors (e.g. SES, family size) and sibling variables (e.g. age, gender, age spacing, and birth order). As mentioned in the earlier section, there have only been two studies looking at TD siblings’ adjustment in the Chinese context (Gau, et al., 2010a; Lin, et al., 2011), both of them provided relatively less focus on the discussion of demographic factors. Hence, the majority of the research reviewed in the following sections is based on Western research; if any, the application of Eastern research is also discussed.
3.2.1 SES

Much discussion of the role of socioeconomic status (SES) is based on its influence on aspects of parenting, but parenting also influences TD siblings’ adjustment. Lower SES has been found to have a potentially strong influence on how families with a child with ASD raise their children compared to other demographic factors (Giallo & Gavidia Payne, 2006; Macks & Reeve, 2007). In Stoneman’s (2005) discussion of research themes it is pointed out that it is possible that some of the negative effects attributed to TD sibling adjustment in previous studies actually were caused by pervasive childhood strains associated with poverty. Parents from different SES and from different living areas bring up their children differently and this might influence how they view things and interact with the environment (Bornstein & Bradley, 2003). Furthermore, SES may moderate the relationship between parental socialisation goals for their children and parenting styles (Spera, 2005).

SES can also influence outcomes for siblings of children with ASD. For example, Macks and Reeve (2007) compared siblings of children with ASD and siblings of typically developing children on their psychosocial and emotional adjustment. The information provided by the parents was compared with that gathered from the siblings themselves. According to Macks and Reeve’s (2007) results, multiple demographic variables including lower SES, having only one TD sibling who is older than the child with ASD, was considered to increase the risk of maladjustment of the TD sibling compared to siblings of typically developing children. As Macks and Reeve (2007) concluded, parental SES along with other demographic factors had more impact on the TD siblings of children with ASD than on siblings of non-disabled children in terms of their psychosocial adjustment outcome.

3.2.2 Family size

If family size is bigger, it might be assumed that this may help to decrease the caretaking burden on the parents themselves. Another explanation for this effect states that, in larger families, parents are less likely to overburden individual siblings with childcare responsibilities and high expectations. Research has supported the finding that siblings who live in families with more than two children are more likely
to be well-adjusted than siblings living in two-child families (Kaminsky & Dewey, 2002; Verte, Roeyers, & Buysse, 2003).

Traditionally, Chinese families were quite big, but nowadays the number of children have been decreasing down to around two children (Cartier, 1995). In Gau and colleagues’ (2010a) research, the families with children with ASD tended to have more children in the household than the families with typically developing children. It is possible that having a child with ASD might influence the parents’ decisions to have more children. However, the influence of family size remains unclear in the Chinese studies.

3.2.3 Age

Another important demographic factor is age of the children. The age of children influences their cognitive ability to perceive and explain experiences and situations around them, including how they interpret the behaviour of the sibling with disability. According to the Piaget’s developmental stage theory and work (Piaget, 1954), children become more capable of abstract thinking as they get older. At an early age, the understanding of the sibling relationship may just rely on the daily experiences such as play or conflict. Although subsequent research offers reinterpretation of Piaget’s findings (Buhrmester & Furman, 1990; Dunn, 1983; Elkind, 1962) it is clear that as children age they develop abstract reasoning and can conserve and think more logically in their mind, which is likely to influence the way in which they perceive and interpret their sibling relationships.

As suggested by Stoneman (2005), sibling role relations of children with disabilities follow a non-normative trajectory, becoming more asymmetrical across time, as the siblings grow older. It is possible that the difference between children with ASD and their TD siblings is greater and more significant with an increase in age.

The influence of TD and ASD siblings’ age, birth order and age spacing have also been linked to TD siblings’ adjustment outcome (Breslau, 1982; Stoneman, 2005). Stoneman (2005) explained the importance of considering the age spacing by using the following example: The experiences of a teenage girl with a sibling with a
disability who is still a toddler are not comparable to those of a teenage girl with a sibling with a disability who is also in their teens. The impact on the TD siblings in the two age groups would be expected to be very different. Siblings with smaller age spacing would have more overlapping life experience together compared to the wider age gap, such as attending the same school or participating in similar out-of-school activities and so on. As for birth order, although previous research has not revealed clear and consistent results, older siblings have sometimes been found to be at increasing risk of having difficulties compared to the younger siblings (Macks & Reeve, 2007; Rodrigue, Geffken, & Morgan, 1993). Chinese families, as was discussed in Section 2.1, value the hierarchy relationship within the family. The older siblings play a leading and modelling role for other siblings and are also expected by their parents to take more responsibility in looking after family members. Unfortunately, there is lack of research considering the influence of birth order within the Chinese family disability research.

In sum, the age of the TD and ASD siblings seems to influence TD siblings’ adjustment in certain aspects. Despite lack of published information regarding the influence of the age in the TD siblings’ adjustment in Chinese populations, it is speculated a similar relationship would be found in Chinese families.

3.2.4 Gender

Typically, it has been found that females siblings are at a greater risk than male siblings for poor adjustment (Mates, 1990). The explanation suggested for this is that girls, in this situation, may be expected to take on additional care responsibilities. However, in recent studies, gender difference in care responsibilities was not so commonly reported compared to research in the early 90s. Differences might instead be more reflective of the differential socialization of women and men which has been reviewed in the earlier section. For example, a few studies identified that female siblings were likely to have a better adjustment outcome, higher levels of social competence or more positive attitude toward siblings relationships than male siblings (Hastings, 2003b; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Mchale & Gamble, 1989; Verte, et al., 2003). While one research study found male siblings
displayed more social skills than female siblings (Quintero & Mcintyre, 2010), most studies tend to find no gender difference in terms of the adjustment outcome (Gold, 1993; Pilowsky, Yirmiya, Doppelt, Gross Tsur, & Shalev, 2004).

Gender not only partially determines outcome, it might also influence the correlates of outcome. Gold’s (1993) research tried to improve several limitations from previous research by including a comparison group of TD children, by obtaining reports from multiple sources and by measuring demographic characteristics (family size, income, ethnicity, parents' education, or sibling age) and linking these to siblings' adjustment outcomes. The results of her research found that siblings of boys with ASD scored higher on the depression measure than siblings of boys without disability. Although no gender differences were found on the analysis of depression scale, the correlates of depression appeared to differ for brothers and sisters of boys with ASD. It was suggested that there may be similar levels of depression among siblings of boys with ASD, but that the factors contributing to depression may differ by gender. However, this research does not provide any possible explanation of how gender difference may affect the siblings.

Even though there are no studies specifically discussing gender effects on siblings of children with ASD in Chinese family, the difference in gender expectation is quite great within the Chinese cultural context. An old saying could support this statement, ‘男主外女主內’ which translated means ‘men should be in charge for the things outside the family, while women are responsible for the household tasks’.

Parents also transfer certain gender-role stereotypes on to their children. Even with economic growth and modernization, gender inequality still exists within Chinese families (Chu & Yu, 2010). The difference in parenting towards sons and daughters might result in stronger gender effects in the Chinese TD siblings than has been shown in Western siblings. Hence, the gender variable needs to be taken into consideration when looking at the TD siblings’ adjustment outcomes in cross-cultural research.
3.2.5 Demographic variables: summary

From the research reviewed here, it is clear that studies usually explore several demographic variables together to determine the influences of the outcome measure rather than just taking one variable into account. However, research into some demographic variables has shown fairly consistent findings, such as SES and family size. Similarly, SES and family size may be influenced reciprocally by parenting stress. Parents who experience high degree of stress may be unwilling or unable to find a job; hence, the unemployment could cause them to have lower SES or force them not to have more children.

Furthermore, the differences in previous research findings may relate to the many methodological challenges in research in this field (see Section 1.5). Due to a large number of demographic factors, which may influence different aspects of the outcome, it is neither straightforward nor easy to ascertain the impact of the variables, particularly without large research samples to clarify the relationships between surveyed variables. Therefore, it is possible that a number of different demographic variables may interact with siblings’ adjustment outcome.

There is relatively less research focused on the discussion of the demographic variables in the Chinese families; preliminary findings have suggested little or no difference compared to other cultural groups or controls. With limited research to provide robust evidence, more research looking at the influence of demographic variables on TD siblings’ adjustment outcome is clearly needed.

In this thesis, multiple demographic variables, including gender of TD siblings and children with ASD, the age spacing and age of siblings, parental SES and family size, were taken into account when examining correlations of TD siblings’ adjustment outcome.

3.3 Influence of psychological variables

The impact of psychological variables that may moderate or mediate adjustment difficulties of siblings of children with ASD has also been studied in Western cultures over a number of years. Indeed, much greater research attention has been
paid to the role of psychological variables than demographic variables in recent years, including factors such as ASD severity, social support, broader autism phenotype (BAP), life events and coping strategies (Hastings, 2003a; Petalas et al., 2012a; Ross & Cuskelly, 2006).

Though some demographic variables are fixed (e.g. family size and gender), it might be possible to adapt other, psychological, variables (e.g. to increase family support and to support the development of appropriate coping strategies) to enhance family experience for siblings. Hence, these flexible psychological variables are a key focus in this thesis. Since the majority of the research on influential psychological variables has mainly focused on the cases in Western countries, this study took a step forward to explore the role of these psychological variables for the experiences of siblings in both a Western and an Eastern country.

3.3.1 ASD severity and challenging behaviours

The level of disability is believed to influence the amount of time spent by parents taking care of a child with disability: the higher level of the disability, the more time parents need to devote to the care of the child (Crowe & Florez, 2006; Floyd & Gallagher, 1997). This implies the parents have less time to spend on other children without disability. When intense support is required, the negative impact on caregivers’ psychological and physical health can be significant (Raina et al., 2005).

Complexity and severity of behavioural disturbances are more easily found amongst children with ASD than those with other developmental disorders (Blacher & McIntyre, 2006; Dabrowska & Pisula, 2010; Griffith, Hastings, Nash, & Hill, 2010). Research indicates that mental health of family members is directly associated with the severity of the child’s autistic symptoms (Benson, 2006; Gadow, Devincent, Pomeroy, & Azizian, 2004; Hastings, 2003a) or challenging behaviour problems of the children with ASD (Hastings & Brown, 2002; Lecavalier, Leone, & Wiltz, 2006).

The behaviour problems of children with ASD and parents’ stress have been shown to reciprocally affect each other. When parents are under stress and adopt certain
negative parenting behaviours, the children’s behaviour problems can be reinforced (Hastings, 2002; Osborne, Mchugh, Saunders, & Reed, 2008).

For the TD siblings, the severity of symptoms of children with ASD or their challenging behaviour has also consistently been found as a strong predictor for TD siblings’ psychological well-being (Benson & Karlof, 2008b; Lyons, Leon, Roecker Phelps, & Dunleavy, 2010; Meyer, et al., 2011). Research also found that the more severe the social and emotional difficulties of the child with ASD, the less they are able to play, communicate and interact positively with TD siblings; hence, the TD sibling’s socialisation skills and adjustment can be significantly affected (Pilowsky, et al., 2004). Indeed, symptom severity of the child with ASD and their challenging behaviour impacts on the TD sibling in a number of ways. For example, in order to catch their parents’ attention, TD siblings of children with more severe ASD may misbehave (Macks & Reeve, 2007).

Although Western studies have shown that symptom severity and challenging behaviour of children with ASD affects TD siblings’ adjustment in various ways, there is a complete lack of published information about Chinese populations. Although some similarities might be expected Western and Chinese families, the precise relations between ASD severity and siblings’ adjustment in Chinese families therefore remains unclear.

### 3.3.2 Social support

Social support from a variety of sources or networks might be perceived as a protective or stress-buffering role in the development of maladjustment (Jackson & Warren, 2000). The role of formal and informal social support in relation to parental well-being has been well studied, with the focus primarily on perceived helpfulness and it is said the degree to which social support is perceived as available plays a larger role in determining individual stress levels than the actual support provided (Bromley, Hare, Davison, & Emerson, 2004; Gill & Harris, 1991; Ingersoll & Hambrick, 2011; Lasgaard, Nielsen, Eriksen, & Goossens, 2010). In terms of the informal support for parents in the Western study, most research into the informal support emphasizes the relationship with the spouse, the extended family and friends
met through support groups (Hastings & Johnson, 2001; Luther, Canham, & Cureton, 2005; Mcconkey, et al., 2008; Raif & Rimmerman, 1993; Tunali & Power, 2002; Twoy, Connolly, & Novak, 2007). The links between informal support and positive outcomes were found in these studies.

A few studies were identified that explored the relationship between social support and outcome on parents with ASD in Taiwan (Lin, Tsai, & Chang, 2008; Shu & Lung, 2005). The research result was similar to that of Western research: social support eased caregiver stress and increased parental well-being.

One study examined cultural differences in the function of social support in mothers of children with ASD. Lin and colleagues (2011) studied the role of social support and coping in Taiwanese and United States (U.S.) families of children with ASD by using questionnaires. The research found there was no difference regarding the amount of social support mothers received in the two countries. Yet when social support and coping strategies were considered together, they were found to increase family adaptability (ability to change its roles and relationships in response to stress) in the U.S. families but not in the Taiwanese. Despite being unable to provide the definitive explanation for this, it may be that the support provided in the two countries differed substantially in terms of quality and efficiency.

The majority of articles discussing family refer to services for parents and the children with ASD. Relatively few studies have evaluated the availability and the role of social resources of supporting TD siblings. Social support for siblings may operate directly and indirectly. Firstly, sibling’s adjustment owes much to parents’ support and attitude; therefore, if parents receive the support that lowers stress levels, siblings can also benefit (Benson & Karlof, 2008a; Dyson, 1989; Hastings, 2003a). Thus, this kind of indirect support from social resources available to parents has been suggested as functioning as a moderator of the impact of ASD severity on siblings’ adjustment (Hastings, 2003a). Secondly, previous studies have evaluated the impact of the social support that TD siblings have received directly. Direct formal social

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8 Authors did not clarify whether they measured formal or informal support.
support for siblings, including support groups such as Sibshops (Meyer, 1994) or intervention programmes (Tsao, Davenport, & Schmiege, 2012), has also shown to construct siblings’ positive feelings toward the child with ASD and enhance their knowledge of ASD; with such support, the siblings may acquire appropriate coping strategies and positive attitude toward their diagnosed siblings so as to build a long-term progressive relationship with their siblings (Conway & Meyer, 2008; Tsao, et al., 2012). However, whilst parents or health professionals can provide the support to TD siblings, whether to receive or use the support still depends on the willingness of the siblings. It is unclear which siblings seek/obtain support or which siblings benefit from it. This is further explored in the present interview study.

As for informal support, Kaminsky and Dewey (2002) investigated sibling relationships of children with ASD compared to children with Down syndrome and siblings of typically developing children. A higher level of the informal social support was associated with the better adjustment outcome for siblings of children with ASD. Specifically, support from the classmates was associated with fewer academic problems and less loneliness in siblings of children with ASD.

As in the review of support for siblings in the Chinese culture, limited resources are available (see Section 2.4), and these are generally targeted at the parents or children with disabilities. Hence, there is lack of research looking at the support for TD siblings. It is possible that the support for TD siblings might vary within the cultural context, as might their tendency to seek out social support; there may also be differences in the extent to which children benefit from support, given the various differences between Western and Chinese culture.

3.3.3 Broader autism phenotype

The behaviour and traits that are conceptually similar to the core ASD symptom domains but not associated with disability or diagnosis have been referred to as the ‘broader autism phenotype (BAP)’ (Folstein & Rutter, 1977). An individual diagnosed with ASD is likely to show high levels of BAP traits, but the reverse is not necessarily true. Research has found that siblings of children with ASD are more likely to have BAP-related difficulties compared to children without an ASD
epigenetic risk factor in their families. Concordance rates for monozygotic twins range from 60% to 82% (Folstein & Rutter, 1977) and the reoccurrence risk of another child diagnosis with ASD in the families was around 10.9% (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010). It was estimated that between 12% to 20% of the non-autistic diagnosis siblings exhibit subclinical traits in social impairment and developmental language abnormalities (Rotatori & Deisinger, 2015).

Although these phenotypic features may be below the diagnostic threshold, they may still have an impact on early development and learning of children with ASD. Multiple studies have found that siblings of children with ASD are more likely to have subtle cognitive communication skills (Ben-Yizhak et al., 2011; Gamliel, Yirmiya, Jaffe, Manor, & Sigman, 2009), academic, and social interaction deficits (Constantino, et al., 2006; Yoder, et al., 2009) or to exhibit neurocognitive impairments (Dawson et al., 2002) compared to siblings of typically developing children. Barak-Levy, Goldstein, & Weinstock (2010), used self-reports from parents and siblings of child with ASD and compared them to those of families with typically developing children. The survey revealed that TD siblings of children with ASD participated less in activities, and had poorer social relations and school performance. Barak-Levy and colleagues (2010) reported similar findings. As suggested by them, this genetically-based pattern may lead TD siblings to be more internalized and introverted and less active than other children. However, it also might be more difficult to have social relations because of the child with ASD at home.

Previous research has found that brothers of children with ASD have more behavioural adjustment problems (Hastings, 2003b; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009b). This perhaps suggests that the extended phenotype of ASD might be more common in boys than girls. This is supported in the research that looks at BAP level in the general population, with males scoring significantly higher than females (Ruzich et al., 2015).

In terms of parents, for example, Ingersoll and Hambrick (2011) investigated parents of children with ASD in the United States by looking at the relationship between the severity of the ASD children and the BAP-traits in the parent, as well as parental stress and depression. They found that both the symptom severity of children and
parent BAP were positively correlated with parenting stress and depression. In addition, parents who had more BAP-characteristics used maladaptive coping strategies more, and adaptive coping ones less, than those who had lower BAP. Similar findings were reported by Murphy et al. (2000), and the reasons for this are still unclear. It also possible that these BAP related traits make TD siblings or parents more vulnerable to experiencing feelings of anger, frustration and rejection (Constantino, et al., 2006; Yoder, et al., 2009). The BAP-related traits may also affect parents’ use of social support, with parents with a higher degree of BAP reporting less social support (Ingersoll & Hambrick, 2011).

Recent research has begun to highlight this possible bias when using parents as the main information provider, because of the personality traits found in the research of families of children with ASD (Ingersoll & Hambrick, 2011; Meyer, et al., 2011). This kind of BAP traits might make parents of children with ASD more sensitive to negative information and lead to the reporting bias of their children’s adjustment outcome.

Due to the increasing number of research studies reporting BAP-related traits in siblings or parents, research has now begun to shift to a more integrated biological-genetic and environmental-family approach to study sibling adjustment. Bauminger and Yirmiya (2001) first proposed a diathesis-stress model for research with siblings of children with ASD. They suggested that this model might account for a variation in sibling functioning in families of individuals with ASD, with the epigenetic vulnerability (diathesis) interacting with environmental stress to influence sibling outcomes. This model takes into account both the epigenetic and environmental influences operating in siblings of individuals with ASD. Orsmond and Seltzer (2009) adopted this model to explore how epigenetic vulnerabilities associated with ASD and environmental stress impact on siblings' well-being. These researchers found that adolescent siblings who had a higher number of BAP characteristics and experienced a greater number of stressful life events, reported elevated depressive and anxiety symptoms. Similar findings based on the diathesis-stress model were reported by Petalas et al. (2012a), revealing that the influence of ASD child behaviour problems on sibling adjustment was moderated by the TD siblings’ BAP traits. The result of
their research supported the use of diathesis-stress model where epigenetic factor (BAP traits) interacted with environmental factors.

As with other siblings’ research, this research faced similar challenges around the use of parents as the main information provider. Whilst it is possible that the presence of BAP traits in the parents may influence their reporting of sibling outcomes, at present there is no reliable self-report measure of BAP for siblings. It is therefore difficult to get around this problem. The question is whether there are other factors influenced by parental BAP traits which might play a fundamental role in determining the experience of stress by parents of children with ASD and their perceptions of their children’s behaviours.

Generally, BAP research to date emphasises how epigenetic vulnerability and environmental stress influence siblings and parents psychosocial outcomes. However, further research still needs to be done to investigate how exactly these biological (BAP-trait) factors and environmental (culture, demographic factors, stressful events), are associated with coping, support-seeking, and ultimately adjustment in TD siblings in both Western and Chinese societies. By doing so, health professionals may better understand what kind of support is important and sufficient for siblings of children with ASD within different culture backgrounds.

3.3.4 Life events and stress

In studies of the general population, negative and undesirable life events have significant impacts on a range of psychopathology and impaired functioning in youth (Luhmann, Hofmann, Eid, & Lucas, 2012; Marum, Clench-Aas, Nes, & Raanaas, 2013). However, life events are not always negative, and research has found that positive life events and social support play a predictive role in developing children’s adaptive behaviour (Jackson & Warren, 2000). In addition, positive life events, social support and adaptive behaviour come along as a cycle: the development of adaptive behaviour and positive interactions with others and society could lead to more positive experiences and life events. These positive life experiences would in turn encourage more adaptive behaviour (Jackson & Warren, 2000).
In fact, outcome is determined more by how an individual perceives and interprets that event (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Luhmann, et al., 2012). Thus, the ways in which an individual views and appraises situations become essential components of life events. The appraisal of life events has been suggested to have a significance influence on children’s behaviour and adjustment in the general populations (Jackson & Warren, 2000).

The impact of stressful life events has been found to interact with other psychological variables to contribute to adjustment in families with a child with ASD. For example, in Orsmond and Seltzer’s (2009) research, if TD siblings had higher level of stressful life events in the past year, their BAP level was found to relate with their emotional disturbance. Furthermore, research on families of children with ASD which has adopted the Double ABCX Model of Family Adaptation (McCubbin & Sussman, 1983) (this model is discussed in more detail in Section 3.5.2) emphasises life events as one of the ‘pile-up demands’ in the family.

The influence of positive life events is less well addressed in the family of children with ASD research. As Lickenbrock, Ekas, and Whitman (2011) and Hodapp, et al. (2005) suggested, the research of family of children with ASD should be balanced between the positive and negative aspects of surveyed concepts, which is also an emphasis of the present research. The positive life event along with social support has found to attenuate the impact of the stress in the general populations (Cohen & Hoberman, 1983; Jackson & Warren, 2000). Smith and colleagues (2010) also found positive events were related to a positive effect in mothers of children with ASD. However, whether positive life events also have a similar buffering function on TD siblings is still unclear. Furthermore, the influence of the life events, whether positive or negative, on Chinese families still needs to be established.

3.4 Coping strategies

Coping is one of the main areas of focus in the present research. Previous research has found that certain types of coping could buffer the influence between stress and adjustment outcome (Aldwin & Revenson, 1987; Compas, 1987; Folkman, 2013), and this has also been found in families of children with ASD (Dunn, Burbine,
Bowers, & Tantleff-Dunn, 2001; Hall, 2012; Ross & Cuskelly, 2006). Hence, if research could identify which types of coping contribute to TD siblings’ adjustment, interventions could be designed to be more systematic.

Firstly, the definition and theory of the coping in general is introduced, and then the discussion focuses on the research of the coping in the family of children with ASD. Secondly, the Double ABCX model which integrates coping as the core component and how the model used to predict family outcome is also discussed in the following section.

3.4.1 Introduction to coping styles

Coping is defined as a kind of dynamic effort in which individuals use internal and external resources to ease the demand that burdens or overwhelms them (Folkman, et al., 1986). There are different ways of categorising coping strategies. In order to prevent confusion, the coping strategies here refer to a specific coping approach (e.g. concentrate effort on doing something about it, or making a plan of action, etc.), while coping styles (e.g. problem-focused coping style, emotion-focused coping style) refer to a group of similar coping strategies. Western researchers have generally dichotomized coping styles into problem-focused versus emotion-focused, active versus avoidance, and functional versus dysfunctional coping (Holahan & Moos, 1987; Lazarus & Folkman, 1984; Seiffge-Krenke, 1993). These three dichotomies are explored separately in order to consider their real-world relevance. Another dual axis model of coping, which considers social context in relation to coping strategy, is discussed along with the Chinese coping concepts.

Lazarus and Folkman (1984) devised the well-known approach to category coping into two styles: problem-focused and emotion-focused coping, based on empirical research. Problem-focused coping style refers to the strategies that attempt to change the nature of the problem in order to cope with a situation. Examples of problem-focused coping style include problem-solving and seeking advice and support from others. Emotion-focused coping style, on the other hand, refers to the coping activities that are designed to distract the attention of the individual affected by a stressful situation, such as avoiding the stressful situation, denial, and engaging in
ruminating. In the family of children with disability, research has identified emotion-focused coping styles being positively correlated with higher parental stress and mental health, while problem-focused coping styles being negatively correlated with those outcomes in studies of samples of parents of children with disabilities, including ASD (Abbeduto, et al., 2004; Dabrowska & Pisula, 2010; Dunn, et al., 2001; Smith, et al., 2008).

Such research appears to suggest that the problem-focused coping style is more adaptive than the emotion-focused one. However, caution is required in this interpretation. Firstly, such broad categorisation of coping strategies into different coping styles has been modified, as this may cause key findings to be overgeneralised and unfocused (Lazarus, 1996). As Lazarus (2000) clarified, even though the concepts of the problem-focused and emotion-focused styles are distinguishable, these two coping styles are not mutually exclusive. People used both styles when dealing with specific stressful events. Furthermore, not all problem-focused styles are adaptive (e.g. quitting one’s job is a problem-focused style, but it does not always lead to the best outcomes), and not all emotion-focused styles are maladaptive (e.g. attempting to solve a problem with a more positive attitude can also be adaptive). Secondly, coping is not static, and it may be that the ability to move flexibly between different coping style is as important as the particular strategy chosen (Folkman & Lazarus, 1980). Thirdly, such categorisation does not take account of personal and social contexts. The efficacy of a strategy may vary from person to person, as it is based on one’s characteristics, age or gender (Gray, 2003; Hobfoll, Dunahoo, Ben-Porath, & Monnier, 1994). Efficacy of strategy may also vary in accordance with different situations (Lazarus, 1999). For example, strategies that are beneficial for those facing stress at work may not be beneficial for mothers of children with ASD. Finally, efficacy and meaning of coping may vary according to different cultural contexts (Chao, 2011; Hsu, et al., 2008; Siu, Spector, Cooper, Lu, & Yu, 2002; Wang, Michaels, & Day, 2011). It is therefore important to take a more nuanced approach to the examination of coping styles; examining individual differences of study participants (such as culture, demographic characteristics, age, or severity of ASD), and exploring how these are related to the efficacy of a coping style.
As suggested by Holahan and Moos (1987), emotion-focused coping aims to regulate one’s emotions. Various emotion-focused strategies can be considered as either active or avoidant. Active coping strategy means individuals try to confront or change the stress itself, while avoidance coping refers to denying or avoiding the stress. The avoidance emotion coping style, is considered non-adaptive and has been subsequently being linked to poor adjustment such as negative mood states, whilst an active coping style is associated with a decrease in negative mood states across a wide range of medical conditions (Herman-Stabl, Stemmler, & Petersen, 1995; Taylor & Stanton, 2007); such findings also apply to the coping styles used by parents of children with ASD (Dunn, et al., 2001; Hastings, et al., 2005).

The third dichotomy of coping styles has been classified as functional or dysfunctional. According to Seiffge-Krenke (1993), functional coping includes using active support-seeking to manage problems, taking concrete action or internal reflection of possible solutions, while dysfunctional coping refers to the characteristics that result in being unable to solve problems immediately (i.e withdrawing from problems and focusing on the control of feelings). According to Seiffge-Krenke (1993) functional coping is similar to the concepts of problem-focused coping, whereas dysfunctional coping includes the control of feeling, which might also sometimes serve an important function. However, the naming of this coping dichotomy is confusing. What might be functional for one person might not be functional for another. With the ambiguous definition and overlapping concepts with another coping dichotomy, this approach was not adopted in the present research.

In addition to the categorisation of coping strategies, another important issue raised from the literature is that the strategies for coping change with time and age. As Lazarus (1996) surveyed in the general population, young adults were found to employ more problem-focused coping style while middle-aged adults used more emotion-focused coping style. With the progress of the different life stages, people use different approaches to deal with things which they think that best meet their needs and situations (Aldwin, Sutton, Chiara, & Spiro, 1996). This shifting of the coping style was also found in the parents of children with ASD, with changes from
problem-focused towards emotion-focused means of coping (Gray, 2006). This is discussed in more detail in Section 3.4.2. Hence, it is important to discuss whether TD siblings cope differently according to their age. These will be addressed further in the analysis sections.

The final issue which needs to be addressed here is that the majority of scales used to evaluate the coping style are mainly established in Western societies. As Hsu and colleagues (2008) suggested, using the scales that relate to cultural/social contexts would help to depict the coping patterns within the Chinese context more explicitly. Chinese culture emphasises reframing one’s way of thinking and adjusting oneself to the environment in order to achieve well-being, while these are regarded as ‘passive’ coping strategies in the Western cultural context (Cheng, Lo, & Chio, 2010; Twoy, et al., 2007). Thus, coping strategies used in the Chinese cultural context are different from those used by the Western counterparts, since Chinese people may not choose the strategies that are more likely to disrupt interpersonal harmony (Hsu, et al., 2008). Cross-cultural research in the general population found that Chinese people are more inclined to use avoidant or emotion-focused coping than their Western counterparts (Cheng, et al., 2010; Maxwell & Siu, 2008).

Within Confucian-based Chinese society, the philosophy also emphasizes the virtue of forbearance (忍, ren), which encourages Chinese people to endure stress and reframe thoughts, because these distressing and stressful experiences are a kind of training to enhance individuals’ inner strength (Cheng, et al., 2010). This coping strategy can also be found in Chinese children when dealing with arguments and conflicts with their peers (Xu, Farver, Chang, Yu, & Zhang, 2006). This coping philosophy involves a sense of concern for others and is linked to the fulfillment of one’s social role.

As Cheng, Lo, and Chio (2010) discuss, the adoption of forbearance, defined as passive or avoidant coping style in the Western culture, as a coping strategy in the Chinese culture, actually helps Chinese people to gain control indirectly through changing thoughts or behaviours to fit the environment. Hence, taking no active actions to deal with problems, means individuals follow the flow of nature and
vicissitudes of the environment. To avoid confrontations and retain the harmony of groups, this passive or avoidant coping seems more beneficial to the Chinese people. As such, the interactions and connections with others are usually considered as a priority in the process of decision making, and thus inform which coping strategies are applied. Passive or avoidant coping actually fits the Chinese philosophy and maintain the interpersonal relationships more than their Western counterparts. Nevertheless, individual differences still exist within the cultural context. Not all the Chinese people would stress interpersonal harmony, although the majority of people are still influenced by these cultural concepts (Triandis, 1995). The distinctive cultural values emphasized in Chinese and Western cultures may foster a preference for some coping strategies over others (Xu, et al., 2006). Further research examining the relation between social contexts and coping strategies is needed.

Adopting the concepts of Hobfoll et al.’s (1994) dual axis model of coping, Hsu, et al. (2008) proposed that ‘active-prosocial’ and ‘passive-prosocial’ coping can reflect Chinese values better than other coping mentioned in the dominant Western research. Prosocial coping is defined as a behaviour when one thinks about the effect of coping on others and emphasises the social consequences. It could be also active or passive. Active-prosocial coping (e.g. ‘I share my responsibilities with relevant people and face problems together’) as defined by Hsu, et al. (2008) is a behaviour when one consciously considers others’ welfare while dealing with problems. Passive-prosocial coping (e.g. ‘I superficially accommodate the other person and privately ignore this matter as much as possible’) however, is used in order to comply with certain reasons or norms, which other people might not agree with. That this latter strategy is preferred within Chinese society reflects its traditional value of prioritising the harmony of a group or community before an individual. Whilst both active-prosocial and passive-prosocial, involve prioritization of others, the former aims to have benefits for all and thus defines as ‘active’, whilst the latter may involve compliance to conform to another’s needs and is seen as ‘passive’. Hence, interpersonal relationships are integral to Chinese conceptions when adopting these coping strategies.

Summarizing the above, whether in Western or Chinese research, coping can be defined through action and attitude. Furthermore, problem-focused and emotion-
focused coping is a dynamic process and changes with time. While the influence of the cultural context has risen from the literature, researchers have turned their attention to how the ways of coping with stress are associated with cultural values. The use of active and avoidant coping might have different interpretations in Western and the Chinese families. Furthermore, when coping with a specific situation like raising a child with disability, it has a fundamental difference and challenges compared to coping in general. It is unclear whether certain coping styles are effective in the context of a family with a child with disability. In the next section, the research of coping in families of children with ASD is reviewed.

3.4.2 Coping style of parents of children with ASD

Research in parental coping amongst Western families has been well accumulated; however, research in siblings’ coping, even in Western families, is relatively less than research into parents’ coping. To address this gap, parents’ coping patterns are reviewed first to better understand how siblings’ coping styles are formed and influenced by their parents.

There are numerous coping measurements that have been used in this previous research, but they do not always match the coping dichotomy concepts discussed earlier. Hence, the dichotomy of the coping is based on the information provided by the authors. Furthermore, studies have found the factor structure of the same coping measurement can sometimes be slightly different, even though the same coping scale with similar participants is used. These issues are also addressed here.

In the research of coping styles among ASD families in the Western population, Dunn, Burbine, Bowers and Tantleff-Dunn (2001) have examined the relationship between coping styles and adjustment outcomes among parents of children with ASD. They indicated that a few coping strategies, such as escape-avoidance and distancing (both categorised as emotion-focused coping) were found to be associated with negative outcomes. Failure to employ positive reappraisal (an emotion-focused coping) and confrontive coping (a problem-focused coping) was shown to correspond to parental depression, social isolation, and spousal relationship problems.
Again, this supports the view that emotion-focused coping is not always related to negative outcomes.

In Hastings and colleagues’ (2005) research, four predominant coping styles were reported in the parents of children with ASD, in clusters somewhat different from those previously discussed here: active avoidance coping (i.e. active attempts to avoid the stressor or escape from its effects: this is closely linked to emotion-focused coping), problem-focused coping, positive coping (includes humour and positive reframing), and religious/denial coping, by using the Brief COPE questionnaire (Carver, 1997) on 135 parents of children with ASD aged 8-17. Parents of children with ASD who utilized escape-avoidance strategies were subsequently found to have poorer adjustment while those used positive coping showed decreases in negative mood and adjusted better.

Similar research conducted by Benson (2010), using the Brief COPE scale with 113 mothers of children with ASD aged 6–9 revealed four different coping dimensions: engagement coping (similar to problem-focused coping, i.e. use of instrument support, active coping, planning, and use of emotional support), distraction coping (i.e. discharge and modulation of emotion), disengagement coping (i.e. withdrawal from the stressor), and cognitive reframing coping (i.e. acceptance, positive restructuring, and use of religious coping). The difference in factor structure from Hastings et al. (2005) may be because of difference in age or symptom severity of the children with ASD.

In the research of Sivberg (2002), parents with a child with ASD were found to adopt distancing and escape coping more frequently than families of children without disability. This may reflect that some parents felt unable to change the existing situation. Due to the complex nature of the autism-related behaviour, the parents of children with ASD need to be flexible in choosing coping strategies in order to meet the needs of their children. In addition, as Smith et al. (2008) suggest, some coping styles may be functional at some points but may not be as effective as they used to be with the changing of the life-cycle.
Gray’s (2002) longitudinal research also showed that the coping responses of parents of children with ASD change over the time. When the children were very young, parents would use more formal support from the treatment providers (one of the problem-focused coping style) along with religious and social withdrawal coping style. Ten years later, Gray (2006) found that the parents used smaller numbers of different coping strategies and had shifted from problem-focused towards the emotion-focused coping. Fewer parents coped through reliance on service providers or family support, and relatively more parents coped through their religious faith and other emotion-focused strategies. It is possible that parents gradually develop their own effective coping skills in order to best fit their situations, and presumably the “most effective” coping strategy changes, as the situation changes over time.

There are only two studies that investigate Chinese parents of children with ASD regarding their coping styles and neither of them involved TD siblings. Wang, Michaels, and Day (2011) focuses on families of children with ASD and with other disabilities. Parents of children with ASD were found to use more planning (a problem-focused style) than parents of children with other developmental disabilities. In Wong and colleagues’ research (2014) of parents of children with ASD, the strategies that were used most frequently were the constructive strategies, and the ones that were applied most infrequently were the confrontational strategies. As Wong et al. note, these two coping strategies are difficult to map onto the cluster of coping styles developed within the Western societies, again emphasising that that cultural values, belief and norms might affect the coping styles of parents of children with some specific disabilities (Wong & Wong, 2006).

In terms of comparing cases from different cultural backgrounds, only one cross-cultural study to date explores how cultural values influences coping in parents of children with ASD. Lin, Ormond, Coster and Cohn (2011) invited 76 Taiwanese mothers and 325 American mothers who all have a child with ASD aged 10-31 to participate in a survey. They found that Taiwanese mothers reported using the problem-focused and the emotion-focused coping styles more often than their American counterparts. In the Taiwanese cases, those families who reported using
problem-focused coping were found to have less depressive and emotional experience within the family, in which researchers suggested the problem-focused coping may act as a protective factor to the Taiwanese families, but this was not applicable to the American families.

Despite this cross-cultural research successfully recruiting a reasonable size of participants from both countries, there are still some key elements needed to address. Firstly, the coping measurement used was the COPE (Carver, Scheier, & Weintraub, 1989) which was developed based on the Western coping study. The inconsistency of the coping results found in the Taiwanese family may be due to lack of the consideration of the Chinese values in term of the coping. Secondly, this research only relied on mothers’ report on family outcome: family adaptability and cohesion. As have discussed regarding TD siblings in this chapter, the adjustment of the TD siblings is usually underestimated and relies too much on parents’ report. Without examining TD siblings directly or other family members, this research would be limited to parents’ perspectives.

3.4.3 Coping style of siblings of children with ASD

Parental coping has been found to have an influence on children’s coping, through modelling, coaching and adjusting to their children’s characteristics (Kurtz, 1996; Power, 2004). There have been a few studies focusing on siblings’ coping and how it relates to the adjustment outcome. In the early years, Roeyers and Mycke (1995) assessed siblings of ASD, intellectual disability, and typically developing children in terms of sibling relationships, stressors and coping strategies. The siblings of the ASD group was also assessed in their knowledge of ASD. Siblings of children with ASD were found to use more ‘other-directed cognitions’ (e.g. blaming another person) coping than siblings of children with intellectual disability. It is worth noting that the instructions with the coping measurement in this study asked siblings what they usually do or think when their diagnosed siblings made them mad. This situation-specific coping mechanism would be different compared to the coping strategy used to deal with having a brother or sister with ASD in general. Another study, conducted by Ross and Cuskelly (2006) recruited 25 TD siblings aged 8-15 years in the questionnaire survey, more than half of whom were younger than their
ASD siblings. The advantage of this research was that used TD siblings’ self-report on their coping strategies and assessed their knowledge of their sibling’s disorder. However, the evaluation of the TD siblings’ adjustment solely relied on the parents’ report. The findings revealed that TD siblings’ adjustment was not associated with either their coping strategies or the knowledge of ASD. Nearly half of the TD siblings who were rated by their parents to have adjustment difficulties fell in the borderline or abnormal range based on the Child Behaviour Checklist (CBCL; Achenbach, 1991). It would have been useful if this research had also gathered the information directly from TD siblings to understand how they evaluate themselves as opposed to their parents’ evaluations.

Furthermore, in contrast to the findings of Roeyers and Mycke (1995), where they found siblings used more other-directed cognitions coping to deal with the anger, Ross and Cuskelly (2006) found that TD siblings used emotional regulation and wishful thinking in response to aggression.

There is only a slight age difference between the two studies, where the average age of the TD siblings in Roeyers and Mycke’s (1995) is younger than Ross and Cuskelly’s (2006) sample. With quite a similar research design in evaluating TD siblings’ coping strategies, it is still unclear what might cause the difference in Roeyers and Mycke’s (1995) and Ross and Cuskelly’s (2006) findings. As Glasberg (2000) compared different age groups of TD siblings of children with ASD, with the increasing of age, TD siblings developed a more mature understanding toward their ASD siblings. In support of that, Orsmond, Kuo, and Seltzer (2009) reviewed the literature and found that when TD siblings were in adulthood, they were more likely to use problem-focused coping. Hence, it is possible that the use of coping strategies also link with TD siblings’ cognitive development and changes with experience.

In the past 10 to 15 years, research on the adoption of coping strategies within Chinese families has been conducted. In spite of the substantial progress that has been made, however, research on coping during childhood and adolescents is still not well-developed and only points out the different strategies or those applied in extreme situations (e.g. earthquake, facing the diagnosis of illness, and loss) (Felder-Puig, Di Gallo, Waldenmair, Gadner, & Topf, 2004; Watson et al., 1988). Thus, it is
unclear whether these strategies are effective in the context of a family with a child with ASD.

Although a little research on coping in parents of children with ASD in Chinese context has shown some pilot findings (Lin, et al., 2008; Wang, et al., 2011; Wong, et al., 2014; Zhang, Yan, Du, & Liu, 2013), little is focused on TD siblings, and the differences and similarities between cultures in siblings’ coping patterns has not been reported.

Summarizing the above, parents and TD siblings do have similar patterns, in that coping styles in both seem to change with time. With increased experience, parents and TD siblings tend to decrease the number of coping strategies they use and focus more on certain types of coping, which are more efficient. Furthermore, the stresses and situations parents and TD siblings faced might also be different. This section has discussed how Chinese philosophy values the use of passive coping to achieve interpersonal harmony. The importance of considering the cultural context is again supported by the research reviewed in above sections.

3.5 Models of psychological adjustment in sibling research

Family is a complex and dynamic system that is influenced by various internal and external factors. In the preceding chapters, factors such as culture, demographic variables (i.e. family size and age), psychological variables (i.e. BAP level, stressful life events and social support) and coping styles have been discussed, as all having a potential influence on the adjustment of TD siblings of children with ASD. A number of theoretical frameworks have been used to explain how families function and the adjustment processes they make when dealing with situations in the family. These frameworks, including the ABC-X model (Hill, 1949), the Family Adjustment and Adaptation Response Model (Patterson, 1988), the Double ABCX model (Mccubbin & Patterson, 1983; Mccubbin & Sussman, 1983), and the Roller-Coaster Model (Boss, 2002), have been applied in research discussing the process of how family members balance demands and resources to retain family resilience. These models share lots of similarities and have been developed from each other with some modifications. For example, the Roller-Coaster Model (Boss, 2002) and the Double
ABCX model (McCubbin & Patterson, 1983; McCubbin & Sussman, 1983) are both adapted from Hill’s (1949) ABC-X model. The former places greater emphasis on the difference between stress and crisis and defined family's perceptions as influenced by multiple sources, while the latter added the pile-up stress and other elements in the model.

The Double ABCX model (McCubbin & Patterson, 1983; McCubbin & Sussman, 1983) was chosen for this research because:

(1) it addresses the roles of coping and support for family adaptation;

(2) family adaptation outcome is defined as a dynamic and ongoing process;

(3) it provides a pathway to a range of outcomes resulting from the family efforts to adapt to the stressor;

(4) it regards stress as a pile-up concept as opposed to a crisis which matches the situation of families of children with ASD.

In terms of studying families with a child with ASD, due to the recent increase in the research that has found BAP-related traits in siblings and/or parents, the direction of research has now shifted to a more integrated epigenetic-vulnerability and environmental-family approach in the studies of family’s adjustment (Ingersoll & Hambrick, 2011; Mohammadi & Zarafshan, 2014). The Diathesis-Stress Model (Rende & Plomin, 1992; Zuckerman, 1999) is one of the models that can be used to explain how ASD epigenetic vulnerabilities and environmental stress may be related to the increasing risk of siblings’ having negative outcomes.

In the following sections, both the Diathesis-Stress model and the Double ABCX model are discussed in detail along with their application in families of children with ASD.

3.5.1 Diathesis-Stress model

Orsmond and Seltzer (2009) first adopted the Diathesis-Stress model (Rende & Plomin, 1992; Zuckerman, 1999) in order to explore how epigenetic vulnerabilities
are associated with ASD and environmental/family stress (influenced by factors such as the severity of the child with ASD behaviour problems, sibling life events, and maternal depressive symptoms). Findings showed that the Diathesis-stress model was partially supported, in that siblings who had a higher number of BAP-characteristics and who experienced a greater number of stressful life events in the past year, reported elevated depressive and anxious symptoms.

The advantage of the Diathesis-stress model is that it takes epigenetic vulnerabilities into consideration. The BAP-related traits have been found related to maternal depression, siblings’ adjustment and parental cognitive appraisal patterns (Constantino, et al., 2006; Ingersoll & Hambrick, 2011; Petalas, et al., 2011; Piven, 1999). Hence, the BAP characteristics may cause parents and siblings of ASD children to be more vulnerable to psychological distress than those who do not display such epigenetically based patterns (Constantino, et al., 2006; Yoder, et al., 2009). This model also emphasises the role of stressful life events in family adjustment, which has been shown to relate to family adjustment.

3.5.2 Double ABCX Model

Despite the Diathesis-Stress model addressing the interaction between epigenetic vulnerabilities and stressful environmental factors, in not tackling the role of coping mechanisms, the Diathesis-Stress model is unable to be used to explain the mechanism through which risk and protective variables contribute to TD siblings’ adjustment. Hence, another model was adopted to explore family adjustment in relation to stress and coping.

McCubbin and Sussman (1983) adapted and extended the ABCX family crisis model (Hill, 1949) to establish the Double ABCX Model by elaborating with, and further integrating, the process of components of family behaviour in response to a stressor. This Double ABCX model contains several factors including stressors and pile-up demands (aA Factor), family adaptive resources (bB Factor), family definition and meaning (cC factor), the family adaptation factor (xX Factor) and a coping factor (BC Factor). The family adaptation factor (xX Factor) represents the outcome of family efforts to achieve a balance of family functioning in response to a stressor.
This model is based on a continuous sequence from positive adaptation to personal maladjustment. The positive adaptation of families with a child with special needs results from balancing the stressors with coping strategies. Thus, professionals can potentially provide interventions to help those families and to improve their efficiency of easing stress.

Figure 3.1 The Double ABCX Model. Based on McCubbin and Sussman (1983)

The Double ABCX Model has been used previously as a theoretical framework for detecting the degree of family stress and how parents cope in both ASD family research (Li, 2012; Renty & Roeyers, 2007; Shin & Crittenden, 2003) and in cross culture family disability research (Shin & Crittenden, 2003). Manning, Wainwright, and Bennett (2011), for example, used The Double ABCX Model in a racially diverse sample (including Eastern and Western participants) among families with a child with ASD throughout the United States. This research explored various variables, including aA Factor (life stress, severity of ASD symptoms, behaviour problems), bB Factor (family resource, social support), BC coping Factor (coping strategies), and cC Factor (reframing the situation) and how they were related to family functioning and parental distress. The research has found that the child with ASD’s behaviour problems and parental capability to redefine stressful events, could affect family functioning and parental distress the most.
Although the Double ABCX Model has been used extensively in family ASD research, it does not consider the biological risk factor (BAP-related traits), which are known to interact with environmental stress to influence parental and sibling well-being. Hence, in order to clarify the relationship between BAP-related factors and the function of coping, The Double ABCX Model and the Diathesis-Stress Model were adapted and combined in this study. The cC Factor (reframing the situation) originally from the Double ABCX model, was not included in the present research model. The reason being the main focus of the present research is TD siblings’ adjustment and their coping strategies. The concept of the cC Factor (reframing the situation) was relatively abstract and there were no suitable measurements identified for younger children. Furthermore, there were already several measurements requiring parents to provide information. Considering the loading on parents and the suitability of measuring this concept on younger children, the cC Factor (reframing the situation) was not directly surveyed in the present study but integrated with other measure constructs (see Section 4.5 for the measure constructs). The importance of this cognitive appraisal of the stressor was still therefore acknowledged.

3.5.3 The present research model

The present research model (Figure 3.2) was an adaptation of Double ABCX and Diathesis-stress models. Due to relatively less research having been done in Chinese culture; the correlations between variables were based on Western research. Both Double ABCX and Diathesis-stress models have their advantages and applications in the research of family of children with ASD. The present research model addressed some key variables, including stressors and pile-up demands (aA Factor), family adaptive resources (bB Factor), TD siblings’ and parents’ coping (BC Factor), as well as TD siblings’ and parents’ BAP level to influence TD siblings’ adjustment outcome (xX Factor). The Diathesis-Stress model was also integrated in the model, with the aA Factor representing the concepts of the stressors, and diathesis variables represented by parent’s and TD siblings’ BAP level. The demographic variables as reviewed in Section 3.2 were also integrated in the present research model.
As mentioned earlier, culture is another factor explored in this research. However, to-date, the role of culture has not been clearly identified in either of these two models. It is likely to play as a fundamental role in influencing parents and TD siblings’ experience, for example by having an impact on factors within the model, such as the family resources (Bb Factor) and the coping mechanisms (BC Factor) adopted. However, the exact nature of these influences is as yet unclear, and so culture has been indicated, but the pathways of impact have not been specified in detail in Figure 3.2.

Figure 3.2 The present research model

![Diagram showing the present research model with Culture, Demographic variables, bB Factor, Family Adaptive Resources, Sibling social support, aA Factor, Stressor & Pile-up demands, ASD severity, Stressful events, BC Factor Coping, Sibling coping, yX Factor, Family Adaptation, Sibling psychosocial adjustment, Diathesis variables, Siblings’ BAP level, BC Factor Coping, Parent coping, Diathesis variables, Parents’ BAP level.]

Note. Solid line = existing evidence of a robust relationship in the Western studies; Doted line = less evidence of a robust relationship in the Western studies.
3.6 Summary and implications for the thesis

There have been substantial empirical studies done with Western families that explored the demographic variables (e.g. SES, age, gender and family size) and psychological variables (e.g. severity of ASD, social support, broader autism phenotype, life events and stress), and coping styles for ASD families, while only a few studies have been done with Chinese families with similar issues. The effects of demographic and psychological variables and coping styles on siblings’ adjustment in Chinese families and the comparison between Chinese and Western cases still remains underexplored.

As reviewed earlier, Chinese parental coping and the attitudes towards seeking support are significantly influenced by cultural values. It is assumed that siblings of children with ASD in Chinese families may confront different internal conflicts compared to their Western counterparts. The hierarchy relationships between parents-children and older-younger siblings are strongly emphasised in Chinese families. TD siblings in the Chinese families need to learn what they should do for their parents and how they meet their parents’, and societal expectations. Thus, when facing challenges, the siblings of individuals with an ASD may use culturally-specific coping strategies to deal with stress and balance with moral debts. However, how siblings in the Chinese families cope has not been well examined. The present research is exploratory in nature. Hence, drawing together a number of key variables that have previously been identified as influencing TD siblings’ adjustment outcome, it is essential to explore these variables altogether in a single, cross-cultural study.

The combination and adaptation of the Double ABCX Model and the Diathesis-Stress Model was also discussed, along with exploring the environmental stressors and the broad autism phenotype, and with an additional cultural component. The research model used in this research was based on the previous empirical evidence and was also theoretically driven to explore the variables that contribute to TD siblings’ adjustment.
3.7 The present study

The present research focused, in the main, on the TD siblings’ perspective. In addition, this research also adopted a cross-cultural perspective in order to compare the similarities and differences in the adjustment processes of siblings of children with ASD in a Chinese and a Western culture. The research contained two interlinked studies. The first study was a large-scale study and using questionnaires to collect data from parents with a child with ASD and from their typically developing children. Taiwanese families were chosen as the representative ethnic Chinese population in this study and the families in the UK were used as the representative Western population, with both choices made primarily for pragmatic reasons, but also the resources for recruiting participants were more available for the researcher.

By examining the variables, including demographic variables (i.e. family size, age, and SES), psychological variables (i.e. life experience, BAP level and coping) and culture, reviewed in the previous chapter, the questionnaire study explored the similarities and differences in the psychosocial adjustment of TD siblings in Taiwan and the UK. Chapter 4 explains the general methodology approach. Next, similarities and differences in the social support and coping strategies that TD siblings use were investigated, and factors which contributed to better coping and adjustment of TD siblings are discussed in Chapter 5. Finally, the extent to which culture affected the effectiveness of various coping styles and TD siblings’ adjustment are considered in the Chapter 6.

The second study was an interview study, which aimed to support the findings from the questionnaire study that were not clear enough to be explained only relying on the measurements. For example, it explored issues such as how the cultural philosophy influences parents’ beliefs about how to raise their children and the attitudes towards certain coping strategies. This is discussed in Chapter 8.
Chapter 4: Quantitative evaluation of predictors of adjustment in siblings of children with ASD: Introduction and Methods

4.1 Overview of the methodology approach in this thesis

There were two approaches used in the present research. An overview of the approach is discussed first and then each individual one is introduced in further detail, in Chapter 4 for the questionnaire study and in Chapter 8 for the interview study.

This thesis used a mix-method approach. A quantitative approach was used first to provide an in-depth exploration of the phenomenon being studied, followed by a selection of interviews to develop the specific issues arising from the questionnaire study in greater depth. The strengths of quantitative and qualitative research combined can vigorously support a conclusion through convergence and corroboration of findings (Johnson & Onwuegbuzie, 2004). More importantly, combining both quantitative and qualitative approaches allows the researcher to extend beyond one-dimensional analysis and explore a broader range of research topics (Morse, 2003). The present questionnaire study was to explore what factors were related to TD siblings’ adjustment, while the follow up interview study was to further explore the possible reasons behind these relationships found from the questionnaires. Furthermore, the interview study also provided an opportunity to explore attitudes toward disability and how parents and TD siblings interpret their experience. This thesis aimed to capture not only the measureable coping strategies, but also the families’ own accounts of their experiences. Hence, it was decided combining quantitative and qualitative designs would be suitable for the present study.

This chapter now focuses on the methodology of the questionnaire study. Choosing measures that reflect cultural characteristics and that are applicable to different cultures is crucial in this cross-cultural thesis. Building on this literature, the present research attempted to distinguish the TD siblings’ point of view from that of the parents’, since the majority of previous studies used parents’ reporting for the majority of measures.
In the following section, there is discussion of how the methodology and the specific measures and procedures of the questionnaire study were selected. After the research questions and design, the constructs of the variables and how the researcher selected appropriate measurements for using in two different cultures are also addressed. The recruitment procedures in the UK and Taiwan and the systematic differences in recruiting participants are presented. The analysis plan is also described.

