

## RESEARCH ARTICLE

# Raising Young Children with Autism Spectrum Disorders in Hong Kong: The Impact of Cultural Values and Stigma on Chinese Parents' Coping Strategies

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## Abstract

Autism Spectrum Disorder (ASD) is a life-long disability. The long term care of children with ASD has effects on families that teachers and support service providers strive to quantify. Observing 'filial piety' towards one's parents is a traditional Chinese virtue and moral standard. Yet despite the acknowledged importance of the family, relatively little is known about the functioning of Chinese families with children with ASD in Hong Kong (HK). Data was gathered from 100 parents of children with ASD to understand how traditional Chinese beliefs, community values, and the day to day experience of raising a child with ASD in HK, influences the coping strategies that parents employ. It is hoped that the results of this study will raise awareness for the need of further public awareness, educational and support services for families who are currently trying to adjust their parenting skills to cater for a family member with ASD.

**Keywords:** *Autism spectrum disorders, Chinese parents, Coping strategies, Cultural values.*

## Introduction

According to the DSM-5 (APA, 2013), the new criteria for the diagnostic features of Autism have moved to using a single diagnosis of Autism Spectrum Disorder (ASD). ASD is a severe disruption of the normal development process and is viewed as a spectrum or a continuum of disorders, with varying degrees of severity and levels of functioning. The new DSM-5 guidelines have moved away from the well-known triad of impairments and instead include just two domains: (1) the social communication domain and (2) the repetitive/restricted patterns of behaviours domain. ASD is a life-long condition that is often diagnosed at 2 years of age. As such, it is the child's parents who are usually the first to notice peculiarities with their child's development that do not follow the typical norm.

The diagnosis of ASD in a child can trigger a range of emotional responses in parents and across family systems. For some, it will constitute a crisis that requires extra ordinary psychological adjustment on a parent's part and contains elements of shame, despair, loss and weakness. For others, the news will be viewed as an

unfortunate event, yet one that has positive implications; it may even provoke psychological growth in some family members, or heightened overall family functioning. The measurement of the meaning that raising a family member with ASD holds for HK/Chinese parents and their view of their family life was the central interest of this study. The importance of assessing familial impact was not only to assist parents with their own psychological distress, but to guide the provision of needed education and support services that can strengthen family coping and positive adjustment. The objective of this study was to investigate the subjective interpretation of HK/Chinese parents' regarding the consequences for caregivers when raising a child with ASD.

## Context

One of the hottest current issues in the field of ASD is the reported tremendous increase in the incidence and prevalence of the disorder. Over the past several years, a truly dramatic increase in the number of children diagnosed with ASD has been reported world- wide [1]. Sturmey and

Fitzer [2] estimate that ASD occurs in approximately 1 in every 150 school aged children, and that it is four times more common in boys than in girls.

According to World Report on Disability [3], there are 1,100,000 cases of ASD in China, and 5.49 children in every 10,000 are diagnosed with the disorder in HK. However, back in 2001, the Census and Statistical Department of HK reported that about 3000 people in HK were diagnosed with ASD, which constituted a prevalence of only 0.05% in the HK population. Then in 2009, the overall prevalence of ASD in HK was considered to be around 3800, which constituted an increased prevalence of only .1% in the general population [4].

Given the above statistics, one could reasonably expect that there must be a significant number of HK/Chinese families raising children with ASD, full-time at home, not seeking a diagnosis and without the assistance of any government support service. Part of the difficulty in providing services to these families is that they choose to remain hidden, resulting in information on the incidence and prevalence of children with ASD in HK being inconsistent and difficult to come by. In view of the increasing prevalence or identification of ASD in the world and the importance of caregivers' mental health in the treatment process, a need for closer examination of the consequences of raising a child with ASD in HK is called for, in order to obtain a better understanding about HK/Chinese parental needs.