4.2 Research questions of the questionnaire study

The questionnaire study explored the differences in the psychosocial adjustment of TD siblings in Taiwan and the UK via parent and child questionnaire. The researcher investigated the differences in TD siblings’ use of social support and coping strategies; the factors associated with these coping strategies; and the influence of culture on the effectiveness of various coping strategies. The questionnaire study aims to address the following questions, with reference to the model presented in Section 3.5.3:

1. What are the similarities and differences in the adjustment of TD siblings in Taiwan and the UK, according to their parents and the siblings themselves?
2. What are the similarities and differences in coping of TD siblings in Taiwan and the UK, according to their parents and the siblings themselves?
3. To what extent does the research model accurately reflect the influences on TD siblings’ adjustment and coping in families of children with ASD in Taiwan and the UK?
   a. What are the associations between the factors in the model?
   b. What are the predictive relationships among the factors in the model?
   c. Do predictive factors have the same influence in the two cultural groups?

4.3 Research design of the questionnaire study

The questionnaire study was large-scale and involved data collected from families who have a child with ASD: from one of the parents and from the TD sibling. This cross-cultural study focused on comparing Taiwan and the UK. One of the research questions focused on the predictive relationships among the factors in the model. Hence, a large number of participants were required to meet the statistics standard.
Despite several advantages of using Internet-based questionnaires, such as saving time, reduced cost, large population access and potentially similar validity to paper-based questionnaires (Riva, Teruzzi, & Anolli, 2003; Yu & Yu, 2007), paper-based questionnaires were used in this research. There are two reasons for using the paper-based questionnaires. Firstly, using paper opens up the research to non-computer literate families and provided more flexibility for participants. Secondly, intellectual property rights place some constrains on reproduction of the questionnaires. Questionnaires in the present research included both open-ended and closed question formats which are discussed in the individual questionnaire sections.

4.4 Participants

The inclusion criteria for the study were:

a. families with a child with ASD between 4 and 18 years old and another TD sibling between 9 and 18 years old;

b. Formal ASD diagnosis in child with ASD confirmed by parent report

c. Child with ASD and TD sibling both living at home

d. TD siblings and parents were able to fluently speak, read, and write either Chinese or English (as appropriate).

The exclusion criteria were:

a. Children with ASD without formal diagnosis or waiting for diagnosis;

b. Participating siblings having a suspected ASD diagnosis;

c. Families whose ethnicity was not of the country in which they were living. For example, Chinese families living in the UK. Because culture was a key element in this research, data was collected from a few families in category (c), but these data were not included in the final analysis.

The details of recruitment process are discussed in Section 4.9.

As suggested by Green (1991) with regard to a suitable sample size, the rule-of-thumb equation is \( N \geq 50 + 8m \) (\( N = \) number of participants, \( m = \) number of predictors) for multiple correlation analysis and \( N \geq 104 + m \) for partial correlation analysis. As indicated in the research model presented in Section 3.5.3, there were 6-7 predictors identified to be used in the regression model. An estimated total of 110 families were therefore needed from each of these two countries in order to perform
a regression analysis incorporating all the variables of interest. The full demographic data of the participants is presented in Section 5.2.

4.5 Constructs

This section highlights the constructs being measured, followed by details of the specific questionnaires chosen to evaluate each construct. It also explains the procedure and criteria which were adopted to determine the suitability of measurements and scales in the two cultural settings. These criteria included scale reliability, cultural flexibility (adaptation of the instrument while retaining the cross-cultural generalizability), and whether they had been used in the previous research.

This thesis is focused on the influence of sibling coping styles on their adjustment and so the present research measured both of those variables. However, it was also important to consider the independent, mediating and moderating effects of other relevant constructs and the justification of those are reviewed here.

4.5.1 Constructs measured via parent questionnaires

This section described parental constructs (e.g. parent coping style) as well as constructs that were not necessarily about the parents, but which were measured via parent report (e.g. ASD severity in child with ASD and BAP traits in TD sibling). In the present research model, constructs measured via parents were set to discuss how did they interact with TD siblings’ factors. These constructs were selected based on the previous literature.

As reviewed in Section 3.2, multiple Demographic factors have been found to be correlated with the psychological and emotional adjustment of families with ASD, including socioeconomic status (SES), the gender of TD and ASD siblings, family size, parental education level, marital status and financial situation (Giallo & Gavidia-Payne, 2006; Hastings, 2003b). Some demographic factors, such as SES, family size and the availability of unpaid childcare from other adults, may vary between Taiwan and the UK (Council for Economic Planning and Development, 2013; Office for National Statistics, 2014b). It is therefore essential to collect thorough information about the background and circumstances of participants in a
cross-cultural comparison study such as the present one. Both Chinese and English demographic measures were used according to the participant’s first language. Within each country, participants may belong to a racial or ethnic minority – this was monitored within the demographic questionnaire.

The **Severity of behaviour** shown by the child with ASD has also been discovered to have a direct effect on parenting and siblings stress (Hastings & Brown, 2002; Ingersoll & Hambrick, 2011). Hence, the severity of the symptoms in the child with ASD was also examined.

According to the research reviewed in Section 3.3.3, the expression of the **BAP** in parents and siblings of children with ASD may place them at higher risk for mental health problems. Previous research indicated the importance of parental BAP level in determining the experience of stress of parents of children with ASD and their perceptions of their children’s behaviours (Cruz, Camargos-Junior, & Rocha, 2013; Ingersoll & Hambrick, 2011).

Having a family member with ASD is not necessarily always a negative experience (Petalas, et al., 2009a). The present research aimed to consider both positive and negative experiences occurring in the same timeframe. Thus although the construct of parent **Life satisfaction** was not originally in either the Double ABCX or the Diathesis-stress model, this construct was evaluated to enable some broad exploration of the balance between positive and negative experiences, looking at parents’ appraisal of their life.

There were other constructs which have been shown to be important in previous research, such as parenting style, feelings of stigma, measures of marital relationship quality, and parent social support etc. (Boyd, 2002; Gau et al., 2012; Rivers & Stoneman, 2008). These constructs might have been expected to influence TD siblings’ outcome. However, it was necessary to keep the questionnaires to a reasonable length for participants. Some of the factors were therefore excluded because there already is consistent evidence to support their influence, such as parental social support which was discussed in detail in Section 3.3.2. Others were excluded because they did not feature within the present research model.
4.5.2 Siblings’ constructs

With some notable exceptions (Hastings & Petalas, 2014; Rivers & Stoneman, 2008), the majority of the research in this field used parents’ reports to gauge TD siblings’ adjustment outcomes. Relatively less research used TD siblings’ responses directly as the major research outcome. Yet it is important to get the information directly from the TD siblings to complement the information from the parents. For example, Siblings’ coping approaches aim to solve different problems from the parents: Parents may focus on how to improve ASD children’s abilities, while siblings may care more about the disturbing behaviour from their siblings with ASD (Lock & Finstein, 2009). Parents’ insight into the TD siblings’ coping approaches may therefore be somewhat limited. Hence, the present research prioritized the use of TD siblings’ self-reporting to measure the constructs that had previously been found to relate to their adjustment outcome.

A few constructs that may influence TD siblings’ adjustment have been identified in previous research, including stressors, BAP level, social support, and coping. The number of Stressful life events experienced has also been shown to relate to psychological problems in TD siblings (Allen, Rapee, & Sandberg, 2008). The important concepts evaluated in the present research were the number and the impact of life events.

As for TD siblings, they have also been found to be more likely to show BAP traits, which may be associated with particular difficulties, compared to children who do not have an ASD epigenetic risk factor in their family (Bailey, et al., 1998; Bolton, et al., 1994). Research suggested that BAP may render some siblings more vulnerable to psychological challenges than are their peers who do not display this epigenetically based pattern (Constantino, et al., 2006; Yoder, et al., 2009). In the present research model, TD siblings’ BAP level might relate to their coping style, how they view their adjustment outcome and perhaps also influence the frequency of the social support they received. These relationships were therefore explored in the present research. Thus, when gathering data from parents and TD siblings, BAP-related traits need to be taken into consideration. Due to the limits of the
measurements available and ethical considerations, TD siblings’ BAP characteristics was not measured directly through self-report, but was based on parent’s evaluation. This is discussed in detail in Section 4.6.1.

As reviewed in Section 3.3.2, siblings’ perceptions of the Social support available to them directly has also been shown to relate to their outcomes. For example it has been found to predict parents’ and teachers’ ratings of their adjustment (Fisman, Wolf, Ellison, & Freeman, 2000; Kaminsky & Dewey, 2002; Wolf, Fisman, Ellison, & Freeman, 1998). Since there are limited formal support resources for TD siblings, the social support construct measured in the questionnaire study referred to informal support. In the following interview study, the function of formal and informal support for TD siblings was also explored. Similar to the parents’ constructs, TD siblings’ feelings of satisfaction with their life was also included.

The influence of siblings’ knowledge of ASD has also been explored in previous research, in terms of whether it linked to the sibling relationship and adjustment outcome (Roeyers & Mycke, 1995; Ross & Cuskelly, 2006). Although it has been shown to be an important variable, linked to sibling outcome, it was not measured in the present study because in a cross-cultural context this in itself would not have been informative, as it would likely have been influenced by broader family and societal views of disability. Measuring all of these factors together would have involved a number of different measures, and this would not have been feasible, given the number of other constructs already being explored in this study. The influence of siblings’ knowledge of ASD is addressed further in Section 8.4.

The constructs outlined above represent a comprehensive set of factors which are measurable by questionnaire, and can be hypothetically linked to coping style, adjustment or both, in the parents and/or TD siblings of children with ASD.
4.6 Measures

The measurements used in the present research were based on the constructs introduced in Section 4.5. This section provides the psychometric properties information of the measurements, and discusses their application in previous related research. The advantage and the limitation of the measurements are also discussed. Selecting valid measures was the first priority. Other criteria included that the measures were reliable, norm-referenced and had been examined in the studied countries. If the measures had not been used in the studied countries, but there was a practical reason for using that measure, such as specific cultural factor, this criterion was relaxed.

As for the standard adhered to in choosing the psychometric properties, George and Mallery (2003) suggest that in most social science research situations, the rule of thumb for describing psychometric properties (Cronbach's alpha) are as follows: ‘\( \alpha > .90 \) – Excellent, \( \alpha > .80 \) – Good, \( \alpha > .70 \) – Acceptable, \( \alpha > .60 \) – Questionable, \( \alpha > .50 \) – Poor, and \( \alpha < .50 \) – Unacceptable’. A test-retest reliability \( \geq 0.70 \) is generally reported as satisfactory. This standard was used in the selection of measures.

Choosing culturally sensitive measures was important in this cross-cultural study, especially because specific cultural differences had been identified between Taiwan and the UK. Some translated measures are suitable if they have been validated, but it is also important to use measures developed specifically for that culture. While every effort was made to insure that the measures were available in validated forms in both English and Mandarin Chinese\(^9\), some of the questionnaires did not have either an English or a Chinese version, and so these were translated specifically for the study.

The measures were therefore selected based on the following criteria: relevant to the research questions, satisfactory psychometric properties, and ideally available in

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\(^9\) Mandarin Chinese is the official language in the People's Republic of China and Taiwan.
Taiwan/UK or had been used in the Chinese/British populations\textsuperscript{10}. All the copies of the questionnaires selected are in Appendix A.

Ten of the 12 questionnaires selected already had validated versions in both English and Chinese, while two required translation. Further details on how questionnaires were translated, if not already available in both languages, is provided in Section 4.7.

In total, there were 8 parent questionnaires and 5 sibling questionnaires, and they are presented in detail below. Where two or more potential measures are available for one construct, there is discussion about why those alternative measures were not selected.

4.6.1 Parent questionnaires

1. Demographic questionnaire

The researcher designed a self-report questionnaire to request background information about families with multiple choice and open-ended questions. The information included their occupation, annual household income, education levels, marital status, and family size, in order to explore the influence of these demographic factors. The researcher also asked parents to provide information about their ASD and TD children. The questionnaire also asked parents whether there were other people who provided unpaid childcare and about the presence of other adults in the home. These questions were included because help from others at home could alleviate parent stress and enhance adjustment. What type of the school the child with ASD attended was also gathered from the parents’ report, because it might relate to the support family received from schools.

The design of the demographic questionnaire was informed by several previous ASD studies. To evaluate the socio-economic status, for example, parental employment categories were adopted from the PACT study (Green et al., 2010) and Click-east (Fletcher-Watson et al., 2013), listing 9 categories from ‘professional’, ‘non-manual

\textsuperscript{10} Taiwan originally based in People's Republic of China, but has been independent since 1949.
skilled’ to ‘still in full time education.’ As for the economic status, parents were asked to report their annual household income. Due to the different costs of taking care of a child with ASD and the differing cost of living, households with similar income do not necessarily face the same financial situations in Taiwan and the UK. It is important to distinguish between the actual income and individuals’ perceptions of their financial status, i.e. whether they feel it is sufficient to support their family. Parents were therefore also asked to evaluate their financial situation using 6 categories (‘Manage very well’, ‘Manage quite well’, ‘Get by alright’, ‘Don't manage very well’, ‘Have some financial difficulties’ and ‘Are in deep financial trouble’).

For the TD siblings, the researcher gathered information from parents about their age, gender, birth order and whether they have received special education or a diagnosis of a development disorder. As for the child with ASD, apart from the diagnosis, the researcher asked for their age, and whether the child has intellectual disabilities or a co-morbid diagnosis in addition to their diagnosis on the autistic spectrum.

To assess the cultural background of the recruited families, some of the questions asked about the parents’ nationality and ethnicity in order to make a cultural comparison. The UK is comprised of different national identities (e.g. English and Scottish) and ethnic backgrounds (e.g. Indian or Polish). In comparison, the population in Taiwan is quite homogenous, although there are still immigrants from such as China and Vietnam. The researcher cannot assume that all the families in the UK identify themselves in the same way culturally, and the same for Taiwan. It was therefore important to ask about both nationality and ethnicity as separate constructs.

2. Autistic symptom severity in the child with ASD: Social Responsiveness Scale, Second Edition (SRS-2)

The SRS-2 (Constantino, 2012) was used to: (1) provide further details of, and support the parent’s declaration of a diagnosis for their child with ASD; and (2) measure the severity of the autistic symptoms. The SRS-2 is a 65-item questionnaire that inquires about a child’s ability to engage in age-appropriate social and communication behaviour, developed in the USA by Constantino (2012). This scale takes a quantitative approach to measuring autistic symptomology of children and
youths between 4 and 18 years of age and it has been reviewed and used in various research studies (Bruni, 2014; Wigham, Mcconachie, Tandos, & Le Couteur, 2012). The SRS-2 has five subscales assessing Social Awareness, Social Cognition, Social Communication, Social Motivation, and Autistic Mannerisms. Parents report their child’s ability to engage in emotionally appropriate reciprocal social interactions by using a 4-point Likert scale to respond to statements which may or may not describe their child. The scale options range from ‘not true’ to ‘almost always true’ with higher scores indicating increased social dysfunction. The total raw score cut-off point as recommended by the original authors is 70 for possible ASD in males and 65 for females.

In UK-based research, the SRS-2 has shown excellent internal consistency (α = .92 in males and females). Construct validity is supported by a significant positive correlation between the SRS-2 total scores and the Repetitive Behaviours Questionnaire 2 (Wigham, et al., 2012). Wigham and colleagues also found a negative correlation between the SRS-2 and the prosocial subscale of the Strengths and Difficulties Questionnaire, indicating external validity. Unfortunately, Wigham et al. (2012) did not provide the information regarding the test-retest reliability.

A Chinese version of the Social Responsiveness Scale (Chinese SRS) is created by Gau and colleagues (2013). The Chinese SRS demonstrates excellent internal consistency (α = .94), test–retest reliability (α = .95), and the scale structure remains the same across school-based or clinic-based samples, suggesting that it is a reliable and valid instrument for the Chinese population in Taiwan.

There are other measurements considered for the autism severity measurement, such as the Autism Behaviour Checklist (Krug, Arick, & Almond, 1980), the Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 1984) the Gilliam Autism Rating Scale (Gilliam, 2006), and the Social Communication Questionnaire (Rutter et al., 2003). Firstly, these measurements are designed for diagnostic and screening purposes and some of them could only be administered by a qualified health professional. Secondly, some of the measurements do not have satisfactory psychometric properties. For example, low sensitivity in younger age populations is found in the Social Communication Questionnaire (Wiggins, Bakeman, Adamson, &
Robins, 2007). Moreover, some of these measures are not available in Chinese (i.e. Gilliam Autism Rating Scale).

The length of the measurement was also an important concern. The SRS-2 takes about 15-20 minutes to finish and provides sufficient information regarding severity of the children with ASD. Furthermore, SRS-2 has been shown to be suitable in cross-cultural research (Frazier et al., 2013; Wang, Lee, Chen, & Hsu, 2012).

3. Parental Coping: Coping Orientations to the Problems Experienced Questionnaire (COPE)

Coping is generally defined as the cognitive and behavioural efforts made to ease the demand that burden, or overwhelm, a person’s resources (Folkman, et al., 1986; Lazarus & Folkman, 1984). There are various measurements that have been used to try to understand coping mechanisms in the family with special needs child and how these relate to other variables. In this section, the Coping Orientations to the Problems Experienced (COPE; Carver, et al., 1989) used in the present research is introduced, followed by a discussion of why this was chosen over other measurements in the present research.

The COPE questionnaire is a theory-based scale developed by Carver, Scheier, and Weintraub (1989) to evaluate people’s use of different coping strategies in a specific stressful situation, here referred to raising a child with ASD. With a total of 60 items, the COPE is divided into 13 sub-scales, which also can be summed into problem-focused coping and emotion-focused coping styles according to the originators. The problem-focused coping includes 5 subscales - active coping, planning, suppression of competing activities, restraint coping and the seeking of instrumental social support, while emotion-focus coping includes seeking of emotional social support, positive reinterpretation, acceptance, denial and turning to religion. There are also three subscales that measure: focus on and venting of emotions, behavioural disengagement, and mental disengagement. The COPE respondents (which here refers to parents) use a 4-point scale ranging from 0 (‘I do not do this at all’) to 3 (‘I usually do this a lot’) to report their use of a stated coping mechanism.
The COPE has been extensively analysed, producing slightly different subscales/factors each time (Hsu, et al., 2008; Lyne & Roger, 2000; Zuckerman & Gagne, 2003). The psychometric properties reported here are for the original 13 subscales version (not including humour, or alcohol and drug use, which were added in the later modification version published in Carver and Scheier (1994). The internal consistency reliabilities ($\alpha = .45–.92$), 8 weeks interval test-retest reliabilities ($r = .46–.86$) and evidence of extensive convergent and divergent validities were reported by the authors (Carver, et al., 1989).

The poor internal consistency reliability has been argued to be due to too many factor extractions and hence an increase in the error variance or because some subscales only contain a single item (e.g. alcohol-drug disengagement) (Endler & Parker, 1990). Others researchers provided satisfactory psychometric properties using the COPE. For example, in an NHS community trust in the UK, the COPE showed a three factor structure namely active coping, emotion-focused coping, and avoidance (Lyne & Roger, 2000). Here the Cronbach’s alpha ranged from .69 –.89.

Pakenham, Samios, and Sofronoff (2005) use the COPE to investigate mothers of children with Asperger’s syndrome. This research has several similarities with the present study, including a research topic looking at the experience of families with children with Asperger’s, as well as the application of the Double ABCX model. Here emotion-focused coping styles are further divided into adjusted and maladjusted, which are labelled emotional approach coping and passive avoidant emotion-focused coping. See Table 4.1 for subscales details. In addition to previous analyses yield, various other factor structures of the COPE, Pakenham, Samios, and Sofronoff’s (2005) research provides a solid factor structure to use in the present research.
Table 4.1 Coping styles factor structures based on the COPE used in the present study

<table>
<thead>
<tr>
<th>Coping styles</th>
<th>Subscales</th>
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<tbody>
<tr>
<td>Problem-focused coping</td>
<td>Active coping</td>
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<tr>
<td></td>
<td>Planning</td>
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<td></td>
<td>Suppression of competing activities</td>
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<td></td>
<td>Restraint coping</td>
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<td></td>
<td>Seeking instrumental social support</td>
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<td>Emotional approach coping</td>
<td>Seeking emotional support</td>
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<td></td>
<td>Acceptance</td>
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<td></td>
<td>Positive reinterpretation</td>
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<td></td>
<td>Turning to religion</td>
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<tr>
<td>Passive avoidant emotion-focused</td>
<td>Denial</td>
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<tr>
<td>coping</td>
<td>Venting of emotions</td>
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<tr>
<td></td>
<td>Behavioural disengagement</td>
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<td></td>
<td>Mental disengagement</td>
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</table>

*Note.* Denial and mental disengagement were not included because of low Cronbach’s alpha coefficients.

Furthermore, the COPE or Brief COPE has been widely used in family research when exploring family coping patterns such as in families with a child with ASD (Benson, 2010; Hastings, et al., 2005; Ingersoll & Hambrick, 2011) and it has also been applied to Chinese populations (Lin, et al., 2011; Mak, et al., 2007; Wang, et al., 2011). The Chinese version of the COPE Scale demonstrates adequate internal consistency reliability ranged from .70 to .84 in the Taiwanese sample (Lin, et al., 2011). All of these lent support for using the COPE to measure the parent coping construct in the present research.

The coping style adopted by parents is a crucial element in this research. There are other coping measures that have previously been used try to understand the coping mechanisms in families with children with special needs. In the following discussion, the researcher briefly reviewed the reasons why these measurements were not used in the present research. These measurements include: the Coping Inventory for Stressful
Situations (Endler & Parker, 1990); the Coping Response Inventory (Moos, 1993); the Family Crisis Oriented Personal Evaluation Scales (McCubbin, Olson, & Larsen, 1987); and the Ways of Coping Questionnaire (Folkman & Lazarus, 1988).

The Coping Inventory for Stressful Situations (Endler & Parker, 1990); and the Coping Response Inventory (Moos, 1993) suffer from the lack of supporting research in different cultures, which potentially limits their application in cross-cultural research. Furthermore, Chinese versions of these measurements are not available.

According to the authors’ concepts of the Family Crisis Oriented Personal Evaluation Scales (McCubbin, et al., 1987), this measure provides not only the coping strategies families employed to cope with distress but also accounts for the effect of social support which provides a better understanding between coping and social support factors. Even though this construct of Family Crisis Oriented Personal Evaluation Scale (McCubbin, et al., 1987) is closer to the present research assumption, this measure has not been frequently applied to Chinese populations, and thus still requires further research (Li-Bin, Wen-Tao, & Yun-Xiao, 2010). It is therefore more appropriate to use COPE rather than Family Crisis Oriented Personal Evaluation Scales (McCubbin, et al., 1987) when measuring parental coping.

The Ways of Coping Questionnaire (Folkman & Lazarus, 1988) is available in Chinese (Chan, 1994) and has good validity and reliability (Chou, Lamontagne, & Hepworth, 1999). However, it was rejected because it required the respondents to focus on a current serious stressor which is different from the present research assumption. Having a child with disability may pile up different stressors across time within the family. This research did not aim to discuss a specific single stressful episode, but rather a long-term situation – having a child with special needs.

Another problem is that Chinese version of the Ways of Coping Questionnaire has shown four relatively different dimensions of coping in the Chinese population compared to a eight factor structure in Western population (Chan, 1994). This issue again highlights the difficulties of using a Western measure with a Chinese population. Hence, the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) was not used.
A final reason for using the COPE is that for the Chinese coping questionnaire used in this research – Coping Strategies in Chinese Social Context (CSCSC; Hsu, et al., 2008) – there has already been sufficient psychometric examination between the COPE and the CSCSC (Hsu, et al., 2008), which provides the cultural comparison elements the present research sought to explore in relation to the coping style. This is discussed further in the next section.


Aguilar-Vafaie and Abiari (2007) stated that the researchers have to be cautious when applying Western based scales to another culture, where social situation and cognitive appraisal is different. This was crucial particularly in relation to coping because previous research has been argued that there is a different coping philosophy in the Chinese culture (Huaibin, 2006; Shek & Tsang, 1993). Hsu and colleagues (2008) suggested that the CSCSC better captures the Chinese coping strategies than the COPE, because the latter does not fully consider the importance of social interactions and the influences on other people when choosing different coping approaches within the Chinese culture.

The Coping Strategies in Chinese Social Context (CSCSC) was developed by Hsu, et al. (2008) based on the assumption that social interactions and connections with others are particularly significant for Chinese people. The CSCSC contains some culture-specific expressions, such as idiomatic phrases (e.g. item 39. 陽奉陰違，反正不要被發現就好, which roughly translates as ‘Obey in public and disobey in private, as long as it is not discovered.’) and the Chinese-specific copying styles (e.g. item 2. Losing is winning - thinking about better things makes it easier to accept). As a culturally specific measurement, the CSCSC has more of a focus on interpersonal networks and on the philosophy of achieving personal harmony, than is typically found in Western measures.

It is possible that even if Chinese people chose the same coping strategies as Western people, these strategies would not necessarily represent a similar philosophy or rationale for the choice. Hence, having a measure originally developed for use in a Chinese population can better reveal how the philosophies of different cultures
influence the families’ approach to coping with stress (see detailed discussion in Section 3.4.1).

The CSCSC consists of 77 items that can be categorized into 4 coping styles which is illustrated in the Figure 4.1. The scale used a five-point Likert scale from 1 (‘almost never’) to 5 (‘almost always’). The internal consistency ($\alpha = .77-.87$) indicated acceptable reliability and the test–retest reliability ranged from 0.81 to 0.90 (Hsu, et al., 2008).

Figure 4.1 Two axes of Coping Strategies in Chinese Social Context (CSCSC)

Due to the relatively new concepts of including cultural context in the coping measurement, the CSCSC suffers some limitations. Firstly, the authors of the CSCSC scale do not provide evidence to support the construct validity and this requires further examination. Secondly, Hsu and colleagues’ (2008) sample consisted of university students, so testing of other more diverse samples is still required in the future. Even though there is evidence that the CSCSC proved to be more effective than the COPE (Carver, et al., 1989) in predicting outcomes such as depression, anxiety, anger, well-being and compatibility-harmony in Chinese populations (Hsu, et al., 2008), further research is still required to support the reliability and validity of the CSCSC scale and its use in Western settings.

There are other Chinese coping measurements, such as Chinese Coping Strategies (Siu, Spector, & Cooper, 2006) and Chinese Coping Scale (Shek & Cheung, 1990).
Unlike CSCSC, none of have information about their relations with other western developed measurements. The present research pioneered the use of a Chinese-specific coping measure in a Western population. Having a Chinese-developed measure makes it possible to discuss the similarities and differences in coping within the social context. Depending on the results of analyses, the present study may support the use of this measure and contribute to discussion of whether this is a useful measure for family research and future research opportunities. The CSCSC was translated into an English version by the research team. Further detail regarding the translation procedure is discussed in Section 4.7.

5. Parental Satisfaction with Life

The Satisfaction With Life Scale (SWLS) assesses a person’s relative life satisfaction using only 5 items (Diener, Emmons, Larsen, & Griffin, 1985). Respondents weigh several domains of their lives on a 7-point scale with higher values corresponding to higher degree of life satisfaction. The internal reliability of this measure ranged from .79 to .89 and two-week interval test-retest was .83 and a 1-month interval was .84 (Pavot & Diener, 1993). The SWLS statements focused on the positive side of the individual’s experience rather than on the negative events. This is essential to this research, because living with a child with disability should not be assumed to be a negative experience or a cause of stress. The present research used SWLS to measure parents’ subjective well-being in general.

The SWLS has been translated into various languages including Chinese (Wu & Yao, 2006). The Chinese version also showed adequate psychometric properties with internal consistency reliability ($\alpha = .84$) and good criterion-related validity with the brief World Health Organization Quality of Life Assessment (Wu & Wu, 2008).

6. Parental BAP characteristics: Autism Spectrum Quotient (Adult Form)

The parent’s broader autism phenotype (BAP) was assessed using the Autism Spectrum Quotient (AQ) (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). The AQ is a 50-item self-report inventory to assess the level of the autistic traits in the general population. This approach of quantifying autistic characteristics produces scores for 10 items for each in five domains: social skills, attention
switching, attention to detail, communication and imagination. The respondents are asked to rate the degree to which they believe they show the behaviour described in the item on a 4-point scale on the categories of ‘definitely agree’, ‘slightly agree’, ‘slightly disagree’ and ‘definitely disagree’. The scoring of the original AQ according to the originator used a dichotomous scale, for the response that indicates autistic feature is scored ‘1’ if ‘definitely agree’ or ‘slightly agree’, and otherwise ‘0’ if ‘slightly disagree’ or ‘definitely disagree’. A high score on the AQ (suggested cut-off 32 out of 50 on the total score) may be associated with a diagnosis of high-functioning ASD or Asperger syndrome. However, in the present research this instrument was not used for screening or diagnosis, but as a research tool to quantify the presence of autistic-type traits in the parents and TD siblings of children with ASD.

The AQ has been validated in culturally diverse samples and demonstrates satisfactory psychometric properties (Ruta, Mazzone, Mazzone, Wheelwright, & Baron-Cohen, 2012; Stewart & Austin, 2009; Wakabayashi et al., 2007). In the original report by Baron-Cohen, et al. (2001), internal consistency of items was acceptable to good (α = .63–.77), and two week test-retest did not differ statistically (t = .30, p = .75) and was strongly correlated (r = .70, p < .01).

The Chinese version of the AQ (AQ-Chinese; Lau et al., 2012; Liu, 2008) has been applied in a Taiwanese sample, and this yielded a 35-item, 5-dimensional factor solution, with the model statistically and semantically coherent with the original model (Lau, et al., 2012). The test-retest reliability (t = 1.35, p = .18, ICC = .40–.72) remained quite stable and strongly correlated (r = .65, p < .001). The internal consistency for the total scale was excellent (α = .84). However, the goodness of fit statistics analysis cut down the original AQ items from 50 to 30 in the AQ-Chinese. The scoring was also different: Lau, et al. (2012) used the 4-point Likert scale instead of the original dichotomous scale. The cut-off score were not available in the Lau and colleague’ (2012), but it was suggested to be 30 out of 50 in Liu’s (2008) study.
The role of the AQ in the present research was used to explore the BAP level within the family and how it related to TD siblings’ adjustment outcome. In order to compare the Taiwanese and UK data, the 50 items of the original version of the AQ-adult and dichotomous scoring were used in the present study. However, potential concern about its cultural suitability is addressed in the Chapter 7.

7. Sibling psychosocial adjustment: Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) was designed by Goodman (1998) as a measure of psychological adjustment in children and adolescents, based on a combination of youth, parent, and teacher reports. It was inspired by the Elander and Rutter parent questionnaire series (Elander & Rutter, 1996), which addressed a well-balanced number of positive and negative behavioural features.

The SDQ is suitable to evaluate children aged 4 to 16 years old, and is completed by parents or teachers. An adolescent self-completion version is also available for 11- to 16-year-olds. There are three components in the SDQ. The first is psychological attributes which contains five subscales, each with five items covering emotional, conduct, hyperactivity/inattention, peer problems and prosocial behaviour. Parents were asked to rate each descriptive statement from 0 to 2, where 0 = not true, 1 = somewhat true and 2 = certainly true, with respect to their non-autistic child.

A higher score on the prosocial behaviour Scale reflects positive behaviour, but the remainder of the four subscales represent problem scores. By summing the problem scores, users can create a ‘Total Difficulties Score’ ranging from 0 to 40, where higher scores indicate more difficulties. The SDQ scores can also be cross referenced with bands which identify individuals according to their difficulty category rated as normal, borderline, and abnormal (Goodman, 1997). Approximately 10% of a community sample scores fall into the ‘substantial risk of clinically significant’ band which is described as abnormal, while a further 10% fall into the ‘may reflect

11 http://www.sdqinfo.com/
clinically significant problems’ band, described as *borderline*. The score range also varies according to country, age and gender as reported in cross cultural research (Goodman, Ford, Simmons, Gatward, & Meltzer, 2000; Muris, Meesters, & Van Den Berg, 2003; Woerner et al., 2004). These norms can be downloaded from the SDQ website.

Although the SDQ has other components, such as an impact supplement and a follow-up outcome measure, only the total difficulties score and the prosocial score were used in the present study because these were used for evaluating sibling adjustment.

The Chinese version (SDQ-C)\(^\text{12}\) is also free to download on-line. The parental version of the Chinese SDQ has also demonstrated satisfied psychometric properties, with acceptable to good test-retest reliability \((r = .71-.90)\) and poor to good internal consistency \((\alpha = .55-.86)\) (Gau et al., 2008).

The SDQ has been translated into 40 languages. Stone, Otten, Engels, Vermulst, and Janssens (2010) reviewed 48 published studies which used different language versions of the SDQ. They reported that internal consistency, test-retest reliability, and inter-rater agreement were satisfactory for the parent version. From the information listed above, the SDQ has not only has been used widely across the cultures and also displays satisfied psychometric properties. The final strength of the SDQ is that there is a self-report version suitable for children and adolescents in the present research.

8. **Sibling BAP characteristics: Autism Quotient (Child/Adolescent Form)**

The Autism Quotient series includes a parent-report child version (AQ-Child) (Auyeung, Baron-Cohen, Wheelwright, & Allison, 2008) and a parent-report adolescent version (AQ-Adolescent) (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006). The present research used both the AQ-Child and AQ-Adolescent depending on the age of the TD sibling. Both the AQ-Adolescent and the

AQ-Child have the same five domains as the adult version. Again each is evaluated from responses to 10 items, with a total of 50-items per questionnaire. The two versions are directly comparable and also relate to the adult self-report AQ described in Section 4.6.1 (6). According to the originator’s reports, the psychometric properties of these two versions are acceptable to excellent (α = .79 for AQ-Adolescent total score and α = .97 for AQ-child total score), while the test-retest reliability is r = .92 for AQ-Adolescent and r = .85 for AQ-Child. Also in that original study (Baron-Cohen, et al., 2006), approximately 90% of the adolescents with AS/HFA and ASD scored above 30 out of 50, suggesting that 30 was a useful cut-off score for distinguishing those who may have significant levels of autistic traits. Due to its use of a 4-point Likert scale scoring, which is different to the AQ-Adult and the AQ-Adolescent, the cut-off score of AQ-Child is suggested to be 76 out of 150 (Auyeung, et al., 2008). In the present study, however, a 4-point Likert scale was used with both the AQ-Child and the AQ-Adolescent, in accordance with the scoring used in other studies also using AQ series measurements (Austin, 2005; Auyeung, et al., 2008; Hoekstra, Bartels, Verweij, & Boomsma, 2007).

The Chinese AQ-Adolescent/Child (Chan & Liu, 2008; Chan, Liu, Chung, Sheh, & Woo, 2008) has been used with Chinese populations. Despite the fact that the Chinese AQ-Adolescent/Child have been widely used in clinic settings, there are no published papers had provided a clear information on the psychometric properties. In an unpublished thesis, the internal consistency reported ranged from .56 to .75 across the subscales, indicating poor to acceptable reliability for the Chinese AQ-Adolescent (Tam, 2013). However, because there are no other BAP measures which exist in a Chinese version, the AQ-Adolescent/Child were chosen for the present study.

It would have been ideal if this research could have obtained the TD siblings’ self-report on the BAP traits so that the researcher could explore the consistency and diversity between parents’ and children’s points of view. Unfortunately, the researcher could not identify any measure that is specifically designed for children/adolescents’ self-report. Hence, the present research used parents to report
their children’s BAP characteristics rather than directly asking the children and this was ethically preferable.

Parents completed measures about their family context, their own traits/experiences and also about those of their non-autistic children. With the exception of the satisfaction with life measurement, all the measurements mapped onto the present research model’s measured constructs, which were stressors, coping, adjustment and the BAP traits. All the parental measures and their psychometric properties are shown in Table 4.2. The next section illustrates and justifies the choice of measures to be completed by siblings enrolled in the study.
Table 4.2 Parental measures and their psychometric properties

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Measurements</th>
<th>Assessed Domains</th>
<th>Psychometric Properties</th>
<th>Instructions for replacing data?</th>
</tr>
</thead>
</table>
| 1. Demographic factors      | Demographic questionnaire     | • Parents: SES, occupation, marital status, family size, education levels, whether any other adult provides unpaid childcare, nationality and ethnicity  
                             |                                | • TD sibling: age, gender, birth order and special education needs or a diagnosis of a development disorder  
                             |                                | • ASD sibling: age, gender and whether any co-morbid diagnosis | Not applicable                  | Not applicable                  |
| 2. **Stressor**: Symptom severity in ASD sibling | Social Responsiveness Scale (SRS) | • Total score = sum of Social Awareness, Social Cognition, Social Communication, Social Motivation, and Autistic Mannerisms | **English version:**  
                             |                                |                                                                 | Internal consistency (α = .94) | **Chinese version:**  
<pre><code>                         |                                |                                                                 | Internal consistency (α = .94) | Test–retest reliability       | Yes                             |
                         |                                |                                                                 | (r = .95)                                      |                                 |                                 |                                 |
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<table>
<thead>
<tr>
<th>Constructs</th>
<th>Measurements</th>
<th>Assessed Domains</th>
<th>Psychometric Properties</th>
<th>Instructions for replacing data?</th>
</tr>
</thead>
</table>
| 3. **Coping**: Parental Coping | Coping orientations to the problems experienced questionnaire (COPE) | ● Problem-focused coping  
● Emotional approach coping  
● Passive avoidant emotion-focused coping | **English version:**  
Internal consistency  
($\alpha = .45-.92$)  
Test-retest reliability  
($r = .42-.89$)  
**Chinese version:**  
Internal consistency  
($\alpha = .70 -.84$) | No |
| 4. **Coping**: Parental Coping | Coping strategies in Chinese social context (CSCSC) | ● Active/ prosocial  
● Active/ antisocial  
● Passive/ prosocial  
● Passive/ antisocial | **English version:**  
Not validated yet  
**Chinese version:**  
Internal consistency  
($\alpha = .77-.87$)  
Test–retest reliability  
($r = .81-.90$) | Yes |
| 5. **Family adaptation**: Parental subjective well-being | Satisfaction with life scale (SWLS) | ● Total scores  
(person’s relative life satisfaction) | **English version:**  
Internal consistency  
($\alpha = .79-.89$)  
Test–retest reliability  
($r = .83-.84$)  
**Chinese version:**  
Internal consistency  
($\alpha = .84$) | No |
<table>
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<tr>
<th>Constructs</th>
<th>Measurements</th>
<th>Assessed Domains</th>
<th>Psychometric Properties</th>
<th>Instructions for replacing data?</th>
</tr>
</thead>
</table>
| 6. **Diathesis variables:** Parental BAP characteristics | Autism spectrum quotient (AQ-Adult Form)         | ● Total score = sum of Social skills, Attention Switching, Attention to Detail, Communication and Imagination | *English version:* Internal consistency ($\alpha = .63-.77$)  
*Chinese version:* Internal consistency ($\alpha = .84$) | Yes |
| 7. **Family adaptation:** TD sibling psychosocial adjustment | Strengths and difficulties questionnaire (SDQ)   | ● Total difficulties scores (Emotional, Conduct, Hyperactivity, and Peer problems)  
● Prosocial behaviour scores | *English version:* Internal consistency (mean $r = .73$)  
Test–retest reliability (mean $r = .62$)  
*Chinese version:* Internal consistency ($\alpha = .55-.86$)  
Test–retest reliability ($r = .71-.90$) | Yes |
| 8. **Diathesis variables:** TD sibling BAP characteristics | Autism spectrum quotient (AQ-Child/Adolescent Form) | ● Total score = sum of Social skills, Attention Switching, Attention to Detail, Communication and Imagination | *English version:* AQ-Child ($\alpha = .97$)  
AQ-Adolescent ($\alpha = .79$)  
*Chinese version:* Not validated yet | Yes |
4.6.2 Sibling Questionnaires

1. Sibling psychosocial adjustment: Strengths and Difficulties Questionnaire (SDQ)

The self-report version of the Strengths and Difficulties Questionnaire (SDQ) is designed for youth aged 11 to 16 years, with the 25 items covering the same factors as the informant-rated SDQ, both devised by Goodman, Meltzer, and Bailey (1998). The age range in the present research was wider than the original SDQ protocol, but the measure has been successfully applied with younger and wider age groups (Liu et al., 2013; Muris, et al., 2003; Yang, 2011).

The self-rated SDQ has satisfactory discriminability between community and clinical samples (Goodman, 2001). Internal consistency demonstrates an homogeneous scale structure, with alpha values of total difficulties ranging from .71 to .82 in different countries (Koskelainen, Sourander, & Kaljonen, 2000).

The Chinese version of the SDQ (SDQ-C) is available and has been used previously in clinical and research settings. For the four difficulty subscales the psychometric properties were poor to acceptable, with alpha coefficients from .40 (peer problems) to .72 (emotional symptoms) and the test-retest reliability was .49 to .67 (Liu, et al., 2013). With another research also conducted in the Chinese adolescents, self-report SDQ exhibited good overall internal consistency ($\alpha = .81$) and acceptable 8-week test-retest reliability ($r = .71$) (Yao et al., 2009). Each SDQ-C subscale score was highly correlated with the corresponding subscale score of the Child Behaviour Checklist -Youth Self Report (Achenbach, 1991) providing evidence of good convergent and discriminant validity (Yao, et al., 2009). Despite some of the unsatisfied psychometric properties in the self-report SDQ-C, researchers still support the utilization in the Chinese populations (Gau et al., 2010b; Yao, et al., 2009).

Using both the parents’ and siblings’ reports on the SDQ serves an important function. Achenbach, McConaughy, and Howell (1987) stated that disagreements between different reports on a measurement are as valuable as agreements, because they highlight different perspectives on the child’s behaviour from different point of views. When the information involves items of behaviour that are specific to the settings, a great deal of variability may exist between the information provided by the parents or the siblings themselves. Therefore, it is important to look from the siblings’ viewpoint to see under what conditions they are most likely to adjust well or be vulnerable.

2. Sibling coping style: Kidcope

Lots of possible measures are available for parents’ coping but only few self-reports are available for children. It is especially hard to choose coping instruments for children and adolescents, as there are limited numbers of selection and also need to consider whether it is suitable for the surveyed populations. Furthermore, studies evaluating coping strategies for siblings of children with special needs are relatively lacking. The Kidcope scale devised by Spirito, Stark, Grace, and Stamoulis (1991) was selected in the present study to evaluate sibling coping strategies. In the instructions, Kidcope asks respondents (here referring to TD siblings) about coping with a specific situation. There are two parts of the questionnaire, the frequency subscale first asks respondent to answer whether they have used the listing coping strategies and the efficacy subscale is to evaluate the efficacy of the coping strategies.

The advantage of the Kidcope is that it provides different response methods according to the child’s stage of development. The younger version (aged 7–12) of the Kidcope uses a yes/no response, while the adolescent version (aged 12–18) uses a 5-point Likert scale on the frequency subscale. When evaluating the efficacy of coping, younger respondents answer with a 3-point scale, while older respondents use 5-point scale. For logistical reasons, the present research only used younger version response format with all TD sibling participants.

For the frequency subscale, individual total scores are calculated for each of three coping styles: active (cognitive restructuring, problem solving, emotional regulation,
and social support); avoidant (distraction, social withdrawal, resignation, and wishful thinking); and negative coping (self-criticism and blaming others). The respondents receive different frequency scores relating to each of these coping styles, depending on how many ‘yes’ responses they have for the items relating to each style. The efficacy scores indicate the value of the various coping strategies to the respondents. Higher efficacy scores show that the respondents evaluate that the coping strategies are efficient and useful to them.

The test-retest reliability is .13–.80 for one week and .16–.64 for two weeks intervals respectively. These test-retest reliability are not consistently satisfactory; however, according to the Spirito, et al. (1988), coping is not a static process but changes with the demands of the situations. Hence, the traditional standard of the test-retest reliability is not always an applicable indicator. The concurrent validity with other coping measurements ranged from .33–.77, such as Adolescent Coping Orientation for Problem Experiences (Patterson & Mccubbin, 1987) and Coping Strategies Inventory (Tobin, Holroyd, Reynolds, & Wigal, 1989). These measurements were considered but not used in the current study, as discussed below.

The Kidcope has been used to assess coping strategies employed by children and youths in various settings, such as children with ASD (Lee et al., 2012) and their siblings (Ross & Cuskelley, 2006), community samples (Pereda, Forns, Kirchner, & Muñoz, 2009) and children facing their illness (Edgar & Skinner, 2003). A Chinese version of the Kidcope (Wong, 1998) is also available and has been used in Chinese populations. The factorial structure (factor loadings, factor variances, and factor covariance) is invariant across age and gender in Chinese populations (Cheng & Chan, 2003). Unfortunately, despite the use of the Chinese Kidcope (Cheng & Chan, 2003; Madeline, 2010; Tay, Wan, Aw, & Kim, 2011), there is no published psychometric properties information available.

Some other coping measurements for children and adolescents are considered for the present research study, but rejected in favour of the Kidcope. A number of the coping measurements for children and adolescents are designed to assess the adjustment to paediatric cancer, such as the Mental Adjustment to Cancer Scale (MACS) (Watson, et al., 1988). These measurements primarily focus on their diagnosis or treatment
response. It could be argued that the concept of coping is different in cancer and in the adjustment process of having ASD siblings, because cancer is directly affects the individuals’ health condition, but having a sibling with ASD is not necessarily an adverse experience. Furthermore, the present research asked TD siblings’ about their coping specifically in reference to having a child with ASD rather than coping in a generic sense.

The Adolescent Coping Orientation for Problem Experiences (Patterson & Mccubbin, 1987) and Coping Strategies Inventory (Tobin, et al., 1989) are also considered in the current study, but these are more suitable for adolescents rather than younger children and are relatively long compared to the Kidcope. As for the Sibling Stress and Coping Inventory (Gamble & Mchale, 1989), it is too complex for completion by children under 13 years old. The usage of the scale is also limited and it is not officially published. There is no Chinese version available. The Coping response inventory-Youth form (CRI-YF) developed by Moos (1993) is for youths aged 12–18 to assess their psychological adjustment, whether they are healthy or with disorders. Hamdan-Mansour et al. (2008) suggested the reliability of the total scores are questionable. The youth form also suffers from the lack of supportive research in different cultures, limiting its application in the cross-cultural research. Although the Children’s Coping Strategies Checklist (CCSC) (Ayers, Sandier, West, & Roosa, 1996) has some advantages, such as its reasonable length and the number of coping strategies it measures, it has quite a few limitations. One of the biggest limitations is the inconsistent factor structure. In sum, the weakness of psychometrics limits the use of these other scales.

Ideally, this research would also have included a Chinese-specific coping measurement for the children and adolescents. However, the majority of research looking at coping style in the younger Chinese population either use observation approach or use a western-developed measurement based on parents’ report. It is still an underdevelopment area for the self-report coping measurement for the Chinese children and adolescents. Hence, the Kidcope was used for these feasible reasons stated above.
3. Sibling Satisfaction with Life

Siblings also filled out the same Satisfaction With Life Scale (SWLS) questionnaire like parents to subjectively evaluate their coping strategies. The psychometric properties were reported in the earlier sections.

4. Sibling social support: Child and Adolescent Social Support Scale (CASSS)

Researchers have also pointed out that the majority of support information was gained from the parents rather than from the youth themselves in previous ASD family research (see discussion in Section 3.3.2). A measure of perceived social support that is multidimensional and assesses support from multiple sources can advance understanding of the role of social support for siblings of children with special needs.

The Child and Adolescent Social Support Scale (CASSS), designed by Malecki, Demaray, Elliott, and Nolten (1999), is a 60-item multi-dimensional scale measuring children’s perceived informal social support from five sources: parents, teachers, classmates, close friends and others in school. Each subscale corresponds to one of the sources of support and consists of 10 items. Children and adolescents respond by rating each item according to its frequency (1 = Never to 6 = Always) and importance (1 = Not Important to 3 = Very Important). The latter explores the meaning of different types of support to the child. Using the information from the subscale scores, it is possible to explore the child’s use of different sources of support and, crucially, the importance of that support to the child. Total frequency and total importance scores can be calculated by summing all five frequency and importance ratings subscale.

The CASSS provides different age versions: Level 1 is appropriate for children aged 5 to 11 years old, and Level 2 is appropriate for use with children aged 11 to 18 years old. For logistical reasons, the Level 1 was used to cover the wider age group in the present research. Roughly 80% of the questions are the same in the two versions (Demaray & Malecki, 2003). The CASSS has demonstrated evidence for its psychometric properties. The reliability of the CASSS total scale in Level 1 is .95. The test-retest reliability is only available for Level 2. With two-months test-retest
reliability of Level 2 total scale is .70, as reported by the creators (Kerres Malecki & Kilpatrick Demary, 2002). The CASSS also shows moderate-to-high inter-correlations among the subscales, providing the convergent evidence for scores according to the authors’ report. The application of CASSS in research with families with a child with disabilities has not yet been extensively investigated. However, the reasons for choosing this measurement were that it included the completed psychometric properties from a wide range of children and adolescents, and from a relatively large sample size. Also, the Chinese translation version is also available and it has been used in a Taiwanese sample: the psychometric properties in Taiwan shows excellent consistency, with internal consistency ranges from .90 to .95 (Tsai, 2005). With the limited choice of support scales for children and adolescents, the CASSS was still considered to be the most suitable for the present research.

The CASSS was mainly measured the informal support from various sources. However, the formal support information was also gathered through parents in the demographic measurement and also in both TD siblings’ and parents’ interview.

5. Sibling Experience: Child and Adolescent Survey of Experiences (CASE)

The impact of stressful life events upon the family was assessed by TD sibling report using the Child and Adolescent Survey of Experiences (CASE) (Allen, Rapee, & Sandberg, 2012). The CASE questions are originally derived from the Psychosocial Assessment of Child Experiences (PACE) by the creators (Sandberg et al., 1993), a semi-structured interview of childhood experiences that covers the similar domains of life events.

The CASE is a checklist measuring childhood experiences with parent and child self-report versions. Overall, the creators found that items that relied on individual interpretation of an ambiguous term have poorer agreement from parents’ and child’s report (Allen, et al., 2012). It is said that children’s definition of things may differ from their parents. What define as a positive or negative life experience depends on individual’s subjective evaluation. Children’s personal interpretation is more central than a parents’ when assessing the stressors in child’s life. This is why the present
research only used the child report version to assess TD siblings’ life experience rather than rely on parents’ report. Both versions are free to download on-line\textsuperscript{14}.

The scale assessed the child’s life events in the past 12 months. Children or adolescents were first asked to report whether they had experienced these events or not. If they had experienced the event, they were asked to report the feeling of the experience by a 6-point scale from 1 (really good) to 6 (really bad). If they had not experienced the event listed, they circled the ‘no’ response and proceeded to the next life event. This approach let the respondents to decide whether the events were positive or negative to them, and then summed up the number of the positive and negative events in their life. Hence, this response format also involved how individual appraised the life experience to them as either positive or negative.

The CASE measure demonstrated satisfactory one-week retest reliability. The test-retest reliability for the total number of life events reported by mother and child was the same ($r = .75$) (Allen, et al., 2012). There were other life event measurements reviewed but not selected for the present research. For example, the Life Events and Difficulties Schedule (Bifulco et al., 1989), the Life Events Checklist (Johnson & Mccutcheon, 1980) and the Stressful Life Experiences Schedule (Williamson et al., 2003) were designed to measure traumatic and stressful events and placed less emphasis on positive life events. Echoing the construct discussed in the Section 4.5, the present study tried to balance measurement of the positive and negative experience of the family. Hence, using a measurement that included both positive and negative side of the life events and involved respondent’s cognitive appraisal of what the experiences meant to them had important application for the present research. There was no Chinese version of the CASE identified. Hence, the CASE was also translated by the research team and examined its translation validity followed by the process presented in the Section 4.7.

The present research aimed to find the measurements that met the constructs for the research model, with a preference for TD siblings’ self-report measures. These

\footnote{\url{http://www.psy.mq.edu.au/CEH/CASE.html}}
constructs included stressors, resources, coping and adjustment and were listed in the Table 4.3.
Table 4.3 Siblings’ measures and their psychometric properties

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Measurements</th>
<th>Assessed Domains</th>
<th>Psychometric Properties</th>
<th>Instructions for replacing data?</th>
</tr>
</thead>
</table>
| 1. Family adaptation: Sibling psychosocial adjustment | Strengths and Difficulties Questionnaire (SDQ) | ● Total difficulties scores (Emotional, Conduct, Hyperactivity, and Peer problems)  
● Prosocial behaviour scores | ***English version:**  
Internal consistency (α = .71–.82)  
Test–retest reliability (4 to 6 months \( r = .51-.62 \))  
***Chinese version:**  
Internal consistency (α = .40–.81)  
Test–retest reliability (8 week \( r = .71 \)) | Yes |
| 2. Coping: Sibling coping           | Kidcope                                           | ● Active coping  
● Avoidant coping  
● Negative coping | ***English version:**  
Test–retest reliability (1 week \( r = .13–.80 \); 2 week \( r = .16–.64 \))  
***Chinese version:**  
Not validated yet | No |
| 3. Family adaptation: Sibling subjective well-being | Satisfaction with Life scale (SWLS) | ● Total scores (person’s relative life satisfaction) | ***English version:**  
Internal consistency (α = .79–.89)  
Test–retest reliability (\( r = .83–.84 \))  
***Chinese version:**  
Internal consistency (α = .84) | No |
<table>
<thead>
<tr>
<th>Constructs</th>
<th>Measurements</th>
<th>Assessed Domains</th>
<th>Psychometric Properties</th>
<th>Instructions for replacing data?</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. <strong>Family adaptive resources:</strong></td>
<td>Sibling social support scale (CASSS)</td>
<td>● Various sources of support (parents, teachers, classmates, close friends and others in school)</td>
<td><em>English version:</em> Internal consistency ( \alpha = .95 ) for level 1; ( \alpha = .94 ) for level 2) ( r = .70 ) for Level 2</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Frequency and Importance subscales</td>
<td><em>Chinese version:</em> Internal consistency ( \alpha = .90-.95 )</td>
<td></td>
</tr>
<tr>
<td>5. <strong>Stressors:</strong> Life events</td>
<td>Life survey of experiences (CASE)</td>
<td>● Frequency of positive and negative events for the past 12 months</td>
<td><em>English version:</em> Test–retest reliability ( r = .75 ) ( r = .70 ) for Level 2</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>● Impact of the events</td>
<td><em>Chinese version:</em> Not validated yet</td>
<td></td>
</tr>
</tbody>
</table>
4.7 Questionnaire translations

There were two measurements required translation, one (Child and Adolescent Social Support Scale; Malecki, Demaray, Elliott, and Nolten, 1999) from English to Chinese, and the other (Coping Strategies in Chinese Social Context; Hsu, Chen, Wang, and Sun, 2008) from Chinese to English. The translators identified whether each item of the questionnaires was linked to the phenomenon of culture being studied. In this study, the first translated version of each scale was conducted by a professional translation service. After the first version was returned from the translation service, the examination of the translations was conducted following the guidelines suggested by Liang and Bogat (1994) and Guillemin, Bombardier, and Beaton (1993). The two main guiding principles were: semantic equivalence and content equivalence.

*Semantic equivalence* is checked by a back-translation procedure, translating back from the new language into the original source language. Two translators conducted back-translations independently from each other and one Chinese / English bilingual speaker then evaluated the equivalence of meaning in the two versions by using a 3-point rating scale (from 1 = low/questionable relevance to 3 = high/unquestionable relevance). Items that were rated as having ‘low’ equivalence were reworded to maintain consistency and translators repeated the same procedure again until high equivalence was achieved. See the examples of checking items semantic equivalence in Appendix C.

*Content equivalence:* In addition to semantic equivalence, it is important that the measures deal with concepts that are meaningful and relevant to the participants in both cultural settings. To achieve this, two bilingual Chinese-English speakers, and one Chinese linguistic expert rated each item on the translated scale for their relevance to Chinese culture using the same 3-point rating process. Those items rated as have ‘low’ or ‘questionable’ relevance were then discussed until the raters agreed that the wording produced good cultural relevance. Only 3 questions from the two translated measures had to be re-translated to ensure content equivalence.
The Coping Strategies in Chinese Social Context questionnaire (CSCSC, Hsu, Chen, Wang, & Sun, 2008) was designed specifically for the Chinese culture. As it has been shown that the Chinese have slightly different approach in coping from their Western counterparts (Hsu, et al., 2008; Siu, et al., 2006), the meaning of CSCSC items would be lost in any attempt to ensure content equivalence, as the content is designed to be specific to a culture. Therefore, the researcher only examined the semantic equivalence in this scale.

4.8 Ethical Issues

The research followed the guidelines and procedures of the School of Education Ethics Sub-Committee, University of Edinburgh. Other ethics guidelines such as the British Psychology Society and the Institutional Review Board (IRB) guidelines from the Taiwanese hospitals were also followed.

The research met the School Ethics Level 2 criterion (see copy in Appendix X). Furthermore, individual approval from city councils (Edinburgh City, Fife and Glasgow) also allowed the researcher to approach local schools to contact potential participants. The research data were collected and stored in accordance with the University’s responsibilities under the UK Data Protection Act 1998. For the Taiwanese data collection, Taiwan's Personal Information Protection Act was adhered to. The researcher of the present study has been working with families of children with special needs for 5 years and is qualified as a clinical psychologist in Taiwan.

The aims and purposes of research should be based on the benefit of the children. Children and adolescents should not be harmed in any way through involvement (Lewis & Porter, 2004). All the participants in this research were voluntary, and it was made clear that they could withdraw anytime without giving any reason. The confidentiality protection and procedure were also explained in the information sheets given to parents and TD siblings. Children and parents were made aware that only in the situation where the TD siblings were considered to be at risk according to Child Protection Act 1989, would the relevant authorities be contacted and action be considered (see Appendix E for the TD siblings’ information sheet).
During the course of the study, an application was made to a UK research database in order to recruit participants. At this point the Kidcope was questioned by some parents on the database ethics panel because it was originally designed for measuring child coping with mixed chronic disease. The reason that it was still used in the present research as the measurement for TD siblings’ coping was justified by previous research which used it with siblings of children with ASD, showing that the format was suitable for the younger children.

4.9 Procedure (including recruitment)

There were two recruitment routes in the UK. One was contacting parents via organizations/schools/hospitals and the other was advertising the study online direct to potential participants. The organizations in the UK were from a variety of settings, including: parent support groups for children with ASD or Asperger syndrome; associations for persons with ASD; special schools and related organizations. Nearly 250 enquiry emails were sent out to these organizations and parent support groups, and around 35 replies were received to assist in the recruitment process in the UK. The researcher got in touch with the key person in the organizations to discuss whether organization-specific ethical approval was required, such as National Autistic Society, in addition to the researcher’s institutional ethical approval (see Appendix D). When all the requirements were met, the researcher sent out parent and sibling information sheets (Appendix E) either by post or newsletters to families via the organizations. As for the schools, there were around 70 schools approached and about 20 were able to assist. The researcher sent the first enquiry letters to the school’s head teacher/key persons expressing the research aims and introducing the research. After schools agreed to assist the recruitment, and permission was obtained from the relevant city councils, such as Edinburgh, Fife and Glasgow councils, the researcher then prepared the information sheets in envelopes for the pupils to bring home to their parents.
The second route was through the social media. The research team set up a website\textsuperscript{15} and Facebook page for the research, aiming to provide more information for potential participants for the research. Links to these were circulated in professional and community networks on Twitter by the project supervisors.

The research gathered information from a parent and a TD sibling aged 9 to 18 years. The parent and child research information was initially developed through the discussion with thesis supervisors. English version of the information sheets were first developed, and then directly translated to the Chinese version. The drafts were then read by a pilot family who had a child with ASD and also a TD sibling to discuss whether the wording or information was clear and easy to understand in both Taiwan and the UK. There were no changes made at this point.

Informed consent was obtained from both the sibling and the parent/guardian. The research information was explained to TD siblings via the sibling information sheet, and the parents were also asked to help to explain the research, according to the siblings’ level of cognitive development. The present research relied on parents to ask their children whether they would like to participate in the study and to pass on the information about the research to them. It might be a risk that parents, in attempting to help the researcher, might inadvertently pressurize their children to participate. Several actions were taken to minimize this possibility. The informed consent information made certain that the children knew they had the choice to decide whether they would like to participate in the research and that they clearly understood their role in the research (Greig & Taylor, 2002). The researcher also provided research information that was appropriate for the children’s and adolescents’ level of cognitive ability. The siblings who did participate were provided a blank envelope to seal their research survey to ensure their confidentiality of these responses.

When the researcher received expressions of interest from parents, it ascertained whether the family met the recruitment criteria, and the researcher spoke with the

\textsuperscript{15} English website: http://www.dart.ed.ac.uk/tuks/; Chinese website: http://tukstaiwan.org/
parents or TD siblings to clarify the inclusion criteria/research procedure if necessary. If all the criteria were met, one of the parents and one sibling were invited to participate in the research and the researcher sent out a survey pack to the family. As in the literature review chapter (Section 3.2.3), the age differences between siblings were found to have influence on TD siblings’ adjustment. Hence, in families with more than one TD sibling, the one whose age is closer to ASD sibling was selected.

Two bound packs of questionnaires (one for the parent and the other for the sibling), each containing full instructions (see Appendix A), and a stamped addressed envelope were sent together for sending back.

Only a three reminder letters were sent out in total to each family, to avoid exacerbating stress for those who might be experiencing difficulties. The first one was sent to inform families that the questionnaires had been sent out to them. If the questionnaires were not returned 4 weeks after first correspondence, another reminder letter was sent. The last reminder letter was sent out after another two weeks and reassured the families that they were not obliged to respond or finish the questionnaire if they no longer wished to. The appreciation of their interests for the research and time of considering the participation was also mentioned. A thank you letter was sent out if the research team still did not hear back. Those families were then marked as ‘no return’ when counting the response rate.

As for the recruitment in Taiwan, the initial plan was to recruit the participants following the same recruitment procedure used in the UK. However, due to differences in standard research practice and in participant expectations, some different procedures were necessary. During the recruitment in Taiwan, the researcher found the number of organizations for children with special needs and parent support groups to be far less than in the UK, and that these are relatively closed groups to the public. Hence, there were systematic differences in the recruitment procedures in the UK and Taiwan.

An alternative recruitment route in Taiwan was via hospital and psychiatry clinics. Five hospitals and three clinics were approached. The researcher collaborated with doctors in three main hospitals and two clinics in Taiwan. The permission from the
Institutional Review Board (IRB) was obtained in each hospital. The type of participants might slightly differ from the other recruitment sources, since these ASD siblings were visited hospitals/clinics regularly. Furthermore, for the patient privacy, researcher could not have any direct contact without going through the hospital system.

The majority of parents recruited in Taiwan were from schools through teachers. Around 68 schools were contacted and 20 were able to assist. Due to the relation bond between teachers and parents, information was more easily passed on to the families with special needs this way than via support groups. The researcher therefore did not have direct contact with participants at this stage.

However, the researcher was very careful about the ethical considerations, making sure that the teachers did not pressure the parents or make them feel obligated to take part in the research. An explanatory form was sent to teachers to help them to pass the information to parents. As a direct quote from the letter to the teacher stated ‘Please do not pressure parents to keep participating in the research if they voice any concerns about continuing with the research.’

Secondly, some Taiwanese families preferred to be anonymous and not to have any information exposed about their family. Hence, a small number of families had their consent forms kept in the organizations or schools where they were recruited. The researcher still has access to the consent forms kept in these organizations. Such requests for anonymity and worries about being identified did not happen in the UK recruitment. This difference can be attributed to the cultural differences and how people view the families with disability/special needs (see discussion in Section 2.3).

Because the research aimed to explore the coping and adjustment of the siblings of children with ASD, it is possible that the process of answering the questionnaires may evoke their past experience and stress of being with their ASD siblings. Another possibility is that the present research might offend families by implying that there is stress when there isn’t or suggesting that the child with ASD might cause stress to their family. Similar to the BAP information gathered for the present research, the researcher had to be cautious about how participants interpreted them. The
information for introducing and explaining the questionnaires was provided in parents’ and TD siblings’ research survey respectively. This was carefully designed to ensure that participants were fully informed about why various measures had been included.

Another step taken to avoid increased stress for parents and siblings was that the cover letter sent with the questionnaires informed the participants of the following: (1) if the participants experience any discomfort during the process, they have the right to discontinue the research; (2) a list of support organizations that families can contact if required; (3) the participants were free to withdraw from the study at any time, without giving a reason.

All the families received a research summary after the research was completed. If the TD siblings had indicated in the questionnaires that they had very serious adjustment difficulties and very low levels of support, the researcher would have discussed with the thesis supervisors the need for further actions. However, none of the participants in this questionnaire study showed significant clinical concerns.

4.10 Analysis plan

In this section, there is a brief review of the data management and statistical analyses planned and justification of the choice of analysis techniques used. This research did not use matched groups due to the importance of maintaining the social / cultural phenomena of two cultures. Using the matched groups, may have eliminated the applicability and reality of the research in the real life settings. Where the UK and Taiwanese groups were compared on questionnaire scores, it is therefore important to bear in mind that these groups were not matched.

4.10.1 Describing the sample

All data were entered into an SPSS version 21 database (IBM, 2012) by the researcher and a postgraduate degree assistant who was fluent in Chinese, according to the published protocol for each individual measure. For example, some items in the SDQ subsets were reversed and then summed to create the subscale scores. The accuracy was confirmed by using a random sample checking procedure and was re-
checked by the researcher. Some data were checked from around 70% of participants. The scoring of the standardized questionnaires was based on the relevant questionnaire instructions regarding reverse scoring. Before conducting the analysis, the procedure was followed to check the data for signs of non-normal distributions by comparing means and medians, examining histograms, skew and kurtosis scores etc. In the following chapter, the demographics of the sample are described, followed by the description of domain scores from each questionnaire, using means and standard deviations for normally distributed data and medians where data were non-normal. The Cronbach's alpha data of the present measurements are listed in Appendix B.

If both parents and TD siblings filled in the same measurements, such as SDQ and Satisfaction With Life Scale, the differences between parent and sibling ratings were compared by using one-way ANOVA. Domain scores were also interpreted relative to published norms where available.

### 4.10.2 Missing data

If either a parent or a sibling missed a whole questionnaire or if over a third of any questionnaire was not complete, the data of that individual were noted as invalid for the analysis involving that questionnaire and excluded from the analysis.

The Little's MCAR test (Little, 1988) was used to check for each questionnaire whether the missing data was randomly missing. Randomly missing data were replaced following the questionnaire manual instructions, where available for example the Social Responsiveness Scale (Constantino, 2012), Autism Spectrum Quotient (Baron-Cohen, et al., 2006), Coping Strategies in Chinese Social Context (Hsu, et al., 2008) and SDQ (Goodman, et al., 1998) (see Appendix F for information). The estimated values were then entered according to the instructions. For example, the AQ score was corrected for missing items by making the following calculation: Total AQ score + (mean item score X number of missing items) (Hoekstra, et al., 2007). Details for the replacement of missing items from other measures can be found in the descriptions of the measures themselves in Appendix F.
The remaining questionnaires did not have instructions for dealing with missing data. For cases with less than 20% missing values on the total items within the questionnaire the expected maximisation (EM) algorithm was applied to replace the missing values. It is based on an estimate of the parameters of the data model and then an unbiased prediction is obtained for the missing values (Dempster, Laird, & Rubin, 1977). This process allowed the present research to retain maximum data points for analysis while minimising the impact of bias.

4.10.3 Comparison between the UK and Taiwan

To answer research question (RQ1 and 2), regarding the similarities and differences in the adjustment and coping of TD siblings in Taiwan and the UK according to their parents and the siblings themselves, several statistics analyses were conducted. After confirming the data normality and dealing with missing data, a series of analyses of variance (ANOVA) and t-tests for continuous data and chi-square tests for categorical variables were performed.

4.10.4 Associations with sibling adjustment: Testing the model I

Research question 3a, b and c (see Section 4.2) aim to explore whether the research model accurately reflected the influences on TD siblings’ adjustment and coping. To examine the associations between potential predictors and adjustment difficulties in siblings, a series of correlational analyses were performed. Variables were selected based on the proposed model for the research (see Section 3.5.3 and Section 4.5). Correlational analyses were also performed to determine if various variables were correlated to the coping strategies of TD siblings. Those significant variables were subsequently investigated using regression analysis to identify predictive relations.

4.10.5 Predictors of sibling adjustment: Testing the model II

The analysis in this section aimed to find the variables that could predict TD siblings’ adjustment outcome. There were various variables considered, following the results from the previous section which examined the associations with sibling adjustment. The reason for choosing the specific regression method is also discussed.
Stepwise regression is commonly used for exploratory data analysis, especially when a large number of variables are to be considered (Cohen, Cohen, West, & Aiken, 2013). This method helps to identify the variables that explain the greatest variation for the dependent variables that the researcher is interested in. Stepwise regression combines the advantage of forward selection and backward elimination. Firstly, based on forward selection, the predictor variables are entered one at a time to decide whether the predictor variable achieves statistical significance. The variables which have the highest correlation with the dependent variable are left in the model. Secondly, the backward elimination step is also considered every time when the new predictors are entered. The entered predictors are deleted in subsequent steps if they no longer contribute appreciable unique predictive power to the regression when considered in combination with newly entered predictors. Lastly, forward selection and backward elimination allowed all the predictors in the model to contribute to the prediction of the dependent variable, thus achieving the best predictors for the model.

Although stepwise regression is useful to determine the most predicative variables in the model when there are large numbers of predictors to explore, it is also criticised for relying too much on the statistics software. Unlike the automatic, mindless processing of the statistic software, the researcher should have more control of the decision based on the theory and the data. There are several drawbacks of using stepwise regression, such as replicable difficulties, sampling error, and the increase of Type I errors (see discussion from Cohen, et al., 2013; Mcintyre, Montgomery, Srinivasan, & Weitz, 1983).

The replication difficulty is also a major concern when choosing the stepwise regression. As stated in Menard’s book (2010), the procedure of stepwise regression is idiosyncratic and difficult to replicate in any other sample unless it was obtained exactly the same way as the original. Furthermore, selecting the appropriate statistical tool for analysis depends on the intended use of the analysis. One of the present research aims is to provide clinical and practical suggestions. If the result is not applicable and is limited to certain populations, then it loses the original intention of this research.
In the present study, some key variables have been examined and discussed in previous research. Hence, another approach, hierarchical multiple regression analysis, would better identify the best multiple linear regressions for predicting the TD siblings’ adjustment using the variables that this research had investigated.

In addition to the difference in their underlying philosophies, the operating differences between stepwise and hierarchical regression analysis are that the order of entry of predictor variables in hierarchical regression are made in advance, in contrast with stepwise regression (Cohen, et al., 2013). The order of entering the predictor variables is based on theory and the researcher’s decision. From 1987 to 2014, there were 9 published papers using the Double ABCX model to discuss topics related to ASD and their family. Four of them entered predictor variables into the multiple regression equation based on the Double ABCX model, and all supported the use of this model as an analysis framework (Manning, et al., 2011; Mcstay, et al., 2014; Pakenham, et al., 2005; Renty & Roeyers, 2007).

Given that numerous variables might influence the outcome, Pearson correlation (for continuous data) and ANOVA (for categorical data) were conducted to explore the variables that had significant relations to the outcome variables. Only those variables that were correlated to TD siblings’ adjustment at the bivariate level were included as predictors in the hierarchical multiple regression analyses.

4.10.6 Moderator analyses: Testing the model III

The research question 3c considers whether the variables have the same influence in Taiwanese and the UK model. Hierarchical regression models were used to examine the moderators, following the Baron and Kenny (1986) approach. The moderator analyses were processed based on the results of the previous analyses.

To examine the fit of the Diathesis-stress model, the interaction effect between stressors and diathesis factors (i.e. parents’ and TD siblings’ BAP level) were also examined. There are more details of moderator analyses along with the process of data analyses in Chapter 6.
4.11 Summary

In summary, this chapter reviewed the constructs scrutinized in the present study, and described measures of parents and siblings self-reports that were selected to evaluate these constructs. Measures were selected using a series of criteria including relevance to research questions, satisfactory psychometric properties, suitability for the age-range and previous use in Chinese populations. A summary of the measures and constructs selected is shown in Table 4.2 and 4.3. The recruitment process was also described. Finally, in Section 4.10, an analysis strategy for the data was outlined.
Chapter 5: Questionnaire study results part I: Adjustment and coping in families of children with ASD

This chapter reports several analyses that explored the relations between variables and comparisons between the Taiwanese and the UK samples. Because most measures are Western in origin, the researcher first analyzed the UK data alone, in order to provide a reporting framework, and then compared data between Taiwan and the UK to identify national differences.

The first section of this chapter explains the analysis approach and data processing. Secondly, the demographic information is analyzed, followed by comparison of the adjustment and coping style between Taiwanese and the UK families. A series of comparisons between two countries in terms of Broader Autism Phenotype, siblings’ social support and life experience, and life satisfaction of parents and TD siblings are also presented.

Using correlation analysis guided by the research model then helped the researcher to explore the possible relations between variables in a systematic way. Due to the complexity and variety of the variables in the research model, correlation analysis was the first step to decide which predictors to enter into the regression model. This chapter is looking at the first 2 research questions – The similarities and differences in the adjustment and coping of TD siblings in Taiwan and the UK according to their parents and the siblings themselves.

5.1 Analysis methods

The specific statistical analyses used were chosen according to the types of variables involved, and this is described in detail below. However, some general principles applied. Before the statistics analysis, the general assumption of the normal distribution needed to be met. When comparing two data sets, the homogeneity of variance was also checked. If Levene’s test for equality of variances indicated a significant difference between the two country groups, the alternative t-test results were reported. Bonferroni corrections for multiple comparisons were applied when more than 5 variables were examined (Curtin & Schulz, 1998). All the following
analyses followed these criteria. Furthermore, the predictors for the UK and Taiwanese model are also presented in the Figure 6.1 and 6.2 to provide a visualization of the relationships in the model.

5.1.1 Inclusion and exclusion criteria

For the Taiwanese sample, 7 out of 98 dyads were excluded from the analysis because they had missing more than 20% of the whole research survey (these questionnaires came from 7 separate individuals, 5 were parents and 2 were siblings). For the UK sample 3 out of 87 dyads were excluded from the analysis (these questionnaires came from 3 separate parents). In total, there were 92 dyads of research survey (both from parents and TD siblings) in Taiwan and 84 dyads of research survey in the UK were completed data. Problems of missing data were minimal, less than 2% of the data from each valid questionnaire needed to be replaced, as follow-up correspondence was sent to participants to obtain missing information. The results from Little's MCAR test (Little, 1988) indicated that these data were randomly missing; that is, there was no discernible pattern of missing data.

Because culture and BAP characteristics were important factors in this research, participants who had multiple cultural backgrounds or were not biologically related to the TD siblings and ASD siblings were excluded from the analyses. Hence, 3 out of the 92 participants in Taiwan and 7 out of the 84 in the UK were excluded from the analyses. The following analyses were therefore based on 89 and 77 dyads of participants in Taiwan and the UK respectively.

Even though there are different approaches suggested to deal with missing category values, in this research the demographic data remained missing in the analysis to maintain the originality of cultural phenomenon. Due to the approach of dealing with missing data in the demographic measurement, the participant numbers vary throughout the analysis and percentages do not add up to 100% all the time.

Nine out of 89 questionnaires in Taiwan and 2 out of 77 questionnaires in the UK were completed by fathers. All the data analyses presented included mothers’ and fathers’ responses. Difference between parents’ response were also discussed if any.
5.1.2 Normality testing

The normality of the data was also checked before processing further analyses. The procedure suggested by Ghasemi and Zahedias (2012) and Kim (2013) was used to check data normality. The data was checked separately by country. Firstly, total mean and median scores of each questionnaire were compared. Skewness and kurtosis scores from SPSS were also examined. The absolute z-score values of skewness and kurtosis could be obtained by dividing their standard errors to check normality. The calculation is as follows:

\[ z_{\text{skewness}} = \frac{\text{Skewness} - 0}{SE_{\text{skewness}}} \quad \text{and} \quad z_{\text{kurtosis}} = \frac{\text{Kurtosis} - 0}{SE_{\text{kurtosis}}} \]

For medium-sized samples \((50 < n < 300)\), an absolute z-value larger than 3.29 indicated non-normal distribution. All the data were normally distributed, except for the following scales listed in Table 5.1. Two SDQ subscales were positively skewed (Figure 5.1 and 5.2), suggesting that Taiwanese siblings reported less adjustment difficulties than UK siblings, and that UK parents reported less difficulties for their TD children than Taiwanese parents.

In order to solve the positive skew, square root transformation was used (Osborne, 2002). With the equation \(Y = \sqrt{X + 1}\), all parents’ and siblings’ SDQ data from both countries were transformed. After adjusting, all the data (both from Taiwan and the UK and from parents’ and siblings’) were normally distributed. In the following analyses, all the SDQ total difficulties data is post-transformation data.
Table 5.1 Data showing non-normal distribution in the parents’ and siblings’ SDQ questionnaires

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Mean (SD)</th>
<th>Median</th>
<th>Z values</th>
<th>Adjusted Z values</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Taiwan</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings’ self-reported SDQ total difficulties score</td>
<td>12.17(5.10)</td>
<td>12.00</td>
<td>$Z_{sk} = 3.60$</td>
<td>$Z_{sk} = 2.60$</td>
</tr>
<tr>
<td><strong>UK</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent rated SDQ total difficulties score</td>
<td>9.59 (7.07)</td>
<td>9.00</td>
<td>$Z_{sk} = 4.51$</td>
<td>$Z_{sk} = 1.64$</td>
</tr>
</tbody>
</table>

Figure 5.1 The original distribution of siblings’ self-reported SDQ total difficulties score: Taiwanese data
Figure 5.2 The original distribution of parents’ rated SDQ total difficulties score: UK data

5.2 Similarities and differences in demographic variables in Taiwan and the UK

A series of one-way ANOVAs and Chi-square tests were conducted to examine similarities and differences between family demographic characteristics in Taiwan and in UK. Means and standard deviations were calculated for all normally distributed interval level variables, while percentage was reported for nominal and ordinal scale.

Figure 5.3-5.6 and Table 5.2 present the parental, ASD siblings and TD siblings’ characteristics by country group. These show that there were some significant differences between families in Taiwan and the UK with respect to their social economic status (SES), such as education level, employment status, job titles and financial status. The household income variable was chosen to represent social economic status, because it has been found to relate closely to individual well-being (Office for National Statistics, 2014c). In the families with children with ASD, some parents may adjust their employment because they need to take care of the diagnosed children (see demographic information listed in Table 5.2). As the employment status
only referred to the parent who filled in the questionnaire, overall household income was considered to be a better index to represent the social economic status of the family. Furthermore, only one positive correlation between parental education level and household income was found in the Taiwanese families. None of the other variables significantly correlated with each other in either Taiwan or the UK. This further supported the notion discussed above that parents might adjust their career in order to take care of their children. Hence, the household income would be a relatively stable index for representing the SES.

The household income data from each country group were transformed into Z-scores to standardize the data according to the official income report of each country. The mean disposable income in the UK was around £31,834, while the Taiwanese average income is around £19,503 (National Statistics, 2013; Office for National Statistics, 2014a). The incomes of 60.3% of the present UK families and 59.3% of the Taiwanese families were above the average according to each country’s income report.

The UK parents had significantly higher education level than the Taiwanese parents. Parents in the UK sample were approximately twice as likely to have a higher education degree. Significantly more UK parents were in professional or non-manual skilled job positions and reported that their situation was financially manageable. Furthermore, more UK parents were not working full-time. They also had more children in the family than the Taiwanese sample. Even when fathers’ responses were removed, this did not account for the full-time/part-time working difference between Taiwan and the UK.

In terms of the TD siblings’ characteristics, they were broadly similar on a large number of demographic variables including age and gender. However, there was a significant difference in TD-ASD siblings’ age difference in Taiwan and the UK. The UK siblings had a wider age gap than the Taiwanese counterparts (see Table 5.2).

Regarding the children with ASD, there was no significant difference in the diagnosis (ASD or Asperger’s syndrome) or in the severity of the diagnosis. The majority of the diagnoses of the children were ASD (72.3% in Taiwan and 61.8% in
the UK), while 27.7% in Taiwan and 38.2% in the UK were diagnosed with Asperger’s syndrome. The numbers of children with these diagnoses did not differ between the two countries ($\chi^2(1, N = 159) = 1.97$).

Furthermore, the severity of the children with ASD did not differ significantly between the Taiwanese and the UK samples. Children with ASD in Taiwan had significantly higher rates of combined intellectual disability, while their UK counterparts had significantly higher rate of comorbid diagnoses. The comorbidity included attention deficit hyperactivity disorder, obsessive compulsive disorder, and epilepsy (Appendix G). The comorbidity rates were lower than in previous studies but highlighted the same pattern of difference between countries. In a prevalence survey of children with ASD in the UK, 70% of the participants had at least one comorbid disorder, and 41% had two or more (Simonoff et al., 2008). Similar research conducted in Taiwan found that 45.7% of the children with ASD had one comorbidity, and 5.3% had more than one comorbidity (Chang, Yen, & Yang, 2013). These two studies may provide a preliminary picture of the difference in clinical/diagnostic practice in Taiwan and the UK.

A higher percentage of the children with ASD in the UK sample were in the mainstream school (52.6%), while the majority of Taiwanese sample had combination education (51.1%) (Figure 5.3). This may reflect differences in the school system policy in the two settings (Wang, 2009).
Table 5.2 Parental and child characteristics of Taiwanese (TW) and the United Kingdom (UK) samples

<table>
<thead>
<tr>
<th>Parental characteristics</th>
<th>TW sample (n = 89)</th>
<th>UK sample (n = 77)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship status (%) with partner</td>
<td>95.5%</td>
<td>82.9%</td>
<td>$\chi^2 (1, N = 164) = 6.92^{**}$</td>
</tr>
<tr>
<td>Level of education</td>
<td>see Figure 5.4</td>
<td></td>
<td>$\chi^2 (5, N = 164) = 21.75^{**}$</td>
</tr>
<tr>
<td>Employment status</td>
<td>see Figure 5.5</td>
<td></td>
<td>$\chi^2 (3, N = 165) = 23.87^{***}$</td>
</tr>
<tr>
<td>Job description</td>
<td>see Figure 5.6</td>
<td></td>
<td>$\chi^2 (6, N = 156) = 25.14^{***}$</td>
</tr>
<tr>
<td>Annual household income (£) Mean (SD) (range)</td>
<td>22,714.39 (13,869.44) (0-58770)</td>
<td>38,631.03 (18,471.73) (0-80000)</td>
<td></td>
</tr>
<tr>
<td>Lower level</td>
<td>16.7%</td>
<td>5.2%</td>
<td>$\chi^2 (2, N = 112) = 5.23^{**}$</td>
</tr>
<tr>
<td>Middle level</td>
<td>35.2%</td>
<td>29.3%</td>
<td></td>
</tr>
<tr>
<td>Upper level</td>
<td>48.1%</td>
<td>65.5%</td>
<td></td>
</tr>
<tr>
<td>Finance status (%) ‘Alright’</td>
<td>51.2%</td>
<td>73%</td>
<td>$\chi^2 (1, N = 156) = 7.78^{**}$</td>
</tr>
<tr>
<td>Others provide unpaid childcare (%) yes</td>
<td>28.1%</td>
<td>42.1%</td>
<td>$\chi^2 (1, N = 165) = 3.56$</td>
</tr>
<tr>
<td>Nationality (%)</td>
<td>TW 98.9%, China 1.1%</td>
<td>UK 96.1%, Irish 3.9%</td>
<td></td>
</tr>
</tbody>
</table>

16 The income was zero because family was relied on benefits.
**Child’s characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD) (range)</th>
<th>Mean (SD) (range)</th>
<th>t (119.86)</th>
<th>t (153)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of children</td>
<td>2.28 (0.50) (2-4)</td>
<td>2.67 (0.84) (2-5)</td>
<td>-3.52**</td>
<td></td>
</tr>
<tr>
<td>CWA age in years</td>
<td>12.21 (3.62) (4.02-21.49)</td>
<td>11.22 (3.51) (5.02-21.34)</td>
<td></td>
<td>1.72*</td>
</tr>
<tr>
<td>TD sib age in years</td>
<td>12.62 (2.81) (7.22-18.03)</td>
<td>12.75 (2.43) (8.59-17.73)</td>
<td>-0.30</td>
<td></td>
</tr>
<tr>
<td>CWA and TD sib age difference</td>
<td>-0.42 (3.29) (-8.13-10.65)</td>
<td>-1.53 (3.52) (-9.88-6.04)</td>
<td>2.03*</td>
<td></td>
</tr>
<tr>
<td>CWA Gender</td>
<td>83.1%</td>
<td>87%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TD sib gender</td>
<td>38.2%</td>
<td>37.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TD sib relationship with CWA</td>
<td>100%</td>
<td>94%</td>
<td>Non-significant</td>
<td></td>
</tr>
<tr>
<td>CWA living at home</td>
<td>96.4%</td>
<td>94.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CWA severity (T scores)</td>
<td>78.55 (8.92) (55-90)</td>
<td>79.95 (9.17) (55-90)</td>
<td>-0.10</td>
<td></td>
</tr>
<tr>
<td>CWA presence of ID</td>
<td>48.3%</td>
<td>24.7%</td>
<td></td>
<td>9.86**</td>
</tr>
<tr>
<td>CWA comorbid diagnosis</td>
<td>19.5%</td>
<td>46.1%</td>
<td></td>
<td>12.71***</td>
</tr>
<tr>
<td>CWA type of school attended</td>
<td>see Figure 5.3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: TD sib = typically developing sibling, CWA = children with ASD, ID = intellectual disability.

* p < .05; ** p < .01; *** p < .001
Figure 5.3 Type of school attended by the children with ASD

Figure 5.4 Parents’ educational level
Figure 5.5 Parents’ employment status

- Full time: UK - 23.7%, TW - 51.7%
- Part time: UK - 11.2%, TW - 42.1%
- Retired: UK - 1.3%, TW - 2.2%
- Not currently employed: UK - 32.9%, TW - 34.8%

Figure 5.6 Parents’ job description

- Professional: UK - 56.5%, TW - 26.4%
- Non-manual skilled: UK - 17.2%, TW - 23.2%
- Manual skilled: UK - 1.4%, TW - 5.7%
- Partly skilled: UK - 2.9%, TW - 3.4%
- Unskilled: UK - 10.3%, TW - 2.9%
- Homemaker: UK - 11.6%, TW - 36.8%
5.3 RQ 1: Similarities and differences in sibling adjustment in Taiwan and the UK

5.3.1 Within-country

The specific strength of the present study is that it uses not only parents’ reports but also siblings’ self-report to evaluate sibling adjustment. In order to compare the parents’ and siblings’ responses on SDQ total difficulties and prosocial behaviour, a paired-sample t-test was used for the transformed SDQ data reported in Table 5.3, for each country separately. This analysis showed that there was no significant difference in the parents’ and siblings’ scores on SDQ (on any sub-scales, on total difficulties or prosocial behaviour score) in the Taiwanese sample, suggesting that Taiwanese parents and siblings had similar perceptions of the siblings’ level of psychosocial adjustment. Compared to the norm data gathered by Liu, et al. (2013) and Yang (2011), the present Taiwanese data scored higher on emotional symptom (t (88) = 2.13, p < .05), hyperactivity/inattention (t (88) = 2.22, p < .05), peer problems(t (88) = 3.19, p < .01), and lower on prosocial behaviour (t (88) = -3.33, p < .01) according to parents’ report. As for TD siblings’ self-report, the present Taiwanese sample scored higher on peer problems (t (88) = 3.23, p < .01), and less emotional symptom (t (88) = - 4.96, p < .001) and prosocial behaviour (t (88) = - 4.09, p < .001) (see Appendix H for normative information). As previously mentioned, SDQ scores can be used to further classify the participants into three clinical categories – normal, borderline and abnormal – according to each country’s normative data (see Appendix H). With only parents’ report on peer problems classified as borderline range, other domains were classified within the normal range.

In the UK sample, however, significant differences between parents’ and siblings’ response were found in emotional symptoms, conduct problems, hyperactivity/inattention, peer problems and total difficulties score. For all of these subscales, TD siblings in the UK evaluated themselves as having greater adjustment difficulties than their parents’ observation. There were no differences for the prosocial subscale.

The differences between the parents’ and children’s responses within the UK sample highlighted the importance of using multiple information while assessing children’s
behaviour and adjustment. These differences between the parents’ and children’s measures led to the decision to use the siblings’ measure as the main outcome variable; the reason being that this study has more of a focus on how the siblings evaluate their own adjustment. As Senner and Fish (2010) suggested using self-report could identify the needs of siblings more directly and support or intervention could target more on their needs. Furthermore, adolescents reports have been found to be as valid as adult informants (Becker, Hagenberg, Roessner, Woerner, & Rothenberger, 2004). Further discussion regarding what may contribute to this difference is presented in Chapter7.

As for the comparison between the country’s norm, UK parents reported their TD children to have more emotional symptom (t (76) = 2.70, p < .01), peer problems (t (76) = 2.36, p < .05) and less prosocial behaviour (t (76) = -2.33, p < .05). For the TD siblings’ self-report, with the exception of prosocial behaviour, all the problems subscales were higher than the British normative data (emotional symptom (t (76) = 4.42, p < .001), conduct problems (t (76) = 2.66, p < .01), hyperactivity/inattention (t (76) = 3.61, p < .01), and peer problems (t (76) = 10.88, p < .001), indicating the elevated adjustment difficulties in the UK siblings. As for the clinical category, both parents’ and TD siblings’ report on peer problems were in the borderline range, while other domains were classified within the normal range.
Table 5.3 Mean (SD) Sibling SDQ adjustment scores (parent and self-rated)

<table>
<thead>
<tr>
<th></th>
<th>TW sample (n = 89)</th>
<th>UK sample (n = 77)</th>
<th>t-value (effect size)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parents</td>
<td>Siblings</td>
<td>Rater</td>
</tr>
<tr>
<td>Total Difficulties score a</td>
<td>3.5 (1.0)</td>
<td>3.7 (0.7)</td>
<td>-2.0 (0.12)</td>
</tr>
<tr>
<td>Emotional Symptoms</td>
<td>2.6 (2.4)</td>
<td>2.9 (2.3)</td>
<td>-1.0 (0.13)</td>
</tr>
<tr>
<td>Conduct Problems</td>
<td>1.9 (1.6)</td>
<td>2.2 (1.5)</td>
<td>-1.3 (0.17)</td>
</tr>
<tr>
<td>Hyperactivity/Inattention</td>
<td>4.4 (2.8)</td>
<td>4.3 (2.1)</td>
<td>0.3 (0.04)</td>
</tr>
<tr>
<td>Peer Problems</td>
<td>3.1 (2.4)</td>
<td>2.7 (1.7)</td>
<td>1.5 (0.20)</td>
</tr>
<tr>
<td>Prosocial Behaviour b</td>
<td>6.4 (2.6)</td>
<td>6.8 (2.2)</td>
<td>-1.2 (0.16)</td>
</tr>
</tbody>
</table>

Note: a Adjusted scores (square root transformation); b Higher scores indicate more prosocial behaviour.

* p < .05;  ** p < .01; *** p < .001
5.3.2 Between-country

In the between-country comparison of the parents’ scores, it was found that Taiwanese parents reported that their TD children had significantly more problems in terms of hyperactivity/inattention, peer problem and total difficulties score than did the UK parents (see Table 5.3 for details). Taiwanese parents also rated their children as having significantly lower prosocial behaviour compared to the UK parents’ ratings of the siblings.

With the exception of the hyperactivity/inattention subscale, the UK siblings evaluated themselves as having significantly more adjustment difficulties but also perceived themselves as having significantly higher prosocial behaviour than their Taiwanese counterparts (Table 5.3).

In terms of clinical categories, there were more UK siblings evaluated by their parents in the normal range on the total difficulties scores than the Taiwanese siblings, which was 76.6% and 64% respectively. Similar patterns were also shown in the prosocial behaviour, where UK parents again had more positive evaluation of their TD children’s prosocial behaviour than the Taiwanese parents.

In contrast to UK parents’ evaluation, TD siblings in the UK showed they had more adjustment difficulties than their Taiwanese counterparts. However, positive evaluation of displaying the prosocial behaviour still found in the UK than the Taiwanese sibling according to their self-report. Again, this clinical category information was consistent with the impression of SDQ scores from the previous table. Figure 5.7 and 5.8 present the percentage of the parents’ and siblings’ self-reports on SDQ scores according to the clinical category.
Figure 5.7 Comparison of parents’ report and siblings self-report on Total Difficulties (by SDQ clinical category)

<table>
<thead>
<tr>
<th></th>
<th>Parents TW</th>
<th>Siblings TW</th>
<th>Parents UK</th>
<th>Siblings UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abnormal</td>
<td>22.5%</td>
<td>5.7%</td>
<td>14.3%</td>
<td>22.7%</td>
</tr>
<tr>
<td>Borderline</td>
<td>13.5%</td>
<td>5.7%</td>
<td>9.1%</td>
<td>25.3%</td>
</tr>
<tr>
<td>Normal</td>
<td>64.0%</td>
<td>88.6%</td>
<td>76.6%</td>
<td>52.0%</td>
</tr>
</tbody>
</table>

Figure 5.8 Comparison of parents’ report and siblings self-report on Prosocial Behaviour (by SDQ clinical category)

<table>
<thead>
<tr>
<th></th>
<th>Parents TW</th>
<th>Siblings TW</th>
<th>Parents UK</th>
<th>Siblings UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abnormal</td>
<td>23.6%</td>
<td>13.5%</td>
<td>2.6%</td>
<td>1.3%</td>
</tr>
<tr>
<td>Borderline</td>
<td>14.6%</td>
<td>15.7%</td>
<td>6.5%</td>
<td>7.8%</td>
</tr>
<tr>
<td>Normal</td>
<td>61.8%</td>
<td>70.8%</td>
<td>90.9%</td>
<td>90.9%</td>
</tr>
</tbody>
</table>
5.3.3 The influence of demographic variables on sibling adjustment

As reviewed in the Section 3.2, various demographic variables might directly or indirectly influence TD siblings’ adjustment outcome. The relations with psychological variables and adjustment are explored later.

These demographic variables, as described in the measurement constructs, were analysed to check whether they might linked with outcome variables (SDQ total difficulties and prosocial behaviour scores). The data from Taiwan and the UK were tested separately. ANOVAs were conducted on the categorical data (parents’ relationship status, education level, employment status, financial status and gender of child) while correlations were conducted on the continuous data (age of child, age gap between siblings, family size and household income).

There was no significance difference found in sibling adjustment across different categories for the following variables (parents’ relationship status, employment status, financial status and gender of child) in Taiwan and the UK respectively. The only exception is in the Taiwanese sample, where parents’ rating of SDQ prosocial behaviour scores significantly differed between parents’ education level ($t (87) = 2.83, p < .05$). Parents with higher educational levels reported more prosocial behaviour of the siblings.

For the continuous data, neither of the parents’ or the siblings’ reports on SDQ showed significant correlations between the age of child with ASD and TD sibling, age gap between siblings or family size in Taiwanese sample. As for the UK sample, the parents rating on the SDQ of both prosocial behaviour score ($r = 0.27, p < .05$) and total difficulties score ($r = -0.27, p < .05$) had significant correlations with the age of the child with ASD. The older the child with ASD was, the higher the prosocial score and the lower the total difficulties score of the TD child, according to the parent report. UK Parents’ rating on SDQ prosocial behaviour also had a significant correlation with the age gap between siblings ($r = 0.25, p < .05$). The bigger age gap between siblings, the more prosocial behaviour parents observed from their TD child. Furthermore, there was a negative correlation between the parents’ rating on SDQ prosocial behaviour and family size ($r = -0.27, p < .05$). The more
children a family has, the less prosocial behaviour the parents reported in siblings’ SDQ. As mentioned in Section 5.2, the standardised household income (Z-scores) was used as the SES index. None of the country groups showed significant correlations between the standardized household income and siblings’ adjustment outcome (either on parents’ or siblings’ report).

5.3.4 Summary

The SDQ was explored in this section. In the within-country comparison, Taiwanese parents and siblings had more consistent points of view regarding the adjustment of the sibling. There was no difference between the parents’ and siblings’ reports in Taiwanese sample, while in the UK, differences were found across the majority of subscales. However, UK parents and TD siblings did have similar evaluation of the display of prosocial Behaviour. The similarity can be seen in the SDQ raw scores and in the clinical category information according to each country’s norms.

As for the between-country comparison, Taiwanese parents reported their children to have more adjustment difficulties than their UK counterparts. Conversely, UK siblings rated themselves as experiencing more adjustment difficulties than their Taiwanese counterparts. Moreover, both the parents and siblings in the UK sample reported significantly higher prosocial behaviour than the Taiwanese sample.

Regarding the demographic variables and SDQ analysis, the majority of the demographic variables did not have significant relations with the TD siblings’ adjustment outcome in the Taiwanese sample. Only higher parents’ educational level was correlated to better parents’ report on SDQ prosocial behaviour scores. No significant relations were found with the sibling SDQ self-reports.

As for the UK families, having older ASD siblings was correlated to better outcomes in parent-reported SDQ prosocial score and total difficulties scores. Likewise parent-rated prosocial behaviour was also associated with wider sibling-ASD age gap and with a smaller family size. Since many of these issues may co-occur in the same families it is not clear which is the most relevant influence. It is interesting that the age of the ASD siblings and the age gap between siblings had positive relations with
parents’ report on SDQ prosocial score, but TD siblings’ age itself did not have such a relation. The age effect on the TD siblings’ adjustment is discussed in Chapter 7.

5.4 RQ2: Similarities and differences in siblings’ and parents’ coping in Taiwan and the UK

In this section, the analyses of coping styles in parents and siblings and between Taiwan and the UK are reported. The country differences and then associations between parental and sibling coping within each country were analyzed separately.

5.4.1 Siblings’ coping

The TD siblings’ coping style was assessed using the self-report Kidcope measure (Spirito, et al., 1991), the scores of which can be categorised into three coping styles (Section 4.6.2 sibling questionnaire 2), namely active coping, negative coping and avoidant coping. In terms of coping style, two subscale comparisons were significantly different across the two countries: active coping (t (128.58) = 3.35, \( p < .01 \)) and negative coping (t (158) = 5.21, \( p < .001 \)). Taiwanese siblings more often opted for active coping (\( M = 3.48, SD = 0.69 \)) than their UK counterparts (\( M = 2.99, SD = 1.08 \)). Taiwanese siblings also used more negative coping (\( M = 1.04, SD = 0.82 \)) than UK siblings (\( M = 0.43, SD = 0.64 \)). There was no significant difference in the use of avoidant coping.

The siblings could further rate the efficacy of the coping strategies if they reported having used such strategies. Taiwanese siblings rated active coping (\( M = 7.07, SD = 2.22 \)) as the most effective style among others, while UK siblings rated avoidant coping (\( M = 6.60, SD = 2.92 \)) the most effective. Both country groups rated negative coping as the least effective. There was no significant differences between country except for negative coping (\( t(107.30) = 2.30, p < .05 \)); Taiwanese siblings rated negative coping as significantly less effective than did their UK counterparts.
5.4.2 Influence of demographic variables on siblings’ coping

The demographic variables were checked again to see if they correlated with the siblings’ coping style. ANOVAs were conducted on the categorical data (parents’ relationship status, education level, employment status, financial status and gender of child), while correlations were conducted on the continuous data (age of child, age gap between siblings, family size and household income).

In the Taiwanese sample, avoidant coping was found to correlate with the age of ASD siblings ($r = .35, p < .01$) and the age of the TD siblings ($r = .30, p < .01$). No significant correlations or ANOVA results were found in the UK sample.

5.4.3 Parents’ coping: Western concepts

Table 5.4 presents the means and standard deviations for the 15 subscales of the parent COPE Inventory (Carver et al. 1989). There are clear differences in terms of the coping patterns in Taiwan and the UK. Taiwanese parents seemed to use reappraising the situation and emotional approach more, while UK parents used more action, problem-solving approach. The instrumental social support also played an important role in both countries. The data in Table 5.4 showed that the three most frequently reported coping strategies used by the Taiwanese sample were: positive reinterpretation and growth ($M = 12.93, SD = 2.11$); acceptance ($M = 12.82, SD = 2.28$); and use of instrumental social support ($M = 12.72, SD = 2.60$). As for the UK sample, planning was the most frequently used strategy ($M = 12.34, SD = 2.47$), followed by active coping ($M = 11.85, SD = 2.36$) and use of instrumental social support ($M = 11.82, SD = 2.95$). The least used coping strategies were substance use strategy in Taiwan and denial strategy in the UK.

For the majority of subscales (9), Taiwanese parents reported using these strategies more than the UK parents did. Only one strategy (substance use) was reported as being used more by the UK parents than the Taiwanese parents, and for five of the strategies there was no difference between the countries. Examination of the difference between scores indicated that Taiwan and the UK samples were most different in religious coping (Difference = 2.73), with Taiwanese parents using this
strategy far more, while the lowest level of cross-cultural differences were found in the use of planning strategies (Difference= 0.03).

The frequency of using each of the three coping styles was established by summing the scores in the subscales (see Section 4.6.1 parent questionnaire 3). Both country groups used more problem-focused coping (TW sample: \( M = 11.76, \text{SD} = 1.85 \); UK sample: \( M = 11.47, \text{SD} = 2.04 \)) than emotional approach coping (TW sample: \( M =11.44, \text{SD} = 1.78 \); UK sample: \( M = 9.43, \text{SD} = 1.69 \)). Passive avoidant emotion-focused coping was the least used in both countries (TW sample: \( M = 8.63, \text{SD} = 1.52 \); UK sample: \( M = 7.77, \text{SD} =1.67 \))\(^{17}\). Although the two countries favoured the same primary coping style, Taiwanese parents used significantly more emotional approach coping (\( t(163) = 7.42, p < 0.001 \)) and passive avoidant emotion-focused coping (\( t(164) = 3.45, p < 0.01 \)) than the UK parents. There was no significant difference in the use of problem-focused coping.

\(^{17}\) The mean score was divided according to the number of the items in the subscales.
Table 5.4 Independent samples t-test comparisons for TW and the UK samples on the COPE inventory

<table>
<thead>
<tr>
<th>Coping strategy</th>
<th>TW sample (n = 89)</th>
<th>UK sample (n = 77)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive reinterpretation and growth</td>
<td>12.93 (2.11)</td>
<td>11.71 (2.71)</td>
<td>t(140.70) = 3.19**</td>
</tr>
<tr>
<td>Mental disengagement</td>
<td>9.11 (2.16)</td>
<td>8.38 (2.39)</td>
<td>t(163) = 2.06*</td>
</tr>
<tr>
<td>Focus on and venting of emotions</td>
<td>11.43 (2.38)</td>
<td>11.06 (3.45)</td>
<td>t(130.13) = 0.79</td>
</tr>
<tr>
<td>Use of instrumental social support</td>
<td>12.72 (2.60)</td>
<td>11.82 (2.95)</td>
<td>t(163) = 2.08*</td>
</tr>
<tr>
<td>Active coping</td>
<td>11.93 (2.16)</td>
<td>11.85 (2.36)</td>
<td>t(163) = 0.23</td>
</tr>
<tr>
<td>Denial</td>
<td>6.57 (2.16)</td>
<td>5.36 (2.30)</td>
<td>t(163) = 3.49**</td>
</tr>
<tr>
<td>Religious coping</td>
<td>8.64 (3.63)</td>
<td>5.91 (3.56)</td>
<td>t(163) = 4.86***</td>
</tr>
<tr>
<td>Humor</td>
<td>8.24 (2.51)</td>
<td>8.18 (3.17)</td>
<td>t(163) = 0.13</td>
</tr>
<tr>
<td>Behavioural disengagement</td>
<td>7.40 (2.14)</td>
<td>6.30 (2.07)</td>
<td>t(163) = 3.34**</td>
</tr>
<tr>
<td>Restraint</td>
<td>10.59 (2.30)</td>
<td>11.33 (3.16)</td>
<td>t(135.001) = -1.69</td>
</tr>
<tr>
<td>Use of emotional social support</td>
<td>11.38 (2.56)</td>
<td>8.88 (2.05)</td>
<td>t(163) = 6.82***</td>
</tr>
<tr>
<td>Substance use</td>
<td>4.76 (1.73)</td>
<td>5.51 (2.470)</td>
<td>t(131.60) = -2.21*</td>
</tr>
<tr>
<td>Acceptance</td>
<td>12.82(2.28)</td>
<td>11.20(2.57)</td>
<td>t(163) = 4.29***</td>
</tr>
<tr>
<td>Suppression of competing activities</td>
<td>11.21(2.33)</td>
<td>10.00(2.26)</td>
<td>t(163) = 3.36**</td>
</tr>
<tr>
<td>Planning</td>
<td>12.37 (2.44)</td>
<td>12.34 (2.47)</td>
<td>t(163) = 0.09</td>
</tr>
</tbody>
</table>

* p < .05; ** p < .01; *** p < .001
5.4.4 Parents’ coping: Eastern concepts

The Chinese coping measure, Coping Strategies in Chinese Social Context (Hsu, et al., 2008) was also used with the Taiwanese and UK parents. The data in Table 5.5 showed that Taiwanese parents reported using significantly more of three coping styles – active-antisocial, passive-antisocial and passive-prosocial coping styles – than the UK parents. The UK parents rated they used significantly more active-prosocial coping than the Taiwanese parents. As reviewed in Section 3.4.1, people who use active-prosocial coping style consider both their own and others’ welfare while selecting coping strategies, which matches the Chinese philosophy of emphasizing harmony with others. However, the Taiwanese sample scored lower on the use of active-prosocial coping style than their UK counterparts, and this was unexpected. This may imply that having a child with ASD in Taiwan requires a different form of coping than from the general Chinese population. It might be challenging for the Taiwanese parents to actively strive for their benefit and also consider and balance others’ welfare at the same time when trying to come up a coping strategy to deal with the situation.

Table 5.5 Independent samples t-test comparisons for the TW and the UK samples on the Coping Strategies in the Chinese Social Context

<table>
<thead>
<tr>
<th>Coping strategy</th>
<th>TW sample (n = 89)</th>
<th>UK sample (n = 77)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active-prosocial coping</td>
<td>39.40 (7.43)</td>
<td>41.80 (7.86)</td>
<td>t(164) = -2.02*</td>
</tr>
<tr>
<td>Active-antisocial coping</td>
<td>26.98 (5.81)</td>
<td>24.51 (4.78)</td>
<td>t(164) = 2.97**</td>
</tr>
<tr>
<td>Passive-prosocial coping</td>
<td>44.40 (7.18)</td>
<td>40.70 (6.40)</td>
<td>t(164) = 3.48**</td>
</tr>
<tr>
<td>Passive-antisocial coping</td>
<td>16.69 (3.61)</td>
<td>15.47 (4.23)</td>
<td>t(164) = 2.01*</td>
</tr>
</tbody>
</table>

*p < .05, ** p < .01
5.4.5 Correlations between Western and Chinese coping

Table 5.6 presents a series of correlations exploring the relations between the Western and the Chinese parent coping styles. One of the research aims was to explore the suitability of using Western developed coping measurement in the Chinese population. Hence, the relation between COPE (Carver, et al., 1989) and CSCSC (Hsu, et al., 2008) was examined.