## Method

### Participants

The total sample for this study consisted of 100x parents from HK/Chinese families who were rearing at least one family member who had been diagnosed with ASD between the ages of 3-18 years. This age group was chosen as it relates specifically to the school age years and thus, should highlight a range of information, educational and support needs by families.

### Data Collection

Three different kinds of data were obtained. Firstly, general demographic data was collected about the child (e.g., gender, disability of the child, birth order of the child, etc.). Secondly, data was collected on the parents' perception of the impact of their child's disability on family behaviour via the use of the Impact on Family Scale (IFS) survey [5]. Finally, parents were invited to be involved in a face to face, semi

structured interview in order to add their personal accounts to this investigation.

### The Survey Instrument

According to Williams, et al., [6] the Impact of Family Scale (IFS) is a reliable, and valid measure of a family member's perception of the effect of a child's disability that can be used across diagnostic groups, and that it can be useful in clinical and health service research. The results of the IFS are presented under four subscale scores (i.e., financial impact, disruption of social relations, general impact, coping) and a total impact score in the results section of this paper. In order to invite as many families as possible, participants were recruited in two ways.

Strategy 1: Recruitment at Autism Information Conference for Parents in HK.

The first recruitment strategy was to approach participants directly at local NGO, (free entry) parent information seminars on ASD that are held annually in HK during Autism Awareness Week. 200 x copies of a flyer explaining the project and giving a web link for either (a) on-line participation, or (b) details for a mail-out data collection method were distributed at this event. 41 x respondents supplied their requested information on-line. While 32 x expressions of interest were either, handed to the first author at the conference, or were posted, e-mailed or faxed to the first author within the following week. 32 hard copy versions of data were then posted out to interested parents. This strategy resulted in a total of 73 completed surveys, achieving a response rate of 37%.

Strategy 2: Recruitment at five community support services for Children with ASD in HK.

The second strategy was to recruit parents indirectly via three NGO special schools and two acupuncture /therapy clinics for children with ASD. While special schools in HK mainly serve students with II, they also serve a number of children with ASD. Teachers nominated the children who were diagnosed with ASD for inclusion in this project. In total, 150 x packages with surveys and self-addressed stamped envelopes were sent out to parents of children with ASD. 38 completed surveys were returned, resulting in a 25% response rate.

### Tri-lingual Language Considerations

The most frequently spoken language in HK is Cantonese, and the written script is known as Traditional Chinese (TC). Not all local HK/Chinese people speak English, and when they

do, proficiency in written and spoken English can vary considerably. In addition, some families relocate from The People's Republic of China (PRC) to live permanently in HK. Putonghua is the language spoken by PRC and the written script used there is Simplified Chinese (SC). All documents used in this study were offered in English, TC and SC. The on-line version of this information was also offered tri-lingually.

### **Fidelity of the Translation of Materials**

All written materials were originally designed in English, and later translated by two Chinese RA's, one from HK and one from PRC, into TC and SC. Both Chinese translations were then checked by 2 x Chinese senior academic research staff from the Department of Education Studies, Hong Kong Baptist University (HKBU). The translations were also checked by a Head of Department in the Language Centre of HKBU who has more than 20 years of experience teaching Asian languages in HK. Finally all documents were piloted with 6 x Chinese parents of children with ASD. No change to the survey materials was requested in the pilot phase.

### **Results of Participant Recruitment**

While 41 x parents chose to complete the survey on-line, most parents (N=70) requested a hard copy survey be posted to them. In total, 111 completed surveys were returned which was an overall response rate of 32%.

### **School Age and Disability Categorizing Procedures**

Eleven (11) of the respondents were not included in this study based on age and disability selection criteria. As the needs of families for support services change once children mature beyond school age [7] only children aged between 0-18 years were included in this study. Consequently, seven children, who were identified as being of post-school age, were not included. In addition, ASD determinations of children were based solely on the self-report of responding family members to an open-ended question about... "*your child's disability*". Four children were identified as having an "other" disability and so, data supplied by these 4 x parents was not included in this study.