After Bonferroni correction, there were no significant correlations between the COPE and CSCSC variables in the Taiwanese sample. It is worth noting that before Bonferroni correction, passive avoidant emotion-focused coping (COPE) had a negative correlation with passive-prosocial coping (CSCSC) (r = -0.24, p = 0.03). In the UK sample, problem-focused coping (COPE) was positively correlated with both active-prosocial coping (CSCSC) and passive-prosocial coping (CSCSC) after Bonferroni correction. This analysis showed CSCSC and COPE had weak or even non-significant correlations in the present Taiwanese sample, which was consistent with the argument that Western-developed coping measures do not relate clearly to the type of coping mechanisms used by the Chinese population, as reviewed in Chapter 3. Furthermore, the COPE subscales all correlated with each other in Taiwan but not in UK. It is speculated that the coping styles measured in the COPE might have overlapping concepts for the Chinese respondents but were more distinct and clear for the UK respondents.
Table 5.6 Intercorrelations among parents coping style on the COPE and the CSCSC

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. COPE problem-focused coping</td>
<td>-</td>
<td>.73*</td>
<td>.34*</td>
<td>-.13</td>
<td>-.07</td>
<td>-.12</td>
<td>-.02</td>
</tr>
<tr>
<td>2. COPE emotional approach coping</td>
<td>.30</td>
<td>-</td>
<td>.33*</td>
<td>-.06</td>
<td>.00</td>
<td>-.09</td>
<td>-.06</td>
</tr>
<tr>
<td>3. passive avoidant emotion-focused coping</td>
<td>.18</td>
<td>-.01</td>
<td>-</td>
<td>-.19</td>
<td>-.05</td>
<td>-.24</td>
<td>-.06</td>
</tr>
<tr>
<td>4. CSCSC Active-prosocial coping</td>
<td>.67*</td>
<td>.11</td>
<td>.10</td>
<td>-</td>
<td>.34*</td>
<td>.54*</td>
<td>-.02</td>
</tr>
<tr>
<td>5. CSCSC Active-antisocial coping</td>
<td>.14</td>
<td>-.06</td>
<td>.30</td>
<td>.26</td>
<td>-</td>
<td>-.10</td>
<td>.40*</td>
</tr>
<tr>
<td>7. CSCSC Passive-antisocial coping</td>
<td>-.11</td>
<td>-.05</td>
<td>.28</td>
<td>-.04</td>
<td>.40*</td>
<td>.26</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: TW sample’s coefficients above the diagonal and coloured in blue; UK sample’s coefficients below the diagonal and coloured in red.

* After Bonferroni correction new p-value = .007

5.4.6 Influence of demographic variables on parents’ coping

In this section, the demographic variables were examined to explore the theoretically possible relations between parents’ coping. Based on the previous research reviewed in the Section 3.4.2, parents’ use of coping might be linked with SES, age and gender of children and family size. Hence, these possible relations were examined with parents’ coping style in two countries separately.

In the Taiwanese sample, results indicated that the parents’ use of problem-focused coping positively correlated with parents’ educational level (F (5, 82) = 2.84, p < .05) and annual household income (r = .32, p < .05). With higher income and educational level, Taiwanese parents tended to use more problem-focused coping. Emotional approach coping was correlated to the gender of ASD siblings (F (1, 81) = 7.24, p < .01). If the child with ASD was male (M = 46.75, SD = 6.99), parents used more emotional approach coping than if she was female (M = 40.22 SD = 5.67).

For the UK families, only one significant relation was found between demographic variable and parents’ coping. The use of problem-focused coping correlated with
family size \( (r = -.25, p < .05) \). The more children in the family, the less problem-focused coping parents would use.

### 5.4.7 Summary

The coping styles used by the siblings were different between the two country groups. Taiwanese siblings used more active and negative coping than their UK counterparts, but they did not differ in the frequency with which they used avoidant coping. As for the efficacy of coping, Taiwanese siblings rated active coping as the most effective style, while UK siblings preferred avoidant coping. The differences in the ratings of frequency and efficacy of coping styles between the two country groups might influence the adjustment outcome in different ways. It was speculated that coping functioned differently according to the cultures, and certain coping style might be suitable or efficient for the Taiwanese but not for the UK families. This is discussed in more depth in Section 7.4.6. In the interview study, there was further exploration of the possible explanations for the difference in sibling coping strategies across the two countries.

For the parents’ coping style, coping measurements based on both Western and Chinese approaches to coping were used in both countries. In the Western coping measure, problem-focused coping style was the most frequently used coping style among the three coping styles both in Taiwan and the UK. For the Chinese coping concept, Taiwanese parents used significantly more active-antisocial and passive-prosocial coping style than the UK parents. Furthermore, UK parents used more active-prosocial than their Taiwanese counterparts, and this was unexpected. The analysis of Western and Chinese coping approaches showed few shared concepts which was consistent with the previous literature review in Section 3.4.1. Moreover, Taiwanese parents seemed to use a variety of different coping strategies more frequently than their UK counterparts.
5.5 Similarities and differences in other variables in TW and UK

5.5.1 Broader Autism Phenotype of parents and siblings

The Broader Autism Phenotype (BAP) of parents and TD siblings was measured by the AQ (Baron-Cohen, et al., 2006), both according to the parents’ report. In the parents’ self-report, there was a significant difference in the scores, with Taiwanese parents reporting significantly higher BAP traits ($M = 18.05$, $SD = 7.58$) than UK parents ($M = 13.06$, $SD = 7.75$); $t (159) = 4.12$, $p < .001$. Taiwanese parents also reported significantly higher BAP traits ($M = 67.86$, $SD = 21.66$) in their children than did the UK parents ($M = 52.85$, $SD = 33.17$); $t (124.29) = 3.44$, $p < .05$. These results suggested that Taiwanese parents evaluated themselves and their TD children as displaying BAP to a higher degree. The higher BAP scores on both parents’ and TD siblings’ mirrored the Taiwanese parents’ response on SDQ, where Taiwanese parents consistently scored their children as having more difficulties (except for the hyperactivity/inattention subscale) and less prosocial behaviour than their UK counterparts. The country-specific norm data further illustrated these between-country differences. This seemed to suggest that Taiwanese parents had a higher standard of children’s behaviour than did the UK parents. The possible influence of this is discussed in more detail in Chapter 7.

The correlations between BAP scores and SDQ were also examined to explore whether the level of the BAP might link with how TD siblings’ evaluated themselves. The results indicated that TD siblings’ BAP score was found correlate positively with their parents’ rating on SDQ total difficulties and negatively with prosocial scores in Taiwanese sample, while UK siblings’ BAP only related positively to parents’ response on SDQ total difficulties. The results are listed in the Table 5.7. These met the expectation that higher level of BAP characteristics correlated to adjustment difficulties.
Table 5.7 Intercorrelations among BAP level and SDQ

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. TD siblings’ BAP level</td>
<td>-</td>
<td>.36*</td>
<td>.62*</td>
<td>-.52*</td>
<td>-0.10</td>
<td>-0.04</td>
</tr>
<tr>
<td>2. Parents’ BAP level</td>
<td>0.18</td>
<td>-</td>
<td>.33*</td>
<td>-.19</td>
<td>0.03</td>
<td>-0.02</td>
</tr>
<tr>
<td>3. Parents rated SDQ Total Difficulties score</td>
<td>.30*</td>
<td>0.11</td>
<td>-</td>
<td>-.56*</td>
<td>0.11</td>
<td>-0.11</td>
</tr>
<tr>
<td>4. Parents rated SDQ Prosocial Behaviours</td>
<td>-0.20</td>
<td>-0.01</td>
<td>-.40*</td>
<td>-</td>
<td>0.11</td>
<td>.22</td>
</tr>
<tr>
<td>5. TD siblings rated SDQ Total Difficulties score</td>
<td>.29</td>
<td>0.15</td>
<td>.29</td>
<td>-0.11</td>
<td>-</td>
<td>-.25</td>
</tr>
<tr>
<td>6. TD siblings rated SDQ Prosocial Behaviours</td>
<td>-0.10</td>
<td>-0.05</td>
<td>-.06</td>
<td>0.22</td>
<td>0.02</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: TW sample’s coefficients above the diagonal and coloured in blue; UK sample’s coefficients below the diagonal and coloured in red.

* After Bonferroni correction new p-value = .008

An individual who displays clinically significant autistic traits is likely to be diagnosed with ASD (Baron-Cohen, et al., 2001). In the present study, it did not imply that the individuals have ASD (and, indeed, no sibling in the sample had a diagnosis of ASD), but rather, the present study focused on the continuous level of the autistic-like traits they displayed. Furthermore, due to lack of cut-off scores in Taiwanese populations, the present study did not explore the percentage of TD siblings and parents in the clinical range. After checking the impression from each country’s data, the mean AQ-Child/ Adolescent score did not correspond to a difference in percentage above cut-off. This clinical category result highlighted the importance of country-specific norms.

5.5.2 Siblings’ social support

The measure of siblings’ social support was the Child and Adolescent Social Support Scale (Malecki, et al., 1999). Taiwanese siblings’ ratings indicated that they received support most frequently from their close friends, teachers and then classmates, while the UK siblings indicated that their top three sources of support were close friends, parents and teachers. In both countries, siblings reported that they frequently received support from teachers and close friends. The mean scores in relation to
maximum possible scores suggested that TD siblings generally felt well supported in both country groups. These results are listed in Table 5.8.

For the similarities and differences between the countries regarding the frequency of social support, UK siblings perceived receiving more frequent support from all sources than the Taiwanese siblings, except for from classmates, where there was no significant difference between countries. The measurement of frequency represented TD siblings’ subjective feeling of the support they received, rather the actual amount of the support provided.

In terms of the importance of the support received, Taiwanese siblings saw classmates as the most important source of support, while for UK siblings the support from teachers was the most important. Even though the total importance scores did not differ by countries, there were differences in terms of the support sources. Taiwanese TD siblings rated the importance of the support from parents, teachers and others in school significantly lower than their UK counterparts, while support from classmates was significantly much more important for them compared with the UK siblings. From the results, it can be speculated that Taiwanese siblings regarded the support from peers (classmates or close friends) as much more important than the support from their parents and teachers.
Table 5.8 The frequency and importance of social support that siblings received

<table>
<thead>
<tr>
<th></th>
<th>TW sample (n = 89)</th>
<th>UK sample (n = 77)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequency:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>44.53 (11.53)</td>
<td>56.04 (9.10)</td>
<td>t(155) = -6.80***</td>
</tr>
<tr>
<td>Teacher</td>
<td>47.89 (13.68)</td>
<td>53.36 (12.09)</td>
<td>t(155) = -2.62 *</td>
</tr>
<tr>
<td>Classmate</td>
<td>46.04 (13.78)</td>
<td>49.52 (11.74)</td>
<td>t(155) = -1.67</td>
</tr>
<tr>
<td>Close friend</td>
<td>51.58 (15.60)</td>
<td>57.67 (10.64)</td>
<td>t(155) = -2.78**</td>
</tr>
<tr>
<td>Others in school</td>
<td>36.64 (14.42)</td>
<td>46.43 (13.34)</td>
<td>t(155) = -4.36***</td>
</tr>
<tr>
<td><strong>Total frequency</strong>^a</td>
<td>226.69 (51.05)</td>
<td>263.03 (45.85)</td>
<td>t(155) = -4.63***</td>
</tr>
<tr>
<td><strong>Importance:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>26.51 (4.83)</td>
<td>28.45 (4.69)</td>
<td>t(163) = -2.61*</td>
</tr>
<tr>
<td>Teacher</td>
<td>26.36 (5.79)</td>
<td>28.94 (4.85)</td>
<td>t(163) = -3.09**</td>
</tr>
<tr>
<td>Classmate</td>
<td>29.00 (5.82)</td>
<td>25.80 (5.46)</td>
<td>t(163) = 3.63***</td>
</tr>
<tr>
<td>Close friend</td>
<td>27.66 (5.73)</td>
<td>28.13 (5.07)</td>
<td>t(163) = -0.56</td>
</tr>
<tr>
<td>Others in school</td>
<td>22.76 (6.50)</td>
<td>24.85 (5.98)</td>
<td>t(163) = -2.14**</td>
</tr>
<tr>
<td><strong>Total importance</strong>^b</td>
<td>132.29 (21.69)</td>
<td>136.18 (21.28)</td>
<td>t(163) = -1.16</td>
</tr>
</tbody>
</table>

* p < .05; ** p < .01; *** p < .001

Note. Frequency was scored on a 6-point scale, Importance was scored on a 3-point scale.\(^{a}\) Total frequency ratings in the measure ranged from 60 to 360, \(^{b}\) Total importance ratings in the measure ranged from 60 to 180, Frequency subscales ranged from 12 to 72 and Importance subscales ranged from 12 to 36.

5.5.3 Siblings’ life experience

The stressful life experiences that siblings had encountered over the past year was assessed using the Child and Adolescent Survey of Experiences (Allen, et al., 2012). There were no significant differences between country groups in the number of positive (t (148) = 0.23, p = .82) or negative life events (t (148) = -0.96, p = .34) that the siblings had experienced. Nor did the impact of positive (t (148) = -0.97, p = .33) or negative (t (148) = -1.95, p = .05) life events differ between the countries. This indicated that siblings from both countries experienced similar amount of positive and negative life events and that the impact of these events was similar. It can be assumed that their stressful life experiences did not differ in the analysis. Even though it did not differ between countries, it might influence the outcome, and this will be discussed in the next chapter.
5.5.4 Parents’ and siblings’ satisfaction with life

Life satisfaction was assessed with the Satisfaction With Life scale (Diener, et al., 1985) that obtained both the parents’ and siblings’ self-report. With higher scores indicating higher life satisfaction (the range of possible scores is 5 to 35), siblings in both countries reported having significantly higher life satisfaction than their parents. The data were as follows: Taiwanese parents ($M = 18.95, SD = 7.66$), siblings ($M = 23.97, SD = 5.91$); the UK parents ($M = 21.06, SD = 7.26$) and siblings ($M = 24.25, SD = 6.80$). The Taiwanese life satisfaction was slightly lower than the UK, but the t-test did not show any significant difference between two countries.

5.5.5 Summary

In this section, several variables were examined, including the BAP characteristics of parents and siblings, siblings’ social support, and also parents’ and siblings’ life experience and satisfaction.

In terms of BAP traits, Taiwanese parents rated themselves and their TD children as having more BAP traits than their UK counterparts. Higher TD siblings’ BAP level was linked with higher adjustment difficulties according to parents’ report in both countries. There were no relations found between TD siblings’ self-report adjustment outcome and their BAP level.

For the overall frequency and importance of the social support the siblings had received, UK siblings reported receiving more overall support from different sources than the Taiwanese siblings. The types of support TD siblings felt important to them also varied between countries: Taiwanese siblings depended more on support from classmates, while UK siblings evaluated support from parents and teachers were important. Both sibling groups also relied on close friends. This result again emphasized the importance of tailoring the support for the TD siblings according to their needs and preference.

Typically developing siblings of children with ASD from Taiwan and the UK did not differ in their life experiences within the range of experiences covered by the measure used. This suggested that siblings form both countries experienced similar
level of positive and negative life events and the impact of the events was also similar. Likewise, overall life satisfaction was comparable in Taiwan and the UK.

In sum, some variables did differ between Taiwan and the UK, including siblings’ BAP level and overall frequency support of received. Siblings’ life experience and both parents’ and siblings’ life satisfaction were similar in the two survey countries.
Chapter 6: Questionnaire study results part II: Predictors of adjustment in siblings of children with ASD

The analyses in the previous chapter revealed several similarities and differences between and within countries. However, exactly how factors combine to give rise to a particular adjustment profile, and whether this varies between the different countries remains unexplored. Therefore, in this chapter, a series of tests were conducted to explore the relation between variables guided by the research model (Figure 3.2) and the research questions. These variables were demographic variables, social support, TD siblings’ BAP level, parental coping and the outcome variables. Firstly, the examination of the relations with these variables and TD siblings’ coping, and then with TD siblings’ adjustment were presented. The Taiwanese and the UK data were analysed separately to explore the cultural similarities and differences, and whether there were the same relations between variables or the strength of association.

6.1 RQ3a. The association between factors in the model: Sibling coping

6.1.1 Exploring the correlations between demographic variables and siblings’ coping (Kidcope)

Pearson’s correlation was computed in the Taiwan and the UK data separately to assess the relation between siblings’ scores on each possible coping style (active, avoidant and negative styles) and a number of demographic variables, including continuous data (age of TD siblings and children with ASD, age-gap between siblings, family income, family size) and categorical data (parents’ relationship status, education level, employment status, finance status and gender of child). The literature reviewed in Section 3.4 suggested that these factors could impact the choice of coping styles. For example, gender (Breslau, Weitzman, & Messenger, 1981; Kaminsky & Dewey, 2002) and the age of the children (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001) have previously been shown to be associated with the coping strategies they used.
Overall, very few significant correlations were found. Avoidant coping had significant positive correlations with the age of the child with ASD ($r = .35, p < .01$) and with the age of the TD sibling ($r = .31, p < .01$) in the Taiwanese sample. When adjusted with Bonferroni corrections, the correlations were still significant. This shows that in the Taiwanese sample, if the age of either the ASD and TD siblings were older, TD siblings would use more avoidant coping. No significant correlations were found in the UK sample.

An age effect on the coping strategies was expected. Previous literature suggested that coping is a dynamic process (see Section 3.4.1), where individuals might learn to use the coping strategies more flexibly or efficiently with the increase of age and experience. However, avoidant coping, which is not considered to be a well-adjusted coping style, was found to relate to the increase of the children’s age in the Taiwanese sample.

These might indicate that situations became more challenging with the increasing of the age for Taiwanese siblings. Despite in the rating of the coping efficacy, Taiwanese siblings rated active coping as more effective than other coping styles. With the increasing of the age, the avoidant coping might work more efficiently than other coping styles. While for UK siblings, the coping style might be more consistent and stable.

6.1.2 Exploring the correlations between siblings’ social support (CASSS) and siblings’ coping styles (Kidcope)

A series of Pearson’s correlations were computed to assess the relations between siblings’ coping styles and the social support they had received from five different sources (e.g. parents, teachers, close friends, classmates and others in school) – both frequency scores and ratings of the importance of each support source. Initially, the contribution of support combined across all five potential sources was investigated.

In the Taiwanese sample, overall frequency of social support showed a significant positive correlation with active coping ($r = .23, p < .05$) and a significant negative correlation with negative coping ($r = -.22, p < .05$). Further analysis explored the
specific sources of the support, and a significant positive correlation between Active coping and the frequency of the support from teachers was found ($r = .35, p < .01$) in the Taiwanese sample. The other four support sources (from parents, classmates, close friends and others in school) did not significantly correlate with siblings’ coping styles. This indicates that the more support Taiwanese siblings received from teachers, the more active coping they might use. There are two plausible interpretations of this finding: (1) teachers’ support led to siblings’ use of active coping; (2) the children who used active coping more often sought teachers support. Active coping has been found to relate to adjustment (see Section 3.4.1). As for negative coping, the correlation with the support from different sources was not significant after the Bonferonni correction. No significant correlation was found between the importance of the support overall and the TD siblings’ coping styles in Taiwan.

For the UK data, the choice of coping styles did not significantly correlate with the frequency or the importance of social support in general. To explore whether different support sources potentially correlated with siblings’ coping styles, further analyses were conducted. Siblings’ negative coping had a significant correlation with the frequency of support received from close friends ($r = -.31, p < .01$), and there was a negative correlation between avoidant coping and the frequency of support received from others in school ($r = -.29, p < .05$). Nevertheless, after the Bonferonni corrections, these correlations were no longer significant. Overall, the importance of support did not have significant correlations with siblings’ coping styles in the UK sample.

Despite the absence of significant relations between the importance of the social support received and TD siblings’ coping styles in Taiwan and the UK, perceived social support still might relate directly to siblings’ adjustment. Perceived social support has been linked to many positive psychological and physical outcomes for both parents and siblings (Ingersoll & Hambrick, 2011; Kaminsky & Dewey, 2002).

The lack of significant impact of the frequency and the importance of social support on TD siblings’ coping styles in the UK sample might explained by the following. Firstly, the correlations between the frequency of the support and TD siblings’
coping styles existed before the Bonferonni corrections. The relations possibly still existed, but the study was underpowered to show the significance. Secondly, the frequency of support UK siblings received was higher than the Taiwanese sample across the various sources. It can be speculated that because the UK siblings generally perceived receiving high levels of support from several sources, there was not a big range in scores, so it would be more difficult to find a correlation. Further evidence is still required to confirm this. In the interview study, there is a chance to generally explore links between social support and coping style in the two countries.

In summary, there were links between coping styles and the source of support that TD siblings’ perceived receiving before Bonferonni corrections. However, only one correlation remained significant after correction and it was between Active coping and the frequency of support from teachers in the Taiwanese siblings. In the UK sample, the coping styles that siblings used did not relate to the frequency or the importance from different support sources.

6.1.3 Exploring the correlations between siblings’ BAP level (AQ-Adolescent/Child) and siblings’ coping styles (Kidcope)

The relation between siblings’ BAP and their coping styles was also examined. Table 6.1 presents the bivariate correlations for each country group. Both in Taiwan and the UK, the siblings’ BAP level did not have significant correlations with their coping styles. Due to the lack of self-evaluation of BAP measure for the children and adolescents, the information of siblings’ BAP level still relied on the parents’ evaluation, and this might explain the lack of significant correlations.
Table 6.1 Intercorrelations among siblings’ BAP level and coping styles in Taiwan and the UK

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Siblings’ BAP level</td>
<td>-</td>
<td>.02</td>
<td>-.05</td>
<td>.01</td>
</tr>
<tr>
<td>2. Siblings’ active coping</td>
<td>-.05</td>
<td>-</td>
<td>.18</td>
<td>.19</td>
</tr>
<tr>
<td>3. Siblings’ avoidant coping</td>
<td>.10</td>
<td>.14</td>
<td>-</td>
<td>.20</td>
</tr>
<tr>
<td>4. Siblings’ negative coping</td>
<td>.05</td>
<td>.14</td>
<td>.24*</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: TW sample’s coefficients above the diagonal and coloured in blue; UK sample’s coefficients below the diagonal and coloured in red.

*. Correlation is significant at the 0.05 level (2-tailed).

6.1.4 Exploring the correlations between siblings’ coping styles (Kidcope) and parents’ coping styles (COPE and CSCSC)

The relations between siblings’ coping scores (active, avoidant, negative) and parents’ coping scores (problem-focused coping, emotional approach coping, and passive avoidant emotion-focused coping) were analysed in this section as listed in Table 6.2.

Table 6.2 Intercorrelations among parents’ and siblings’ coping styles (COPE and Kidcope) in Taiwan and the UK

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Parents’ problem-focused coping</td>
<td>-</td>
<td>.73*</td>
<td>.34*</td>
<td>-.15</td>
<td>-.05</td>
<td>.13</td>
</tr>
<tr>
<td>2 Parents’ emotional approach coping</td>
<td>.30</td>
<td>-</td>
<td>.33*</td>
<td>-.08</td>
<td>-.06</td>
<td>.05</td>
</tr>
<tr>
<td>3 Parent s’ passive avoidant emotion-focused coping</td>
<td>.18</td>
<td>-.01</td>
<td>-</td>
<td>.05</td>
<td>.01</td>
<td>-.03</td>
</tr>
<tr>
<td>4 Siblings’ active coping</td>
<td>.13</td>
<td>.20</td>
<td>.18</td>
<td>-</td>
<td>.18</td>
<td>.19</td>
</tr>
<tr>
<td>5 Siblings’ avoidant coping</td>
<td>.09</td>
<td>.08</td>
<td>.10</td>
<td>.14</td>
<td>-</td>
<td>.20</td>
</tr>
<tr>
<td>6 Siblings’ negative coping</td>
<td>.34*</td>
<td>.07</td>
<td>.13</td>
<td>.14</td>
<td>.24*</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: TW sample’s coefficients above the diagonal and coloured in blue; UK sample’s coefficients below the diagonal and coloured in red.

*. Bonferroni-adjusted correlation is significant at the 0.008 level (2-tailed).
In the Taiwanese sample, significant correlations were only found within parents’ coping styles. That is, Taiwanese parents’ and siblings’ coping were not significantly correlated.

For the UK data, a significant positive correlation was found between siblings’ negative coping and parents’ problem-focused coping \((r = .34, p < .01)\). This unexpected finding seems contradictory to the perspective current in the literature that problem-focused coping is regarded as a relatively better adjusted coping style, while negative coping style is more maladjusted. Furthermore, children have been shown to learn their coping styles from their parents (Kliewer, Fearnow, & Miller, 1996). Parents and children’s coping might also influence with each other. It is possible that parents’ used problem-focused coping as part of the result to deal with their TD children’s negative coping.

Further partial correlation analyses were conducted to explore possible explanations. According to the literature (see Section 3.2 and 3.3), several factors were taken into account. These included parents’ and siblings’ BAP level, severity of child with ASD, and the age of siblings and children with ASD. None of these variables eliminated the statistically significant relation between parents’ problem-focused and siblings’ negative coping.

To further examine the foundation of this unexpected relation, the subscales within the parents’ problem-focused coping score (active coping, planning, suppression of competing activities, restraint coping, and seeking of instrumental social support) were then analysed independently to find out the possible connections with siblings’ negative coping. Positive correlations were found between siblings’ negative coping and parents’ use of suppression of competing activities \((r = .39, p < .01)\), restraint coping \((r = .38, p < .01)\) and seeking of instrumental social support \((r = .32, p < .01)\).

The idea of the suppression of competing activities is that individuals suppress their attention to other activities in which they might engage, in order to concentrate more on dealing with the stressor (e.g. I focus on dealing with this problem, and if necessary let other things slide a little). Restraint coping is that individuals cope passively by holding back their coping attempts until they can be of use (e.g. I hold
off doing anything about it until the situation permits). Seeking of instrumental social support meant that individuals seek assistance, information or advice about what to do (e.g. I try to get advice from someone about what to do). These parental coping strategies might be hidden from TD siblings or not as obvious for TD siblings to be aware of, leaving TD siblings feeling like their parents used avoidant coping and not dealing with them.

As for siblings’ negative coping, it consisted of self-criticism (e.g. I blamed myself for causing the problem) and blaming others (e.g. I blamed someone else for causing the problem). It was possible that if parents are taking action to solve a problem, TD siblings might interpret this ‘taking of responsibility’ to imply that the parents are to blame. Another possibility is that parents who used more problem-focused discuss/focus on the problem more, which made siblings aware that there is actually a problem, for which they then begin to apportion blame. It brings about the issue that the strategies that are useful or adjusted for parents may not be so for the siblings. It is possible that these problem-solving approaches did not directly benefit siblings’ methods of coping.

For the Chinese-developed coping measurement CSCSC (Hsu, et al., 2008), the correlations between parents’ coping and siblings’ coping were also examined. None of the correlations were found in Taiwan and the UK data. The correlations table is presented in the Table 6.3. The use of the Chinese coping measurement was still exploratory. Based on the analyses above and in the following regression analyses, the COPE was therefore used as the main parental coping measurement.
Table 6.3 Intercorrelations among parents’ and siblings’ coping styles (CSCSC and KidCOPE) in Taiwan and the UK

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Parents’ active-prosocial coping</td>
<td>-</td>
<td>.54*</td>
<td>.34</td>
<td>-.02</td>
<td>.03</td>
<td>.20</td>
<td>.04</td>
</tr>
<tr>
<td>2. Parents’ passive-prosocial coping</td>
<td>.62*</td>
<td>-</td>
<td>-.10</td>
<td>.04</td>
<td>.04</td>
<td>.15</td>
<td>.11</td>
</tr>
<tr>
<td>3. Parent s’ active-antisocial coping</td>
<td>.26</td>
<td>.11</td>
<td>-</td>
<td>.40*</td>
<td>-.05</td>
<td>-.06</td>
<td>.09</td>
</tr>
<tr>
<td>4. Parent s’ passive-antisocial coping</td>
<td>-.04</td>
<td>.26</td>
<td>.40*</td>
<td>-</td>
<td>-.25</td>
<td>-.07</td>
<td>-.10</td>
</tr>
<tr>
<td>5. Siblings’ active coping</td>
<td>.15</td>
<td>.06</td>
<td>.12</td>
<td>-.09</td>
<td>-</td>
<td>.18</td>
<td>.19</td>
</tr>
<tr>
<td>6. Siblings’ avoidant coping</td>
<td>.06</td>
<td>.08</td>
<td>.06</td>
<td>.10</td>
<td>0.14</td>
<td>-</td>
<td>.20</td>
</tr>
<tr>
<td>7. Siblings’ negative coping</td>
<td>.21</td>
<td>.16</td>
<td>.08</td>
<td>.21</td>
<td>0.14</td>
<td>.24</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: TW sample’s coefficients above the diagonal and coloured in blue; UK sample’s coefficients below the diagonal and coloured in red.

* Bonferroni-adjusted correlation is significant at the 0.007 level (2-tailed).
6.2 The relation between coping and adjustment

In Taiwanese sample, TD siblings’ Active coping was positively correlated with siblings’ self-report on SDQ prosocial behaviour ($r = .37$, $p < .01$), while avoidant coping ($r = .22$, $p < .05$) and negative coping ($r = .28$, $p < .05$) was positively correlated with siblings’ self-report on SDQ total difficulties. Negative coping ($r = −.25$, $p < .05$) was negatively correlated with parents’ report on SDQ prosocial behaviours.

As for the UK sample, TD siblings’ avoidant coping ($r = .30$, $p < .01$) and negative coping ($r = .32$, $p < .01$) were positively correlated with self-report total difficulties scores on SDQ. Avoidant coping ($r = −.31$, $p < .01$) was also negatively correlated with parents’ report on SDQ prosocial behaviours.

In terms of the parents’ coping and TD siblings’ adjustment outcome, none of the correlations was found in the Taiwanese sample. Parents used emotional approach coping was positively correlated with TD siblings self-report adjustment difficulties ($r = .23$, $p < .05$) was found in the UK sample. Furthermore, if Taiwanese parents used more passive avoidant emotion-focused coping, they also evaluated their TD children experienced more difficulties ($r = .27$, $p < .05$). There were no correlations found between parents’ coping and their evaluation on their TD children’s adjustment outcome.

In summary, TD siblings’ coping styles were more related with their self-report adjustment outcome in both countries. Only in the UK sample, there was a little relation found between parents’ coping and TD siblings self-report, and parents’ coping also linked with how parents’ viewed their TD children’s adjustment.

6.3 The relations found in the present research model

All the correlations between variables were listed in Figures 6.1 and 6.2. There were more links found between variables in Taiwanese families than in their UK counterparts. In the Taiwanese findings, siblings’ coping were found to relate to the age of ASD and TD siblings and to social support, while parents’ coping were more related to the demographic variables (ASD siblings’ gender, parental educational
level and household income), severity of ASD and parents’ BAP level. Typically developing siblings’ adjustment were also linked with the support TD siblings received, the stressors in life, and the coping style TD siblings used. The first impression from these results was that siblings’ coping was more related to children’s own variables (age) and the support they received, while parents’ coping was influenced by multiple sources. Parents’ variables did not have strong links with TD siblings’ coping or adjustment, but more related to how they evaluated their children’s adjustment. Moreover, the severity of the children with ASD also influenced how parents used of certain coping style in the Taiwanese findings.

For the UK families, it was surprising that social support and coping did not significantly correlate. The social support TD siblings received was related with the stressors (life events, severity of ASD siblings) and TD siblings’ adjustment outcome. A correlation between parents’ and siblings’ coping was only found in the UK sample. Either parents’ or TD siblings’ variables was more related to each other, such as parents’ coping was related with TD sibling’s BAP level and coping, the family size and also how parents viewed of their children’s adjustment.

Despite Carver, et al. (1989) indicating that the COPE questionnaire could be used for both dispositional and situation-specific coping approaches, in the present research parents were asked to respond in relation to when they confronted difficulties or stressful events in their lives, whereas TD siblings’ were asked to respond to their coping questions specifically in relation to their ASD siblings. It has been suggested that dispositional coping approaches are relatively stable in terms of contexts and time in contrast to the situational coping approach which are more variable (Moos & Holahan, 2003; Watson & Hubbard, 1996). This could be a possible explanation as to the lack of relations between parents’ and TD siblings’ coping and with other variables examined in the present research model.

Furthermore, there were similar number of relations overall found in the UK model and Taiwanese one. The support TD siblings’ received, coping styles they used and stressors in life were all related to TD siblings’ adjustment outcome in both countries. While UK model had more interaction between parents’ and TD siblings’ variables, Taiwanese siblings’ variables were relatively less linked with their parents’ variables.
In the following section, several correlations were processed to explore the predictors that might link with TD siblings’ adjustment outcome. Factors that may directly or indirectly influence TD siblings’ adjustment outcome were identified and reported in Figures 6.1 and 6.2. In the next section, these identified variables found separately from Taiwan and the UK were then processed to build up the regression models.
1. Siblings’ BAP level had significant positive correlation with parents’ rated SDQ total difficulties score and significant negative correlation with parents’ rated SDQ prosocial behaviour.
2. Parents used passive avoidant emotion-focused coping was positively correlated with parents’ rated SDQ total difficulties score.

Negative relation  Positive relation
1. Parents used emotional approach coping was positively correlated with TD siblings self-report on SDQ total difficulties scores.

- Negative relation
- Positive relation
6.4 RQ3b and 3c. Factors predicting sibling adjustment in the model: Taiwan and the UK

The outcome of the TD siblings’ adjustment was based on sibling-rated SDQ. The variables were entered into hierarchy regression analyses in the order of their possible causal explanation based on the Double ABCX model. For the Taiwanese sample, the following variables from the correlational analyses conducted in Section 6.1-6.2: Step 1, Demographic variables (age of the ASD and TD siblings); Step 2, Stressor and Pile-up demands (negative life events impact); Step 3, Family Adaptive Resources (positive life events impact, total support received and siblings’ life satisfaction); and Step 4, Coping (siblings’ avoidant and negative coping) to predict TD siblings’ adjustment difficulties (total difficulties score, SDQ). Together, these variables explained 49% of the variance in the model. The model changed significantly when the stressors and resources were entered, but the demographic and coping variables did not show a significant impact when entered into the model.

Regarding the TD siblings’ prosocial behaviour, Step 1, Family Adaptive Resources (positive life events impact and total support received), and Step 2, Coping (siblings’ active coping) were entered. Around 36% of the variance in prosocial behaviour can be predicted by these variables. The results of the models were listed in Tables 6.4 and 6.5.
Table 6.4 Hierarchical regression analysis predicting siblings’ SDQ Total Difficulties Score in Taiwan

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Total Difficulties</th>
<th>ΔR²</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1 Demographic variables</td>
<td></td>
<td>0.06</td>
<td></td>
</tr>
<tr>
<td>Age of ASD siblings</td>
<td></td>
<td>0.31</td>
<td></td>
</tr>
<tr>
<td>Age of TD siblings</td>
<td></td>
<td>−0.18</td>
<td></td>
</tr>
<tr>
<td>Step 2 Stressor and Pile-up demands</td>
<td></td>
<td>0.25***</td>
<td>0.51***</td>
</tr>
<tr>
<td>Negative life events impact</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3 Family Adaptive Resources</td>
<td></td>
<td>0.17***</td>
<td></td>
</tr>
<tr>
<td>Positive life events impact</td>
<td></td>
<td>−0.05</td>
<td></td>
</tr>
<tr>
<td>Total support received</td>
<td></td>
<td>−0.23</td>
<td></td>
</tr>
<tr>
<td>Siblings’ life satisfaction</td>
<td></td>
<td>−0.27</td>
<td></td>
</tr>
<tr>
<td>Step 4 Coping</td>
<td></td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>Siblings’ avoidant coping</td>
<td></td>
<td>0.05</td>
<td></td>
</tr>
<tr>
<td>Siblings’ negative coping</td>
<td></td>
<td>0.12</td>
<td></td>
</tr>
<tr>
<td>Total R²</td>
<td></td>
<td>0.49</td>
<td></td>
</tr>
<tr>
<td>Total F</td>
<td></td>
<td>(8, 55) = 6.51 ***</td>
<td></td>
</tr>
</tbody>
</table>

* p < .05, ** p < .01, *** p < .001

Table 6.5 Hierarchical regression analysis predicting siblings’ SDQ Prosocial Behavior in Taiwan

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Prosocial Behavior</th>
<th>ΔR²</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1 Family Adaptive Resources</td>
<td></td>
<td>0.29***</td>
<td>0.05</td>
</tr>
<tr>
<td>Positive life events impact</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total support received</td>
<td></td>
<td>0.51***</td>
<td></td>
</tr>
<tr>
<td>Step 2 Coping</td>
<td></td>
<td>0.07**</td>
<td>0.26**</td>
</tr>
<tr>
<td>Siblings’ active coping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total R²</td>
<td></td>
<td>0.36</td>
<td></td>
</tr>
<tr>
<td>Total F</td>
<td></td>
<td>(3, 75) = 13.97***</td>
<td></td>
</tr>
</tbody>
</table>

* p < .05, ** p < .01, *** p < .001
In the UK model, the variables analysed in Section 6.1-6.2 were entered: Step 1, Stressor and Pile-up demands (siblings’ BAP level); Step 2, Family Adaptive Resources (total support received and siblings’ life satisfaction); and Step 3, Coping (parents’ problem-focused and emotional approach coping, and siblings’ avoidant and negative coping). The model predicted 35% of the variance in siblings’ adjustment difficulties. There were significant changes when entering the stressors, resources and coping variables into the model.

In predicting the siblings’ prosocial behaviour, the Stressor and Pile-up demands (severity of child with ASD) was entered in the first step and Step 2, Family Adaptive Resources (positive life events impact, total support received and parents’ life satisfaction). These variables predicted 20% of the variance in TD siblings’ prosocial behaviour. The results for the regression analyses are summarized in Tables 6.6 and 6.7.
### Table 6.6 Hierarchical regression analysis predicting siblings’ SDQ Total Difficulties Score in the UK

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Total Difficulties</th>
<th>ΔR²</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1 Stressor &amp; Pile-up demands</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings’ BAP level</td>
<td>0.06*</td>
<td>0.25*</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2 Family Adaptive Resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total support received</td>
<td>-0.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings’ life satisfaction</td>
<td>-0.29*</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 3 Coping</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents’ problem-focused coping</td>
<td>-0.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents’ emotional approach coping</td>
<td>0.21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings’ avoidant coping</td>
<td>0.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings’ negative coping</td>
<td>0.37**</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total R²</strong></td>
<td>0.35</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total F</strong></td>
<td>(7, 60) = 4.46***</td>
<td></td>
<td></td>
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</tbody>
</table>

*p < .05, ** p < .01, *** p < .001

### Table 6.7 Hierarchical regression analysis predicting siblings’ SDQ Prosocial Behavior in the UK

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Prosocial Behavior</th>
<th>ΔR²</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1 Stressor &amp; Pile-up demands</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The severity of child with ASD</td>
<td>0.07*</td>
<td>0.27*</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2 Family Adaptive Resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive life events impact</td>
<td>0.17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total support received</td>
<td>0.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents’ life satisfaction</td>
<td>-0.16</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total R²</strong></td>
<td>0.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total F</strong></td>
<td>(4, 65) = 4.04**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05, ** p < .01
In this section, hierarchical regression analyses were used to determine which variables were related to the TD siblings’ adjustment outcome. The variables that predicted the Taiwanese and the UK families were not exactly the same. According to the present study, Taiwanese siblings’ adjustment was more linked with their own variables, such as their life experience, the support they received, and their use of coping styles. However, UK siblings’ adjustment was more related to internal as well as family factors. These included the severity symptoms in the child with ASD, their BAP level, the support they had and parents’ coping styles.

The regression analyses demonstrated that TD siblings’ adjustment was predicted by various variables in Taiwan and the UK. While the Taiwanese model was more related to the children’s internal variables, the UK model received influence from mixed sources. The notion that coping style influenced children’s adjustment was only supported in the UK model. Furthermore, in the UK model, BAP level also placed TD siblings at a greater risk of adjustment difficulties, a result consistent with previous research.

6.5 Influence of culture and other moderator variables

6.5.1 The moderator analysis of BAP

As suggested by the Baron and Kenny (1986) when there is inconsistent relation (e.g. a relation appears in one setting but not in the other, or for one subpopulation but not for the other) a moderator effect could be considered. In the regression models conducted in Section 6.4, the predictive relation between TD siblings’ BAP level and their adjustment outcome was only found in the UK model. As also suggested by previous research examining the interaction between family function and BAP level, (Mohammadi & Zarafshan, 2014; Petalas, et al., 2012a), the moderator effect of the BAP was examined.

In the first part of this section, to examine whether BAP level of TD siblings or parents were moderators of the relations between ethnicity/culture and the evaluation of TD siblings’ adjustment outcome, hierarchical regressions were conducted. All the
data were centred, to reduce multicollinearity between the variables, except for the dependent variable.

In the first analysis, whether BAP level moderated the relations between ethnicity/culture (Taiwan and the UK) and TD siblings’ adjustment outcome was examined. In the hierarchical regression model, sibling’s self-report on SDQ total difficulties score was the dependent variable. Country group was entered in the first step of the regression models to examine ethnicity/culture. To examine whether siblings’ BAP level moderated the relations between ethnicity/culture and TD siblings’ adjustment outcome, siblings’ BAP level was entered at Step 2. The interaction variables were entered at Step 3 (sibling’s BAP score × country). The result indicated that country group significantly interacted with sibling’s BAP level and their response to adjustment evaluation.

Taiwanese TD siblings reported lower levels of adjustment difficulties than those in the UK. Taiwanese siblings who were reported to have lower BAP level had similar levels of adjustment difficulties to siblings in the UK. Taiwanese siblings who were reported to have higher level of BAP showed fewer adjustment difficulties. Conversely, UK siblings who were reported to have higher level of BAP showed elevated adjustment difficulties. In an identical hierarchical regression where prosocial behaviour was the dependent variable, there was no moderator effect. All the results are plotted and listed in Figure 6.3 and Table 6.8, respectively.
Figure 6.3 Interaction between country and TD siblings’ BAP level in predicting TD siblings’ adjustment outcome.

Table 6.8 Hierarchical regressions of TD siblings’ adjustment (self-report)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Total difficulties (SDQ)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Step 1</td>
<td>Step 2</td>
<td>Step 3</td>
</tr>
<tr>
<td>Step1: Country</td>
<td>-.26**</td>
<td>-.29***</td>
<td>.11</td>
</tr>
<tr>
<td>Step2: Siblings’ BAP level</td>
<td>.12</td>
<td>.24*</td>
<td></td>
</tr>
<tr>
<td>Step3: Country × BAP level</td>
<td></td>
<td>-.48*</td>
<td></td>
</tr>
<tr>
<td>(F) values</td>
<td>11.76**</td>
<td>6.99**</td>
<td>6.39***</td>
</tr>
<tr>
<td>(R^2)</td>
<td>.07</td>
<td>.08</td>
<td>.11</td>
</tr>
<tr>
<td>(R^2) change</td>
<td>.02</td>
<td>.03*</td>
<td></td>
</tr>
</tbody>
</table>

* \(p < .05\), ** \(p < .01\), *** \(p < .001\)

With the unexpected effect of the TD siblings’ BAP level in two different countries, the possible moderator effect of the parental BAP level between countries to explore whether parental BAP level interacted the way parents’ evaluated their children’s adjustment was further explored. Firstly, the country group was entered in the first block of the regression model. The parental BAP level was entered at Step 2. Lastly, the interaction (parental BAP level × country) was entered to explore the possible moderator effect.

For both countries, parental BAP scores were positively related to parent’s evaluation of their TD children’s adjustment. When the parental BAP levels were low, parents in Taiwan and the UK reported similar levels of adjustment difficulties.
of their TD children. When parental BAP levels were higher, Taiwanese parents rated their children to have more adjustment difficulties than their UK counterparts. An interaction effect was not found. This indicates that there was no moderator effect of the BAP level between two countries. The results of this regression analysis is summarised and plotted in Figure 6.4 and Table 6.9 respectively.

Figure 6.4 Interaction between country and parents’ BAP level in predicting TD siblings’ adjustment difficulties.

![Diagram showing interaction between country and parents’ BAP level]

Table 6.9 Hierarchical regressions of TD siblings’ adjustment (parents’ report)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Total difficulties (SDQ)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Step 1</td>
</tr>
<tr>
<td>Step1: Country</td>
<td>–.26**</td>
</tr>
<tr>
<td>Step2: Parental BAP level</td>
<td>.09</td>
</tr>
<tr>
<td>Step3: Country × BAP level</td>
<td>–.15</td>
</tr>
<tr>
<td>F values</td>
<td>11.65**</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.07</td>
</tr>
<tr>
<td>$R^2$ change</td>
<td>.07**</td>
</tr>
</tbody>
</table>

* p < .05, ** p < .01, *** p < .001
6.5.2 Testing the Diathesis-stress model

The second part of the moderator analysis was to examine the utility of the Diathesis-stress aspect of the model used in the present research. To test this model of TD siblings’ adjustment, the interaction terms between stressors (i.e. severity of ASD, life experience) and diathesis measures (i.e. parent’s and TD siblings’ BAP level) were also examined. Both Taiwanese and the UK data were examined separately to examine the fit of the model in the country. Again, all the data were centred, to reduce multicollinearity between the variables, except for the dependent variable. Both stressor variables were entered to the regression model to examine whether it interacted with the diathesis variables (i.e. TD siblings’ BAP level) to put TD siblings at greater risk to experience adjustment difficulties. The SDQ total difficulties score were first examined, where nothing significant was found. Followed by Orsmond and Seltzer’s (2009) analysis approach, separate subscales of the SDQ were then further examined.

Only one moderator effect was evident in the UK data and none in Taiwanese data, with TD siblings’ BAP level moderating the effect between TD siblings’ peer problems and the severity of ASD. When the severity of the children with ASD was lower, TD siblings who were reported to have higher BAP level by their parents showed more peer problems than those with lower BAP level in the UK data. Despite limited number of interaction found, this preliminary finding of the present research further supports the utilization of the Diathesis-stress model. The result is presented in Figure 6.5 and Table 6.10.
Figure 6.5 Interaction between the severity of children with ASD and TD siblings’ BAP level in predicting TD siblings’ peer problems in the UK.

![Graph showing the interaction between the severity of children with ASD and TD siblings’ BAP level in predicting TD siblings’ peer problems in the UK.]

Table 6.10 Hierarchical regressions of TD siblings’ adjustment (peer problems) in the UK.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Peer problems (SDQ)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Step 1</td>
<td>Step 2</td>
<td>Step 3</td>
</tr>
<tr>
<td>Step 1: Siblings’ BAP level</td>
<td>.31**</td>
<td>.32**</td>
<td>.45**</td>
</tr>
<tr>
<td>Step 2: Severity of ASD</td>
<td>–.02</td>
<td>–.08</td>
<td></td>
</tr>
<tr>
<td>Step 3: BAP level × Severity of ASD</td>
<td>–.29*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F values</td>
<td>8.01**</td>
<td>3.95*</td>
<td>4.63**</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.10</td>
<td>.10**</td>
<td>.16</td>
</tr>
<tr>
<td>$R^2$ change</td>
<td>.00</td>
<td>.07*</td>
<td></td>
</tr>
</tbody>
</table>

* p < .05, ** p < .01, *** p < .001
Chapter 7: Questionnaire study discussion: Adjustment in siblings of children with ASD

7.1 Summary of key findings

Questionnaire study aimed to explore the similarities and differences between the adjustment and the coping styles of the typically developing siblings of children with ASD in Taiwan and those in the UK. In general, the research outcomes have supported the predictions of TD siblings’ adjustment by using a combination of the Double ABCX model and the Diathesis-Stress Model. One of the emphases of this research is that the TD siblings’ reports have been used to explore the predictors of outcomes, since the majority of the recent research merely used the reports from parents or other information providers.

Several factors were confirmed to contribute to TD siblings’ adjustment outcome. Apart from the impact of informal social support, which was equally apparent in both countries, the variables influencing the adjustment of siblings in Taiwan can be characterized as ‘internal’. They included the sibling’s own coping style and, not the amount of life events, but the sibling’s self-report of the impact of these events. In other words their perception of life events, rather than the events themselves, had a predictive influence on adjustment. In the UK, influences were more mixed. Internal variables included, again, the impact of life events and self-reported life satisfaction, sibling coping style and also their BAP traits. However some external variables also had an influence: the severity of ASD in the sibling and the parental coping style. Thus the UK influences had a mixed profile.

The present research did not use matched groups in order to maintain the application of the research to real life settings as much as possible: matching groups would have involved removing culturally-specific key demographic differences between the countries, i.e. the ‘essence’ of the culture may have been lost in the formation of the matched groups. Instead, any key between-country differences in e.g. sibling adjustment and coping that were found were considered in terms of the differences in demographic and psychological variables between countries that might have
contributed to these findings. Hence, the following discussions were based on comparison with the normative data from each country, as well as data comparisons between similar, but non-matched groups from Taiwan and the UK, in order to provide an overview of similarity and difference in the two countries.

Based on the response to the SDQ, Taiwanese parents reported that their TD children had more peer problems compared to the normative data, and was classified within the borderline of the clinical range, while other domains on average were classified within the normal range. In contrast to the parents’ evaluation, Taiwanese siblings did not themselves report elevated levels of adjustment problems. Despite the slightly higher percentage of TD siblings evaluated by their parents as being within the clinical range, both Taiwanese parents and TD siblings’ had quite similar perceptions of TD siblings’ adjustment outcome in terms of the average scores on SDQ. As for the prosocial behaviour on SDQ, despite lower than the normative average, both parents and TD siblings’ reports were still within the normal range. Therefore the overall conclusion from these data is that Taiwanese siblings and parents agree that their overall adjustment is, on the whole, good. But there are some siblings experiencing difficulties, particularly in the peer domain, suggesting that some support is therefore required.

In contrast, for the UK families, both parents and TD siblings’ self-reports showed elevated adjustment difficulties, compared to normative data, especially in the peer problems domains. As for the prosocial behaviour, TD siblings’ self-reports did not show elevated difficulties. It is notable that in Taiwan the siblings reported fewer problems of themselves than their parents did of them, but the reverse was found in the UK data. The elevated adjustment difficulties in the UK siblings and the peer problems showed in both countries highlights the need for concern around TD siblings’ adjustment outcome.

The findings from TD siblings’ coping showed that the Taiwanese siblings more often used active and negative coping than their UK counterparts, while there was no difference in the frequency of using avoidant coping. In terms of coping efficacy, Taiwanese siblings rated active coping as the most effective one in comparison with
the other two coping styles, while avoidant coping was, surprisingly, rated the most effective coping style in the UK samples. For the parents’ coping style, Taiwanese parents used emotional approaches and the passive avoidant emotion-focused coping more often than UK parents, while there was a similar frequency of using problem-focused coping style in both Taiwanese and UK families. Both Taiwanese parents and TD siblings used a greater variety of coping strategies and used these more often, compared to their UK counterparts. Nevertheless, despite these differences in individual coping styles the overall patterns of coping were surprisingly similar and it is questioned whether these statistical differences reflect socially meaningful differences in coping patterns when assessed with a Western measure.

Of greater interest was the fact that the uses of different coping styles in Taiwanese parents were significant related to each other, while this was not the case in the UK. Moreover, findings from the Chinese-specific coping measure showed there were differences in the use of coping styles between Taiwan and the UK, where Taiwanese families again showed a pattern of a higher frequency of mixed coping strategies when coping with stressful situations. The correlations between the Chinese and Western parent coping measurements used in the present study indicated overlapping concepts but diverse philosophy in Chinese and Western coping. In the exploration of the coping relationship between parents and siblings, neither the Taiwanese nor the UK families had a strong connection in terms of the coping strategies they used. However, there was one relation found between parents’ regarding the use of problem-focused coping and the TD siblings’ used of negative coping in the UK families.

In the moderator analyses, TD siblings’ BAP level was found to have moderator effects between countries. Taiwanese siblings evaluated by their parents as having a higher BAP level, showed fewer adjustment difficulties than those with a lower BAP level, whereas the opposite pattern was found in the UK siblings. This may indicate that Taiwanese TD siblings’ BAP level had a negative impact on their ability to evaluate their adjustment difficulties, although it was unclear why this was not the case in the UK. Furthermore, in the moderator analysis exploration of the diathesis-
stress element of the model, UK siblings’ BAP level was also found to interact with the severity of children with ASD in predicting TD siblings’ peer problems in the UK. If their ASD siblings’ severity was low, TD siblings who showed low BAP level displayed fewer difficulties with peers, whereas if ASD severity was high and TD siblings’ BAP was high then peer problems were low. More importantly, when the severity of ASD siblings’ was high, TD siblings who were reported to have higher BAP level showed fewer difficulties than those with lower BAP level. It is possible that when both stressors and level of diathesis variable were high, TD siblings were less able to identify the difficulties they experienced, compared to those with lower diathesis. This identified an important application for health professionals to consider the BAP traits of respondents. If individuals have showed higher level of the BAP traits, other information providers are necessary to increase the validity of the information.

It is also important to note that the difficulties on adjustment were based on the TD siblings self-report. If using the parents’ report on TD siblings’ adjustment difficulties, it is expected that higher TD siblings’ BAP level would link with higher adjustment difficulties according to parents’ evaluation. Similar results are also supported by other research, using parents’ evaluation as a measurement outcome (Mohammadi & Zarafshan, 2014; Petalas, et al., 2012a). The present research findings partially supported the Diathesis-stress model which emphasized how epigenetic vulnerabilities and stressors may interact to place certain siblings at risk.

In this chapter the possible explanations of the results and related research that is consistent to, or contrasts with, present research findings will be discussed. The sibling adjustment outcome between the two countries will be discussed first. Both parents’ and TD siblings’ coping and TD siblings’ social support are also discussed in detail. After these, whether the present research results provided a good fit to the research model, along with the complicating factors and measurement issues are discussed. Finally, the limitations and clinical applications of the present research are also presented.
7.2 Sibling adjustment in Taiwan and in the UK

In the present data, Taiwanese siblings were fairly well adjusted according to their self-report, whereas UK siblings reported much higher difficulties among all the behaviour problems, although not in prosocial behaviour. It appears that of all the aspects of adjustment, difficulties in siblings’ peer relationships compared to country norms was an area of concern for siblings and their parents in both countries. This finding is consistent with other Western based studies (Bågenholm & Gillberg, 1991; Hastings, 2003b; Hymel, Rubin, Rowden, & Lemare, 1990). However, it has not previously been shown in Chinese studies. There are two possible explanations for this. Firstly, it is possible that the impact of a child with ASD makes it difficult for siblings to spend time with peers. As the research literature has reported, it required a significant amount of time to take care of the sibling with a disability; thus, they may have had relatively less time to spend with their peers and opportunities to participate in leisure activities might also have been restricted (Barak-Levy, et al., 2010; Gold, 1993; Holmes & Carr, 1991; Meadan & Gamble, 1989; Stoneman, 2005). Secondly, research has suggested that TD siblings displayed very mild to significant difficulties in emotional understanding compared to siblings of children without ASD even at an early age (Cassel et al., 2007; Meadan, et al., 2010; Yirmiya et al., 2006). Social emotional understanding is associated with difficulties interpreting emotional events and poor peer relationships (Bauminger & Kasari, 2000; Losh & Capps, 2006). Peer relationships play an important role in developing teens’ self-identify, feelings of acceptance and influences their long term psychological adjustment (Woodward & Fergusson, 1999). Health professionals, therefore, need to be aware of the difficulties that TD siblings may have with their peers.

In the comparison of samples between Taiwan and the UK, Taiwanese parents’ reports consistently rated their TD children as having more difficulties than their UK counterparts. Similar scores were found in a large community sample in China (Du, Kou, & Coghill, 2008) and also in Taiwan (Gau, et al., 2010b). This provided important information, suggestive of how behaviour was viewed within the cultural context. Chinese parents might have higher standards and expectations of their
children’s behaviour compared to Western parents (Chao, 1994; Chen & Stevenson, 1995; Chen et al., 1998).

As for the siblings’ self-reports, the present research showed that the Taiwanese samples reported less difficulties in emotional and behavioural problems than their UK counterparts. The results were in accord with those in other research applied in ethnic Chinese populations. Studies have found that Chinese adolescents are less likely to report themselves as having emotional and behavioural problems than Western populations (Du, et al., 2008; Wang, Liu, & Wang, 2014; Yao et al., 2009). Therefore this finding does not necessarily reflect a difference in the actual level of functioning, but instead on culturally-specific pressures which impact on responses to questionnaires.

Lalwani, Shavitt, and Johnson (2006) concluded that people in collectivist countries (including China and Taiwan) are more likely to display socially desirable responding in order to present oneself in a culturally accepted and approved light than those from individualistic countries. Unfortunately, there is no such information available on the tendency to report in a socially desirable fashion in children or younger populations within Chinese culture. Such a tendency might be exacerbated in families of children with ASD. One Western study carried out by Higgins, Bailey, and Pearce (2005) suggested that caregivers may have felt pressure to present a socially desirable image of themselves and of their families. Hence, norm data, instead of a clinical category band, was used to solve this possible socially desirable responding tendency in Taiwanese siblings.

Furthermore, the lower than average scores on siblings’ prosocial behaviour in the Taiwanese samples are interesting, as they appear to contradict previous discussion of collectivism, which emphasises and values behaviour involving positive social interactions and the socially desirable responding as discussed earlier. In the discussion of prosocial behaviour and coping in the previous chapter (see Section 3.4.1), Hsu, Chen, Wang, and Sun (2008) divided behaviour into active-prosocial and passive-prosocial according to the intention. The former involves consideration of other’s stand points and an attempt to achieve solutions that all parties would be
happy with, whilst the latter involves sacrificing their own interests or opinions and trying to match up with others’ preferences. In this regard, it is possible that the concepts of the prosocial behaviour on the SDQ were viewed in a more multidimensional manner in the Chinese context than in the UK. Although the factor structure of the SDQ was not the focus of the present thesis, factor structure studies of the Chinese SDQ have supported this notion (Du, et al., 2008; Liu, et al., 2013). Furthermore, the scoring patterns of prosocial behaviour on the SDQ were found to be consistently lower in the Chinese population compared to the Western norm data (Liu, et al., 2013; Yang, 2011).

The findings of the SDQ highlight the importance of understanding parents and TD siblings’ responses within their own culture. For example, in Chinese society, children are disciplined to behave obediently and follow norms of socially acceptable behaviour (Wang & Chang, 2010). Conduct problems, such as the expression of aggression or offense is not allowed as it challenges the virtue of respecting the elderly and parents in Chinese culture (Ho, 1996). Also, in-group harmony is prioritised, while personal needs and feelings are seen as less important in this cultural context. To fulfil the expected social roles and to conceal one’s emotions and to follow the social norms are highly valued in the philosophy of Chinese-collectivism (Oyserman, Coon, & Kemmelmeier, 2002). In the research of Savina, Coulacoglou, Sanyal, and Zhang (2012), the levels of externalising and internalising behaviour among children from different ethnic and cultural backgrounds are compared. The findings showed that Chinese children displayed more anxious feelings and lower impulsive aggression compared with those in other cultural groups. This Chinese philosophy also encourages Chinese people to repress their emotions: expression of emotion should be carefully regulated as group harmony and hierarchies are usually considered the priority (Bond, 1993). As expected, such cultural specificity and the social expectation to inhibit emotional expression and the stress on maintaining relationships would profoundly affect the outcomes of the Taiwanese cases. The present Taiwanese data also fitted the impression discussed above with lower conduct problems among other behavioural domains shown, whether from parents or TD siblings’ report.
Another issue is whether the lower level of prosocial behaviour within the present Taiwanese sample is a cause for concern. Chen and colleagues (2000) found in their Chinese samples that children’s prosocial orientation was negatively associated with externalising behaviour problems, and prosocial-cooperative behaviour also has been found to be highly related to the quality of social and peer relationships (Newcomb, Bukowski, & Pattee, 1993). Hence, to interpret the results of the SDQ in the present Taiwanese sample, the possible culture factors behind these findings must be taken into consideration. In connection with the peer problems discussed earlier, it is speculated that this lower level of prosocial behaviour in Taiwanese siblings did link to the difficulties that TD siblings experienced.

7.3 Sibling coping and social support in Taiwan and in the UK
Since lots of variables are fixed or settled, such as ages of ASD or TD siblings and the family’s social economic status, variables which can be adjusted, such as coping style, and which might in turn influence TD siblings’ adjustment outcome, are of particular interest. The literature review highlighted the relationships previously found between TD siblings’ coping style and adjustment outcome, (Orsmond, et al., 2009; Ross & Cuskelly, 2006). The findings relating to the present research model also suggests that coping plays an important function in TD siblings’ adjustment outcome. The findings from siblings’ coping showed that the Taiwanese siblings more often used active and negative coping than their UK counterparts, while there was no difference in the frequency of using avoidant coping. The preference for using a wide variety of different coping strategies was also supported in Liu and colleagues’ (2004) research, in which they found Chinese adolescents used multiple coping strategies when faced with a problem or stressful situation. The frequent use of multiple coping strategies by Taiwanese siblings might suggest that siblings are merely more aware of the coping strategies they have used. This might also be a culture specific characteristic, as both Chinese parents and TD siblings in the present research had shared this response pattern. Whether the use of a wide variety of coping strategies is more beneficial than using a narrower range, or how the utilisation of multiple coping strategies relates to the adjustment is still an under researched area. At least in the present research data, TD siblings in Taiwan did
report having fewer adjustment difficulties than their UK counterparts. A future area research could be to follow up this data set to further support this notion.

Social support was also related to siblings’ coping style. In line with previous research (Conway & Meyer, 2008; Tsao, et al., 2012), the present Taiwanese data suggested that the presence of informal social support is linked to the use of more active coping strategies. Social support was also linked with TD siblings’ adjustment in the UK data. The data on social support also suggested that UK siblings, in particular, reported frequent parent support and viewed that support as very important. The lack of relations between TD siblings’ BAP traits and social support in both countries suggests that this relationship applies across the board.

Surprisingly, there was no links found between TD siblings’ BAP level and their coping styles in the present research. The only relationship found was between parental BAP level and parents’ coping style, with higher BAP level linked with the preference of using passive-avoidant coping in the Taiwanese data only. This link between parental coping and their BAP level was consistent with Ingersoll and Hambrick’s (2011) research, where higher parental BAP was associated with using the maladaptive coping strategies. However, none of the previous research identified discussed the relation between TD siblings’ BAP level and their use of coping. As previously discussed, one limitation was that assessment of BAP level relied only on parental report, and this limitation should be addressed.

7.4 Evaluating the model
In this section, the predictors of TD siblings’ adjustment and coping in Taiwan and the UK are discussed separately. Any relations found in Taiwan and the UK are also compared. The last part of this section discusses whether the relations found from both countries fit with the combination of the Double ABCX model and the Diathesis-Stress model.
7.4.1 Predictors of adjustment in Taiwan

Different to the UK model, Taiwanese siblings’ adjustment outcome were more related children’s internal variables, such as the impact of their life events and the coping strategies siblings had used.

As expected, the life events impact contributed to TD siblings’ adjustment outcome in the Taiwanese model. These relationships were consistent with the literature discussed in Section 3.3.4. Furthermore, it was the impact of the life experience, rather than the absolute number of the events, that had the power to influence TD siblings’ adjustment outcome. This is consistent with the literature review, where individuals’ perception and explanation of experiences had a more crucial impact on the outcome (Allen, et al., 2012; Swearingen & Cohen, 1985). Hence, the present research brought out this important implication of assessing TD siblings’ appraisal of their experience rather than the cumulative number of the life events. Taiwanese siblings’ adjustment did not relate to their parents’ coping style but related more to their own. As for the prosocial behaviour, again, TD siblings’ prosocial behaviour was related to their use of active coping, but was not associated with their parents’ coping approach, either directly or indirectly. These findings in a Chinese context for the first time are important. Because of the cultural differences, it had been unclear whether TD siblings’ coping would relate to adjustment in the same way as other Western based research. This is confirmed in the present research. Different types of coping styles were found to contribute to TD siblings’ adjustment outcome in Taiwan and the UK. The link from sibling coping to adjustment is important because it suggests that teaching positive coping styles is an accessible and practical way to intervene to improve outcomes.

The BAP factor did not play a significant role in predicting TD siblings’ adjustment outcome in the Taiwanese model. This was surprising, because a higher BAP level has been found to relate to poor adjustment in Western literature (Meyer, et al., 2011; Petalas, et al., 2012a). From the normality test in Section 5.1.2, Taiwanese siblings’ self-report SDQ data was positively skewed. When further compared with Taiwanese normative data, Taiwanese siblings’ SDQ did not match the clinical impression from
the community sample, with a much lower percentage of the siblings falling into the clinical concern range. Despite not significant in the bivariate level, there was a trend showing that, with the increasing of the siblings’ BAP level, fewer difficulties were reported by TD siblings (see Figure 6.14). It could be argued that the Taiwanese siblings’ BAP level might result in the TD siblings being less aware of the difficulties they had, to some extent. However, the evidence is not strong enough to conclude why this is the case in the Taiwanese sample. More information and analyses are needed to further clarify this finding in the Taiwanese data.

7.4.2 Predictors of adjustment in the UK

In the sample of UK families, TD siblings’ self-reported adjustment difficulties were predicted by mixed factors. A number of these findings correspond with past research, as has been discussed. For example, social support received by TD siblings’ were associated with their coping and adjustment outcome, as shown in the literature discussed in Section 3.3.2. However, other interesting findings in the present UK model were around the role of BAP level and the influence of parental coping, and these will be the focus of the discussion here.

Several studies have found a relationship between siblings' BAP level and their adjustment outcome (Meyer, et al., 2011; Mohammadi & Zarafshan, 2014; Orsmond & Seltzer, 2009; Petalas, et al., 2011). In the present research, the inter-correlations among TD siblings’ BAP level and SDQ were evident. This further provided evidence of how BAP level influences individuals’ adjustment outcome whether from self-report or informant’s evaluation. This again addressed the importance of looking at the influence of epigenetic vulnerability within the families of children with ASD.

The coping styles that parents and siblings use could also explain differences in adjustment outcomes across the UK data. Despite significant correlation results, parents’ use of problem-focused coping and emotional approach coping did not appear to influence TD siblings’ adjustment as strongly as TD siblings’ own coping
parents’ emotional approach coping (i.e. seeking social support for emotional reasons, acceptance, positive reinterpretation, and turning to religion) in the present research contains the important concept of cognitive reframing. This emphasises individuals’ restructuring of beliefs about the situations, which has found to be related to parental well-being in families of children with ASD in previous research (Benson, 2010; Obeid & Daou, 2015). This coping approach can be helpful especially when the situation cannot be changed directly or is uncontrollable (Austenfeld & Stanton, 2004; Stuart & Mcgrew, 2009). Based on social learning theory, parents can act as models and promote adaptive coping styles in order to enhance the coping ability and adjustment of their children. The reason for this parent coping variable not being a strong predictor of sibling adjustment within the model used in the present study, and indeed the relatively small number of connections between parent and sibling coping in general, is unclear. In the interview study (Interview study), there will be more discussion regarding the type of the coping parents and TD siblings used and how TD siblings perceived their parents use of various coping strategies, including emotional approach coping.

Previous studies on siblings with a variety of disabilities tend to focus on identifying siblings’ specific coping strategies and how they manage stressful situations and how the coping styles relate to siblings’ adjustment. One study found an association between siblings’ adjustment and their coping styles (Smith, Elder, Storch, & Rowe, 2015), and another reported associations between siblings’ relationships and their coping styles (Orsmond & Seltzer, 2007a), whereas others did not find any significant relations (Giallo & Gavidia Payne, 2006; Ross & Cuskelley, 2006). In the present research, UK siblings reported their preference for using avoidant coping over active and negative coping but apparently this was employed without much success. The active coping, supposedly a well-adjusted means of coping, was not related to outcome in the UK siblings, either in terms of total difficulties or prosocial behaviour, and this is surprising. It is possible that children and adolescents of this
age are not capable of using adaptive emotional control skills well, or using an active problem-solving approach efficiently, to deal with conflicts with siblings or stressors.

Consistent with the literature reviewed in Chapter 3 on siblings’ coping, other-directed cognitions (e.g. blaming others), which is a type of negative coping, was associated with poor sibling adjustment and was commonly reported in dealing with stressful situations (Mchale & Gamble, 1989). Roeyers and Mycke (1995) found that siblings of children with ASD used more other-directed cognitions to cope with the distress of interaction with their siblings compared to other groups (including the siblings of children with intellectual disabilities and the siblings of children without disability). The author also suggested that this other-directed cognition resulted in TD siblings’ negative outcome. These could be further clarified in Interview study, which offered more opportunity to understand why TD siblings chose certain type of coping strategies.

7.4.3 Comparison of predictors of sibling adjustment in Taiwan and the UK

Results from both the Taiwanese and the UK model emphasize the importance of informal support for siblings, especially the support from school, where they spend a majority of time with their peers and teachers daily. Research has indicated the role of peer relationships in facilitating the development of prosocial behaviour and adjustment in early childhood (Jeffrey Parker, 2006) and adolescence (Laible, Carlo, & Raffaelli, 2000; Wentzel, 2014). This pattern has also previously been found in the siblings of children with a developmental disability. Opperman and Alant (2003) addressed the importance of the peer relationship in adolescent siblings of children with a developmental disability, as it not only provides peer support for the TD siblings but also encourage them to follow their peers to use optimal coping strategies. This is supported by the present research, whether for the Taiwanese or the UK siblings, there are potential benefits found between social support and coping style. Since TD siblings spend quite a long time in school, the relationships with their peers and teachers are crucial to them. If health professionals in school can promote support to the TD siblings, it could prevent an adverse adjustment outcome.
The influence of parental coping on siblings’ adjustment differed between Taiwan and the UK. Despite Taiwanese parents appearing to have a better insight of their TD children’s adjustment, there was more links between parent coping and sibling adjustment in the UK model. Siblings in the UK also viewed parents’ support as a more important source of social support than in Taiwan. When adopting coping strategies, parents in the UK might therefore also need to consider the possible influence on their TD children. The need to balance between problem solving and considering the impact on the TD siblings’ needs and feelings, might be the important message for the UK parents.

The TD siblings’ satisfaction with life contributed to their adjustment outcome in the UK. Despite not as evident as in the predicting model, Taiwanese TD siblings’ life satisfaction did show links with their adjustment outcome. With greater life satisfaction, fewer adjustment difficulties were found. The concept of life satisfaction refers to individual’s subjective view of their life and well-being. Based on previous literature, it is expected that the more controllable and manageable an individuals’ life, the more satisfaction they might have (Athay, 2012). It is unclear why life satisfaction seems to play more of a role in UK than Taiwan.

The severity of the ASD siblings’ symptoms also linked with TD siblings’ prosocial behaviour in the UK model, although this was not the case in the Taiwanese model. As reviewed in Section 3.3.1, the severity of symptoms or challenging behaviour of the children with ASD has found to be a strong predictor for TD siblings’ psychological well-being. As Hastings (2003a) has found, if children had fewer severe ASD symptoms and their families had received a high level of formal social support, their TD siblings were at less risk of displaying behaviour problems. In the present UK data, higher ASD severity was linked with TD siblings’ displaying more prosocial behaviour. These needed to be further clarified in the following interview study. Although the present research did not evaluate formal support directly, support services for siblings are generally more available in the UK than in Taiwan, and this perhaps explains the finding of a significant relation between ASD severity and sibling outcome in the UK only. It is possible that if ASD siblings had more
profound problems, various sources of formal support would have been provided for the TD siblings in the UK, resulting in better adjustment. Formal support provision will be further discussed in the interview study.

7.4.4 Factors that linked with coping in Taiwan

The discussion of this and next section was based on the results from the correlation analysis. Taiwanese siblings’ coping strategies were, to some extent, related to their perceptions of social support and to the age of both ASD and TD siblings. In terms of the social support, teachers’ support significantly contributed to an increase of TD siblings’ use of active coping. It is possible that with help or encouragement from teachers, TD siblings learned to use this functional coping style. It is equally possible that siblings who had developed this coping style then made better use of the support provided by the teacher. This result is important for educational settings in Taiwan. This might be particularly suitable for Chinese culture, given the parent-child relation and parenting style discussed in Chapter 2. It is possible that teachers play a buffering role in helping TD siblings to deal with peer problems and also have a less intense relationship than that with parents.

The unexpected relationships between the age of child with ASD and TD siblings and the use of avoidant coping was also found in the Taiwanese data. The older the TD siblings, or the child with ASD, the more avoidant coping the TD siblings used. This finding was unexpected as the literature indicated, mature and experienced TD siblings are more likely to use more effective coping strategies (Rossiter & Sharpe, 2001). From the review in the earlier Section 3.2.3, with the development of cognitive ability, older TD siblings would be expected to better understand the behaviour of the child with disability. How then can the findings from the present study best be explained? One possibility might be that the challenging behaviour of children with ASD increases over time, resulting in more sibling avoidant coping. However, there was no relation found between the severity of ASD siblings and any age-related factors.
When the children with ASD grow older, stress might ‘pile-up’ over time, leading to TD siblings using more avoidant or negative coping strategies. However, the present research was not longitudinal research, so could not explore changes in family dynamic over time within the Taiwanese families. It is also possible that with increasing age, TD siblings in Taiwan experienced more stress in their life and were less able to use adjusted coping strategies. Further follow up with these Taiwanese families would be needed to confirm this speculation. Health professionals could target the development of well-adjusted coping strategies especially in older Taiwanese children. The relationships between family members and the family dynamic also need to be explored in order to clarify the reason why older siblings use the adverse coping strategies.

### 7.4.5 Factors that linked with coping in the UK

For the UK data, the sources of informal support did not have strong links with TD siblings’ coping style, and this was surprising. Nevertheless, the support from close friends and others in school approached significance. Siblings in the UK reported receiving a high level of support from various sources. It is plausible that consistently high frequency of the support provided to the TD siblings might weaken the chance of finding links between social support and coping.

Based on the previous literature, coping is a constantly changing and learning process. It is suggested that children learn ways of coping through the world around them, especially from their parents (Kurtz, 1996; Power, 2004). However, neither country had strong relations between parental and siblings’ coping. The only one significant correlation found in the UK families between parental problem-focused coping and siblings’ negative coping was surprising. There are a number of possible explanations for this. Firstly, if parents focus on dealing with challenges relating to the child with ASD, the TD siblings might either neglect their own needs in order to support their parents, or might turn to negative coping because of a perceived lack of focus on them. However, parents use of problem-focused coping might also result from noticing their TD children using negative coping strategies, that is, parents may try to do something proactive about the situation, in order to help the siblings. This
finding also emphasises that parents were coping with all of their children in their family.

This preliminary result highlights that as parents choose coping strategies they also need to consider the influence of their coping strategies on TD siblings. Furthermore, it is not suggested that parents use of problem-focused coping necessarily had an adverse effect on TD siblings but rather emphasised the importance of considering such relationships. In Interview study, parents and siblings were interviewed and their perspectives about coping strategy choice were compared.

7.4.6 Comparison of factors that related to sibling coping strategies in Taiwan and the UK

The differential patterns from the two models showed that UK parents had somewhat greater influence, in terms of coping style, on their children compared to their Taiwanese counterparts. This suggests that UK parents and TD siblings might have more chance to interact and learn the coping strategies together. This might also be associated with the fact that UK parents more were able to work part-time rather than full-time according to the demographic information in Figure 5.6; hence, had more chance to interact with their children. In Interview study, the interview data further explored how parents delivered and modelled coping strategies to their TD children in Taiwan and the UK. Another possible reason for the lack of links between Taiwanese parents’ and TD siblings’ coping, may be attributed to both coping measurements being developed based on Western coping concepts. This will discuss alongside other measure issues (see Section7.6). Furthermore, as the present research model suggested that coping styles might mediate the relation between stressors and psychological outcome, further consideration of mediation analysis in future research is recommended.

The present research data also suggested that the presence of social support was linked to the use of more adjusted coping strategies in the Taiwanese data. For the Taiwanese siblings, their coping strategies could benefit from the support from teachers. Despite no strong links between social support and coping in the UK data,
potential links were also found. These connections from social support to coping provide further clues as to the clinical impact of these findings: training in positive coping strategies may be delivered in a relevant social support context, such as after-school peer support or teacher-led training, depending on the culturally-specific patterns which have observed in the present research.

7.4.7 Does the model provide a good fit for the data?

In the present research, the research model illustrated in Figure 3.2 (see Section 3.5.3) was a combination of the Double ABCX model and the Diathesis-Stress model. Nearly half of variance in TD siblings’ outcome was explained by the Taiwanese model, whereas around one-third of adjustment outcome was predicted in the UK model. This suggests that the models are a relatively good fit with the data, but that the inclusion of further variables may be required to produce a more complete model of sibling outcomes.

Overall, the relations between variables which were analysed did fit the present research model, such as the links found between TD siblings’ coping, social support and their adjustment outcome. These have been consistently found in the previous research, where social support and coping are related to individuals’ well-being (Conway & Meyer, 2008; Dunn, et al., 2001; Tsao, et al., 2012). Furthermore, the present research is one of few studies that found TD siblings’ coping, to some extent, linked with their self-reported adjustment outcome.

As well as the original concepts of the Double ABCX model, coping (Factor BC) is linked with stressors and pile-up demands (Factor aA), and family adaptive resources (Factor bB) influences the family adaptation factor (Factor xX). With other expected links between variables being found, the absence of correlations between stressors and TD siblings’ coping in the present research was surprising. According to the model, it is expected that coping strategies mediated relations between stressors and outcomes. Furthermore, the stressors were found, in the present research, to have a direct link with the TD siblings’ adjustment in both countries. Hence, it is plausible
the relationship between stressors and adjustment outcome was mediated by TD siblings’ coping, which could further analysed in future.

Unlike other research adopting the Double ABCX model with families of children with ASD (Bristol, 1987; Manning, et al., 2011; Mcstay, et al., 2014; Pakenham, et al., 2005; Paynter, Riley, Beamish, Davies, & Milford, 2013; Pozo, Sarriá, & Brioso, 2014), the present research focused on TD siblings’ adjustment and used their self-report for the majority of the analysis. This was a successful strategy. In comparison to other studies, the present research found a similar numbers of relations within the model. More importantly, TD siblings’ adjustment was understood through their point of view. This allows health professionals and parents to understand what factors relate to their TD children’s experience and can contribute to their adjustment outcome. The value of using TD siblings’ self-report was also emphasized in recent research (Hastings & Petalas, 2014).

It is reasonable to speculate that TD siblings’ BAP level might link with siblings’ self-reported adjustment, given the preliminary evidence found in the Taiwanese model in the present study. This finding also addressed the importance of considering the Diathesis-stress model with the Double ABCX model, where the interaction between BAP level and the environment stress factors was emphasised. Many studies have discussed how level of the BAP characteristics render some family members more vulnerable to the experience of stressful events, and links to difficulties in accessing social support and influences the strategies they used to cope with situations (see Section 3.3.3). A similar discussion of the moderator effect of the BAP level was also found in research by Petalas and colleagues (2012a), suggesting the TD siblings’ BAP level might moderate the relation between parental mental health and sibling relationship.

The Diathesis-stress model would predict an interaction, leading to poorer outcomes when diathesis and environmental stressors were high. The present research examined whether the stress variables (i.e. severity of children with ASD and life events) operated in conjunction with the diathesis measures (i.e. parents’ and TD siblings’ BAP level) to put siblings at greater risk of adjustment difficulties. Only
one relation was found in the UK model. In the presence of lower severity of ASD symptoms, TD siblings with higher BAP levels reported more difficulties with peers than those with lower BAP levels, whereas in the presence of a higher severity of ASD symptoms, TD siblings’ reporting on peer problems were similar, regardless of their BAP level. This result partially supported the utilization of Diathesis-stress model in demonstrating an interaction between stressors and the BAP level in influencing TD siblings’ adjustment outcome. The outcome was poorer when diathesis was high and environmental stressors were low. However, when the environmental stressors were high, the influence of high or low diathesis did not differ much.

The absence of more extensive diathesis-stress type interactions in the present Taiwanese data might relate to how this epigenetic factor was viewed in the Chinese culture. In the present Taiwanese data, TD siblings’ or parents’ BAP levels were much higher than their UK counterparts. Furthermore, there was a positive correlation between parental BAP level and siblings’ BAP level in Taiwanese families, but not the UK families. It is possible that if parents had higher BAP level it might also influence the way they evaluated their TD children’s BAP level and related outcome. Such rater bias is also discussed in similar research (Orsmond & Seltzer, 2009; Petalas, et al., 2011), and may have prevented the discovery of relations between environmental stressors, epigenetic factors and sibling outcomes in the present study.

Despite the absence of robust correlations between BAP level and some variables, the moderator analyses in Section 6.5.1 still supports the importance of assessing BAP level in families of children with ASD, in order to understand how epigenetic factors interact with environmental stressors to influence individuals’ adjustment outcome.

Looking together at the combination of the Double ABCX and Diathesis-stress models, one key exception was the absence of a relationship between siblings’ BAP level with family adaptive resources (Factor bB) and TD siblings’ coping (Factor BC), in both countries. There are some reasons that might contribute to the absence
of these relationships. Firstly, the siblings’ BAP level was assessed by their parents and this might weaken the correlation power between other variables that were reported by the siblings themselves. Further research is therefore still required in relation to this aspect of the present research model. In order to increase the validity of BAP assessment, using other informants, such as both parents, might be useful. In the present research, Taiwanese parents reported higher on their own and their children’s BAP level than did UK parents. This higher degree of BAP characteristics requires further investigation, such as gathering complete information on family history of ASD diagnoses. The need for Chinese BAP norms for children is also required.

Secondly, appraisal of the stressor was not included in the present model. As some research studies have shown the role of BAP level in relation to cognitive ability/rigidity and how it interacts with stressors and coping (Ingersoll & Hambrick, 2011; Petalas, et al., 2012a; Wainer, Ingersoll, & Hopwood, 2011), this might help to clarify the relations in the present model.

In addition to the appraisal variable, the combination model might be further strengthened by the inclusion of other variables, to explain an even greater portion of variance in sibling outcome. Such variables might include knowledge of ASD, sibling relationships, parental psychological stress etc. These have also been discussed in relation to TD siblings’ outcome (Petalas, et al., 2012a; Roeyers & Mycke, 1995).

In general, the present research supported the utility of the combination model for framing and understanding the experiences of siblings of children with ASD. Despite the absence of some of the expected correlations, the results generally confirmed the importance of the survey variables in predicting TD siblings’ adjustment outcome. Further research is still required to clarify the role of the BAP level and to increase the information validity.
7.5 Complicating factors

7.5.1 Informant discrepancies

In this study, the TD siblings’ adjustment was evaluated by the parents’ ratings and siblings’ self-report on SDQ. One of the common issues of using more than one informant for the same measurement is informant discrepancies. Such discrepancies have been found among informants from a variety of cultural backgrounds. For review and meta-analysis see Achenbach, Mcconaughy, and Howell (1987) and De Los Reyes and Kazdin (2005). As the information providers might have different mind-sets and reference situations for evaluating behaviours, disagreements among the informants are commonly found (Achenbach et al., 2008).

For the present research, the information differences were important, as they suggested a gap between parents’ and children’s perceptions in viewing the TD siblings’ adjustment, in the UK, but not the Taiwanese sample. Typically siblings in the UK reported having more adjustment difficulties than their parents’ did. This might explain why the UK TD siblings preferred avoidant coping. Using these indirect, distancing strategies to avoid dealing with a situation, TD siblings might be less involved in conflicts and arguments. Hence, their parents might underestimate the difficulties that their TD children faced. For clinical applications, the discrepancy between informants highlights the importance of understanding individuals’ own points of views. Furthermore, the discrepancy reflected the difference between parents’ and TD siblings’ mind-sets in viewing the situation. Both informants’ reports have their own value in understanding TD siblings’ adjustment. There is perhaps no ‘true’ picture of outcome: siblings might be more aware of their own adjustment, but might be susceptible to response bias. Equally, parents may be unaware of sibling difficulties, or may have a more measured approach to what constitutes ‘difficulties,’ based on their longer experience. The important point is perhaps that it is important to listen to concerns about sibling adjustment, whether these are raised by parents or siblings.
7.5.2 Western versus Eastern attitudes

Parental coping has been discussed due to the assumption from previous literature that it influences their children in many ways. The present research adopted two measurements that were developed based in Western and Chinese cultures separately. Since Chinese coping has found to have fundamental differences in terms of coping concepts and the philosophy behind them, it is reasonable to look at the response patterns within the two cultures.

For the Western coping questionnaire (COPE, Carver, Scheier, & Weintraub, 1989), both Taiwanese and the UK parents had similar preference patterns in coping styles. It was noticeable that Taiwanese parents used coping strategies more frequently than the UK samples did, a finding which corresponds with existing literature (Lin, et al., 2011). The greater use of various sustained coping strategies by Taiwanese parents may also suggest that these parents were more aware of the coping strategies they have used. In the Chinese coping questionnaire (CSCSC, Hsu, et al.), Taiwanese parents again use a significantly higher frequency of mixed coping strategies. This result provided further evidence that Taiwanese parents do have a wider array of coping styles than UK parents and this is not just an effect of the Western COPE measure. To some extent, Taiwanese parents’ data mirrored the siblings’ data which also indicated more frequent use of a variety of coping strategies than their UK counterparts. As discussed earlier, Chinese parents and children were found to prefer to use a variety of coping strategies (Liu, et al., 2004). It also therefore be speculated that members of the same family have certain similarities in their ways of coping or awareness of their use of these coping strategies.

Taiwanese parents were more likely to use religious coping than UK parents. The same finding was also consistent with other research conducted in Chinese families with children with ASD (Wang, et al., 2011). So far, neither the function of religious coping in the families of children with a disability, nor the complex roles of religious coping have been widely explored or addressed (Benson, 2010; Ekas, Whitman, & Shivers, 2009; Tarakeshwar & Pargament, 2001). The religious coping in the COPE may refer to a more dysfunctional form of coping in contrast to the typical concept of
religious coping. It appears to be the cognitive reappraisal/reframing element of religious coping that is effective when individuals confront challenges in life (Ekas, et al., 2009; Maltby & Day, 2003). However, in terms of the COPE assessment of religious coping, more items are related to emotional support rather than cognitive reappraisal (e.g. ‘I put my trust in GOD’, and ‘I try to find comfort in my religion’) (Hastings, et al., 2005; Pakenham, et al., 2005). The present study suggests that Taiwanese siblings’ also rely more on religious coping: their response on Kidcope (item 16: I pray), showed that they pray much more than their UK counterparts. Even though it is hard to tell whether this religious coping in TD siblings’ questionnaire is maladaptive or not, future research is still required in order to distinguish the function of religious coping in families of children with ASD, especially under different culture contexts.

Surprisingly though, significantly lower levels of active-prosocial coping, suggested to be part of the specific philosophy of Chinese coping, were reported by Taiwanese parents compared to their UK counterparts. The prosocial and antisocial dimensions on the CSCSC refer to the coping responses that are influenced by, and are used in reaction to, the social context. As stated in Hsu et al. (2008), prosocial coping could help individuals’ well-being and harmonious interpersonal relationships. In other words, if individuals adopt active-prosocial coping more frequently, the better they may be able to calmly deal with stressors. Hence, the lower level use of active-prosocial coping in Taiwanese parents might relate to issues such as stigma and the availability of intervention or social support in Taiwan. Furthermore, in the present research data, TD siblings in Taiwan also reported a lower level of prosocial behaviour compared to their UK counterparts. To some extent, Taiwanese parents and TD siblings shared certain similarities, such as their preference for using a variety of coping strategies and a lower level of using/displaying prosocial coping/behaviours. There might be some cultural specific factors that contribute to this.

However, these proposed explanations still wait for verification in future studies. The present research, nevertheless, focused more on providing an insight into comparing
how families with children with ASD in the Chinese and Western cultures deal with their stressors. This is significant as it investigates the potential of how a culture shapes people’s coping styles.

7.6 Measurement issues

In the discussion of the SDQ, previous research which explored the different factor structures of the Chinese SDQ was identified (Du, et al., 2008; Liu, et al., 2013). In the Chinese context, subscales such as emotional and peer problems and total difficulties were suggested to be more multifactorial than those in the Western contexts. This has been supported in other research, where researchers argued that the internal consistency and test–retest reliability of the peer problems scale is poorer than the other SDQ subscales in a number of different language version (Capron, Théond, & Duyme, 2007; Goodman, 2001; Muris, et al., 2003).

While the factor structure of the SDQ was not the focus of the present thesis, nevertheless, some consideration of whether this may aid interpretation of the results is useful. Du et al. (2008) suggested that certain items appeared to have different functions or meanings in Western and Chinese cultures. For example, they suggest that cross-cultural differences in scores on some the items which comprise the peer problems subscale, in fact reflect a different understanding of the questions in the questionnaire, rather than real differences in peer relationships. Similar comments were also found in analysis applied previously with the Taiwanese samples. Liu et al. (2013), for example, found an overlap between the peer problems and prosocial factors in the parents’ and teachers’ versions of SDQ. However, the other behavioural domains measured in the Chinese SDQ were quite consistent. There were also different factor structures found between the parents’ and children’s report on SDQ (Gau, et al., 2010b). These issues might influence the present research at some levels. Firstly, it might influence the variables that contribute to TD siblings’ adjustment in the present UK and Taiwanese models. More parents’ variables were found to link with TD siblings self-reported SDQ in the UK model compared with the Taiwanese one. That is, UK TD siblings’ adjustment was more related to mixed variables, including the influence from their parents. It is not clear whether this was a
result of the different factor structure between parents’ and children’s SDQ found in the Chinese, or purely reflected the cultural difference between the two countries. Secondly, the lower the level of the prosocial behaviour in the present Taiwanese data might also be influenced by the factor structure issues. What should be regarded as prosocial behaviour might be interpreted differently in the Chinese culture.

Another measurement issue relating to the child self-report SDQ is that the age range of children involved in the present research is wider than that suggested in the manual. However, there is also other research using the SDQ below the age of 11 years, to suggest it is appropriate for use in wider age groups both in Western (Laurens, Hobbs, Sunderland, Green, & Mould, 2012; Muris, Meesters, Eijkelenboom, & Vincken, 2004) and Chinese populations (Liu, et al., 2013; Yang, 2011). Muris, Meesters, Eijkelenboom, and Vincken (2004) used the SDQ in with children between 8 to 13 years old and found the psychometric properties were acceptable and comparable to an older sample. Although Becker, Hagenberg, Roessner, Woerner, and Rothenberger (2004) suggested that children above 11 years will be more able to reflect accurately in their self-report for clinical use, the SDQ in the present research was not for diagnosis or assessment purposes, but for the understanding of TD siblings’ adjustment in general. Furthermore, no siblings in the present research sample expressed difficulties in completing the SDQ.

Using a cross-cultural design, there is an inevitable need to consider the application of the measurement instruments in different cultural settings. Considering the SDQ first, as the results between the norm data and the clinical category band on the SDQ were inconsistent in Taiwanese data, comparison to the norm data may be a possible solution in future research, in order to depict the overall samples more precisely rather than assertively dividing the continuous scores into different categories. Hence, when using the clinical category band on SDQ in different cultural settings, researchers should be aware of its limitations.

In the analysis of coping measurements, there were overlapping and divergent concepts found between Chinese and Western coping. The results from the Taiwanese coping data were consistent with prevalent views in Chinese culture, in
that passive-prosocial coping (a coping style emphasized in Chinese culture in which one puts aside one’s preference in order to comply with socially acceptable ways) was the most commonly used in the present Taiwanese data. It is possible that the concepts of passive-prosocial and/or active-prosocial coping may have been interpreted differently in the UK and in Taiwan. With both active-prosocial coping and passive-prosocial significantly related to problem-focused coping in the present UK data only, it is possible that prosocial coping might function/be interpreted in a comparable way to problem-focused coping in the UK families. This still required further research to clarify the proposed speculations.

In the present Taiwanese data, there were lots of correlations found between COPE subscales in contrast to the UK data, suggesting that Taiwanese parents may not see these coping styles as dissimilar. This was also supported in the existing research, which suggested that Chinese families would not see problem-focused and emotion-focused coping (including emotional approach and passive avoidant emotion-focused coping style) as two distinct coping styles (Wong, et al., 2014). As Wong and colleagues’ (2014) further argued, emotion-focused coping could be seen as relationship-focused strategies that focused on interdependence and interpersonal harmony. The information suggested that coping research needed to consider the action and attitude within the Chinese culture (Hsu, et al., 2008), like the approach adopted in the present research. Using both Eastern and Western developed measures, particularly for concepts that involve cultural factors such as coping, is an important approach in research.

When measuring TD siblings’ coping, there are also similar challenges, in this case due to the lack of cultural-specific coping measurement available for the Chinese siblings. Similar to their parents, Chinese adolescents have been found to use forbearance or ‘do nothing’ as coping strategies to prevent conflicts with others (Hamid, Yue, & Leung, 2003). Furthermore, by using Chinese measures, Xu and colleagues (2006) also found that Chinese parents’ value orientation and coping style influenced children’s choice of coping strategies. This was not found in the present study, and hence, it would be plausible that the lack of relations between parents’ and
TD siblings’ coping in Taiwanese families might result from measurement issues. It is also possible that younger generations might be more Westernized nowadays and the cultural constraints less powerful for teenagers today than for their parents.

Another measurement limitation in this research is lack of satisfactory psychometric properties in one measurement (i.e. Kidcope) in Taiwan and the UK. Further, the norm for the Taiwanese populations (i.e. for the AQ-child/adolescent and SRS) has not been published. The present research tried to use the best measures that could be identified and provided a thorough discussion of these measurements. Without direct psychometric properties information and cultural specific norms of these measurements, the limitation is acknowledged. As reviewed in the siblings’ coping measurement, one possible instrument for use in future research is the Children’s Coping Strategies Checklist (CCSC) (Ayers, et al., 1996), which may allow an investigation of siblings’ coping in a more comprehensive way. Future studies should therefore identify the factor structure consistency of the CCSC and its application in cross-cultural settings, in order to support its utilization.

7.7 Implications for the following interview study

The interview study, to be discussed in the following chapter, offered the opportunity to follow up some of the issues raised in the present questionnaire study in further detail. In this section, two main issues were addressed first. Further considerations are presented at the start of Chapter 8.

Firstly, when evaluating the efficacy of the coping strategies that they used, UK siblings rated avoidant coping as the most effective coping styles compared to active and negative coping, whereas Taiwanese siblings rated active coping as the most effective. The interview study could also help to understand these cross cultural differences. Previous research has found that when dealing with low control situations, that is, when coping in situations in which there is little or nothing that can be done to influence the situation, using an avoidance approach might be useful (Suls & Fletcher, 1985). The presence of low control situations, such as dealing with challenging behaviour of the child with ASD, might contribute in part to the UK siblings’ choice of avoidant coping. Hence, the avoidant type of coping, might still
be rational and functional in some circumstances, when the situation at that moment is difficult for the family to alter. Whether parents and TD siblings viewed the situation as unchangeable or uncontrollable, remains to be further explored in the interviews.

Secondly, as discussed in the above section, different types of coping contributed to TD siblings’ adjustment outcome in the two countries. It is therefore also worth further exploring parent and sibling views on the efficacy of certain types of coping strategies that are used in Taiwan and the UK. In the interview study, some qualitative information would be available to clarify whether there are consistent cultural traits between questionnaire response and the interview. Whether the higher frequency of informal support showed in the UK families linked with the way TD siblings coped or adjusted, could also be further discussed.

7.8 Conclusion

In this chapter, the results of Questionnaire study were discussed. There were some important findings within countries and between Taiwan and the UK. Firstly, it is important to emphasise that TD siblings in both countries reported high levels of life satisfaction. This suggests that, despite some difficulties, the majority of TD siblings did feel satisfied with their life in general. This does not, however, imply that enhancing the support available to siblings is not important, as other findings make clear. Secondly, adjustment difficulties were found in some siblings. The importance of using culturally specific norms was also emphasized.

In the discussion of the combination of the Double ABCX and Diathesis-stress models, the data in the present research was successfully guided by this framework to explore the variables in relation to TD siblings’ adjustment. The theory that epigenetic factors interacts with the stressors was also partially supported. The influence of the BAP level was evident in parents’ coping and the way they evaluated their children’s adjustment. Siblings’ BAP level also played a role in predicting sibling self-reported outcome in the UK.
The parent coping styles of Taiwanese parents in the present research were found to relate to each other, which further supported the idea that the Western developed measurement had overlapping or indistinct coping concepts for the Chinese populations. Developing culture sensitive coping measures for siblings in future research was therefore also emphasized.

In summary, the present research found several cultural similarities and differences in terms of coping and factors that influence TD siblings’ adjustment outcomes. Tailoring sibling intervention and support to cultural context, as well as individual preferences, is therefore important to enhance their adjustment outcomes. In the next chapter, several families from Taiwan and the UK were interviewed to explore the possible explanations for some of the findings from the present questionnaire study.
Chapter 8: Qualitative exploration of adjustment in families of children with ASD

8.1 Introduction

8.1.1 Introduction

Questionnaire study provided an opportunity to explore patterns and to test relationships with a set of quantitative data from two different cultural backgrounds. Several factors were found to predict TD siblings’ adjustment, and the possible explanations were discussed in more detail in Chapter 7. However, it remains unclear why some parents and siblings develop and use specific coping strategies and adjust better than others. How does cultural context influence factors such as the perceptions of social support a family needs, their attitude toward accessing the support, and what, if any, are the differences in parents’ views of appropriate and well-adjusted behaviour between Taiwan and the UK? The mechanisms behind these issues still require clarification. Hence, the follow up interviews were conducted to investigate the parents’ and TD siblings’ life experience with children with ASD.

The structure of interview study was guided by the Interpretative Phenomenological Analysis (IPA) approach. This chapter presents, how the interview questions were developed, the process of inviting the interviewees to participate, the analysis method, and the findings.

8.1.2 Rationale and interview questions

Questionnaire study provided answers to research questions regarding the similarity and difference of siblings’ adaptive behaviours and coping patterns between Taiwan and the UK (RQ1 and 2). Guided by the Double ABCX and the Diathesis-stress models, Questionnaire study partially supported the relationships within the model (RQ3). Interview questions for Interview study were developed based on Questionnaire study results and therefore extend from the research questions of the Questionnaire study – exploring what might contribute to the similarities and
differences found in Questionnaire study and the explanations for relations which were present and absent in the quantitative data.

The major finding of the Questionnaire study was that there were difference in terms of the variables that predict TD siblings’ adjustment outcome in Taiwan and the UK. Taiwanese siblings’ adjustment was more about their internal factors and life experiences (i.e. positive/negative life events, coping and social support). In the UK model, TD siblings’ adjustment was related to both internal factors, demographics characteristics (i.e. severity of ASD sibling and family size) and also the influence of parents’ coping. It would be interesting to find what caused these differences between Taiwan and the UK in the Interview study.

In Questionnaire study there was a significant difference between UK parents and TD siblings on the evaluation of TD siblings’ adjustment. The reasons why the UK parents and their TD children had such distinct views of adjustment requires further investigation. Interviews can further provide insight into the families’ experience. Did parents misinterpret their TD children’s ability to handle the situations, or did TD siblings hide their needs and difficulties from their parents?

Furthermore, Chinese parents’ constantly evaluated their children as having difficulties across various domains in the Questionnaire study. It was speculated that Chinese parents might view their children with higher standards than their UK counterparts, for cultural reasons. This could be clarified through the interviews.

New research questions also arose from the discussion in Chapter 7. For example, there were no significant correlations between parents’ and siblings’ coping styles in the Taiwanese sample, but there were in the UK. Given the evidence from previous literature, it was speculated that parents’ coping styles might influence siblings’ styles to a certain degree. Why was this not the case in the Taiwanese sample? Were there other factors that more strongly determined how children cope in Taiwan? Interview study aimed to capture not only coping strategies or capacity, but also the philosophy and experience behind them. As shown in the previous literature, coping is not static but a dynamic process. The questionnaires might reflect the families’
choice of certain styles of coping, but the reason for, and the effects of, using the coping styles remained unclear.

There were other unexpected relationships found in Questionnaire study. In particular, UK siblings’ negative coping was positively related to parents’ use of problem-focused coping. How do parents and TD siblings develop the coping patterns? The interview study allowed the exploration of the explanations behind these coping styles and to compare within the social contexts of the two country groups.

UK siblings’ prosocial behaviours showed a positive correlation with their use of negative coping and a negative one with the parents’ emotional approach coping. The directions of these relationships were too complicated to interpret from the questionnaire data alone. Furthermore, the siblings’ BAP characteristics and the severity of the children with ASD predicted siblings’ adjustment in the UK model, but not in the Taiwanese one. In the moderator analysis, a different influence of siblings’ BAP level in Taiwan and the UK was also found. However, the limited information could not explain why this was the case.

Social support played an important role in predicting TD siblings’ adjustment both in Taiwan and the UK. Social support was linked to TD siblings’ stressors (i.e. life events) and coping in Taiwan, while in the UK siblings it was only associated with the stressors in their life (i.e. life events, severity of ASD siblings). Despite the importance of the social support emphasised in the questionnaire study, it is still not clear whether there are cultural differences in siblings’ approach to gaining support (e.g. support was provided from the professional, or families needed to find the support themselves) or what types of support are available in both countries. Furthermore, Questionnaire study did not clarify the formal support available in Taiwan and the UK. These were also explored in the interview study.

In summary, the research questions of the interview study:

1. From parents and TD siblings’ point of view, how do they evaluate the relationship between TD and ASD siblings?
2. What kind of coping strategies do parents and TD siblings use when facing a stressful situation and what are their views on the efficacy of the coping strategies they have been choosing?

3. How do parents and TD siblings evaluate TD siblings’ adjustment so far?

4. What kind of formal and informal support have families received? How do they think this support affects the family?

5. Do parents have certain role expectations of their TD children? Do TD siblings feel their parents hold expectation of them?

The full interview questions can be found in the Appendix I.

8.2 Method

As reviewed in Chapter 4, this research used a mix-method approach. The quantitative approach allowed the systematic exploration of TD siblings’ adjustment and to look at some very specific relationships. While qualitative approaches are more focused on induction, discovery, exploration and theory/hypothesis generation (Johnson & Onwuegbuzie, 2004). The combination of quantitative and qualitative approaches not only can complement each other but can also provide insight into various perspectives or units of analysis (Bergman, 2008; Creswell, 2014).

Interpretative Phenomenological Analysis (IPA) was adopted as the analysis approach for Interview study. This analysis approach draws upon concepts from phenomenology, hermeneutics, and ideography, which focuses on people’s experiences and perspectives and how individuals understand their world (Smith, Flowers, & Larkin, 2009). IPA is concerned with trying to understand experiences from the participants’ perspective. As Smith et al. (2009) stated, IPA is a suitable approach when the research questions focus on investigating the person-in-context. The IPA approach is not suitable to generalize from findings but it focuses more on a selected group. The IPA approach has also been used to explore the experiences of parents of children with ASD (Cullen-Powell, Barlow, & Cushway, 2005) and of the TD siblings (Petalas, et al., 2009a; Petalas, Hastings, Nash, Reilly, & Dowey, 2012b). Compared to other approaches (such as discourse analysis), IPA is particularly well-suited as an analysis method of the present research, because it explores how
individuals form and interpret their experience in relation to the environmental context and how they make sense of their experiences (Brocki & Wearden, 2006).

8.2.1 Participants

The IPA approach suggests a smaller sample size (usually ranging from 1 to 15) in comparison to bigger sample sizes commonly used in other qualitative approaches (Brocki & Wearden, 2006; Smith, et al., 2009). Smith et al. (2009) suggested that a sample of 5 or 6 would be a reasonable size. This suggested number allowed researchers to capture in-depth information, and is also big enough for exploring the similarity and differences among participants.

The IPA approach also encourages a fairly homogeneous sample (Larkin & Thompson, 2011). A closely defined group can help the researchers focus on particular characteristics of a population that are of interest and can provide the best insight into the research questions (Smith, et al., 2009). Purposive sampling is one of the non-probability sampling techniques based on selecting specific characteristics (Ritchie, Lewis, & Elam, 2003). There are several types of purposive sampling approach, including homogeneous samples, heterogeneous samples and stratified purposive sampling etc. (Ritchie, et al., 2003). In the present research, homogeneous samples within each country were selected followed by the guidance of the IPA approach (Smith, et al., 2009).

Research bias is one of the potential disadvantages of purposive sampling (Guarte & Barrios, 2006; Tongco, 2007). However, this is only the case when the judgment and selecting criteria of the samples lack consideration and do not follow by the research framework or theories. As long as the researchers are aware of the limitations and are committed to reflexivity, the bias can be lessened. Being reflexive and supervised by other professionals, could help the coherence and validity of the analytic process (Brocki & Wearden, 2006; Larkin & Thompson, 2011). Discussion of reflexivity is presented in Section 8.2.5.

Families who completed the first questionnaire study were selected for demographic background checks. Those who encountered difficulties (e.g. delayed returning of the
packs) in the questionnaire study were excluded from the interview database. This was because it would then be difficult to compare their Questionnaire study data with the following interview.

Using the guidance of the IPA approach (Smith, et al., 2009), I tried to choose interview families who lived in same part of the UK (e.g. Scotland) to achieve homogeneous samples. Families living in the same part of the UK might have had similar support service experience as a result of council policy or funding priorities. As the literature review in Chapter 2 indicated, demographic characteristics could play an import role in TD siblings’ adjustment. With the limited numbers of interviewees available, it is difficult to select samples with similar demographic characteristics from a wider range of demographic variables. However, the need for this approach was acknowledged in the selection process, before recruitment became difficult.

An enquiry email was sent and attached with the interview information to ask about taking part in the follow-up interview (see Appendix J for information). Five letters were sent out to UK families who met the criteria, and two families agreed to participate. The relatively sensitive research topic may have led to the low response rate (Arber, 2001). The personal nature of the interview requires more direct interaction with the interviewer and the sharing of more detailed information compared to Questionnaire study. Those who took part in the interview might be more willing to discuss their situation than others. Therefore, they would be more likely to share certain characteristics that differed from those who were not willing to participate in this project. Also, families might not have had time available to participate in the interviews. Two parents in the UK and one in Taiwan were turned down because of time constraints.

For feasibility and practicability reasons, the enquiry emails were sent out again this time to all the families in the database. The advantage of this approach was that, although the interview sample might be less homogeneous, it might result in an interview sample that was representative of the Questionnaire study sample as a whole. There were some limitations and risks in using this approach. The first
possible risk stemmed from recruiting families who might have a higher motivation to focus on their TD children’s adjustment, than those who did not wish to participate in the interview study. Secondly, the demographic characteristics of the interview families might differ from Questionnaire study, and therefore would not represent the families from Questionnaire study as a whole. Thirdly, families were recruited across the UK, and the social services and resources might differ according to the areas where they lived. With these limitations in mind, I needed to interpret the interview data more cautiously and not over generalize the findings.

As for the families in Taiwan, fifteen letters were sent out and eight families agreed to participate. One of the parents dropped out because of limited time. Although the recruitment criteria did not limit the gender of the participants, all the parents who participated in the interviews were mothers. In total, both Taiwan and the UK had 7 dyads of mothers and siblings in the interview. All the interviewees’ background information is listed in Table 8.1.

The final sample of participants included in the interviews from Taiwan and the UK did not appear to be different whether in age or gender of the ASD and TD siblings, diagnosis of the siblings, family size, mother’ employment, severity of ASD sibling, parental and TD siblings’ BAP level and their adjustment difficulties. In these respects the interview participants from both countries were very similar.

However, the goal was to recruit interviewees who represented their country group from Questionnaire study. As I further compared the interview participants with the larger sample in Questionnaire study, a few differences were found. The age gap between ASD and TD siblings appeared to be wider in the Taiwanese interview sample in contrast to the Study one. The parental BAP level was lower and TD siblings’ self-report adjustment difficulties were higher in the UK sample compared to Questionnaire study. The rest of the variables, including siblings’ BAP level and the severity of the children with ASD proportions and scores, did not seem to differ from Questionnaire study in either country. Smith and Osborn (2003) argue that, with such a small sample used in the IPA approach, it is not feasible to ascertain whether the selected sample is representative. The researchers should make efforts to
choose a closely defined group who are best suited to exploration of the interview questions.
<table>
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<tr>
<th></th>
<th>Age</th>
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<th>Diagnosis</th>
<th>No. children</th>
<th>Mother’s employment</th>
<th>ASD severity</th>
<th>BAP level</th>
<th>Siblings’ adjustment</th>
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<td>23.7% Full-time</td>
<td>79.95</td>
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</table>

a. Higher scores indicate more severe symptom. b. The data provide here was used to present the level of BAP characteristics rather than referring to any ASD diagnosis. Higher scores indicate more autistic-like traits. c. Data was based on siblings’ self-report. Higher scores indicate more adjustment difficulties. d. (H) individual’s score higher than the norm. e. The data was invalid due to missing data of more than 5 items.
8.2.2 Interview procedure

The advantage of using a semi-structured interview format is that, not only can it ease the language barriers, but the flexible structure helps to encourage potentially interactive responses from the interviewee and interviewer (Louise Barriball & While, 1994). Semi-structured interviews are potentially as valid as structured interviews (Nock, Holmberg, Photos, & Miche, 2007). With a clear set of instructions for interviewers and questions prepared in advance, a semi-structured interview enabled the researcher to conduct interviews in a similar manner in both cultural settings.

A semi-structured interview format was developed to elicit responses relating to the parents' coping styles, their perceptions of their child’s coping style and their adjustment. Siblings were asked about their coping style and experience with their ASD siblings. These interview questions were developed based on the analysis of the first questionnaire study as mentioned in the earlier section.

The interview questions were first developed in English. The translation of the interview questions into Chinese were done first by the thesis author and then discussed with colleagues with translation qualifications to maintain the consistency of the interview questions. Despite efforts to maintain the consistency of the interview questions in Chinese and English versions, the subtle difference in language might still have had a potential influence in each country. This is also discussed in the section on reflexivity in Section 8.2.5.

Before the formal interviews, two pilot interviews were conducted and supervised by thesis supervisors to familiarise the interviewer with interview process. Such preparations could help researcher focus on the research aspects and the possible influence of the questions addressed in the interview (Cridland, Jones, Caputi, & Magee, 2015). After the pilot interviews, opening and closing statements were added to enhance the interview rapport, and prompts were included for the interviewer to elicit interviewees’ responses in further detail.
The interviews were conducted either by home visit, through SKYPE (communication software) or on the phone according to the parents’ preference. There were three home visits, three SKYPE interviews and one phone interview in the UK. For the Taiwanese sample, there were four home visits and three phone interviews. It might be argued that phone or SKYPE interviews are different from face-to-face interviews. In contrast, Bryman’s (2008) concluded that phone interviews were not significantly different from face-to-face ones in terms of the quality of the response or the details of the information provided. However, the potential limitation of phone interviews was that the interviewees’ body language was not observable. Interview notes were also taken during the interviews, to help the researcher to reflect on the interview situation, the ideas and thoughts of the interviewee. These notes were used to inform the later analyses. Furthermore, all data were anonymously transcribed, neither the sources nor the methods of gathering data were disclosed. The transcribers were all blind to the data collection method to prevent any possible bias of predetermined responses.

The average interview time was around 30–40 minutes per person. When the interviewer first arrived, both the parent and the sibling were given interview information sheets and sufficient time to discuss any concerns about the interview. After obtaining permission from the parents and siblings, interviews were conducted individually without the third person present. The interviewer also gave clear instructions at the start and end of the audio recording by saying, ‘I am going to press/stop the recording button’. Each parent and sibling received a £5 gift voucher (or 250 New Taiwan Dollars) after the interview. The interviews were entirely conducted in the interviewees’ first languages, either Chinese or English.

### 8.2.3 Ethical issues

When conducting the research with children and adolescents and interviewing them on sensitive topics, ethics are always important. As with Questionnaire study, Interview study also followed The British Psychological Society (BPS) Ethics Guidelines, The University of Edinburgh Research Ethics and Procedures, and it was granted approval by School of Education ethics committee. Furthermore, for the UK
interviews, Disclosure Scotland clearance was also sought, and obtained, as the researcher had contact with children and teenagers in the interviews (related documents are in Appendix K). Regarding the Taiwan interviews, since I myself have been working with children and families with special needs for 5 years and have the qualification of a clinical psychologist in Taiwan, no further clearance was required for the Taiwanese sibling interviews.

The ethical considerations were addressed in a similar manner to Questionnaire study (see Section 4.8). The anonymous protection procedures were also explained in the information sheets given to parents and TD siblings. Because the design of the research aimed to explore the coping and adjustment of the siblings of children with ASD, it was possible that the interview process would evoke their past experiences and the stress of being with their disabled siblings. Therefore, the cover letters sent with the interview questionnaires made clear the following:

(1) If the participants experience any discomfort during the process, they have the right to discontinue the research at any time;

(2) A list of support organizations that families can contact if required;

(3) During the interview, if the researcher thinks the participants are experiencing discomfort, she will ask if they wish to stop.

None of these situations occurred during the interviews.

The information sheet also clearly indicated the limitations of confidentiality: If the researcher found that the participant was in danger or possible harm, the family situation would be discussed with thesis supervisors (although this did not arise in any interview).

8.2.4 Approach to data analysis

Data were analysed following the IPA guidelines (Pietkiewicz & Smith, 2014; Smith & Osborn, 2003). Firstly, all the audio files were transcribed into Chinese or English according to the language spoken by the researcher and participants during the
interview. The notes taken during and after the interview were also considered when analysing the data. Because English is not the first language of the researcher, a transcribing company was used for the UK interviews in order to insure accuracy and quality. A professional transcriber transcribed the Chinese interviews, and the quotations included in this chapter were separately translated into English by a translation company. Secondly, all the transcriptions were formatted in a common format and the researcher read through all of the transcriptions repeatedly until familiar with the content. Through the reading process, the left margin was used to mark and make notes of significant statements from the interviewees. The main function of the notes was either helping to summarise or to find the connections and/or contradictions between statements. As suggested by Smith et al. (2009), the developed themes may be carried forward from the first participant’s account to be built on or added to subsequent accounts. Hence, each transcript was then put aside for 2 to 4 weeks, and the researcher re-read and annotated in the previous notes if something new was found.

There are some procedures suggested by Yardley (2008) to enhance the validity of qualitative data. First, triangulation is a way of gathering data through different time periods or through different researchers. In this analysis, interview contents were also compared with the participants’ questionnaire response after building up the analytic themes. This assisted with consideration of whether the themes identified from the interviews matched the impressions from Questionnaire study. Secondly, an audit procedure with the supervisors and colleagues ensured that the themes produced are reliable rather than simply being based on the researchers’ own preference. This audit process increased the reliability and validity of the data (Morrow, 2005).

The aim of the IPA approach is not to build up an objective statement of the phenomenon (Smith, 1996). In the discussion of the interpretative role of the researcher, Brocki and Wearden (2006) described ‘…the fact that the researchers have chosen to utilise this method of data analysis must involve a tacit acceptance of this role’(p.98). Researchers are inevitably influenced by their experience and existing knowledge. However, clear acknowledgement of researcher’s experience
and preconceptions in the research topics, can increase the transparency of the analytic results (Brocki & Wearden, 2006).

When the thesis author, supervisors and colleagues agreed that all the meaningful and important texts were identified and the emerging codes from the data were consistent, these codes were then clustered together to form subthemes. The research team then looked at the relationships between each subtheme and then clustered them together to form the major themes. The initial groups of subthemes were checked to see whether they could be combined or split up to reduce overlap and redundancy among the subthemes. By clustering subthemes across the various sets, the final master list of 4 themes emerged.

8.2.5 Reflexivity

It is unavoidable for a researcher to have certain preconceptions when carrying out this type of research. As Malterud (2001) stated, preconceptions do not count as a research bias as long as the researcher is aware of their possible influence and addresses the issues. The preconceptions and personal values may then contribute to the specific research areas.

I am originally from Taiwan. Due to my past working experience, I was aware of being more confident and more reflective when interviewing in Taiwan. Taiwanese parents asked more questions regarding their worries about the children and would seek suggestions after the interviews. Having conducted interviews in two countries, I felt that the Taiwanese parents looked on me as a professional/advisor, whereas the UK parents treated me more as an information collector. In qualitative research, the researcher is also playing a role in the co-construction of interview data with the participants (Pietkiewicz & Smith, 2014; Smith & Osborn, 2003). By regularly discussing these issues with thesis supervisors and receiving feedback from colleagues, I hoped to maximise the credibility of the qualitative data.

Furthermore, I grew up with a sibling with special needs. This information was shared with families on the information sheets in advance of the interviews. This enabled me to make a connection with the siblings and their families. To conduct the
interview with other siblings that share similar situations also evoked my personal life experience. It is also important to recognize the way I delivered the questions, which might lead participants to give predetermined responses. Hence, using the semi-structure interview format and clear instructions would decrease the potential of this influence. The research data were continually re-examined and reviewed, with the feedback from clinical colleagues and thesis supervisors. Research notes were also taken to help myself to be more reflective when interpreting the interview data. With regular supervision and support from my supervisors as well as the professional network from clinical psychologist colleagues, the interview process went smoothly.

8.3 Results

8.3.1 Themes and reporting

The results section is not structured according to the research questions, but rather discusses the themes that appeared across the interviews as a whole. Four themes appeared in the data for both Taiwan and the UK. Even though some of the themes have the same title, at times the interpretation and content differ substantially between the two countries. In the following section, the themes will be discussed in turn. As each theme is identified, it will be defined and displayed in a related figure. Taiwan and UK findings will be discussed side-by-side, providing contrasts where appropriate.

None of the quotes were attributed to the interviewees to maintain anonymity. As for the abbreviation at the end of the quotes, TW marks the quotes from Taiwanese families, and UK marks those from the UK. The capital letters ‘P’ after TW or UK means that the quotation is from the parents, ‘S’ refers to the quotation from the TD siblings and ‘S-ASD’ refers to the ASD siblings. The same letter stands for the same family members. For example, ‘TW-BP’ means that this quotation is from the Taiwanese parents whose family is coded as B, while ‘TW-BS’ is from the TD sibling in the B family. The ‘TW-BS-ASD’ refers to the Taiwanese B family ASD sibling.
There were four core themes found in both the Taiwanese and the UK families. The first theme, ‘The influence of ASD’, illustrates how the family members in both contexts had been influenced by the child with ASD in different aspects of life. The second theme ‘Family resilience’ focuses on how those families responded and adjusted to stress. The parents’ and the TD siblings’ coping styles is also included in the discussion of this theme. In accordance with the above theme, the next one, ‘What we do as a family’, is related to how the siblings were involved with, and responded to, expectations from their parents. Lastly, ‘The support needed’ covers the informal and formal resources the families had approached. Quotations from the parents and siblings in both countries will be used in order to support the discussion of these core themes and the related subthemes and codes.

8.3.2 Theme 1: The influence of ASD

The first theme portrays how the ASD children’s behaviour influences exterior judgments from the wider society. The parents and siblings in the interviews shared their views about ASD, including both positive and negative aspects, from the daily interaction with the children with ASD and their experience of interacting with those unrelated to the family. Despite the first three subthemes being the same across Taiwan and the UK, there are subtle differences in the related codes. The fourth subtheme applied only to the UK families, and focused especially on how they looked at their TD children/siblings beyond the diagnosis. These subthemes and codes are summarized in Figure 8.1.
Figure 8.1 Theme 1: The influence of ASD and its related subthemes

Taiwan

Positive influence

Distance and conflicts

Limitations and concerns

Embarrassment

Fair share of time and attention

Keep inside our family

The influence of ASD

Relationships and time with others

UK

Positive influence

Distance

Limitations and concerns

Embarrassment

Relationships and time with others

Fair share of time and attention

We are the same, like others

Beyond the diagnosis

Not because of ASD
**Positive influence**

Throughout the interview, almost all the Taiwanese parents and UK siblings and their parents expressed how they had been positively influenced by the child’s symptom-related behaviours. The parents from both countries noticed that the experience of interacting with a child with ASD enabled their TD child to be more aware of others’ needs and more willing to help those in disadvantaged situations.

He (TD sibling) often reaches out to his friends who are bullied at class and takes care of their feelings. (TW-CP)

There was only one UK parent who mentioned a lack of positive impact on the TD sibling.

I don’t think there is really … I can’t really see any positives in having a brother with autism, no. (UK-EP)

However, the positive expression toward the child with ASD was only revealed by the siblings in the UK interview but not in the Taiwanese interviews. Most UK siblings would use some examples to illustrate how their ASD siblings influenced them in a positive way.

... if I didn’t have him I wouldn’t be who I am today. So yes he has made me who I am today. I find it really well that I have him. (UK-DS)

This subtheme represents how Taiwanese parents and both UK parents and siblings viewed the positive influence of living a child with ASD. Despite none of the Taiwanese siblings explicitly describing the positive influence, they did describe things that they enjoyed doing with their ASD siblings.

**Limitations and concerns**

Nevertheless, although there are positive influences discussed above, some limitations and concerns still existed in both countries. For example, one UK parent had a different view and mentioned her concerns regarding the responsibilities added to the TD child. She said:
I don’t think it makes him more caring. I don’t think it necessarily makes him more understanding than he would have been if he didn’t have ES-ASD1 and ES-ASD2. It has probably given him more responsibility which is not necessarily a good thing. (UK-EP)

The first code within this subtheme is ‘Distance and conflicts’ for Taiwanese model, while only ‘Distance’ for the UK one. Both the Taiwanese and the UK siblings expressed their feeling of distance between them and their ASD siblings. The limited sharing of interests and abilities might be one of the reasons. As the severity of the ASD can include no verbal communication and displaying challenging behaviours, some TD siblings expressed their difficulty in having mutual interactions with their ASD siblings, and some mentioned it was not easy to play with their siblings due to the restricted ability of their ASD siblings and limited shared interests. This was consistent with the parents’ descriptions, where they noticed their children could only feel comfortable when they stayed in some places they are familiar with and had limited interaction with others.

They would play separately although they play in the same place. They only pass information as playmates. (TW-BP)

I think we are quite … we play quite a bit but he can’t play. I can kind of push him on the swings, or stuff like that. I can jump on the trampoline with him but I can’t play with him or stuff like that. (UK-DS)

In addition to this distance, the conflicts between siblings were mentioned in both Taiwanese parents’ and siblings’ interview. For example, the bickering between siblings and even fights over daily matters were frequently revealed by both siblings and parents. Thus, this would have negative impact on the harmony of family atmosphere.

They would quarrel at breakfast table… They might even be late for school when they bicker over something trivial. The brother [TD sibling] would feel very bad, thinking he could never have a good time staying at home, and mum would scold them both. (TW-FP)

Mostly it might be some disagreement over something. Or he [ASD sibling] picks at me, or I pick at him. Something like this. (TW-FS)

The difference between Taiwan and the UK families might be associated with the understanding of the ASD-related symptom and behaviour. As later in the subtheme
of ‘Beyond the diagnosis’, UK parents had a more clear description of how they
distinguish a behaviour and whether it is related to the ASD difficulties or not, and
how this help them set the expectations of the children.

The second code of this subtheme is ‘Worries’. However, there was a substantial
difference in the concerns of the parents and the TD siblings in the two countries. For
the Taiwanese parents, they revealed an implicit sense of concern about the negative
impacts on siblings’ characteristics, such as being unable to communicate things
clearly and lacking self-confidence.

_He shows lower self-approval and lacks self-confidence._ (TW-BP)

_The teacher thinks the younger brother [TD sibling] copies his elder sister’s
[ASD sibling] behaviour, and will have a tantrum whenever you don’t give in
to his demands. It takes some time for him to calm down. His emotions are
like a roller coaster._ (TW-FP)

Parents from both countries expressed concerns about whether their TD children
would be able to adjust to society in the future. Even though their TD children were
adjusted well at the moment, they still reveal their worries about they might not be
able to adjust well in their adolescence or adulthoods.

_My fear is actually, I know a lot of people who have very well behaved
children with a disabled sibling and then when they get to 15 or 16 they go
off the rails and that is my concern. He [TD sibling] will accept all this and
then when he gets to 16 he will really struggle. When his friends can do lots
of things that he won’t be able to do because he has got a disabled sibling. So
I feel that potentially we are just storing all this up and then when he is 16 he
will go mad._ (UK-DP)

Most of the parents in Taiwan, moreover, felt anxious about how their TD children’s
married life might be affected due to having an ASD sibling, which was never
mentioned by the UK parents:

_You’d think about a lot of things ... whether this would affect my elder
daughter’s [TD sibling] marriage in the future...._ (TW-BP)

In relation to concerns there were more similarities between the siblings across
countries than there were between the parents. The TD siblings also revealed their
concerns about the future in the interviews. Both Taiwan and UK TD siblings had a
strong sense of responsibility for looking after their ASD siblings and shared a major concern about how their sibling would progress in the future. Some TD siblings worried about if they would be able to look after their ASD siblings in the future, and that others might bully their siblings if they cannot look after them.

*I’m worried that my job doesn’t pay me enough, and that I don’t have time to take care of my brother.* (TW-DS)

*...will he be like this forever? Will he ... what will happen to him when he is older? Will he be in a good environment when he is older?* (UK-DS)

**Relationships and time with others**

Dealing with the opinions of others was consistently mentioned by TD siblings in both countries. There are two codes in this subtheme for the UK families, namely ‘Embarrassment’ and ‘Fair share of time and attention’ while another ‘Keep inside our family’ was especially for Taiwanese families.

In the code of ‘Embarrassment’, the TD siblings from both countries expressed their uncomfortable feelings when others reacted negatively toward the behaviours of their ASD siblings in public. Older siblings particularly found it difficult to respond to those situations and would blame their parents, especially when it caught the attention of their peers. Parents from both countries also noticed the TD children’s difficulties in reacting to other’s opinions.

*He [TD sibling] was very upset returning from school that day and complained about their studying at the same school. He does not like that other teachers or students know he has such a brother. When asked by some classmate about his brother, he would tell a half-lie and stop the discussion.* (TW-GP)

A few parents in the UK also mentioned that in their children’s teens, parents found that TD siblings were more aware of other people’s opinions of them. However, this did not appear as obvious as in the Taiwanese data.

*I think there have been times when he [TD sibling] has done really, really well with it and been quite ... but at 12, 13 he is embarrassed when we are out if [ASD sibling] does something that he thinks is going to be noticed by*
people around and about…. I think that is the basis of why [TD sibling] finds it more difficult now than he found it two or three years ago. (UK-AP)

Younger siblings in the UK seemed to be more able to talk about their ASD siblings with their peers. One younger UK sibling explained clearly to his peers:

_I am just like, before we come into my house I am like, I will say to my friends, 'look, my brother has got this thing and he doesn’t react the way that we would to other situations so if you could be as sensitive as you can do and just be really nice to him that would be great’ and they are just like ‘oh yes, that is ok’ and sometimes they are 'oh my cousin has got that as well’. (UK-BS)_

When the parents talked about the extra time and care they need to look after their children with ASD, they appeared concerned about quality time with their TD children. This code, ‘Fair share of time and attention’, is quite a consistent code, as both the Taiwanese and the UK parents spent a relatively long time discussing this. The parents from both countries expressed that they would like to spend more high quality time with their TD children if possible.

_I’ve kept that in mind, so I spent separate time with the two of them individually. Since my daughter [TD sibling] is sensitive, I think she knew very well what was happening, but she said nothing. (TW-GP)_

_I think you have to really work at making them [TD sibling] feel that they can approach you and you are never too busy for them, to listen to them or talk to them or whatever. (UK-CP)_

A younger TD sibling in the UK displayed attention seeking behaviour, according to the parent, for example, saying that ‘so as soon as [ASD sibling] comes through the door at the weekend … he [TD sibling] will immediately start saying things to wind his brother up. (UK-AP)’, while others (especially older TD siblings) understood the necessity for their parents to spend extra time on their ASD siblings. One example, from a sibling: ‘… if you really need to spend that much time with the disabled sibling, just like talk to the other sibling that isn’t disabled and tell them that they are sorry about not spending time with them. (UK-DS)’

In Taiwan there was a special code, ‘Keep inside our family’. Some of the Taiwanese parents taught the TD siblings not to explain too much to others about their
diagnosed siblings. Those parents also mentioned their children having been seen as a stigma of the families by society and the lack of empathy from others.

*Mum told me not to tell other people about this, so I don’t really talk my brother [ASD sibling] with others.* (TW-BS)

It is possible that dealing with the stress and opinions from others is quite stressful for the Taiwanese families, especially for the parents and this might relate to the parents’ support seeking behaviour in the fourth theme ‘The support needed’ which is discussed later.

**Beyond the diagnosis**

While in the UK the fourth subtheme is called ‘Beyond the diagnosis’ because it is more related to how parents and siblings tried to maintain cohesion in family function. Both parents and siblings learnt to look beyond the limits of the diagnosis.

Even though the limited ability of children with ASD might affect their families from doing some activities, all the UK parents said they still tried to do things like other normal families, and enjoyed doing family activities together. Those parents still required all their children to behave according to certain standards. This code is called ‘We are the same, like others’.

*I think it is about being valued as an individual and that is what I try and reinforce … just because a child has autism does not mean they should be …I don’t think they should be put on a pedestal.* (UK-EP)

When a few TD siblings in the UK mentioned the time they spend with their siblings, they described their relationships as quite similar to any other sibling relationship. Here is one example from a parent and a TD sibling’s quotation from the same family.
They still have sibling squabbles like you would expect really but they are fairly few comparatively I would say [sic]18. (UK-GP)

I think he can have like really good moments and stuff, and we can get along perfectly fine quite a lot of the time, and I think that is good because we like to get along quite well most of the time just like other siblings. (UK-GS)

One sibling in the UK described how his two siblings with ASD did not affect him at any level throughout the interview. Contradicting his parents’ observation ‘he [TD sibling] doesn’t like to invite people around the house because I think he is a bit embarrassed of [ASD siblings]’s behaviour... he [TD sibling] will get quite cross with [ASD sibling] ...because [TD sibling] finds it very embarrassing’. This TD sibling in the interview expressed quite a good relationship with his two siblings. This inconsistency draws attention to the difference between parents’ and siblings’ perspectives.

So far in my life I have been fine with having autistic brothers and I don’t think they have really affected me in any way ... I am fine with them and I think they are fine around me and everyone else. (UK-ES)

Parents in the UK also clarified whether things are related to the symptom of the ASD or not. This code is called ‘Not because of ASD’.

FS-ASD sometimes gets a bit more slack from me and my husband but I don’t really expect the kids to give him anymore slack apart from because he is younger.... I think the major factor in FS-ASD getting more time just now is because he is younger as opposed to because he is autistic. (UK-FP)

Furthermore, a few parents and TD siblings in the UK also mentioned that they did not define their ASD children by the diagnosis. This, however, was not seen in the Taiwanese interview and was only applicable to the UK interviewees.

18 The grammar errors were noticed but remained unchanged to maintain the original description, [sic] will not be marked in the following quotations.
8.3.3 Theme 2: Family resilience

The second theme, ‘Family resilience’, represents the family’s progress in dealing with ups and downs in their life. This theme reflected mainly the parents’ progress of adjustment and how they accepted the fact of having a child with ASD in order to make this process smoother for the family as a whole. The parents also expressed the stress they have been facing and that the help from others is crucial for them. In general, the UK parents described in greater detail about how they adapted their attitudes toward the situation more than their Taiwanese counterparts. Both the UK and Taiwanese parents mentioned the importance of giving themselves some private time to do things they like and of looking on the bright side. Figure 8.2 below summarized theme 2.
Figure 8.2 Theme 2: Family resilience and related subthemes

Taiwan

- Early years struggle
  - Time and space for self
    - Self-valued
  - Learning process
  - Siblings' coping strategies
  - Take a break
  - Family resilience
  - Coping

UK

- Early years struggle
  - Time and space for self
  - Tale a break
  - Family resilience
  - Learning process
  - Siblings' coping strategies
  - Cross that bridge when we come to it
  - Coping
Early years struggle

The first subtheme in both countries is called ‘Early years struggle’. Raising a child with ASD can influence various aspects of life for parents. Both the parents in Taiwan and the UK had struggled to adjust in the first few years. For example, they talked about the stress from different sources and how they were told to raise their children with ASD. Too many worries and being busy looking for interventions for the children had made them mentally and physically exhausted.

Yes negative things might lead to horrible nightmares. Over these years of hard work, I got depression myself, and suffered from bouts of depression. Then I made best efforts to go back to normal. (TW-PG)

After their children’s diagnosis parents from both countries felt that they needed to find resources and make lots of decision for their ASD children. They were also less aware of the needs and influence of their TD children in these early years. When the situation became more settled and with progress, parents started to think about giving some time and space for themselves and their TD children. Hence, the second subtheme is call ‘Take a break’ in both countries.

Take a break

The parents from both countries had learnt from experience to deal with stress and reduce the tensions within family. Both parents from Taiwan and the UK became aware that taking a break is needed. The first code was ‘Time and space for self’, and parents in both Taiwan and the UK pointed out the need for quality time for themselves and their TD children. Some parents would exercise, while others did things they liked in order to relax.

My husband has his hobbies and I have mine and we know how critical it is that we both get a little bit of head space to pursue those. (UK-CP)

In this subtheme, parents acknowledged stress and negative impacts in both countries, and the need to tackle that, but that the UK parents placed slightly more emphasis on keeping rational and thinking about how to deal with the situation than their Taiwanese counterparts. Most of UK parents emphasised the importance of keeping
calm so that they could make the best decisions for their family. This code therefore is called ‘Keep calm and rational’ under the UK subtheme.

Well I have learnt, over the years since having them that I have to keep calm. And if I am not keeping calm, I have to leave and give myself that time... it is not always easy but it is probably the most important thing - to know when it is time to stop and just calm down yourself. (UK-AP)

In terms of the Taiwanese families, the second code under this subtheme is called ‘Self-valued’. This code was more related to parents’ perception of their empowerment process and how they changed their perspectives. Parents in Taiwan emphasized how they transformed the experience to see their inner strength and ability to handle the stress. As one of the parents mentioned:

At such moments I feel my own self-value and know I am able to do something good. This is how I comfort myself and seek self-approval, so I could keep on walking. (TW-AP)

This Taiwanese code represented parents’ self-growth and feeling of empowerment. It is more related to parents’ own resilience than to the family as a whole. This was not seen in the UK parents.

Coping

The third subtheme under this theme was called ‘Coping’. It represented the process that parents and siblings in both countries have been through and their attitude to dealing with the situation and the stress in their life. The first code ‘Learning process’ was related to the parents. Both the Taiwanese and the UK parents had the same first code and they represented identical meaning in both countries - how parents learnt and changed their attitude to accept the situation. The second code focused on the TD siblings’ coping strategies and how they relied on their parents’ help in both countries. The difference in UK parents’ modelling of coping was also presented in this second code. A special third code which applied only in the UK, included both parents’ and TD siblings’ philosophy of positively interpreting the situation in their life, which this was not emphasized in the Taiwanese families.
The first code ‘Learning process’ refers to parents’ accumulating experience to deal with the situation. It was quite common for parents in both countries to use professional programmes as a way of developing coping strategies. Professional programmes, or information exchange, indeed helped parents to revise their coping strategies. Almost all the parents in Taiwan and the UK expressed that they had experience of seeing a therapist or getting professional support. Some of them had spent years finding their own coping strategies, which would best fit their situations. A higher degree of knowledge enabled the ASD parents to have more confidence in dealing with the challenges in their life. Some parents from Taiwan and the UK also emphasised the need to keep coming back to learn new skills and to develop as the children get older.

*I went to sessions and regularly saw a therapist. For me, it was not only learning about how to bring up kids, but a therapy for myself ... I would partake of sessions over and over again, yet it still helps a lot because my vision might change when my child grew older. (TW-BP)*

The majority of parents from Taiwan and the UK mentioned their experience of being accepting of having a child with ASD. They looked at the positive characteristics of the child and changed the way they used to view the things through years of learning.

*Now I have come to accept my child’s condition. At the very start, I tried to find answers for his condition, and even took him to take other remedies or medical treatments, but now I have come to accept who he is, and do what I can do without thinking too much. (TW-CP)*

The second code focused on the TD siblings’ coping. Typically developing siblings’ coping strategies appear to be less flexible than those of their parents. For younger siblings (around 9 to 10 years old) in Taiwan, feeling anger and upset was frequently mentioned. However, this was not the case for the younger siblings in the UK. Surprisingly, younger UK siblings expressed acceptance and open attitudes towards their ASD siblings and the social life around them. Older siblings in Taiwan and the UK expressed a certain degree of suppression and felt that they had no other choice but to take avoidant coping strategies.
I’m more pessimistic. I think of myself really badly. There are some issues that I’d deal with, but others I’d let them rot. (TW-ES)

Older siblings explained if there was nothing they could do could make things better, they would prefer to just give in to their ASD siblings to avoid unnecessary conflicts. Some older siblings expressed their worries of adding extra pressure on their parents’ shoulders.

When I [TD sibling] know there is something that I can’t help or really make better, I don’t really like to tell them [parents] because I know it will upset them more that they know that I am sad as well, (UK-GS)

This age effect on TD siblings’ coping was also found in Questionnaire study, where the age of ASD and TD siblings linked with TD siblings use of avoidant coping.

Only in the UK did parents commonly mention how they tried to act as models for their TD children in order to teach them how to deal with the stressful situations and let their TD children know their feelings were acknowledged.

I have always tried to be open with them [TD sibling] and talk to her and let her know it is ok to express frustration ... I think I have also modelled at times with her, when I have been to see her, when I have been upset, I have cried in front of her, ... I hope it has been that open and honest communication that has helped her to understand some of what is going on. (UK-GP)

Sometimes situations exceeded TD siblings’ ability to handle. The TD siblings from both countries reported that they still relied on their parents’ assistance.

I find sometimes I calm down. I try and calm down them down and then I tell my mum or dad and they usually sort it for me. (UK-CS)

The fourth code was found only in the UK families and was called ‘Cross that bridge when we come to it’. In addition to mentioning the importance of a positive attitude and accepting their children’s situation, more than half of UK parents showed a general attitude of not worrying too much about the future. It was commonly found that parents in the UK tried to teach their TD children to deal with things in positive ways. The following quotations are from the same family, coded as B:
Yes, but I don’t think it is going to be too bad. I think nothing too worrying will happen... Cross that bridge when it comes to it. (UK-BS)

I think our approach is generally one of being positive and just dealing with situations as and when they arrive .... (UK-BP)

Other TD siblings in the UK expressed a similar philosophy for dealing with the situation.

You know how mums and dads say it is going to be all right and stuff like that. They say if you have cut yourself that it is not going to kill you and stuff like that. They kind of say it is going to be fine. (UK-DS)

In contrast to the UK families, this positive attitude, and not worrying in advance, was not expressed in either the Taiwanese parents’ or TD siblings’ interviews. Despite parents in Taiwan talking about their transformation and accepted of the situation of their ASD children, constant worry was commonly shown in the parents and some of TD siblings’ descriptions, as discussed in the code of ‘worries’. It is speculated that this may relate to the stigma and attitude toward disability and the social support resources in Chinese cultures, which is discussed in conjunction with the fourth theme ‘The support needed’.

Unlike the literature which suggests that religion plays an important role in family’s coping (Coulthard & Fitzgerald, 1999; Kamei, 2014), there was only one parent, and a sibling from a different family in Taiwan that mentioned the use of religion to help them go through the process. No siblings or parents in the UK mentioned the use of religion as a means of coping.

Yes religion gives you a boost and comfort at the same time. Buddhism and Taoism attribute this to ‘Karma,’ or anything you had done in the past. I don’t agree with this, and I think that Christianity, in this regard, seems more positive and tells us to keep praying. (TW-AP)
8.3.4 Theme 3: What we do as a family

The third theme both in the Taiwan and the UK families related to the relationships within the family, and how parents expected and viewed their TD children’s role in the family. The first subtheme is called ‘Family as a whole’. Despite both countries having an identical subtheme and related codes, Taiwanese parents stressed the family bonds more strongly within this subtheme than their UK counterparts. The second subtheme was different in Taiwan and the UK. The Taiwanese families were more focused on parents’ and TD siblings’ interpretation of the differential parenting, whilst the UK parents emphasized more how they respected their TD children as independent individuals. The subthemes and related codes are summarized in Figure 8.3.
Figure 8.3 Theme 3: What we do as a family and related subthemes

<table>
<thead>
<tr>
<th>Taiwan</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared responsibility</td>
<td>Shared responsibility</td>
</tr>
<tr>
<td>Feeling of being neglect</td>
<td></td>
</tr>
<tr>
<td>The reasonable one</td>
<td></td>
</tr>
<tr>
<td>Family as a whole</td>
<td>Family as a whole</td>
</tr>
<tr>
<td>What we do as a family</td>
<td>Involve siblings</td>
</tr>
<tr>
<td>Differential parenting</td>
<td>Reasonable to give way</td>
</tr>
<tr>
<td></td>
<td>Understanding</td>
</tr>
<tr>
<td></td>
<td>Siblings as individuals</td>
</tr>
</tbody>
</table>
Family as a whole

In this subtheme, the parents from both countries expressed how their TD children share the responsibilities of being part of the family, from sharing the housework to looking after their ASD siblings when parents were busy.

*You can that say that she plays the role of a little helper, of a class constable, or of a caretaker. For example, if both Mum and Dad are busy, she [TD sibling] takes care of you [ASD sibling] so that you don’t fall. (TW-BP)*

Furthermore, the parents in the UK reported providing information regarding the ASD for their TD children in the early stages post-diagnosis. By using materials like books or DVDs, the parents tried to involve their TD children in the family adjustment process. This code is especially for the UK families called ‘Involve siblings’. This code is similar to an earlier code called ‘We are the same, like others’ which discussed how UK families tried to do activities together.

*I think it changes depending on age. I think when they [TD sibling] are younger it is important to be able to talk with them through why, to try to explain why their sibling [ASD sibling] might be behaving in a particular way and we found it was really important to try and give [TD sibling] time. (UK-AP)*

This involvement of siblings in coming to terms with the ASD was not seen in the Taiwanese families.

The second subtheme for the Taiwanese and the UK families was different. For Taiwanese families’, it is named ‘Differential parenting’, while for the UK families, it is called ‘Understanding’.

Differential parenting

The second subtheme in Taiwan reflects a variety of parenting styles. Since the parents in Taiwan were aware of their limited time and the different standards that they had set for their TD child and their child with ASD, they explained that some activities may require modification and that TD siblings needed to adjust in order to meet the needs of their ASD siblings. Some of the TD siblings in Taiwan expressed
their feelings of upset and unfairness at this in the code named ‘Feeling of being neglected’.

I have tried to care more about my daughter [TD sibling], although it was almost impossible. With my elder son’s situation [ASD sibling], there was a long way ahead before we could adjust to a better state. It would take a lot of effort and strength. But still, I didn’t neglect how my daughter was affected by all this. I was trying my best. (TW-AP)

She (Mum) cared about my older brother [ASD sibling] but not me. She wouldn’t let me play with others, nor with my classmates. She had me stay home and didn’t let me go out on my own. I was all alone at home with no one to talk to. (TW-AS)

The Taiwanese siblings expressed the neglected feeling due to the different parenting standards. Even though the TD siblings had been taught by their parents why they needed to give way to their siblings with ASD, they expressed that it is rationally understandable, but not emotionally acceptable.

My older sister forced me to lend her things, but I didn’t want to. Mom and Dad would scold me and say that I (TD sibling) should yield to her. (TW-GS)

Furthermore, the Taiwanese parents expected the TD siblings to understand the challenged situation well. The parents would assume that their TD children would be able to ease the tension in a reasonable manner whenever the situation is challenging. The code is hence entitled as ‘The reasonable one’. The word ‘should’ was mentioned by most of the Taiwanese parents in the interviews. The following quotation from a mother and a TD sibling illustrates the different perspectives from parents and from TD siblings.

I think he [TD sibling] should have understood better and should not have such a response because he knew what his elder brother [ASD sibling] was like … I had already devoted so much to take care of my son, but I didn’t know why she, being a normal child, couldn’t understand. (TW-AP)

…as if it was my [TD sibling] fault … Mum would say, ‘Why don’t you yield to her? You know very well that she [ASD sibling] has problems.’ (TW-AS)

The differential parenting can be found quite often in the research of family experiences with a child with disability (see Section 1.4). The findings from this study suggest that the Taiwanese TD siblings’ negative feelings of being neglected
might be due to insufficient information and knowledge provided to them. For example, some Taiwanese parents expected that their TD children would understand what ASD is like simply from their experience of interacting with their siblings. Some siblings could explain certain behaviour characteristics related to ASD. However, there was a gap between parents’ expectations of TD siblings’ understanding the ASD and the actual level of knowledge TD siblings had perceived. One example from the Taiwanese family could support this:

**Interviewer:** Does anyone help your TD child to understand what is ASD?

**Parent:** We only told her [TD sibling] because her sister [ASD sibling] had developmental delay and needed to go to special class. We did not specifically explain what is ASD. The teacher from the primary seemed to play some videos to show them. She [TD sibling] knew her younger sister was slow at words and many other things, so they naturally knew about it. (TW-C)

**Interviewer:** Do you know anything about ASD?

**TD sibling:** Probably yes and no, I have no idea. (TW-CS)

UK parents did express that there was differential parenting, but they saw this as their efforts to treat the TD children as individuals, which formed the subtheme called ‘Understanding’.

**Understanding**

Unlike the Taiwanese families, the subtheme in the UK emphasized the way parents and siblings delivered and received the information. The code ‘Feeling of being neglected’, which was found more frequently in the Taiwanese siblings, seems less sufficient to explain the data in the UK’s cases. Instead, ‘Reasonable to give way’ can better depict the UK data. This was because most TD siblings in the UK expressed a greater degree of understanding regarding the need to give way to their ASD siblings. There were still worries expressed by the TD siblings while mentioning the feeling of being told they had to be the reasonable one.

*I think it can be quite difficult when I know that, even if I think I am right, and he [ASD sibling] is wrong, I just have to agree with him and just sort of let it go. (UK-GS)*
The feeling of differential parenting did show in Taiwan and the UK siblings’ interviews. However, UK siblings addressed more on the understanding and difficulties of their ASD siblings, which it might link with the knowledge and information regarding the ASD provided from their parents discussed in the earlier code.

When the UK parents tried to involve their TD child in the family, they seem to respect siblings’ reactions and feelings more than the Taiwanese parents did. They also valued TD siblings as an individual in order to ensure that they feel themselves to be treated as importantly as other children. This code is therefore entitled as ‘Siblings as individuals’.

Even if you can’t always solve the problem, to let the child [TD sibling] know that you understand, you acknowledge their problem ... just to let them [TD sibling] know that they are valued. (UK-BP)

I think to make them [TD siblings] feel special. You need to give them time and attention ... they are their own unique people as well. (UK-CP)

The subthemes ‘Differential parenting’ in Taiwan and ‘Understanding’ in the UK were both about how TD siblings interpreted the differential parenting. Despite Taiwanese siblings describing how their parents expected them to be the rational one, understanding the reasons behind the differential treatment, they seemed to have less understanding of the ASD siblings’ difficulties and appeared to feel more negatively about the differential parenting. In contrast, UK siblings were better able explain their ASD siblings’ difficulties and the reasons why their parents needed to sometimes have different standards. They also appear to be more understanding of the differences in how they were treated. It is speculated that these cultural differences were linked with the greater understanding of ASD and explanations provided by parents in the UK.
8.3.5 Theme 4: The support needed

The last theme is related to the support that families have received and the types of the support they reported needing. This included informal support from friends, extended family members and parents’ partners. Formal support included access to professionals and help from the school system. Lastly, families in both countries mentioned that the support they needed varied with different stages and that they had clearer ideas of how to access resources after years of experience. There are differences in how these issues were expressed in the two countries, leading to some differences in codes. These subthemes and codes in Taiwan and the UK are listed in Figure 8.4.
Figure 8.4 Theme 4: The support needed and the related subthemes

<table>
<thead>
<tr>
<th>Taiwan</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Extended family bond</strong></td>
<td><strong>Extended family</strong></td>
</tr>
<tr>
<td><strong>Partner's role</strong></td>
<td><strong>Joined work with partner</strong></td>
</tr>
<tr>
<td><strong>They are not in our shoes</strong></td>
<td><strong>Informal support</strong></td>
</tr>
<tr>
<td><strong>Communication with professionals</strong></td>
<td><strong>Communication with professionals</strong></td>
</tr>
<tr>
<td><strong>Improve the support system</strong></td>
<td><strong>Support is there</strong></td>
</tr>
<tr>
<td><strong>Informal support</strong></td>
<td><strong>Informal support</strong></td>
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<tr>
<td></td>
<td><strong>The support needed</strong></td>
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The support needed
**Informal support**

Within this subtheme, the first code is entitled ‘Extended family’ to address the UK cases. In the UK, only a few of the families have extended family members who live nearby to help them with childcare. In Taiwan, because of the bond between extended family members, the tension between them and their extended families was frequently mentioned even though some their extended family members did not live nearby. The tension was mainly caused by disagreements about childrearing and extended family members’ lack of knowledge of ASD. Such stress in relation to interactions with the extended families had made this informal support less helpful in Taiwan than in the UK. Hence, instead of using ‘Extended family’ (for the cases in the UK), the Taiwanese code is ‘Extended family bond’ is therefore used as the Taiwanese code, which can better address the difference in Taiwan.

*I could go home and lock everything outside, and escape from my parents or parents-in-law, who have quite a lot of opinions on how we should bring up our children. I was often criticized. Though I let them to do so, I still persisted in my own way. (TW-GP)*

*My mother is still living, and my husband’s parents, they are all in their 80s now, but they have always given a lot of support through the years. They are not local, so not daily support, but they have always been happy to come and help in the holidays and spend time with the boys. …. We have had good strong family support which I think is very important. (UK-AP)*

Another source of informal support is from the partner and this second code is called ‘Partner’s role’ in Taiwan and ‘Joined work with partner’ in the UK. The role of the partner was significantly different in Taiwan and the UK. Most Taiwanese mothers described that it was mothers themselves who consulted professionals about programmes to help their children. The lack of time and being responsible for the financial resources of the family, fathers were found to be less available and capable of taking care of their ASD children than mothers. Thus, in some cases this would probably cause lack of mutual understanding and make communication difficult between mothers and fathers. As a mother in Taiwan described the difficulties with her partner:
Sometimes even if I told my husband, he didn’t know how to help. I ended up not telling him unless there were some major incidents. (TW-CP)

Despite the influence of BAP level having not been emphasised during the interview, this still highlights an issue between informal support and the BAP level. From the example below, it has shown that the displayed ASD patterns of her husband seem to be connected to his indifferent attitude toward parenting.

Our household is unusual in that, my husband, had he been diagnosed, he would have been found having worse problems than my son [ASD child]. He is similar to my son in that they both live in their own worlds. He never bothers with any of these problems. He never participates in our children’s activities. Whether it is school activities or going to see a doctor, he never takes part. (TW-AP)

In contrast to Taiwan, the fathers or partners in the UK were usually more involved in taking care of the children and more involved in the decision making. In some of the UK families, the parents reported that they would work part time, or choose a job with flexible working hours, in order to spend more time at home with their children.

But my husband and I both work part time and the reason for that is to make sure that we are home for the boys in the afternoon ... because the boys wouldn’t be able to manage with a child minder or a nursery or something like that. My husband and I both had to reduce our hours to part time to work with the boys. (UK-CP)

This subtheme also includes the issues of receiving supports from the friends – both the parents’ and the siblings’. However, in Taiwan the lack of understanding of ASD and the negative social stigma had made the parents feel distant from their friends or parents. The parents in Taiwan found it stressful to explain the situation to the people around them. As some Taiwanese parents discussed, the help or concerns from their friends would become an extra burden sometimes. Hence, the Taiwanese code is entitled ‘They are not in our shoes’, while in UK the code is called ‘Friends and others’ to reflect the differences between the two countries.

Sometimes I’d talk to my close friends, but most of the time, I don’t think they understand. Sometimes I even feel hurt by their reaction, so I wouldn’t go
Both the Taiwanese and the UK parents agreed that friends they had met through the support groups can understand them better as they had shared some similar experience. Hence, their supports seemed to be more helpful than those who did not have similar experience. Making friends from the parents support groups or through related organizations enabled the parents to expand their social networks without feeling the stress of making friends with those who had little knowledge of ASD. Such social networks were not limited to information exchange only, but, most importantly, it provided emotional support.

Apart from the parents, the TD siblings in both countries also expressed their needs for the support from their friends, as it could help them to release their stress if they had someone to talk to. However, some siblings found that their friends were ignorant to the ASD, so the support from their friends was only limited.

However, TD siblings who participated in the present research still found friends helpful even though the help available from friends was limited.

**Formal support**

Formal support resources include medical consultation, the education system and social services. The first code in this subtheme is called ‘Communication with professionals’ in both countries. All of the parents in Taiwan and the UK who
participated in the research mentioned that they actively looked for resources in relation to ASD once their children had been diagnosed. They also participated in training programmes or joined support groups to enhance their knowledge of raising a child with special needs. The reported accessibility to the services varied from area to area. For example, those who lived in a suburban area found it was not as easy as those who lived in the urban area because they would have to do the research and inquire about the information themselves. Some parents, both in Taiwan and in the UK, found it most challenging in the early stages since they had to fight in order to get support for their children, while others found the process went smoothly.

*In the beginning, I had to look for the resources all by myself, which was probably to do with the city or county I lived in. I used to live in XX County, and there were fewer resources, so I had to make phone calls and search on my own. Now it’s the XX Foundation that sends out related information. Before that, we didn’t know where to go for classes or for diagnosis. We had to call the social workers to ask. ... The process became smoother after joining the foundation. (TW-CP)*

*We do get a lot of support and a lot of help in comparison to some families but I think that is mainly because we have been so forceful about asking for it and fighting with people to get what we feel we need. (UK-CP)*

Some parents in Taiwan had an expectation that formal resources, such as information about support groups and professional help, would be provided to them and their ASD children once their children had been diagnosed. Despite parents in Taiwan searching out the resources for their ASD children, and sometimes needing to fight for it like the UK families, Taiwanese parents emphasized the insufficiency of the formal support more frequently than the UK families. Hence, the code for the cases in Taiwan was therefore entitled ‘Improve the support system’.

*Not even needed to mention the schools did not have enough professional resources for my child. (TW-DP)*

*It was even worse in the high school. There was no support whatsoever at all. I had to force the school and insisted the treatment and care my child should have. (TW-EP)*
With online information more available and more parents in the UK willing to travel or to relocate their homes in the area that could offer their ASD children more resources, the issue of accessibility in the UK was less evident than it was in Taiwan.

Slightly different to the cases in Taiwan, what the UK parents revealed in this code ‘Support is there’ is that as time went by the support they needed could be different, so they would reach for the support whenever it was needed. Therefore, even when the children with ASD had settled down, the parents might still need to relocate the families if the support was no longer sufficient for them. Some parents also mentioned their TD children would go to the support group whenever they needed. Some went to the activity occasionally, while others found the service more suitable in their teenage years. Overall, the UK families were more resourceful about how to search and access support and services than the Taiwanese families.

*I think that that [to go to a sibling support group] may even be more important as he gets into his teens, at an age where they may well talk about it and what the difficulties are and what the solutions are to some of the difficulties. (UK-AP)*

*For a couple of years it was really good. As parents as well it was really good to be able to go and talk to other parents who completely understood what we were talking about. But probably over the last couple of years [TD sibling] hasn’t particularly wanted to go. Things with [ASD sibling] had settled a bit and we didn’t particularly need to go in the same way as we did when we first started going. (UK-GP)*

The differences of informal and formal support in Taiwan and the UK families were addressed in this theme. The difference in attitudes toward disability and receiving informal support from others were significant between parents in Taiwan and those in the UK. To a certain degree, the Taiwanese siblings were also influenced by their parents’ attitudes toward the support they had received from friends. To improve such unevenly-developed formal support in Taiwan is the most urgent task for the relevant medical institutions. While accessibility and information relating to social support is more available in the UK, the British parents looked forward to different types of support could be offered as their ASD children progressed.
8.4 Discussion

In order to further explore a number of issues raised in Questionnaire study, including why TD siblings and their parents decided to use certain types of coping strategies, the influence of having a family member with ASD, the attitudes toward caretaking roles, the experience of seeking and receiving social support in both countries, and parents’ views of the adjusted behaviours were included in the interview study. The discussion in this chapter mainly focuses on the qualitative findings, reviewing key results and linking them back to previous literature, while links between interview and questionnaire findings, and the limitations and reflections on the process are in Chapter 9.

Though there were some similarities within parents and siblings, and also between two countries, there were, however, many differences too. The parents in Taiwan appeared to have higher expectations of their TD children, in particular for them to be more considerate regarding the situation of their ASD siblings, while the UK parents seemed to have a more positive attitude toward their TD and ASD children’s development and future than the Taiwanese parents. The more negative attitudes in Taiwan might result from a lack of resources, or how disability is viewed in society.

The interview data from both the Taiwanese and the UK families formed four core themes, which were ‘The influence of ASD’, ‘Family resilience’, ‘What we do as a family’ and ‘The support needed’. In each individual core theme, parents and TD siblings expressed their own perspectives in terms of dealing with the influence of their ASD siblings.

In the first theme, the families in Taiwan and the UK both discussed ‘The influence of ASD’. The issue of sibling conflicts and the negative impact on siblings’ relationships was mentioned more frequently by the Taiwanese families than the UK ones. The UK families emphasized the positive side of the children with ASD and that they should not be limited by their diagnosis. This difference in responses might be caused by cultural differences in views of disability, as the social stigma of having
a child with a disability is quite prevalent in Chinese culture (Huang, et al., 2009; Qian, Smith, Chen, & Xia, 2001). The perceptions of social stigma were certainly more apparent in the Taiwanese families.

In both countries, the parents expressed their concerns regarding the future and the future stress of the TD siblings. However, the Taiwanese parents also mentioned that they worried that having an ASD sibling might influence their TD children’s marriage in the future. Again, there was a greater distinction in terms of acceptance in society of disability in the last code of this theme. Therefore, the Taiwanese families would rather keep their family problems within the family. This was consistent with previous research findings that within Chinese families where a child has a disability, the parents had a higher caregiving burden due to social stigma (Ji et al., 2014; Mak & Kwok, 2010). It has been suggested that such feelings of discrimination and stigma may restrict parents of children with ASD from seeking support in Chinese cultural contexts (McCabe, 2007). According to the interview information, the formal support provided for the TD siblings was relatively limited and felt to be insufficient by the majority of the Taiwanese families. Despite Taiwanese parents awareness of the help or support needed for their TD children, the limited resources available were one of the concerns which arose in the interview data. The siblings in the current research also perceived that they were receiving less formal support in Taiwan than their UK counterparts. However, as shown in the questionnaire and in the interview, there were fewer differences in terms of the informal support received from peers according to the Taiwanese and the UK siblings. A few Taiwanese parents told the children not to mention the child with ASD at school. Some siblings did as they were told, whereas the others did not mention feeling the need to withhold this information. This suggested that TD siblings’ perception toward ASD might be influenced by parents and also the reaction from others in their social life.

In the present interview data, feelings of stigma were more common in the siblings from Taiwan then the UK. However, the typically developing siblings from both
countries expressed that they had experienced some level of embarrassment or discomfort while explaining the disabilities of their siblings with ASD to others, and especially that challenging behaviours of the child with ASD in public were the most difficult for them. This suggests that feelings of stigma are not restricted to Taiwan. Worries about people’s reaction and feelings of stigma have also been shown in Western research (Gray, 1993; Mascha & Boucher, 2006; Roeyers & Mycke, 1995). Nevertheless, there were still a few TD siblings from both countries who expressed a positive attitude about their experience of others’ opinions.

The parents in the UK preferred not to label their ASD children with their disability, but believed that their children might have more potential than the diagnosis might suggest. Parents also expressed that they tried to clarify which behaviours were related to the ASD, in order to discipline all of their children with consistent standards, in an attempt to decrease the possible influence of differential parenting. In contrast, Taiwanese parents emphasized that their TD children should learn to accept and understand the limits of their ASD siblings. Cultural belief has found to influence parents’ beliefs and attitudes about ASD and also the way they interpret the symptoms (Mandell & Novak, 2005), and that seems to have been the case in the present data.

Furthermore, siblings attitudes toward their ASD siblings has previously been found to be similar to that of their parents (Lobato, 1983). This was also supported in the present interview data, where TD siblings in Taiwan and the UK had differing attitudes toward their ASD siblings. To some degree, UK siblings’ attitudes seemed to be the same as those of their parents. The UK siblings praised their ASD siblings and did not ascribe all of their challenges to the disability. This might relate to their parent’s attitude toward the disability. Research has found that if parents have a positive attitude toward their children with disability (Gupta & Singhal, 2004; Petalas, et al., 2009a) and are aware of the possible influence of differential parenting (Mchale, et al., 2000), it appears to promote siblings’ relationships and understanding (Stoneman, 2001). A similarity in attitude between parents and siblings in Taiwan
was not as evident as in the UK families. With Taiwanese parents more focused on the limits of their ASD children, TD siblings had both positive and negative attitudes toward their ASD siblings.

Such similarities between parent and sibling attitudes were also found under the second theme of ‘Family resilience’. UK siblings expressed some similar ideas to their parents - not worrying too much and helping their ASD siblings to ease anxiety. This, therefore, has suggested a connection between the coping strategies of siblings and those of their parents. In accordance with the literature, which suggests that coping is a dynamic progress (see Section 3.4.1 for details) this qualitative study showed that the parents in the UK tried to be the models for their TD children in terms of applying coping strategies to deal with stress. In Questionnaire study, UK parents and TD siblings did show some links with each other, which again supports the notion that parents and TD siblings’ coping influence each other to a certain degree. Moreover, parents from both countries in the interviews did express they would help their TD children, especially when the situations were too difficult for them. However, this seems to be stronger in the UK families than the Taiwanese. This might relate to UK parents emphasising the importance of involving their TD children in family activities and trying to model coping strategies to their children.

The second theme primarily deals with coping, and focuses on how families learnt from the experience after receiving the diagnosis of their ASD children. Both the Taiwanese and the UK parents were aware of their own limits and the importance of taking some time off. The Taiwanese parents talked more about the struggles, while the UK parents mentioned the strategies they would use to deal with the challenges and obstacles. These patterns were consistent with the findings from the questionnaire, where the Taiwanese parents appeared to consistently evaluate the situation or their own behaviour according to a higher standard than their UK counterparts. Other research also found that Chinese parents of children with a disability are more pessimistic about their children’s future and adjustment than Western parents (Lin, 2011; Wang et al., 2013; Wang, et al., 2011). As discussed
earlier, UK parents and siblings interpreted of the situation more positively than their Taiwanese counterparts.

It is interesting to note that helping others and self-growth were emphasised by the Taiwanese parents, and these seemed to involve collective and individualistic-oriented philosophy respectively. This coexistence of collectivism and individualism in both Chinese and Western cultures and individuals has been recognized (Tamis-Lemonda et al., 2008). Qualitative studies have shown that Chinese women who experienced serious injury or a life-changing event, focused on helping people and their inner-growth (Chiu, Clark, & Daroszewski, 2000; Wu, Zhai, & Liu, 2009). With limited literature in Taiwan, further discussion on these findings is difficult.

Previous research has suggested that Chinese caregiving obligations are bonded with its cultural philosophy (see literature reviewed in Section 2.3). Concerns about the perceptions of society and the caring burden in the Chinese parents seem to be two core issues in both present and previous literatures (Holroyd, 2003; Mak & Kwok, 2010; Tait, Mundia, & Fung, 2014). These caregiving obligations also influence how Taiwanese parents pass the information on to their TD children. For example, emphasizing bonded responsibility and understanding was shown in the Taiwanese data, whereas this responsibility was addressed differently by trying to involve TD siblings in the family activities but also respecting the sibling as individuals in the UK families.

In the present interview data the TD sibling’s age was found to relate to the coping strategies used. Older siblings in both countries were found to use more avoidant or suppression strategies, and younger siblings in Taiwan appeared to show more difficulties in coping than their UK counterparts. The results of the questionnaire study also supported that age could affect the Taiwanese siblings’ coping. In Interview study, as the TD children in Taiwan and the UK grew older, more avoidant coping strategies were used. Avoidant coping was interpreted as maladaptive in the previous literature (see Section 3.4.1). However, in the findings of Interview study, using avoidant coping appeared to help TD siblings in the UK reduce their concerns
that they would cause their parents to worry. This might have made it adaptive to some extent. Feeling that they cannot control the situation and they did not feel that they had efficient strategies to help their ASD siblings or parents, older siblings in Taiwan and the UK would use avoidant coping to get away from the stress and tension. As follows the discussion in Section 7.7.3, this again supports previous findings showing how individuals’ feeling of control of a situation, play a crucial role in coping. However, the potential long term negative impact of using avoidant coping is worrying. Health professionals could target issues like teaching TD siblings to re-evaluate the stressful situation and to increase the flexibility and confidence in using a variety of coping strategies.

The relation between age and TD siblings’ coping has not been a strong focus of previous research, where emphasis has been more on what kind of coping strategies TD siblings used in order to deal with different tasks (Roeyers & Mycke, 1995). The preliminary findings from a small number of studies did reveal some plausible relation between the factor of age and the TD siblings’ coping (Orsmond, et al., 2009; Ormond & Seltzer, 2007b). Being more mature and with more flexibility to use coping strategies freely, Ormond, Kuo, and Seltzer (2009) has suggested that TD siblings would adopt coping approaches more effectively in adulthood than in adolescence. However, with the present research focused on children and adolescents, older siblings seemed to use less well-adjusted coping strategies than the younger ones. Longitudinal study and cross-sectional comparison between different age groups are still needed in order to further clarify how the TD siblings’ age relates to how well they apply coping strategies. Further research should be explored to see whether avoidant strategies lead to maladaptive outcomes in all circumstances.

The third theme, ‘What we do as a family’, captured the views of parents and siblings on the family dynamic, and again showed significant differences between the cases in Taiwan and the UK. The parents from both countries emphasised the importance of family coherence. Both the Taiwanese and UK parents talked about sharing responsibility as part of being a family member, but with UK parents placing more
emphasis on the importance of encouraging their TD children to be involved in family activities along with their ASD siblings. In contrast to the UK families, most Taiwanese families expected their TD children to take over the responsibility in the future for their families. This finding is consistent with that of Lin, Tsai, and Chang (2008), who reported that parents of children with ASD in Taiwan expected their TD children to accept the lifelong obligation to look after their siblings. Furthermore, in the present research the TD children in Taiwan were expected to be able to deal with the situation calmly.

Some TD siblings in Taiwan and the UK found signs of differential parenting upsetting and unfair. Such negative feelings have been found to be harmful to siblings’ relationships (Rivers & Stoneman, 2008). Despite more UK siblings expressing that they could understand why their parents had to have different standards for the ASD siblings and themselves, they still found it quite challenging at times. Parenting of the TD children and the ASD children were found to be significantly different in Taiwan. The Taiwanese parents expected their TD children to behave and understand their stress. This higher standard of behavioural expectation in Taiwanese parents was consistent with the impression from Questionnaire study. Therefore, more open communication between parents and their TD children might be helpful for a better mutual understanding in this case. It has been found in Western research that open communication between family members and adapting coping approaches to fit the needs of the family can improve family coherence (Altiere & Von Kluge, 2009; Greeff & Walt, 2010). The effects of mutual communication have not previously been studied in Chinese culture.

The Taiwanese parents also mentioned that they expected their children to have good knowledge of ASD even though there was a huge gap between how parents and their TD children understood the symptoms and difficulties of the ASD children. The UK parents used strategies and materials to deliver information about ASD to their TD children, according to their cognitive ability, while the Taiwanese parents relied mainly on professional workers, teachers, or experience to deliver the information.
This might also explain some of the links between parents’ and TD siblings’ coping and the variables that predicted TD siblings’ adjustment in Questionnaire study: UK siblings’ adjustment and coping were more related to mixed variables, such as themselves and family, while Taiwanese siblings’ adjustment outcome was more associated with their internal variables.

It has been supported by previous Western research that if parents could provide their TD children with appropriate information regarding the ASD according to their age, it could help the siblings’ relationships (Roeyers & Mycke, 1995; Sage & Jegatheesan, 2010). The present interview data also supported the importance of acquiring knowledge regarding ASD, whether helping parents to have suitable behavioural expectations of their TD children or to decrease the feeling of differential parenting in TD siblings. However, this greater awareness of ASD, and parents’ sharing of their feelings, seemed to make some UK siblings reluctant to disclose their difficulties to their parents. That is, it suggests that it is important to understand how sibling coping and outcome might be impacted by differences in what information is shared, and how this is done.

No research to date that has explored how Chinese siblings perceive knowledge of ASD and how this has influenced their adjustment. From the present interview data, it is speculated that Taiwanese parents tend to deliver the information regarding the ASD more vaguely than the UK parents, and this perhaps explains the lower level of acceptance of differential parenting. However, this research was not designed to conclusively show a clear link between the two. Therefore, it requires further research to clarify the links between TD siblings’ negative feeling towards the differential parenting and the lack of knowledge of the ASD in the Chinese/Taiwanese families.

The last theme ‘The support needed’ was related to the support given to the family. The Taiwanese families had ‘close’ relationships with their extended families, but these relationships also appeared to be tenser than those in the UK, with some parents in Taiwan saying that they had been criticised on parenting by their extended
families. In Questionnaire study it was found that the Taiwanese families had a lower percentage of unpaid childcare than their UK counterparts. As such childcare is typically provided by grandparents or other relatives, this may provide some explanation for the findings. The research on Western families has indicated that grandparents’ involvement could help to share the responsibility of the child-care, and could provide emotional support to decrease the level of parental stress (Lee & Gardner, 2010). Given the lower level of unpaid childcare in the Taiwanese families, found in Questionnaire study, it is speculated that extended families’ views on parenting are based less on actual experiences of interacting with the child with ASD, than they are in the UK, so they may be more likely to make suggestions that cause tension for the parents. As discussed in Section 2.1, Chinese families tend to have a strong bond with their extended families, and also value the filial piety which all the family members should respect and obey to the elderly (Mehta & Ko, 2004). Therefore, whenever there is a disagreement between the younger generation and the elderly, things would become worse and extra stress would be added to the parents of the child with ASD from this kind of informal support, whereas it is expected that there is the opposite relationship in the UK. The tension between extended families might also influence TD siblings in Taiwan, receiving less support from them, although this was not explored in the present study.

Parents in both countries have experienced different levels of challenges to strive for formal support and resources for their families. The formal support was also mentioned in relation to the first theme ‘The influence of ASD’ discussed earlier. In the present findings, Taiwanese parents who lived in suburban or small towns found it difficult to access services or participate in social activities which were organized for TD siblings. Furthermore, such social services or support in Taiwan is still limited to those living in the city or parents with higher social economic status due to the uneven development of services across the country. The need to increase the accessibility of resources may be one of the main tasks for the Taiwanese government (Chiou, Chang, Chen, & Wang, 2009). Although this cannot be shown conclusively, it was found in Questionnaire study that Taiwanese siblings did report
receiving less support (mainly informal support) across various sources. More services in Taiwan focused on parent support (i.e. how to raise their ASD child), with only a limited numbers of services targeting help at the TD siblings. Siblings in Taiwan are conferred some practical support, e.g. free meals at school etc. because of the diagnosis of their ASD siblings. However, in relation to emotional support, there was only one TD child who received therapy sessions in the hospital after being referred by her parents. Formal support for the children with ASD and their TD siblings in Taiwan is urgently needed. In contrast to Taiwan, the UK families were more resourceful and knew how to access to social resources. Based on the data from this small sample, there also appeared to be more resources available in the UK. The TD and ASD children in the UK could therefore participate in different types of support groups and activities.

8.5 Conclusion

This qualitative research has indicated there were similarities and differences between the Taiwanese and the UK families. A negative tone more frequently appeared from parents’ and siblings’ transcriptions in Taiwan, while a more balanced tone (both positive and negative) was found in the transcriptions of the UK families. This could be seen across a number of the themes. Nevertheless, this does not suggest that the Taiwanese families had more negative views about their families, but simply that the ways in which those families expressed their situations was more negative. Since the severity of the children with ASD in two countries did not significantly differ, engrained cultural philosophy may be one of reasons that the expression patterns were different in the Taiwanese and the UK families.

The findings from the present interview study also addressed the fact that when using coping strategies TD siblings considered their impact on other family members, and the efficacy of using them, especially in the UK families. Parents and TD siblings coping was also found to influence each other to some extent in both countries. Parents’ perception of the outside world also affected the social support their family received, especially in Taiwan. In Chapter 9, findings from the questionnaire study
and the interview study are pulled together in order to provide a comprehensive discussion.
9.1 Summary of main findings

This research aimed to explore some key elements that influence TD siblings’ adjustment, and focused on the contribution of culture to the factors that have affected TD siblings’ adjustment outcome. A number of variables were found which helped explain TD siblings’ adjustment in Taiwan and the UK, with the Taiwanese model related more to children’s internal variables and social support received, whereas the UK model was more influenced by a wider mixture of variables.

There are a number of important findings which arose from the interlinked questionnaire and interview studies. Firstly, the questionnaire results in comparison with country’s normative data, TD siblings in the UK rated themselves as having elevated adjustment difficulties in various domains, whereas TD siblings in Taiwan only showed elevated difficulties in peer problems. Secondly, a culturally-specific response pattern was found between Taiwan and the UK, where Taiwanese parents consistently rated their TD children as having more negative outcomes than their UK counterparts on the SDQ and in the interviews. This might have involved the evaluation and expectations of children’s behaviour in Chinese society, which Chapter 7 explored in detail. Thirdly, compared to the Taiwanese families, a greater gap was found between UK parents and their TD children in the evaluation of TD siblings’ adjustment in the questionnaire study. However, there were more shared perspectives between UK parents and siblings, compared to their Taiwanese counterparts, found in the interviews. Lastly, the coping measures, both Western and Eastern, used in this study had shown some application within both Chinese and Western cultures. However, the meaning of some of the items described in the measurements may have a somewhat different interpretation within each cultural context.

This chapter aims to draw together and compare the findings from the two interlinked studies in this thesis. The TD siblings’ adjustment and coping are
discussed along with the comparison between Taiwan and the UK, followed by the implications for clinical and educational practice. The limitations and suggestions for future research are also discussed.

9.2 Findings from questionnaire and interview study relating to sibling adjustment

The results of the questionnaire study have provided some important information. Firstly, siblings appeared to be better adjusted in Taiwan than the UK, according to their self-report. One of the possible explanations could be that Taiwanese siblings did adjust remarkably well. However, in the interview data, Taiwanese siblings did express more negative influences from their ASD siblings than their UK counterparts. It is possible that socially desirable responding in the present Taiwanese data might contribute to these questionnaire differences.

Secondly, bigger gaps between parents’ and TD siblings’ responses on the evaluation of TD siblings’ adjustment difficulties were discovered in the UK sample than in the Taiwanese sample. Goodman (1997) suggested that around 10% of a British community sample had a substantial risk of clinically significant difficulties, being noted as ‘abnormal’ in the SDQ. According to this clinical band in the SDQ, the response of the UK families showed there were around twice this number of TD siblings’ self-report showed adjustment difficulties, compared to the community sample, while only slightly more than 10% were identified from parents’ evaluation. Parents in Taiwan also evaluated their TD children as having very elevated adjustment difficulties compared to the community sample. However, the Taiwanese TD siblings’ self-reports were closer to the community sample, suggesting no evidence of elevated adjustment difficulties. Hence, it could only be concluded that there are slightly elevated difficulties in the UK siblings, while the evidence was not that consistent in the Taiwanese data.

The discrepancy in reporting of adjustment difficulties between parents and TD siblings raises the question of which report should be relied upon (e.g. for research
and clinical practice) and whether this differs between countries. Goodman, Ford, Simmons, Gatward, and Meltzer (2000), suggested that the parents’ data is more useful than children’s self-report in detecting children’s emotional problems since children may not aware the difficulties come from inner distress. Moreover, younger children are considered to be less able to evaluate or report their emotional disturbance and their reports may have limited diagnostic use (Becker, et al., 2004). This study was not, however, designed to conduct any clinical diagnosis, but to focus on how TD siblings reflected their experience of having a brother or sister with ASD. Hence, TD siblings’ self-report was used as the outcome measure in the model analysis rather than the parents’ report. As discussed earlier, despite the possible socially desirable responding being a potential issue when using self-report measurements, the response reflected TD siblings’ experience of what they have been through and also how TD siblings viewed themselves through the use of SDQ to some extent.

Findings from both the questionnaire and interview study, suggested that Taiwanese parents tended to evaluate their TD children according to higher standards than their UK counterparts. This finding is consistent with other research in Chinese settings using the SDQ, in which the Chinese populations scored higher on the problems scales and lower on the prosocial scale than the studies conducted in Western countries (Du, et al., 2008; Huang et al., 2012; Lai et al., 2010). This consistent pattern of evaluating children’s behaviours in Chinese parents in some respects reflects the Chinese parenting style which is characterised as more restrictive and harsh than Western parents (Chao & Tseng, 2002). This Chinese authoritarian parenting is based on helping their children to learn societal values, and develop appropriate behaviours (Shek & Chan, 1999). Moreover, parents of children with ASD were found to use more authoritarian parenting than parents of typically developing children in Taiwan (Gau, et al., 2010a). According to the findings of Chen, Dong, and Zhou (1997), authoritarian parenting is negatively related to children’s peer acceptance and sociability-competence in the Chinese population. In the present Taiwanese data, particularly peer problems were highlighted on the SDQ.
It is possible that this harsher rating of children by Taiwanese parents is somewhat detrimental to TD siblings, for example, there was a more negative tone across the Taiwanese sibling interview transcription than was found with their UK counterparts.

As for the UK data, UK parents’ response patterns were quite similar to Petalas and colleagues’ (2009b), who also surveyed parents of children with ASD in the UK. Both the present, and Petalas et al.’s (2009b) findings, indicated elevated levels of emotional problems in TD siblings compared to norms. The possible elevated emotional problems in the UK siblings might result from the TD siblings’ understanding of their parents’ stress and a desire not to upset their parents with their problems. The interviews revealed that UK TD siblings did not want to put extra stress on their parents and kept worries to themselves, this might explain the findings of elevated emotional problems from the questionnaires.

As for the prosocial behaviour, the UK parents’ and TD siblings’ evaluation of prosocial behaviour were similar, the majority of them were within the normal range. In contrast, it is interesting to note that, both from the parents’ evaluation and TD siblings self-report, the display of prosocial behaviour was lower in the Taiwanese siblings compared to the normative data. Nearly one-third or a quarter of TD siblings’ prosocial behaviour was rated below the normal range according to parents’ and siblings’ self-reports, respectively. This is consistent with previous research, in which Chinese parents evaluated their children as having less prosocial behaviour than the Western counterparts (Liu, et al., 2013; Yang, 2011; Yao, et al., 2009).

As reviewed in Chapter 2, the clear hierarchy within Chinese families has provided a description of typical parent-child relationships and parenting, which may explain this result. In Chinese society, high use of authoritarian or controlling parenting is seen as normal (Chao & Tseng, 2002). Children are expected to obey and respect their parents and elders, and any rebellion is not allowed (Ho, 1996). To praise children’s prosocial behaviour is considered to be unnecessary in Chinese society as it posits a risk of challenging parents’ authority and spoiling the children. In the present research, parents’ evaluation on prosocial behaviour of their children has also
reflected this special background of Chinese culture. In contrast, parents in the UK showed consistently more positive evaluations and comments about TD siblings than the Taiwanese parents in both the questionnaire and the interview data in this study. For example, the UK parents tended to adopt a more positive tone in the interviews, praising their ASD and TD children more than the Taiwanese counterparts.

This is not to suggest that Taiwanese parents did not value their children’s prosocial behaviour. Rather, Chinese parents tend to express their warmth and care in a more subtle and implicit fashion by being sensitive to children’s distress and providing instrumental support (Chao, 1994; Chao & Tseng, 2002). This sensitivity corresponds with the finding that the Taiwanese parents were closely aware of their TD children’s adjustment difficulties in the questionnaire study. However, there is a risk that TD siblings might be less aware of such subtle and implicit support from their parents and hence feel undervalued, or that their parents have a preference for their ASD siblings. Indeed, this interpretation was supported in the present interview study.

In the interview data, both the Taiwanese and the UK siblings expressed the influence of the children with ASD, including both negative and positive aspects. However, the Taiwanese TD siblings emphasised their negative feelings, such as anger and upset, while the UK siblings showed more acceptance and understanding of their ASD siblings, similar to their parents in the interview data. It also seemed that Taiwanese siblings are more honest and open with their parents than the UK siblings. Siblings in the UK may not want to worry their parents, so they tended not to mention their difficulties to them and this may have been evident in the larger gap in SDQ ratings. There was also evidence that the UK siblings have better knowledge of the symptoms of ASD, and this might explain their wish to avoid putting an additional stress on their parents. This is consistent with Tritt and Esses’ (1988) findings based on Western culture, suggesting TD siblings were aware of parents’ stress and would keep their worries inside rather than let their parents knew about the difficulties they had experienced. Several quotes from the UK siblings expressed that
if they could not really do anything to make the situation better, they would prefer to keep things inside them or do nothing about it. These interview findings might provide some insight into the reason why the questionnaire sample of UK TD siblings showed elevated emotional difficulties and rated the avoidant coping style as the most effective coping style for them. The avoidant coping style includes distraction, social withdrawal, resignation, and wishful thinking. These coping strategies helped individuals to avoid dealing with the stressors which might be too difficult or when there is nothing they can do to change the circumstances. Avoidant coping style might function as a protective response to a situation that is not fully understood or that individuals perceived as uncontrollable (Donaldson, Prinstein, Danovsky, & Spirito, 2000).

Although how TD siblings’ feelings were affected by their knowledge of the ASD was not measured directly in this questionnaire research, some evidence from the interview study could provide the insight of how they are related. Firstly, TD siblings’ levels of knowledge of ASD were shown to be different in the Taiwanese and the UK data. Parents in the UK provided ample information on ASD to TD siblings according to their age and levels of understanding. Parents in the UK emphasised the crucial roles of getting TD siblings involved in family activities and educating them as to why different standards applied. In contrast, the Taiwanese parents paid less attention to how much their TD children understood about the symptoms or related behaviours of ASD, but seemed more likely to assume their TD children should understand and accept differential parenting compared to their UK counterparts. This is also consistent with the TD siblings’ transcriptions, UK siblings could clearly state that their ASD siblings’ behaviours were related to the ASD symptoms, while Taiwanese siblings were more likely to comment on the distress of their ASD siblings’ behaviour and less likely to link this with the symptoms. Such different levels of understanding of the relationships between the ASD symptoms and challenging behaviours was also previously found in a cross-cultural study, where Asian TD siblings were less able to explain the behaviour than their Western counterparts (Sage & Jegatheesan, 2010). Different levels of understanding could
cause different attitudes of TD siblings toward their ASD siblings, as illustrated in the Taiwan and the UK interview data. Indeed, as Lobato and Kao (2002) have discussed, clear knowledge of symptoms and behaviours might facilitate siblings’ relationships and their understanding toward the situation they faced. Other research also found a positive sibling relationship was linked to the accurate knowledge of a sibling’s disability (Beyer, 2009; Mavropoulou & Baloyianni, 2007; Roeyers & Mycke, 1995).

Since the majority of the children with ASD do not have visible physical defects, it may be difficult for children to understand from appearance why their ASD siblings may act in a certain way or behave differently than they expected. Therefore, to educate the TD siblings on ASD is necessary, but what is more important is how parents deliver the information and for them to be aware of the possible influence. If the information is not clear, TD siblings are more likely to feel differential parenting, while on the other hand, after delivering the information, parents need to encourage their TD children to be open with any difficulties and worries, to limit the use of avoidant coping strategies and a lack of communication about any sibling difficulties. It is therefore speculated that mutual information exchange between parents and TD siblings would be more crucial than to just pass the information to the TD siblings. However, this only happens when information on coping strategies is given along with the education of what ASD is. Without the former it might enhance the use of maladjusted coping and lead to the maladjustment. Whilst this interview was a small sample, it suggests that the parents’ communication with the TD siblings is still not clear and can lead to misunderstanding.

The proposed explanations of the UK siblings adjustment difficulties still require further evidence to support them, especially the relations between the knowledge of ASD and the preference for using avoidant coping. Further research could also adopt TD siblings’ self-reporting to compare with other informants to further test and verify the possible explanations proposed above.
9.3 Research model and other factors that relate to siblings’ adjustment

To some extent, the combination of the Double ABCX and Diathesis-stress models did provide a useful way of conceptualising how variables may contribute to TD siblings’ adjustment. By narrowing down the numbers of variables, separate models that can explain the TD siblings’ adjustment outcome in Taiwan and in the UK were found. The two different predictable models provide the evidence of cultural similarities and differences in how variables influenced the TD siblings’ adjustment outcome.

As demonstrated in Section 6.4, there were differences in terms of the variables that linked with TD siblings’ adjustment outcome in Taiwan and the UK. In this section, some variables found in the predictive models from both countries were discussed and linked to the findings from the interview study. Since some of the variables were hard to quantify in the interview study (i.e. BAP level), and others have already been discussed in this chapter and in Chapters 7 and 8 (e.g. coping), only the severity of ASD and social support are discussed further in this section.

**Severity of ASD**

The findings in the questionnaire study have shown that, in the UK model the severity of the child with ASD’s symptoms did correlate with siblings’ prosocial behaviour, but that it also linked with social support to influence TD siblings’ adjustment difficulties. However, this influence of the ASD severity was not found in the Taiwanese prediction model. Typically developing siblings’ adjustment and experience has previously been found to vary according to their ASD siblings’ severity in several Western studies (Benson & Karlof, 2008b; Pilowsky, et al., 2004). Hastings (2003a) also found that formal support moderated the impact of ASD severity on their TD siblings’ adjustment.

The influence of the ASD severity and challenging behaviours were also shown in the interview study. From the interview transcriptions of TD siblings in both Taiwan and the UK, challenging behaviour of their ASD siblings has been illustrated. Both
Taiwanese and UK siblings had some level of conflict and arguments with their ASD siblings.

There was no significant difference between the severity of symptoms of children with ASD in the two samples. Why then, had the severity of symptoms more of an influence on the UK siblings than the Taiwanese siblings? This is perhaps because, as mentioned earlier, the UK siblings were more aware of the symptoms of their ASD siblings and had been taught by their parents’ knowledge of ASD, so they may have been sensitive to the effects of these symptoms. There might also be other possible explanations. For example, UK siblings were more likely to be in a mainstream school together than the Taiwanese siblings. Siblings in the UK also appeared to spend more time doing things together. It is probable that if siblings spent more time together, they would be more influenced by each other. Of course, this does not suggest that TD siblings should not spend time with their ASD siblings, nor that parents should avoid sharing information about ASD with the TD sibling. On the contrary, through the clear information educating TD siblings to understand their ASD siblings’ situation and mutual communication, this could further improve sibling relationship as discussed earlier.

**Social support**

In terms of social support, the questionnaire study showed that informal social support played a more important role in predicting TD siblings’ prosocial behaviour in Taiwan than in the UK. In the interview study, there was an opportunity to explore this further, and here the accessibility of formal social support was also discussed.

Parents in the UK mentioned that their TD children participated in various activities which did not just provide counselling or intervention, but gave their TD children a chance to interact with other children. Most siblings in the UK had attended a support group or received the support from health professionals at some point. In contrast, Taiwanese parents found resources for their TD children were limited and the resources were more readily available in certain geographical areas. Parents in
both countries noticed an uncertain attitude from their TD children about being in a support group. Parents in the UK preferred not to push their TD children to participate in the activities offered by the support groups when they did not want to. Some siblings were nervous about attending the support group or did not feel that support was necessary at the moment. However, parents from both countries still acknowledged the benefits of having formal or informal support from a long term perspective.

However, in the prediction model, the role of informal social support in the Taiwanese model more strongly contributed to TD siblings’ prosocial behaviour than in the UK model. In the bivariate analyses, informal social support was found to link with TD siblings’ negative life events, the severity of ASD and also their adjustment outcome in the UK model. When using hierarchical regression, other independent variables are also accounted for in a multivariate analysis. Hence, the magnitude of regression coefficients is influenced by relationships between the multiple variables entering into the model (Cohen, et al., 2013). It is possible, therefore, that influence of the informal social support was not as strong when considering other variables at the same time.

From the questionnaire and interview data, the UK siblings reported they had received more both formal and informal support from various sources than their Taiwanese counterparts. Furthermore, the difference in the formal support between two countries was firstly noticed at the recruitment process. There were various parents or siblings support groups in the UK, which was open to both local and international families.

The Taiwanese attitude of keeping things within the family may also restrict the resources delivered. In Taiwan’s medical system, after children have had a confirmed diagnosis, parents can decide whether they would like to receive social and early intervention support for child with ASD. Even though the medical system has a record of the children with ASD, it is still parents’ decision to register in the support system or not. If parents refuse to register, they will not actively receive the National
Health Insurance (NHI) information. Children with ASD can also decide whether they would like to receive a Major Illness Card (MIC) or Disability Manual which relate to the social welfare, medical and educational support. The worries of being stigmatised, discussed in Section 2.3 about parents’ attitude toward disability, might influence Taiwanese parents refusal of these services. From the census report of the government, one-third of children with disabilities do not received government premium subsidy (Lin, Lin, Yen, Loh, & Chwo, 2009). Hence, it is not surprising that some parents in Taiwan described a lack of information and support from different resources. If parents leave the NHI system, it becomes their responsibility to approach the support and services they need. As some parents were recruited through the hospitals, it can be assumed that a number of Taiwanese parents who agreed to participate in the study, especially the interviews, probably were part of the NHI system. In other words, the patterns of keep inside our family found here might be even stronger in families who did not participate in the research. Whether to receive the support or not for their families is a dilemma for many parents in Taiwan. Worrying about being stigmatised has been found to deter Chinese parents from seeking informal or formal support for their families (Mak & Kwok, 2010; Wang, et al., 2011). Although the interview questions did not ask directly whether the parents decided to receive social support, or if they felt stigmatized by society, the concerns of people’s perceptions were constantly mentioned in the Taiwanese data. Hence, the ‘Keep inside our family’ appears as one of the subthemes in Taiwan in contrast to the UK families.

Another factor that influences parents’ experience of informal support that was found in the interview study was the stress from the extended family in Taiwan. As Chinese families value the interdependence and relationships with extended family members, it is possible that the feeling of stigma toward disability might influence the extended families more strongly than the Western families. Some Taiwanese parents described that they faced stress from their extended family questioning their parenting and medical decisions during the interview. This is supported by other research, where Chinese mothers as caregivers felt extra stress from the extended family (Chang &
Hsu, 2007; Lin & Chung, 2002) and felt they were usually the one to be blamed and responsible for their children’s disability (Holroyd, 2003). The family bond and involvement made Taiwanese parents concerned about approaching their extended families for informal support. In contrast to that, the UK families are more independent and able to make decisions with less interference from their extended families. However, extended families in both Taiwan and the UK were still very helpful for providing child minding when those parents needed a hand. This finding is also consistent with both Chinese (Lin, et al., 2008) and Western research (Luther, et al., 2005).

Bringing the findings from the questionnaire and interview studies together, the UK families had a greater variety of support to choose from to fit their needs and situations. Parents from both countries emphasized the benefits of the formal and informal support for their TD children, but also acknowledged the need to respect TD siblings’ decision as to whether to attend activities or support groups. The concerns of Taiwanese families in approaching formal support might result from negative perceptions from society and the limited resources in certain geographical areas. This provided an important insight when providing support for the Taiwanese families. As Mak and Kwok (2010) suggested, not only is there a need to improve the accessibility of the social support system, but also to transcend such negative attitudes toward disability to help to provide better support to the Chinese families with children with ASD.

In summary, the combinations of Double ABCX and Diathesis-stress models were used to provide a solid framework when exploring the various variables that influenced TD siblings’ adjustment outcome. In the next section coping style is discussed in detail along with the comparison of Chinese and Western coping philosophy.
9.4 Coping

Coping was a key topic in this thesis. Since many factors cannot be changed (e.g. the BAP level and severity of ASD), identifying coping styles that linked with TD siblings adjustment can have important applications. In comparing the TD siblings’ coping between two countries in the questionnaire study, there were several similarities and differences. Firstly, the frequency of using the coping style in two countries was different. The Taiwanese siblings used more active and more negative coping than their UK counterparts, whereas UK siblings would prefer to use avoidant coping more. Most importantly, the UK siblings rated avoidant coping as the most effective coping style among the three coping styles, whereas TW siblings preferred active coping to the others. These questionnaire findings were supported by the interview findings. In the interviews, the UK siblings expressed the need to give way or to distract themselves in order to handle the situation, and these strategies are defined as avoidant coping. On the contrary, the Taiwanese siblings expressed, to some extent, feelings of unfairness and anger in dealing with challenging situations, and more evidence of using active and negative coping. Even though the Taiwanese siblings revealed that their parents had given them suggestions on how to cope with their ASD siblings, in some circumstances, this did not seem to make it any easier for them to accept.

As discussed in the previous section, with a better understanding of ASD, TD siblings would consider the possible stress loading on their parents and hence choose the avoidance as the coping style. The use of avoidant coping strategies was found to be relevant to individual stress or mental distress (Herman-Stabl, et al., 1995). This is consistent with the present findings, where TD siblings use of avoidant coping was linked with the higher adjustment difficulties according to their self-reports. It will be a concern in the long term that TD siblings in the UK continue to use this maladjusted coping.

Parents’ coping was also considered a factor when discussing what extent it impacted on sibling coping. Parents’ coping in Taiwan and in the UK shared some similarities
according to the questionnaire study. That is, parents from both countries used problem-focused coping as the main coping style. There was also a trend of changes over time in coping style revealed in the interview data. After the early stage of receiving the diagnosis, parents from both countries would focus more on looking for resources and help to deal with the problems regarding their ASD children. After their ASD children have settled down and they are more capable to cope with the situation, parents would shift from problem-focused coping to emotional approach coping or self-development. Such changes in the parents’ coping patterns has also been found in longitudinal qualitative research (Gray, 2002, 2006). As for previous quantitative research, only two studies which compared different age groups were identified. While one found changes in the parents’ coping among toddlers and adolescents (Smith, et al., 2008), Hastings and colleagues (2005) did not find differences in coping between parents of preschool and school-age children.

The Taiwanese parents also used different types of copying more frequently than their UK counterparts according to the questionnaire result. This is supported by other research which showed that Chinese parents used different coping style simultaneously to deal with stress (Mak & Ho, 2007). In many cases, using one coping style is not usually efficient enough; therefore, a variety of strategies seems to be necessary. Without looking specifically at the relationship between parental coping and its efficacy, it is too early to draw any conclusion here. However, combining the impression from the questionnaire and the interview data, it is speculated that the higher frequency of using the coping styles could reflect that the Taiwanese parents faced a greater variety of stressors (i.e. financial status and others providing help with child care) (see Section 5.2), and so perhaps had to use a variety of different coping strategies to deal with these different situations.

The link between parents’ and siblings’ coping was only found in the UK families and not in the Taiwanese families in the questionnaire study. Similarly, in the interview study, relatively few Taiwanese parents mentioned teaching or modelling the coping style for their TD children. In contrast, some parents in the UK
acknowledged that they tried to model coping styles for their children, although there was no evidence found of a link between parents’ and siblings’ coping style. According to the interview data, families in the UK spent more time together as a family. This might provide the chance for parents to model their coping and interact with their children.

However, at the present stage, the benefit of this is still not clear since UK siblings did use more avoidance coping than the Taiwanese siblings and also showed higher adjustment difficulties according to siblings’ self-report. As reviewed in Section 3.4.1, coping is not a static but a dynamic process, and it changes with different life stages. As reported in Orsmond, et al. (2009), there were differences found in terms of using social support and coping strategies between adolescent and adult siblings. This could be further supported if future studies were to follow up children from the present research in a longitudinal study to discuss the changes in coping style and the possible influences on this.

Another issue when explaining the present research results was the construct differences between the situational (Kidcope) and dispositional (COPE) measures of coping used. As a result of the interviews, parents’ coping aimed to solve the family situation as a whole, while TD siblings might focus on the interaction with their ASD siblings. The wording used in the Kidcope questionnaire mainly encouraged TD siblings to respond according to the kind of coping strategies they used when encountering stressful situations with their ASD siblings. The type of coping gathered by using Kidcope might be influenced by situational variables at the time of measurement (Spirito, et al., 1988). Hence, it might not be as stable as the measure of parents’ coping with their lives in general. Hence, the lack of the significant relations between parents’ and TD siblings’ coping in the present questionnaire study could be further explained by the use of more conceptually similar coping measures in future research.

The conceptual research model used in the present research also suggested that coping might serve as a mediator. Coping, perhaps in conjunction with social support
might mediate the relationship between stressors (e.g. life experience and severity of child with ASD) and TD siblings’ adjustment outcome. This has been suggested or supported in several other psychological research studies (Hastings, 2002; Patterson, 1988; Runtz & Schallow, 1997), and could be tested using the present dataset in future.

9.5 Implications for clinical and educational practice

The importance of the present research was in the use of the combination of the Double ABCX model and a model of epigenetic vulnerability of family members to explore TD siblings’ adjustment outcome. The use of Double ABCX model was partially supported. Some direct or indirect influences of TD siblings’ BAP level on their adjustment outcome were evidenced in the present Taiwanese and UK samples, again providing support for epigenetic vulnerability in the model. More importantly, the studies reported in this thesis are the first to explore these issues in Taiwanese families.

Crucially, a number of findings from this research highlight the importance of parents and health professionals being aware of cultural differences when they work with siblings and families. For example, one novel finding related to cross-cultural differences in coping, particularly because both Chinese and Western measures of coping were used in this study: both Taiwanese parents and their TD children shared a similar pattern of using (or being aware of using) a greater variety of coping strategies more often than their UK counterparts. This might depict cultural specific coping characteristics. The importance of considering culture factors when exploring coping strategies was therefore emphasized and supported in the present research.

A further important discovery, with implications for practice, was that not all findings seemed to fit with the stereotype of Chinese behaviour and coping. For example, prosocial coping, which was assumed to fit with Chinese philosophy was not as common as expected in the Taiwanese families. The stress or stigma of raising a child with ASD might have decreased parents’ willingness to use prosocial coping
in the present Taiwanese data. Taiwanese siblings also showed less prosocial behaviour compared to their UK counterparts, again counter to expectations. It is argued that this may be because the concepts of prosocial behaviour in the Western-developed SDQ were viewed in a more multidimensional manner in Chinese culture.

Furthermore, a relationship between parents’ well-adjusted coping style and TD children’s poorer coping and adjustment was found in the UK families in the present study. In previous research, the majority of the findings suggest that well-adjusted coping strategies benefited the parents’ outcome, while relatively little research focuses on the influence of such coping strategies on child coping and adjustment, and vice versa. The important finding from this relationship is that parents’ and TD children’s coping could influence each other, either in a positive or a negative way. The present research emphasises the importance of parents being aware of TD siblings’ feelings and ways of coping.

Findings also have implications for how professionals might best support parents and siblings in different countries. For example, the regression analysis suggests that whilst promoting active coping might be effective for prosocial behaviour for TD siblings in Taiwan, it may be more important to work with UK siblings to move away from negative coping, in order to decrease adjustment problems. In the discussion of Section 7.4.2, the possible explanation and the reasons for this has been explored. However, what could be suggested for now is what can be consider as adaptive coping strategies for children in one culture may not be so in other cultures.

Furthermore, the open communication between parents and TD siblings is also addressed. The findings from the present research also suggested that parents might need to be supported to be aware of the coping strategies their TD children adopt in dealing with situations, as these sometimes might be performed in a subtle way, such as the negative coping found in the UK data. Siblings could understand why parents used certain types of coping strategies, and also learnt from their parents’ modelling to expand their variety of coping strategies. When adopting certain coping styles, parents should acknowledge their influence on their TD children and consider their
feelings. In addition, health practitioners need to take interrelationship between the families with an ASD child and others into account while helping the Taiwanese families to develop an adjusted coping style.

Both the Taiwan and UK findings showed the importance of social support for TD siblings’ adjustment. If TD siblings have access to support at school, whether through teachers or peers, adjustment outcomes might improve. Since TD siblings spend quite a long time in school, the relationships with their peers and teachers are crucial to them. If health professionals in school can promote support to the TD siblings, it could decrease the possible adverse adjustment outcome.

Adapting the support according to different cultural contexts is vital (Kim, Sherman, & Taylor, 2008; Taylor et al., 2004). As the findings from this study have implied, the social support system in Taiwan, especially formal support, still needs to be further developed to fit its social context. There is no value in offering additional social support if societal factors mean that people will be reluctant to access that support. Therefore in Taiwan, a cultural change in the perceptions of people with disability is clearly needed. This could perhaps be done in a similar manner to UK anti-stigma campaigns19 aimed to reduce prejudice and discrimination towards mental health conditions. Positive attitudes have increased following such campaigns (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014).

The attitude towards the disclosure of having children with ASD and how they explain ASD to their TD children are important areas that need further work (Harris & Glasberg, 2003). Since the Taiwanese siblings were shown from the questionnaire study to benefit from acceptance and support from peers, encouraging parents to support their children in explaining ASD to their peers may be beneficial. Schools in Taiwan could develop better support systems for the siblings; especially since Taiwanese TD siblings highlighted the importance of support from their peers and

19 http://www.time-to-change.org.uk/
teachers. Schools could also introduce information about disabilities, including ASD, to pupils to decrease the stigma of the disability.

As for the UK families, it is more important to give TD siblings opportunities to talk about their worries and problems with their parents. Parents and teachers need to be aware that the TD siblings’ distress might be displayed in a more subtle fashion and not easy to recognise.

Establishing a siblings’ support system may have long-term benefits (Conway & Meyer, 2008; Tsao, et al., 2012). With the UK parents emphasising the advantages of participating in different types of activities for their TD children, the accessibility of the related support information is important. As for the type of the support provided, it could vary from leisure activities or information on ASD or coping strategies. The support provided for the TD siblings needs to be gradual and tailored to the individuals’ age and preference, since some of the TD siblings have different attitudes and responses toward receiving support from others. Based on the findings above, it is speculated that using the internet and other social media may be a good and flexible way for TD siblings to decide when to approach the support they prefer. The Sibs website (http://www.sibs.org.uk/) provides a good example of using the internet to deliver support tailored for different age groups of siblings. Through the experience learned from the UK, it will be a practical and useful approach for Taiwan to set up a similar anonymous communication and interaction platform for siblings of children with special needs.

Furthermore, there is a need to consider the influence of BAP level when providing support to the families. The present and previous research all found the influence of BAP level on various domains in families of children with ASD (Bailey, et al., 1998; Bolton, et al., 1994; Mohammadi & Zarafshan, 2014; Petalas, et al., 2011; Sucksmith, et al., 2011). BAP level was also found to interact with stressors in the present UK data, if the TD siblings had a higher BAP level, they were more likely to experience difficulties than their peers. Health professional and educators should acknowledge how this vulnerability trait might influence TD siblings who are more sensitive to
stress and emotional distress. Professionals should also address how the social, cognitive, and behavioural patterns might be influenced by the BAP level.

9.6 Limitations and suggestions for future research

Limitations which may have been in operation across both studies are discussed in this section. Despite careful considerations when choosing suitable measurements and approaches to recruit participants, the present research has encountered some limitations. The participants in this research were all volunteers which might contribute to a certain degree of bias, with parents who were particularly concerned or less stressed about their TD children’s adjustment perhaps being more likely to agree to take part in the study. Parents from Taiwan might have had more positive attitudes to disability than some others who did not choose to participate in the research. This possible volunteer bias is difficult to examine or overcome, given the sensitive nature of the family research. As Hodapp, Glidden, and Kaiser (2005) have acknowledged this limitation in the research of family of children with ASD, and said that including a large sized sample from the various sources is the main way to address this issue. In the present research sample, more than half of the UK parents had a higher education degree and an above average level of annual income, which may also decrease the generality of the findings. This is in common with much research in this field (Rosenthal, Rosnow, & Kazdin, 2009). However, the present research did try to approach families from diverse geographical areas and through a variety of national organizations and schools. In relation to the interviews, the present research did recruit participants from diverse geographical areas in the UK and Taiwan.

It is also important to note that there were slightly different approaches in recruiting participants in Taiwan and the UK, and again, although unavoidable due to limited support systems and organisations in Taiwan, this may have had some impact on findings. Around a quarter of the Taiwanese families were recruited through hospitals and private clinics, whereas UK families were from various support groups and organizations. These subgroups of participants may share certain characteristics,
for example, the need to use medical services or that the use of medication for their ASD children regularly. However, this research still tried to gather the information of the severity of children with ASD by using the SRS questionnaires to decrease the possible sample bias.

Furthermore, there were several analyses conducted in the present research. Despite the reasonable size of participants recruited in Taiwan and the UK, the present research did not reach the ideal number suggested by the statistics literatures. However, correction methods were used to decrease the chances of type I errors. To further improve the analysis the use of Structural Equation Modelling (SEM) is suggested for future research. By using SEM, the directional and nondirectional linear relationships among a set of variables can be tested along with examining whether the measured constructs fit the research model (Maccallum & Austin, 2000; Weston & Gore, 2006).

Past research mainly used parents’ reports for evaluating TD siblings outcomes while the present research has explored both parents’ and siblings’ points of views in order to provide a different perspective on their experiences. There was a greater gap between the UK parents’ evaluation and the TD siblings’ than was the case with their Taiwanese counterparts. Interview findings implied that such discrepancies may have been because the TD siblings were quite mature, and understood the family circumstances well, and so would keep the stress to themselves sometimes. Hence, when evaluating the adjustment of the TD siblings, in a clinical or educational setting, it is also crucial to gather the information from different informants and siblings themselves as well (Giallo, Gavidia-Payne, Minett, & Kapoor, 2012; Verte, et al., 2003). This could be extended in future research by gathering the views of teachers as well as both parents, where present, and by using measures from all three groups within analysis exploring predictors of outcome. To further explore whether specific domains of adjustment outcome are influenced by certain variables more than others, it may be of interest to further examine predictors of sub-scales scores of the SDQ in future studies.
In order to avoid potential confounding factors that might be involved in the use of various national background samples, immigrant families in the UK and Taiwan were excluded from the present research. It is understood that this research has its limitations as there are diverse immigrant communities in the UK and, to a lesser extent, in Taiwan, and future research is needed to investigate the experiences of the immigrant families. Another issue was that despite the fact that the present research did not limit which parents participated, the majority of parents in the questionnaire study, and all of the parents in the interview study were mothers. Previous research has found that there are some differences in terms of coping (Hastings, et al., 2005; Kaniel & Siman-Tov, 2011; Pisula & Kossakowska, 2010) and in viewing their TD children’s adjustment (Griffith, Hastings, & Petalas, 2014) between mothers and fathers of children with ASD. As reviewed in the Section 2.1, Chinese fathers have more of a financial role whereas mothers are responsible for the children’s education. It is also expected that Chinese fathers would have a different perspective compared to their Western counterparts. Future research should seek to include more fathers’ participation.

There were some significant relations found in both Taiwanese and the UK models, such as the link between siblings’ coping, stressors and social support. Future research could replicate the design of the present research and increase the number of participants to see whether the evidence could be replicated. The present interview data was suggestive of differences in parenting style between the two cultures. As discussed in Section 2.2, such future research could also include parenting measures in addition to measures of TD siblings’ adjustment, since parenting style of children with disability has found to be different to parents of children without disability or control counterparts (Gau, Chiu, Soong, & Lee, 2008; Rutgers et al., 2007). Considering how parenting style impacts on the parent-child relationship, and the way parents viewed their children’s behaviours, it would be useful if future research could include this measurement construct. Such a measure would allow exploration of how the parenting style is determining children’s adjustment outcome.
In the present interview study, the importance of cognitive appraisal in coping was also highlighted. Further research could target on how TD siblings appraise the situation and its relation with coping. Other researchers have demonstrated parents’ appraisal in terms of coping (Tunali & Power, 2002; Twoy, et al., 2007), however, less has focused on TD siblings.

Furthermore, it will be highly valuable if a longitudinal research study is conducted in the future to investigate TD siblings’ adjustment through different stages of their life, especially when they get into their adulthood (Gray, 2002; Hastings, 2007; Orsmond & Seltzer, 2007b). Of particular interest is the extent to which the variables measured in the present study influence adjustment, and whether this pattern of influence changes as siblings age.

Despite these potential limitations, this research can still help parents, teachers and other professionals to be aware of the potential challenges that siblings of children with ASD face, especially those with unidentified emotional disturbance. Without the participation of the TD siblings, it would be impossible to have a better understanding of how to provide a better quality of support to the families with children with ASD.

9.7 Conclusions
This thesis set out with the intention of exploring and discussing the similarities and differences in TD siblings’ adjustment in Taiwan and the UK. Through the questionnaire study and selected followed up interview data, it has provided a picture of how variables operate in culturally-similar and culturally-specific ways to predict TD siblings’ adjustment and the adoption of different coping styles in the two countries. The quantitative and qualitative data also highlighted similarities and differences in the perspectives of the parents and the TD siblings in the two cultures. With the key findings from the two studies drawn together in this chapter, this research has provided several key clinical and policy applications.
Future research could continue to use and develop culturally sensitive measurements, such as a Chinese specific measure of child coping, as it is clear from the present study that understanding cultural differences in perceptions of adjustment and coping is vital if we are to support siblings effectively. Future research that evaluates TD siblings’ adjustment, gathering and analysing the self-report from the siblings’ is also highly recommended. Through some significant interrelations between variables, and other relations requiring further exploration, this research has provided an outlook for future research.

Despite its limitations, this study is one of only a few to explore the TD siblings’ adjustment by using both parents and children self-report and in both Chinese and Western culture settings, and thus makes a meaningful contribution to the literature on families of individuals with ASD. This study has demonstrated both the positive and negative impact of having a brother or sister with ASD for the TD siblings. Siblings in both countries did show a high satisfaction with their life, despite some challenges, although the continuing development of appropriate support remains vital. Factors that were identified in the present studies as contributing to TD siblings’ adjustment outcome are potentially important for health and educational professionals working with families of children with ASD in the two cultural contexts.
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Appendix A

Parents and TD siblings’ Questionnaires
Information and Questionnaires for Parents and Guardians

Dear [Name],

Thank you so much for taking the time to assist with this project. I realise that you must already have many demands on your time, so your help is very much appreciated.

There are two questionnaires enclosed, one for you and another for your child. There are 8 questionnaires for you and 5 for your child. They come with full instructions, but if your child has any queries I have given them my phone number so that they can (with your permission) give me a call. If you could help to ensure that your child fills in their pack as independently as possible I would be very grateful, as it is important that they too feel free to be utterly honest with their opinions.

Before you complete each questionnaire please read over the instructions. Note that some questionnaires are to be completed about your child with autism and some about their typically developing sibling. Questionnaire responses will be considered completely confidential. Some questions ask for personal information (e.g. your ethnic background). This is because there are a number of groups of families participating in the research, and it is important to see whether the groups are similar or not. If, though, there are any questions you would prefer not to answer, just leave them blank. Equally, feel free to be utterly honest in giving your opinions.

After you and your child finish all the questionnaires, please put them into the freepost envelope and post them back. Feel free to contact me [joy.tuk@ed.ac.uk or 07413859760] if you have any queries, either about you or your child's questionnaire pack or about the research in general.

With best wishes,

Joy Tsai

Institute for Education, Community & Society (IES) 1.14 St. John's Land, Merchiston Campus, University of Edinburgh, Holyrood Road, Edinburgh, EH8 9AQ. E-mail: tuk@ed.ac.uk. Telephone: 07413859760.
About the questionnaire in your research pack

This is a bit of information about the questionnaire in your pack, and why they're being used for the study.

Number 1: About Your Child and Family

This is a series of questions asking about your child and their family. We have included these questions to gain some understanding of the context in which your child is living, to help us understand the experience of the whole family. There may be times when we ask you to provide answers that relate to your child and your family.

Number 2: About Your Child with Autism: Social Rejection Questionnaire (SRQ)

The SRQ is a standardised test designed to assess social rejection in children with autism. This is a short test that can be used in the classroom. It is important that you know your child's social skills level in order to complete this test.

Number 3: About you: Autism Spectrum Questionnaire (AUQ: Adult Form)

The AUQ is a standardised test designed to assess the adult's social functioning. It is important that you understand your child's social skills level in order to complete this test.

Number 4: About your child: Autism Spectrum Questionnaire (ASQ: Child Form)

The ASQ is a standardised test designed to assess your child's social functioning. It is important that you understand your child's social skills level in order to complete this test.

Number 5: About your child: Children's Coping Strategies Questionnaire (CCSQ)

The CCSQ is a standardised test designed to assess your child's coping strategies. It is important that you understand your child's coping strategies in order to complete this test.

Number 6: About your child: Children's Coping Strategies Questionnaire (CCSQ: Adult Form)

The CCSQ is a standardised test designed to assess your child's coping strategies. It is important that you understand your child's coping strategies in order to complete this test.

Number 7: About your child: Children's Coping Strategies Questionnaire (CCSQ: Children's Form)

The CCSQ is a standardised test designed to assess your child's coping strategies. It is important that you understand your child's coping strategies in order to complete this test.

Number 8: About your child: Children's Coping Strategies Questionnaire (CCSQ: Teachers Form)

The CCSQ is a standardised test designed to assess your child's coping strategies. It is important that you understand your child's coping strategies in order to complete this test.

If you have any questions about the questionnaire, please don't hesitate to contact us at info@uk-survey.co.uk. Alternatively, if you wish to have a discussion with a different person, you can reach us at info@uk-survey.co.uk. There is also more information on the study website: www.uk-survey.co.uk/about.
Now that you have read the information sheet, and understand the information about the research, it is up to you to decide whether you want to take part in the study. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive. If you wish to take part in the study or future studies, please complete the consent form. Thank you!

Please Tick

1. I have read and understood the TUKS information sheet
2. I understand that I can withdraw my family from the study at any time
3. I understand that data will be anonymously coded and stored confidentially and securely
4. I am willing to take part in the TUKS questionnaire study
5. I consent to be approached about future research projects
6. I would prefer not to take part in the questionnaire study
7. I would like to discuss this further with you before deciding about taking part

Parent/Guardian’s Name ..................................................
Signature ........................................... Date ..............................
Relationship to child with ASD & sibling ..............................
Contact telephone number ................................................
Preferred time (if any) for contacting you ............................

Number 1: About Your Child and Family
* - All information you provide will be confidential

1. Please tell me about your child who has a diagnosis on the autistic spectrum
* - If you have more than one child who has autistic spectrum diagnosis, please write about the one whose age is closest to the participating sibling
Date of Birth ............................. Gender: M / F Living at home: Y / N

2. Child’s diagnosis:
Autism □
Asperger syndrome □
Other □ Please specify: ..............................................................
Not yet confirmed □

3. Does your child have intellectual disabilities in addition to their diagnosis on the autistic spectrum?
No □
Yes □ Please specify level (e.g. mild, moderate) if known: ...................
Unconfirmed □

4. Does your child have any other diagnosis in addition to their diagnosis on the autistic spectrum?
No □
Yes □ Please specify, if known: ..................................................
Unconfirmed □

5. Does your child with autism currently attend preschool/school?
Attend: Special Education School □ Mainstream School □ Combination □
Does not attend □
Other □ Please specify: ..............................................................
6. Please tell me about all other children in your family:

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Living at home?</th>
<th>Special educational needs? (if you please specify)</th>
<th>Sibling relationship to child with autism *</th>
</tr>
</thead>
<tbody>
<tr>
<td>M/F</td>
<td>Y/N</td>
<td></td>
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<tr>
<td>M/F</td>
<td>Y/N</td>
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<td>M/F</td>
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<tr>
<td>M/F</td>
<td>Y/N</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

* : please indicate whether full sibling, step-sibling, half-sibling or other relationship.

7. Are there any other adults who either live with you or provide unpaid childcare (more than one day per week) e.g. grandparents?
   No ☐
   Yes ☐ please specify how many and the relationship to the child with autism
   ............................................................

8. Please tick the box of your current status:
   Single ☐ Living with spouse/partner ☐
   Other ☐ please specify ........................................

9. Please tick the box of your final educational qualification
   Primary School or less ☐
   Partial Secondary/High School ☐ left at ______
   Secondary/High School graduation ☐
   Partial College (at least one year) or specialized training ☐
   Standard college/University graduation ☐
   Postgraduate Degree or beyond ☐
   Other (please specify) ........................................

10. Please indicate whether you are employed
    Full-time ☐ Part-time ☐ Please indicate job title .........................
    Student ☐ Retired ☐ Not currently employed ☐

   If applicable, please tick the box below which is closest to your current/last job description
   professionals: e.g. doctors, lawyers, teachers, managers ☐
   non-manual skilled: e.g. typist, police officer, fireman ☐
   manual skilled: e.g. toolmaker, fitter, ambulance man ☐
   partly skilled: e.g. bus conductor, postman ☐
   unskilled: e.g. cleaner, porter, messenger ☐
   chronically unemployed for the majority of adult life ☐
   homemaker who has not worked for majority of adult life ☐
   self-employment ☐
   still in full time education ☐
   not known ☐

11. After tax your annual household income is around
    Which of the phrases best describes how you are managing financially these days?
    Manage very well ☐ Manage quite well ☐ Get by alright ☐
    Don't manage very well ☐ Have some financial difficulties ☐ Are in deep financial trouble ☐

12. What do you consider to be your nationality/ethnicity? (e.g. Scottish/British....)

13. What is/was your parents' nationality/ethnicity?

14. Have you ever lived in another country more than 5 years?
    No ☐
    Yes ☐ Please indicate the country and how long you lived there.........................
**Number 2: About your child with Autism**

(SRS)

The Social Responsiveness Scale (SRS) is a highly standardised test designed for screening and assessment for autistic disorder and behavioural problems.

Please complete Questions 1 to 65. Thank you!

---

**Number 3: About you (AQ)**

**How to fill out the questionnaire**

Below are a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer.

**PLEASE DO NOT MISS ANY STATEMENT OUT.**

**Examples**

<table>
<thead>
<tr>
<th></th>
<th>Definitely Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Definitely Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1. I am willing to take risks.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 (circled)</td>
</tr>
<tr>
<td>E2. I like playing board games.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 (circled)</td>
</tr>
<tr>
<td>E3. I find learning to play musical instruments easy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>E4. I am fascinated by other cultures.</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Please turn to the next page and answer the questions. Thank you!
<table>
<thead>
<tr>
<th></th>
<th>Definitely Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Definitely Disagree</th>
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<tbody>
<tr>
<td>1.</td>
<td>1</td>
<td>2</td>
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<td>2.</td>
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<td>9.</td>
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<td>10.</td>
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<td>11.</td>
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<td>17.</td>
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<td>33.</td>
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<td>34.</td>
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<td>35.</td>
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<td>Number 4: About you (COPE)</td>
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</table>

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress. Then respond to each of the following items by circling one number, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true for you as you can.

Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU—not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1 = I usually don't do this at all  
2 = I usually do this a little bit  
3 = I usually do this a medium amount  
4 = I usually do this a lot

Examples

<table>
<thead>
<tr>
<th>Item</th>
<th>Definitely Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Definitely Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>36. I find it easy to work out what someone is thinking or feeling just by looking at their face.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. If there is an interruption, I can switch back to what I was doing very quickly.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. I am good at social chat.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. People often tell me that I keep going on and on about the same thing.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. When I was young, I used to enjoy playing games involving pretending with other children.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. I like to collect information about categories of things (e.g., types of car, types of bird, types of train, types of plant, etc.)</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. I find it difficult to imagine what it would be like to be someone else.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. I like to plan any activities I participate in carefully.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44. I enjoy social occasions.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45. I find it difficult to work out people's intentions.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46. New situations make me anxious.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>47. I enjoy meeting new people.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>48. I am a good diplomat.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>49. I am not very good at remembering people's dates of birth.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50. I find it very easy to play games with children that involve pretending.</td>
<td>1   2   3   4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please turn to the next page and answer the questions. Thank you!
<table>
<thead>
<tr>
<th></th>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I try to grow as a person as a result of the experience.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2.</td>
<td>I learn to work or other substitute activities to take my mind off things.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3.</td>
<td>I get upset and let my emotions out.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4.</td>
<td>I try to get advice from someone about what to do.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5.</td>
<td>I concentrate my efforts on doing something about it.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6.</td>
<td>I say to myself “this isn’t real.”</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7.</td>
<td>I put my trust in God.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8.</td>
<td>I laugh about the situation.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9.</td>
<td>I admit to myself that I can’t handle the situation, and quit trying.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10.</td>
<td>I restrain myself from doing anything too quickly.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11.</td>
<td>I discuss my feelings with someone.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12.</td>
<td>I use alcohol or drugs to make myself feel better.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13.</td>
<td>I get used to the idea that it happened.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14.</td>
<td>I talk to someone in finding other ways to handle the situation.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15.</td>
<td>I keep myself from getting distracted by other thoughts or activities.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16.</td>
<td>I daydream about things other than this.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17.</td>
<td>I get upset, and am really aware of it.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18.</td>
<td>I ask God’s help.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19.</td>
<td>I make a plan of action.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20.</td>
<td>I make jokes about it.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21.</td>
<td>I accept that this has happened and that it can’t be changed.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22.</td>
<td>I hold off doing anything until the situation permits.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23.</td>
<td>I try to get emotional support from friends or relatives.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24.</td>
<td>I just give up trying to reach my goal.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25.</td>
<td>I take additional action to try to get rid of the problem.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26.</td>
<td>I try to lose myself for a while by drinking alcohol or taking drugs.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27.</td>
<td>I refuse to believe that it has happened.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28.</td>
<td>I let my feelings out.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29.</td>
<td>I try to see it in a different light, to make it seem more positive.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30.</td>
<td>I talk to someone who could do something concrete about the problem.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31.</td>
<td>I sleep more than usual.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32.</td>
<td>I try to come up with a strategy about what to do.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33.</td>
<td>I focus on dealing with the problem, and if necessary let other things slide a little.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
### Number 5: About you (Coping)

Again, please think about how often you have used the following coping methods when encountering stressful events by circling one number.

<table>
<thead>
<tr>
<th>Method</th>
<th>Always occur</th>
<th>Rarely occur</th>
<th>Somewhat often</th>
<th>Occasionally</th>
<th>Almost never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Change the goal - maybe there will be better developments in different fields.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Losing is winning - thinking about better things makes it easier to accept.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Take a controlling attitude.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Search for relevant knowledge or information.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Lower my expectations and needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Find the problem and try to resolve it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Engage in stimulating behavior (such as racing cars and drinking) to numb myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Seek assistance or help from others in action.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Leave displeasing environments or interpersonal relationships.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Trust my own intuition rather than my thoughts in dealing with things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Use non-cooperation to express my opinions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Devote more effort to achieve my goals.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Share my responsibilities with relevant people and face problems together.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Specifically accommodate the other person and privately ignore the matter as much as possible.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Do things according to my own determination, because I am the one who is most concerned about myself, and I want to improve my condition the most.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Fully rest to recuperate my energy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Do other things to divert attention.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Be more realistic that there are more options; it would be nice if I did not think so much about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Think about people who have more difficulties than me, so that I can better accept my situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

20. Use exercise to adjust my body and mind.                            | 2            | 3            | 4              | 5            |
21. Consider feasible methods and their efficacy, and then choose the most appropriate method. | 2            | 3            | 4              | 5            |
22. Work hard to solve problems with friends or family.                 | 2            | 3            | 4              | 5            |
23. See it as training in BC - it will be fine if it is over.            | 2            | 3            | 4              | 5            |
24. Consider the position of the other person, and then make some adjustments about my perspectives or behavior. | 2            | 3            | 4              | 5            |
25. Resist unreasonable requests.                                       | 2            | 3            | 4              | 5            |
26. Convince others that it is also very important to them to achieve the goal. | 2            | 3            | 4              | 5            |
27. Fight back so the other knows I am not weak.                        | 2            | 3            | 4              | 5            |
28. Decrease terms with the other side and use the smallest cost possible to exchange for the greatest benefit. | 2            | 3            | 4              | 5            |
29. Set goals and plan how to complete them.                            | 2            | 3            | 4              | 5            |
30. Share and analyze experiences of those who have encountered the same stress. | 2            | 3            | 4              | 5            |
31. Just do my own work and ignore the work of others.                  | 2            | 3            | 4              | 5            |
32. Endure it for a while, and then let it go.                          | 2            | 3            | 4              | 5            |
33. Wait and see - make further decisions based on how things develop.  | 2            | 3            | 4              | 5            |
34. Act according to existing social norms.                             | 2            | 3            | 4              | 5            |
35. Keep persevering, because things may still change.                  | 2            | 3            | 4              | 5            |
36. Clarify the division of responsibilities.                           | 2            | 3            | 4              | 5            |
37. Change my mind to accommodate other people or the environment.      | 2            | 3            | 4              | 5            |
38. Meditate or listen to music to relieve stress.                      | 2            | 3            | 4              | 5            |
39. Obey in public and disobey in private, as long as it is not discovered. | 2            | 3            | 4              | 5            |
40. Follow the requests or guidance of parents, teachers, or instructors to resolve problems. | 2            | 3            | 4              | 5            |
41. Try to think about what I can learn from this difficult situation.   | 2            | 3            | 4              | 5            |
42. The event has already happened and can only be accepted.            | 2            | 3            | 4              | 5            |
43. Act to make others feel at a disadvantage.                          | 2            | 3            | 4              | 5            |
<table>
<thead>
<tr>
<th></th>
<th>Almost never</th>
<th>Rarely</th>
<th>Somewhat</th>
<th>Often</th>
<th>Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>44.</td>
<td>Use the experiences of others to encourage myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>45.</td>
<td>Leave others to avoid experiencing more stress.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>46.</td>
<td>It is right to listen to the helpful opinions of others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>47.</td>
<td>Refuse others to place one's own advantage.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>48.</td>
<td>Explain my views to the other side and understand their views.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>49.</td>
<td>Adjust the goal based on current resources.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>50.</td>
<td>In order to step forward, step back first so that the other side will also partially compromise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>51.</td>
<td>Adjust my ideas or behaviors - after all it is easier to change myself than to change others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>52.</td>
<td>Seek the opinions or assistance of professionals.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>53.</td>
<td>Use the resources under my control so that others will give up on their profits or opinions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>54.</td>
<td>Do superficial work so as to middle through.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>55.</td>
<td>Marshal the opinions and efforts of relevant people to face problems together.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>56.</td>
<td>Work hard to seek my power or profit, even if it harms relevant people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>57.</td>
<td>Divide a problem into smaller parts, and deal with small parts one at a time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>58.</td>
<td>Resist being influenced by others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>59.</td>
<td>Deal with problems with the principle of not harming mutual feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>60.</td>
<td>Give the responsibility to others so that they can worry about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>61.</td>
<td>Opposing sides are always full of tricks, so I can deceive the other side to avoid harm or gain what I want.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>62.</td>
<td>Let the problem disappear and ignore it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>63.</td>
<td>Try to use a more positive and proactive attitude to face problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>64.</td>
<td>Stay back and refuse to fight with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>65.</td>
<td>Think clearly about what I really want, and rank the items by priority.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>66.</td>
<td>Everyone has their own difficulties, and thinking from the perspective of others brings empathy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Number 6: About you (Satisfaction with Life)

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by circling the appropriate one number. Please be open and honest in your responding:

3 = Strongly Disagree
2 = Disagree
1 = Slightly Disagree
4 = Neither Agree or Disagree
5 = Slightly Agree
6 = Agree
7 = Strongly Agree

1. In most ways my life is close to my ideal. 1 2 3 4 5 6 7
2. The conditions of my life are excellent. 1 2 3 4 5 6 7
3. I am satisfied with life. 1 2 3 4 5 6 7
4. So far I have gotten the important things I want in life. 1 2 3 4 5 6 7
5. If I could live my life over, I would change almost nothing. 1 2 3 4 5 6 7

Number 7: About your child without Autism (AQ)

How to fill out the questionnaire

Please answer each of the following questions about your typically developing child by circling a number that reflects your answer to the question most appropriately. If there is any question that you feel not able to comment, please ask your son, daughter, partner or the person to answer.

PLEASE DO NOT MISS ANY STATEMENT OUT.

Examples

<table>
<thead>
<tr>
<th></th>
<th>Definitely Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Definitely Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. S/he is willing to take risks.</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>2. S/he likes playing board games.</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>3. S/he finds learning to play musical instruments easy.</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>4. S/he is fascinated by other cultures.</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>

Please turn to the next page and answer the questions. Thank you!
<table>
<thead>
<tr>
<th></th>
<th>Definitely Agree</th>
<th>Slightly Agree</th>
<th>Slightly Disagree</th>
<th>Definitely Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. She prefers to do things with others rather than on her own.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. She prefers to do things the same way over and over again.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. If she tries to imagine something, she finds it very easy to create a picture in her mind.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. She frequently gets so strongly absorbed in one thing that she loses sight of other things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. She often notices small sounds when others do not.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. She usually notices house numbers or similar strings of information.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. She has difficulty understanding rules for polite behaviour.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. When she is read a story, she can easily imagine what the characters might look like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. She is fascinated by dates.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. In a social group, she can easily keep track of several different people’s conversations.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. She finds social situations easy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. She tends to notice details that others do not.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. She would rather go to a library than a birthday party.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. She finds making up stories easy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. She is drawn more strongly to people than to things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. She tends to have very strong interests, which she gets upset about if she can’t pursue.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. She enjoys social chit-chat.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. When she talks, it isn’t always easy for others to get a word in edgeways.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. She is fascinated by numbers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. When she is read a story, she finds it difficult to work out the characters’ intentions or feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. She doesn’t particularly enjoy fictional stories.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. She finds it hard to make new friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. She notices patterns in things all the time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. She would rather go to the cinema than a museum.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. It does not upset him/her if his/her daily routine is disturbed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. She doesn’t know how to keep a conversation going with her/his peers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. She finds it easy to “read between the lines” when someone is talking to her/him.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. She usually concentrates more on the whole picture, rather than the small details.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29. She is not very good at remembering phone numbers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30. She doesn’t usually notice small changes in a situation, or a person’s appearance.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>31. She knows how to tell if someone listening to her is getting bored.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32. She finds it easy to go back and forth between different activities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33. When she talks on the phone, she is not sure when it’s her turn to speak.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. She enjoys doing things spontaneously.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. She is often the last to understand the point of a joke.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Statement</td>
<td>Definitely Agree</td>
<td>Slightly Agree</td>
<td>Slightly Disagree</td>
<td>Definitely Disagree</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>------------------</td>
<td>----------------</td>
<td>-------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>36. She finds it easy to work out what someone is thinking or feeling just by looking at their face.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>37. If there is an interruption, she can switch back to what she was doing very quickly.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>38. She is good at social chit-chat.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>39. People often tell her/him that she keeps going on and on about the same thing.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>40. When she was in preschool, she used to enjoy playing games involving pretending with other children.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>41. She likes to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>42. She finds it difficult to imagine what it would be like to be someone else.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>43. She likes to plan any activities she participates in carefully.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44. She enjoys social occasions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>45. She finds it difficult to work out people's intentions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>46. New situations make her/me more anxious.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>47. She enjoys meeting new people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>48. She is good at taking care not to hurt other people's feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>49. She is not very good at remembering people's date of birth.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>50. She finds it very easy to play games with children that involve pretending.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Number 8: About your child without Autism**

(Strengths and Difficulties Questionnaire)

For each item, please circle the box for Not True, Somewhat True or Certainly True that you think best describes your typically developing child. It would help us if you answered all items as best you can even if you are not absolutely certain or if the item seems difficult. Please give your answers on the basis of the child's behavior over the last six months.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Considerate of other people's feelings</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2.</td>
<td>Restless, overactive, cannot stay still long</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3.</td>
<td>Often complains of headaches, stomach aches or sadness</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4.</td>
<td>Shares readily with other children (tramps, toys, pencils, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5.</td>
<td>Often has temper tantrums or hot tempers</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6.</td>
<td>Rather solitary, tends to play alone</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7.</td>
<td>Generally obedient, usually does what adults request</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8.</td>
<td>Many worries, often seems worried</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9.</td>
<td>Helpful if someone is hurt, upset or feeling ill</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10.</td>
<td>Constantly fidgeting or overwring</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11.</td>
<td>Has at least one good friend</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12.</td>
<td>Often fights with other children or bullies them</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13.</td>
<td>Often unhappy, down-hearted or tearful</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14.</td>
<td>Generally likes by other children</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15.</td>
<td>Easily distracted, concentration wanders</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16.</td>
<td>Nervous or fidgety in new situations, easily loses confidence</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17.</td>
<td>Kind to younger children</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18.</td>
<td>Often likes to be alone</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19.</td>
<td>Prefers to be left alone or bullied by others</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20.</td>
<td>Often volunteers to help other children (parents, teachers, other children)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21.</td>
<td>Thinks things out before acting</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22.</td>
<td>Stays from home, school or elsewhere</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23.</td>
<td>Gets on better with adults than with other children</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24.</td>
<td>Many fears, easily scared</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25.</td>
<td>Sees tasks through to the end, good attention span</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behavior or being able to get on with other people?

<table>
<thead>
<tr>
<th>No</th>
<th>Yes: Minor Difficulties</th>
<th>Yes: Definite Difficulties</th>
<th>Yes: Severe Difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?
  - Less than
    - a month
  - 1-5 months
  - 6-12 months
  - Over a year

- Do the difficulties upset or distress your child?
  - Not at all
  - Only a little
  - Quite a lot
  - A great deal

- Do the difficulties interfere with your child's everyday life in the following areas?
  - HOME LIFE
  - FRIENDSHIPS
  - CLASSROOM LEARNING
  - LEISURE ACTIVITIES

- Do the difficulties put a burden on you or the family as a whole?
  - Not at all
  - Only a little
  - Quite a lot
  - A great deal

---

**Thank you!**

You have finished all the questionnaires. I am very grateful for your help and the information you have provided.

After your child has given you the completed questionnaire which will be in the sealed envelope, please put your questionnaire and the child’s into the pre-paid envelope and post both of them back to me.

I hope that this research can form a richer understanding of the feelings, needs, and experiences that are grounded in real life stories told by parents and siblings about growing up with a child with autism.

Thank you very much for your family participating in this research.

Best Regards and thanks!

From,

Joy Tsai
Information and Questionnaires for Siblings

Dear [Name],

Thank you very much for helping me out with this project! Please complete these 5 questionnaires (Don’t worry - you don’t have to do them all at once)

Before you fill in the questionnaires please read the instructions very carefully (each questionnaire is a little bit different). When you are filling them in remember that it is not a test - there are no right answers and no wrong answers. I just want you to let me know how you are really feeling. And no one knows that except you (no one apart from me will know what you’ve said). Please try and answer all the questions. If it is hard to make a choice, please try to find the one that is closest to your feeling. Try and find a place in the house where you can complete the questionnaires quietly on your own.

If you get stuck please just e-mail (tuka@ed.ac.uk) or phone me (Joy: 07428169400) and I’ll phone you back and help you out - but remember to ask permission from the person who looks after you before you phone.

Once you have completed all the questionnaires please put them in the envelope that comes with the package. Give it to your parents to post to me.

Thank you very much for helping me!

From,

Joy Tsai
**Consent Form for Siblings**

Now that you have read the information, and understand about the project, it is up to you to decide whether you want to take part in the study. You are free to stop at any time, without telling me why. If you want to share your experiences with me, please complete the form below. Thank you!

### To be completed by the sibling

<table>
<thead>
<tr>
<th>Please circled your answer (YES or NO)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I have read the information sheet about the research</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I have had a chance to think about it and to ask questions about the research</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I understand that I can change my mind at any time</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I understand that you won’t tell anyone my answers, unless something I say makes you worried that I am in danger</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I am happy to take part in the study</td>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>

Your Name ........................................

I am: Boy ☐  
Girl ☐    
My date of Birth (Birthday) is .................

Please sign your name here (Sibling's signature) ........................................
**Number 1: Child and Adolescent Survey of Experiences**

This questionnaire asks about events people may find bad or upsetting, as well as events people may find good or enjoyable.

If an event **DID** happen to you in the **LAST 12 MONTHS**, tick the box under the word "YES". You also need to tick a box to say HOW GOOD or HOW BAD the event was for you.

If the event **DID NOT** happen to you, tick the box under "NO" and just skip to the next question. If you make a mistake, just cross out your answer and tick the correct box.

You also can write down your own events on Item 39 and 40.

**Examples**

<table>
<thead>
<tr>
<th>Did that happen?</th>
<th>HOW GOOD or HOW BAD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>

In the last 12 months

<table>
<thead>
<tr>
<th></th>
<th>Did that happen?</th>
<th>HOW GOOD or HOW BAD</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. We moved house</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>42. My parent(s) started a new job</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

In the first example, the person describes "They moved house in the past 12 months" and this experience is "A little bad" for him.

In the second example the person describes his parents' "did not start a new job", so he ticks No and move on to the next question.

Please ask for help if you have a question or don't understand something. Please turn to the next page and answer the questions. Thank you!
<table>
<thead>
<tr>
<th>In the last 12 months</th>
<th>Did that happen?</th>
<th>HOW GOOD or HOW BAD?</th>
</tr>
</thead>
<tbody>
<tr>
<td>20.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had a big argument with someone special to me (who is NOT in your family)</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>21.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I made a new special friend</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>22.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I saw something bad happen (e.g., car accident, someone losing a loved one)</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>23.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I changed schools</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone in my family died</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>25.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People in my family had a big fight or argument (not including you)</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>26.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My exam got married, engaged or began seeing someone else</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>27.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone broke into my house</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>28.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone in my family left home</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>29.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was in a fight (not with people in my family)</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>30.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I did badly in an important test or exam</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>31.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone special to me died (who is NOT in your family)</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>32.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was chosen to be class monitor, prefect or school captain</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>33.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was seriously told off or punished by a teacher</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>34.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I took up a new hobby / sport / activity</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>35.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found out that I had to repeat a grade in school</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>36.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Someone special to me was really sick or injured (who is NOT in your family)</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>37.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My dad got married, engaged, or began seeing someone else</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
<tr>
<td>38.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I went on a special holiday (e.g., overseas, around the UK)</td>
<td>Yes/No</td>
<td>Rate: Good/Quite Good/Alright/Quite Bad/Really Bad</td>
</tr>
</tbody>
</table>

**Number 2:**

**Child and Adolescent Social Support Scale**

The next three pages, you will be asked to respond to sentences about some form of support or help that you might get from either a parent, a teacher, a close friend, or people in your school. Read each sentence carefully and respond to them honestly. There are no right or wrong answers.

For each sentence you are asked to provide two responses. First, rate how often you receive the support described and then rate how important the support is to you. Please answer the following questions by marking your responses. Below is an example. Please read it carefully before starting your own ratings.

**PLEASE DO NOT MISS ANY STATEMENT OUT.**

**Examples**

<table>
<thead>
<tr>
<th>Number</th>
<th>How Often?</th>
<th>Importance?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

In this example, the person describes his teacher helps me solve problems as something that happens "some of the time" and that is "important to her."

Please ask for help if you have a question or don't understand something. Do not skip any sentences. Please turn to the next page and answer the questions. Thank you!
<table>
<thead>
<tr>
<th>My Parent(s)</th>
<th>How Often?</th>
<th>Important?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>Almost Never</td>
</tr>
<tr>
<td>1. Show they are proud of me</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2. Understand me</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3. Listen to me when I need to talk</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4. Make suggestions when I don't know what to do</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5. Give me good advice</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6. Help me solve problems by giving me information</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7. Tell me I did a good job when I do something well</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8. Nicely tell me when I make mistakes</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9. Reward me when I've done something well</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10. Help me practice my activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11. Take time to help me decide things</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>12. Get me involved in the things I need</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My Classmates</th>
<th>How Often?</th>
<th>Important?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>Almost Never</td>
</tr>
<tr>
<td>25. Treat me nicely</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>26. Like most of my ideas and opinions</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>27. Pay attention to me</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>28. Give me ideas when I don't know what to do</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>29. Give me information so I can learn new things</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>30. Give me good advice</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>31. Tell me I did a good job when I've done something well</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>32. Nicely tell me when I make mistakes</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>33. Notice when I have worked hard</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>34. Ask me to join activities</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>35. Spend time doing things with me</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>36. Help me with projects in class</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My Close Friend</th>
<th>How Often?</th>
<th>Important?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>Almost Never</td>
</tr>
<tr>
<td>37. Understands my feelings</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>38. Sticks up for me if others are treating me badly</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>39. Helps me when I'm lonely</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>40. Gives me ideas when I don't know what to do</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>41. Gives me good advice</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>42. Explain things that I don't understand</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>43. Tells me he or she likes what I do</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>44. Nicely tells me when I make mistakes</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>45. Nicely tells me the truth about how I do on things</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>46. Helps me when I need it</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>47. Shares his or her things with me</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>48. Takes time to help me solve my problems</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>People in My School</td>
<td>How Often?</td>
<td>Important?</td>
</tr>
<tr>
<td>---------------------</td>
<td>------------</td>
<td>------------</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>About Half</td>
</tr>
<tr>
<td>49  Care about me</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>50  Understand me</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>53  Listen to me when I need to talk</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>52  Give me good advice</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>53  Help me solve my problems by giving me information</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>54  Explain things that I don't understand</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>55  Tell me how well I do on tasks</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>56  Tell me I did a good job when I've done something well</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>57  Nicely tell me when I make mistakes</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>58  Take time to help me decide things</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>59  Spend time with me when I need help</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>60  Make sure I have the things I need for school</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
</tbody>
</table>

### Number 3: Kidcope

We are trying to find out how you deal with different problems in your life. Below is a situation that may be difficult for you to deal with. Please read the situation and answer the following questions.

**SITUATION:**

The experience of having a sister or brother who has special needs.

1. Please answer the following questions by circling your response.

   1. Does this situation make you nervous?
      - Not at all
      - A little
      - Somewhat
      - Pretty much
      - Very much

   2. Did this situation make you sad?
      - Not at all
      - A little
      - Somewhat
      - Pretty much
      - Very much

   3. Did this situation make you angry or mad?
      - Not at all
      - A little
      - Somewhat
      - Pretty much
      - Very much
2. Please circle whether you used any of the following ways to help deal with this situation. If you DID try the way to help deal with this situation, circle the word “YES” and also need to think about How much it helped you. If you DID NOT use the way to help deal with this situation, circle the word “NO”. You still need to think about How much it helped you. If you make a mistake, just cross out your answer and circle the correct box.

Examples

<table>
<thead>
<tr>
<th>Did you do this?</th>
<th>How much did it help?</th>
</tr>
</thead>
<tbody>
<tr>
<td>E: I just tried to forget it.</td>
<td>Yes, not at all, a little, a lot</td>
</tr>
<tr>
<td>E: I stayed by myself.</td>
<td>Yes, not at all, a little, a lot</td>
</tr>
</tbody>
</table>

In the first example, the person describes “I tried to forget it and it helped a little”. The second example, the person describes “I did not stay by myself and it helped a lot”.

Please ask for help if you have a question or don’t understand something. Do not skip any sentences. Please start answering the questions in the next page. Thank you!

<table>
<thead>
<tr>
<th>Did you do this?</th>
<th>Did you try?</th>
<th>How much did it help?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I just tried to forget it.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>2. I did something like watch TV or played a game to forget it.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>3. I stayed by myself.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>4. I kept quiet about the problem.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>5. I tried to see the good side of things.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>6. I blamed myself for causing the problem.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>7. I blamed someone else for causing the problem.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>8. I tried to fix the problem by thinking of answers.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>9. I tried to fix the problem by doing something or talking to someone.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>10. I yelled, screamed, or got mad.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>11. I tried to calm myself down.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>12. I wished the problem had never happened.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>13. I wished I could make things different.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>14. I tried to feel better by spending time with others like family or friends.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>15. I didn’t do anything because the problem couldn’t be fixed.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
<tr>
<td>16. I prayed.</td>
<td>Yes, No</td>
<td>not at all, a little, a lot</td>
</tr>
</tbody>
</table>
### Number 4: Strengths and Difficulties Questionnaire

For each item, please circle the box for Not True, Somewhat True or Certainly True that you think can most describe you. It would help us if you answered all items as best you can even if the item seems dull! Please give your answers on the basis of how things have been for you over the last six months.

<table>
<thead>
<tr>
<th></th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
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<td>2.</td>
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<tr>
<td>3.</td>
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<td></td>
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<tr>
<td>4.</td>
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<td>5.</td>
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<td>6.</td>
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<td>7.</td>
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<td>8.</td>
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<td>9.</td>
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<tr>
<td>10.</td>
<td></td>
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<tr>
<td>11.</td>
<td></td>
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<tr>
<td>12.</td>
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<tr>
<td>13.</td>
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<td>14.</td>
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<td>15.</td>
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<td>16.</td>
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<td>17.</td>
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<td>18.</td>
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<td>19.</td>
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<td>20.</td>
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<td>21.</td>
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<td>22.</td>
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<td>23.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Overall, do you think that you have difficulties in one or more of the following areas: emotions, concentration, behavior or being able to get on with other people?

<table>
<thead>
<tr>
<th>No</th>
<th>Yes-Minor Difficulties</th>
<th>Yes-Definite Difficulties</th>
<th>Yes-Severe Difficulties</th>
</tr>
</thead>
</table>

If you have answered “Yes”, please answer the following questions about those difficulties:

- How long have these difficulties been present?
  - Less than a month
  - 1-5 months
  - 6-12 months
  - Over a year

- Do the difficulties upset or distress you?
  - Not
  - Only a little
  - A lot
  - Quite a great deal

- Do the difficulties interfere with your everyday life in the following areas?
  - Home life
  - Friendships
  - Classroom learning
  - Leisure activities

- Do the difficulties make it harder for those around you (family, friends, teachers, etc.)?
  - Not
  - Only a little
  - A lot
  - Quite a great deal
Well done!

You have finished all the questionnaires. I am so proud of you! Thanks so much for sharing your experience.

Please now put this questionnaire into the small envelope provided and seal it. Give it to your parents and they will post it back to me.

Thank you very much for helping me!

From

Joy Tsai
Appendix B

Reliability statistics of the present research sample
<table>
<thead>
<tr>
<th>Survey/Questionnaire</th>
<th>UK</th>
<th>Taiwan</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent questionnaires</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Responsiveness Scale</td>
<td>.94</td>
<td>.94</td>
</tr>
<tr>
<td>Coping orientations to the problems experienced questionnaire</td>
<td>.88</td>
<td>.91</td>
</tr>
<tr>
<td>Coping strategies in Chinese social context</td>
<td>.91</td>
<td>.94</td>
</tr>
<tr>
<td>Satisfaction with life scale</td>
<td>.89</td>
<td>.94</td>
</tr>
<tr>
<td>Autism spectrum quotient (AQ-Adult Form)</td>
<td>.97</td>
<td>.89</td>
</tr>
<tr>
<td>Autism spectrum quotient (AQ-Child/Adolescent Form)</td>
<td>.97</td>
<td>.91</td>
</tr>
<tr>
<td>Strengths and difficulties questionnaire</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total difficulties scores</td>
<td>.88</td>
<td>.60</td>
</tr>
<tr>
<td>Prosocial scores</td>
<td>.71</td>
<td>.77</td>
</tr>
<tr>
<td><strong>Sibling questionnaires</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strengths and difficulties questionnaire</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total difficulties scores</td>
<td>.70</td>
<td>.66</td>
</tr>
<tr>
<td>Prosocial scores</td>
<td>.60</td>
<td>.73</td>
</tr>
<tr>
<td>Kidcope</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency scale</td>
<td>.68</td>
<td>.61</td>
</tr>
<tr>
<td>Efficacy scale</td>
<td>.95</td>
<td>.71</td>
</tr>
<tr>
<td>Satisfaction with Life scale</td>
<td>.99</td>
<td>.81</td>
</tr>
<tr>
<td>Child and adolescent social support scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency scale</td>
<td>.97</td>
<td>.97</td>
</tr>
<tr>
<td>Importance scale</td>
<td>.96</td>
<td>.97</td>
</tr>
<tr>
<td>Child and adolescent survey of experiences</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>


Appendix C

Translations example
Translation Questionnaire: Coping Strategies in Chinese Social Context

The original language of the questionnaire is in Chinese. Firstly, all the items were translated by a translation service from Chinese to English. Two Chinese-English speakers, who were both born in Taiwan and were sent to study abroad in western countries since their early years, translated the English version back to Chinese independently. The Chinese linguistic expert then rated both translation versions from translator 1 and 2 by using a 3-point rating scale (from 1 = low/questionable relevance to 3 = high/unquestionable relevance)

Original source language: 相信自己的直覺而非自己的想法來處理事情

Translation from a translation service: item 10. Trust my intuition rather than deal with things rationally.

Chinese-English speakers Translator 1: 相信直覺而不是想怎麼去解決事情 (Chinese linguistic expert rated: 2- high semantic equivalence)

Chinese-English speakers Translator 2: 比起待人接物的理想，更相信直覺 (Chinese linguistic expert rate: 1- low semantic equivalence)

Due to the low semantic equivalence in the Translator 2 example, the procedure of the back-translation in item 10 was repeated again until the two translators and the Chinese linguistic expert reached an agreement. The final translation was decided and settled to “Trust my own intuition rather than my thoughts in dealing with things”.

Original source language: 相信自己的直覺而非自己的想法來處理事情

Translation from a translation service: item 10. Trust my intuition rather than deal with things rationally.

Chinese-English speakers Translator 1: 相信直覺而不是想怎麼去解決事情 (Chinese linguistic expert rated: 2- high semantic equivalence)

Chinese-English speakers Translator 2: 比起待人接物的理想，更相信直覺 (Chinese linguistic expert rate: 1- low semantic equivalence)

Due to the low semantic equivalence in the Translator 2 example, the procedure of the back-translation in item 10 was repeated again until the two translators and the Chinese linguistic expert reached an agreement. The final translation was decided and settled to “Trust my own intuition rather than my thoughts in dealing with things”.

Appendix D

Ethical Approvals
Dear Hsiao-Wei

The Psychosocial Adjustment of Siblings of Children with Autism Spectrum Disorder (ASD) in Taiwan and the UK: Influence of BAP-characteristics, coping strategies, demographic factors and social support

The School of Education Ethics Sub-Committee has now considered your request for ethical approval for the studies detailed in your application.

This is to confirm that the Sub-Committee is happy to approve the application and that the research meets the School Ethics Level 2 criterion. This is defined as “covering novel procedures or the use of atypical participant groups – usually projects in which ethical issues might require more detailed consideration but were unlikely to prove problematic”.

A standard condition of this ethical approval is that you are required to notify the Committee, of any significant proposed deviation from the original protocol. The Committee also needs to be notified if there are any unexpected results or events once the research is underway that raise questions about the safety of the research.

Yours sincerely

Dr S Bayne
Convener, School Ethics Sub-Committee
Joy Tsai c/o Evelyn McGregor  
Institute for Education, Community & Society (ECS)  
2.16 St. John's Land  
Moray House School of Education  
University of Edinburgh  
Holyrood Road, Edinburgh EH8 8AQ  

Date  10 June 2013  
Your ref  
Our ref  SCS/JAI  
Direct dial  0131 469 3162  

Dear Ms Tsai,

I am writing in response to your application requesting permission to undertake research in schools in The City of Edinburgh.

Your request has been considered, and I am pleased to inform you that you have been given permission in principle to undertake your research. I must stress that it is the policy of this Authority to leave the final decision about participation in research projects of this kind to Head Teachers and their staff, so that approval in principle does not oblige any particular establishment to take part.

I request that you forward a copy of your completed findings to me when they become available. In this case an electronic summary of your thesis would be preferred. Your work may be of interest to a number of staff in the Children and Families Department.

I would like to thank you for contacting the Children and Families Department about your work, and wish you every success in the completion of your project.

Yours sincerely,

JULIE INNES  
Administrative Officer

Business Support, Schools and Community Services, Children and Families  
Level 1-3, Waverley Court, 4 East Market Street, Edinburgh, EH8 8BG  
Tel 0131 469 3162 Fax 0131 529 8213 E-mail julie.innes@edinburgh.gov.uk
Ms Joy Tsai
Institute for Education,
Community & Society (ECS),
114 St. John's Land,
Moray House School of Education,
University of Edinburgh,
Holyrood Road,
Edinburgh,
EH8 8AQ

Dear Ms Tsai,


Thank you for your completed research application form in respect of the above.

I now write to advise you that this department has no objection to you seeking assistance with your project from Schools in Glasgow. I would confirm however that it is very much up to the Heads of Establishments to decide whether or not they participate and assist you in your research.
A copy of this letter should be sent to the Heads of Establishments when contacting the schools.

This approval is also on the condition that as there are young people involved regarding this project, and they are less than 16 years of age, parental/carers consent must be requested, and given, before such involvement. All researchers must have recently approved Disclosure Scotland checks.

I hope that this is helpful and that you have success with your project.
Yours sincerely

Michele McClung

Dr Michele McClung
Principal Officer
Planning, Performance and Research Unit
Dear Joy

Supporting siblings of children with ASD

Thank you for your request to carry out the above research within Kilmaron Special School, Cupar, which I am pleased to approve.

The headteacher of Kilmaron School will be pleased to pass on relevant materials to the families concerned, but of course the final decision regarding participation rests with the families.

Best wishes for your research; I look forward to learning of your outcomes.

Yours sincerely

Bryan Kirkaldy
Head of Education (North)

cc Isla Lumsden (Headteacher, Kilmaron Special School)
Ken Keighren (Education Officer)
Jennifer King (Depute Principal Psychologist)

Rothesay House, Rothesay Place, GLENROTHES, KY7 5LT 08451 555555 ext. 444207
Appendix E

Parent and TD Sibling Information Sheets
**About me:**
My name is Joy Tsai. I am a PhD student in the University of Edinburgh, with a particular interest in autism spectrum disorders (ASD). I am a clinical psychologist and have been working with families with special needs for several years. I relate strongly to this subject as I have family experience of disability.

**About the research:**
The research will explore the experiences of the typically developing brothers/sisters (siblings) of children with ASD in Taiwan and the UK. We aim to understand sibling experiences, how they cope with any difficulties, the support they make use of, and the role that culture and sibling characteristics plays in coping strategy use.

- **Who can take part in this research?**
We are looking for typically developing siblings of children with ASD or Asperger Syndrome to participate in the study. Siblings need be aged 9 – 17 years and only one sibling per family can participate. If you have more than one child aged 9-17 years it would be best if the sibling closest in age to the child with ASD took part. Please give the sibling the ‘Information for Siblings’ sheet and help explain the study to them if required.

- **What will my child be asked to do?**
Your child will be sent a pack of questionnaires to fill in and asked to post them back in a stamped addressed envelope provided. The questionnaires explore topics such as their support from others, their adjustment and how they cope with the events in their life. It should take about 30 minutes to complete. Questionnaire packs will come with complete instructions, but if your child has any queries they can (with your permission) phone or email me and I will call back to discuss.

- **What will I be asked to do?**
You will be asked to complete a questionnaire pack. This contains questions about your family, your background, your child with ASD and their sibling. Again, this should take about 30 minutes to complete.
● **Will my child with autism be involved?**
No. Although you and your typically developing child will be asked some questions about your child with ASD, they themselves will not be directly involved – this research is only for parents and siblings.

● **What about ethics and confidentiality?**
All data will be stored securely, and only myself and my supervisors will have access to it. Individuals will not be identified by name in any research report. The research has been approved by the ethics committee at the School of Education, University of Edinburgh. The project data will be collected and stored in accordance with the University's responsibilities under the UK Data Protection Act 1998.

● **What should I do if I have concerns?**
Please contact me, or my supervisors Dr. Sue Fletcher-Watson (sue.fletcher-watson@ed.ac.uk) or Dr. Evelyn McGregor (evelyn.mcgregor@ed.ac.uk).

● **Is there any obligation to take part?**
I would very much appreciate it if you feel you can become involved, but neither you nor your child are obligated to take part. If you do participate you can change your mind at any time and leave the study.

● **What are the benefits for participating for me and my child?**
I hope that all of the families involved will find it interesting to share their experience and reflect on sibling experiences. You and your child will be sent a summary of the final report. We hope this research will help to identify the best ways to support siblings of children with ASD in the future.

● **How can we take part in this research?**
**Please e-mail to: tuks@ed.ac.uk** and then I will sent you the survey package with a stamped addressed envelope to post it back. If you have any questions, please e-mail or phone (07428169400) me to discuss and I can call you back to save your costs. Thank you!
About this research
This research is about you! I’m trying to find out what it’s like to grow up in a family when your brother or sister (sibling) has autism. At the end of the research I would like to give some information to families. It would explain what siblings think about what it is like to have a brother or sister with autism, what makes your life easier and what makes it more difficult.

About me
My name is Joy 😊 and I come from Taiwan. I study in the University of Edinburgh and I am doing research with families who have children with autism. I am also a sibling who has grown up with a sister with special needs. That is why I am doing this research and think is it important.

Who can take part in this research?
Children/Adolescents aged 9 – 17 years who have a sibling (brother or sister) with autism. Only one child in each family can take part.

How can I take part?
If you would like to take part, please write your name on the agreement (consent) form. Your mum or dad (or whoever looks after you) needs to write their name too. After that they need to post the form back to me. If you have any questions you can phone me or ask your parents and I will contact you to tell you a little bit more about the research and answer any questions you have.

What will I be asked to do?
I will send you some questionnaires to fill in and post back to me. The questionnaires will ask about lots of different things, like how you get on with your brother or sister, what you like to do in your free time, and how you are feeling. The questionnaires will take about 30 minutes to fill in, but you don’t have to do it all at once. If you find any bits difficult to fill in, then you can phone me and ask me about it.
What will my parents be asked to do?
Your mum or dad (or the person who looks after you) will be asked to fill in some questionnaires too.

Will you contact my school?
No, I won’t contact any other people in your life. Only you and one of your parents will take part in this research.

Will my brother/sister with autism take part?
No. I might ask you some questions about your brother/sister, but they will not take part. The important people in this study are you – the siblings!

Will you tell anyone else what I say in the questionnaires?
I will keep your questionnaires safe and won’t let anyone else see them. I will write some reports about what everyone says in the questionnaires, but I won’t say who said what and I wouldn’t use your name. If something you write makes me worried that you are in serious danger I will have to tell someone. I will contact you first and you can let me know who you want me to tell, like your favourite teacher.

Do I have to take part?
No – you don’t have to take part if you don’t want to. I hope that lots of siblings will be able to take part, and it would be really good if you could help me, but if you don’t want to be in the project, that’s fine as well.

THANK YOU FOR READING THIS!
Appendix F

Replacement of Missing Items
• Social Responsiveness Scale (SRS)

Missing data: enter the median value

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• Autism Spectrum Quotient

If five or fewer answers were missing, the AQ score was corrected for missing items by performing the following calculation: total AQ score + (mean item score x number of missing items) (Hoekstra, Bartels, Verweij, & Boomsma, 2007)

• Coping Strategies in Chinese Social Context

Missing data: enter the mean value

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Appendix G

Lists of Comorbidity of Children with ASD
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<th>Taiwanese families frequency</th>
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<td>Auditory processing disorder</td>
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<td>Tourette syndrome</td>
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Appendix H

SDQ Normative Data
### UK norm

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<th>Parent SDQ</th>
<th>Mean score (Standard deviation)</th>
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<tr>
<td>Total Difficulties Score</td>
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<tr>
<td>Emotional Symptoms</td>
<td>1.9 (2.0)</td>
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<tr>
<td>Conduct Problem</td>
<td>1.6 (1.7)</td>
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<tr>
<td>Hyperactivity/inattention</td>
<td>3.5 (2.6)</td>
</tr>
<tr>
<td>Peer Problem</td>
<td>1.5 (1.7)</td>
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<tr>
<td>Prosocial Behaviour</td>
<td>8.6 (1.6)</td>
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### Self-Report SDQ

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<tr>
<td>Emotional Symptoms</td>
<td>2.8 (2.1)</td>
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<tr>
<td>Conduct Problem</td>
<td>2.2 (1.7)</td>
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<tr>
<td>Hyperactivity/inattention</td>
<td>3.8 (2.2)</td>
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<tr>
<td>Peer Problem</td>
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**UK clinical category band**

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This score is close to average, clinically significant problems in this area are unlikely

This score is slightly raised, which may reflect clinically significant problems

This score is high, there is a substantial risk of clinically significant problems in this area
### Taiwanese norm

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<td>9.6 (5.3)</td>
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<td>Prosocial Behaviour</td>
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<table>
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Appendix I

Interview Questions
Parents’ Interview Questions

Opening

Many thanks for providing such a great opportunity for sharing your experience with me. I would like to hear from you about your family, and in particular about (name of sibling) and (name of child with autism). I’d like to talk about several different topics that are related to your family and your experience.

Each topic will start with a short statement, and I will ask you what you think about it, and whether you agree or disagree according to your experience. Please don’t feel obliged to agree! Some of the statements might really fit your experiences and some might not be true for you at all. There are no right or wrong answers, please just feel free to tell me how things are for your family.

At any point of interview, please let me know if you need a break, if there is anything you would prefer not to discuss or whether there is anything that you would like to address in more detail. If you have any concerns related to the interview, please do not hesitate to ask me.

If you are thinking about how things are with NAME and your family, it might be useful to think about how they have been over the past six months or so.

Is there anything you would like to ask me, or is it okay to just begin?

• opening/warm up
  ○ Tell me a bit about your family: who lives here? How are things going as a family at the moment?

• siblings interaction

Statement: I don’t think my children spend enough time doing things together.
  ○ How do you think about that? Is that true for (sibling name) and (child with autism name)? Or not true? What is the situation in your family?
    ▪ If parents only answer: they don’t have much time being together
      • Is there any reason behind that, example: busy schedule, big difference in ability, not get along well
  ○ What will you describe siblings relationship so far?

• Coping

Statement: People deal with difficult days in different ways.
  ○ What do you think the situation is for you? How do you deal with any difficulties you experience? What about name (sibling)?
    ▪ If parents can’t describe, provide them some example
such as coping with lack of sleep due to child with autism, coping because of bullying at school

- How did you deal with children’s conflict/argument last time?
  - If parents only answer: just walk away, ignore it …short answer
    - Does that strategy help most of the time?
    - What strategy that helps the most/and not so helpful

- When was the last time that (name of sibling) and (name of child with autism) had any conflict/argument, how did name (sibling) deal with that?
  - If parents can’t describe
    - Do you think name needs some help to help him/her to cope better?
    - Did that help to solve the situation?

**Adjustment**

Statement: I do think my child name (sibling) has struggled to adjust having a brother/sister with autism.

- Do you agree with that or disagree? What is your experience?
- How do you think name manage to adjust so far?
  - What things you think name adjust quite well?
  - Why does that worry you the most?
    - (observation from child’s behaviour?)
    - can you give me an example

**Support**

Statement: I think my family have received sufficient support from different sources, such as friends, ASD organisation, schools, professionals and so on.

- Do you agree with that, or disagree? What is your experience of support for your family?
- What kind of support is most important and useful to you?
  - If parents just name it
    - Why is that important/ useful to you?
- Does name (sibling) receive support themselves? Where from?
  - School teacher? friends?
  - How does name (sibling) response to that?

**Role expectation**

Statement: I hope name (sibling) can model appropriate behaviour to his/her brother/sister.

- What do you think about this?
Do you think you have expectations about what name’s role is as a brother/sister of a child with autism.
  • for example, do siblings model appropriate behaviour? Or provide a caring role?

End

Thank you so much for your time. The information you provided is very helpful. Do you have anything else that you want to address, or anything that I have missed? ……ok thank you so much.
siblings’ interview questions

opening

I’d like to talk about several different topics that are related to your family and your experience.

Each topic will start with a short statement, and I will ask you what you think about it, and whether you agree or disagree according to your experience. Please don’t feel obliged to agree! Some of the statements might really fit your experiences and some might not be true for you at all. There are no right or wrong answers, please just feel free to tell me how things are for you and your family.

Is there anything you would like to ask me, or is it okay to just begin?

opening/ warm up

Tell me a bit about yourself and your family – who lives here? What are your favourite things to do outside school? What about (child with autism) – what does he/she like to do?

siblings interaction

Statement: Some siblings spend a lot of time together, others don’t spend so much time together.

What about you and name? Do you do things together often or not really?

What is the reason that you don’t spend much time with name?

What things you enjoy doing together with name?

Coping

Statement: People deal with difficult days in different ways.

What do you think the situation is for you? How do you deal with any difficulties you experience?

If sibling only have short answer, give them some example

• coping because of bullying at school because you have a sibling with autism

Last time when you felt not so happy with name, what happened? Can you tell me more about that?

How did you deal with that?

• Does that way of handling things help most of the time?
  • Why you think that can help?

• Have you ever tried other ways but found they are not so helpful?

How did your parents deal with it when you and name were not getting on?
• Did that help?
• What things do you think they can do to help when…?

• Adjust process
Statement: Sometimes it might be great to have a brother/sister with autism, sometimes it might be hard.
  o How do you think it is for you just now?
  o How do you think things have been for you?
    ▪ Whether there are any particular things that are difficult about having a brother or sister with autism, and any particular things that are good about having a brother or sister with autism.

• Support
Statement: I have been getting some help from my family/teacher/parents or others.
  o Do you feel you receive the support you need?
    ▪ Who provides the most support?
    ▪ If not. what is the reason?
  o If you had to give advice to other siblings, what would you tell them about the sorts of support they might find helpful?

• role expectation
Statement: I think my parents wish me to help my brother/sister in some way and I try to do that.
  o Do you agree with that?
  o Do you think your parents wish you to be a little helper, like taking care of name?
    ▪ I would describe myself as …..to my brother/sister.

End
Thank you so much for sharing your experience with me. Do you have anything else that you want to address, or anything that I have missed? It has been a great time to be with you. The things you have told me are really valuable and important. Thank you so much.
Appendix J

Interview Information Sheets
Thanks for taking part in the TUKS: Siblings support project last time. I hope that you find the experience of the study is enjoyable. I really appreciate you and your child sharing so much information with me, now I would like to invite both of you to participate in the further interview survey.

**About the interview:**
The interview will take around 40 minutes with you and 30 minutes with the participating sibling. I can visit your home or any other place that you prefer. However, we do need to have a private and quiet space for you and your child to take part in the interview. The time and date will be arranged whenever suits you best. I’m happy to meet you at the weekend or, if you live locally, then in the evening too.

- **What will I be asked to do?**
  I will be asking you for more detail about the four main topics of the project, including your experience raising a child with autism, your thoughts about your typically developing child, how you feel about a sibling’s role including expectations for the future. There will also be time to chat about any other things you would like to share with me. There is no obligation that you have to answer all the questions, however anything you want to say will be highly valued.

- **What will my child be asked to do?**
  Your child will also be asked about the experience of having a brother/sister with special needs, how do they manage it and the happiness and difficulties they have encountered.

- **Will my child with autism be involved?**
  No. Although you and your typically developing child will be asked some questions about your child with ASD, they themselves will not be directly involved – these interviews are only for parents and siblings.

- **How does the interview process work?**
I will do two interviews with you and your child, separately, in a quiet space. With your permission, I will audio-record the interview. We will plan to take about 1 hour for the interview with you and I will talk to your child for about 30 minutes. Both of you can withdraw at any time without needing to give a reason.

- **What about ethics and confidentiality?**
The interview will be transcribed by me into a written record. All data will be stored securely, and only myself and my supervisors will have access to it. Individuals will not be identified by name in any research report. The research has been approved by the ethics committee at the School of Education, University of Edinburgh. The project data will be collected and stored in accordance with the University’s responsibilities under the UK Data Protection Act 1998.

- **What should I do if I have concerns?**
Please contact me (tuks@ed.ac.uk), or my supervisors Dr. Katie Cebula (katie.cebula@ed.ac.uk) or Dr. Sue Fletcher-Watson (sue.fletcher-watson@ed.ac.uk).

- **Is there any obligation to take part?**
I would very much appreciate it if you feel you can become involved, but neither you nor your child are obligated to take part. If you do participate you can change your mind at any time and leave the study.

- **What are the benefits for participating for me and my child?**
I hope that all of the families involved will find it interesting to share their experience and reflect on sibling experiences. You and your child will be sent a summary of the final project report. We hope this research will help to identify the best ways to support siblings of children with ASD in the future.
Hi! This is Joy from the TUKS: Siblings Support Project. Thank you so much for sharing your experiences with me so far. The information you provided is really helpful. This time I would like to visit you and your parents to hear more about your story!

**What will happen in that day?**
I will arrange with your parents to visit your family one day, probably at your home. I will talk to one of your parents first for around 40 minutes. After that you and me will have another chat in a safe and quiet place for 30 minutes. If you want someone else to sit in with us that’s fine - please let me know.

**What will I be asked to do?**
I will ask you some questions thinking a little bit more about some of your answers to the questionnaires. I’d like to find out a bit more about your feelings about having a brother or sister with special needs and any other things that you would like to share with me. It will take about 30 minutes to finish, but if you feel tired and need a break, that is fine!

**Will my brother/sister with autism take part?**
No. I might ask you some questions about your brother/sister, but they will not take part. The important people in this study are you - the siblings!

**Will you tell anyone else what I say in the interview?**
I will use an audio recorder to help me remember what you said. I will keep the tape safe and won’t let anyone else hear them. I will write some reports about what everyone says in the interview, but I won’t say who said what and I wouldn’t use your name. If something you say makes me worried that you are in serious danger I will have to tell someone. I will contact you first and you can let me know who you want me to tell, like your favourite teacher.

**Do I have to take part?**
No - you don’t have to take part if you don’t want to. I hope that lots of siblings will be able to take part, and it would be really good if you could help me, but if you don’t want to be in the interview, that’s fine as well.
Appendix K

Disclosure Scotland Clearance
## Applicant Personal Details

- **Surname:** TSAI
- **Forename(s):** HSIAO-WEI
- **Date of Birth:** 28/01/1982

## Convictions

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## Cautions

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## Other Relevant Information

- **NONE**

## Other Government Information

*Not applicable to the level of disclosure.*

**END OF DISCLOSURE**