### **The Interview**

When parents agreed to participate in this project, they were given the option to have a face to face individual interview to discuss their family's individual story. 30% of the respondents took up this offer. Fifteen (15) interviews were randomly selected, transcribed, translated and

analyzed and used in an effort to further explain the findings of the IFS data. All of these parents spoke TC. The interview was designed to obtain general information on issues such as needs of, access to, and use of information, education and therapy services, and general topics on family adjustment to living with a child with ASD.

The interviews were conducted by 2 x research assistants (RA's) who had recently graduated with a Master of Education degree. Both RA's could speak English, TC fluently. The interviewer contacted each family by telephone and arranged a mutually convenient time to visit. The interview questions on the demographic items varied little in their format. Some questions required only simple yes or no responses such as Are you \_\_\_'s [target child's name] biological mother? The interviewer recorded this information manually on prepared data collection sheets. Other questions were asked using a semi-structured set of questions. Informants delivered with considerable emotion, a vast amount of personal information and often harrowing details of their lives. The interviews were audio taped and translated into English for analysis. The transcriptions were member checked by the RA's as soon as possible post interview to maintain the reliability and integrity of the data.

### **Data Analysis**

Information obtained from the parent interview and the Impact on Family Scale was organized, classified and synthesized. Initially, demographic child and parent characteristics were summarized to identify the family context in which the members were functioning. The data has been standardized with a mean value of 50 and a standard deviation value of 10. This means that the data was comparable and that it was possible to rank the data using Skewness values. All data analyses were done using the SPSS version 12. An ethnographic approach was used to analyze the interview data. The interviews were audio taped digitally, transcribed and translated, and a sample of the transcripts were back-translated to check the accuracy of translations. The credibility of the analysis was checked by member checking the translations back to selected respondents and asking them for their perceptions regarding the "truth" of the analysis.

## **Results**

### **General Description of the Families and Children with ASD**

In the sample (n=100), 31% were within the pre-school age range (i.e., 3-5 years olds); 59% were within the primary school age range (i.e., 6 – 12

year olds), 10% were of secondary school age (i.e., 13-18 years). 75% were male children and 25% were female children, with a mean age of 7.9 years. Most families were unsure of the term intellectual ability. Overall, parents rated their child as functioning at either an average or below average intelligence level. In this group of children, 25% were considered to be below average intelligence and 20% of children were considered to be of average intelligence, while the majority (55%) of parents indicated that they just did not know. Consequently, it cannot be said that the heterogeneity of the ASD population is illustrated in this group.

Only twelve families indicated that their child had an additional medical, sensory or emotional problem. In their parent's opinion, 5x children had significant speech impairments, 2 x children had hearing impairments, 1 x child had an anxiety disorder, and one child was known to have had grand mal seizures as an infant. The birth order of the children varied. In 73% families, the child with ASD was the eldest; in 20% of families they were the second born child, and in 25% of families, occupied a medial position. Family size varied from 2 to 6 members. However, in the majority of cases (73%), there was only the one child.

### Use of Support Services in Hong Kong

It should be noted that there is very little consistency in the provision of free medical and/or therapy as a support service in HK. Consequently, the use of and the ability to access free HK Government therapy services varied.

Some parents mentioned accessing free speech therapy sessions, once per month. An even fewer number of parents mentioned that their child had been offered any occupational therapy (OT) treatments. However, in each case, the waiting period was very long (up to a year).

Some families had only accessed Hospital therapy when the child was very young. One parent told the investigator that upon receiving their child's diagnosis, a nurse had told her not to worry as boys were always slower in talking. At that time, the child was 2.5 years old and had no verbal communication skills. The mother remembers wondering how she was going to convey to her son's new pre-school teacher, the sentiments of that nurse. That was the extent of the support service that they were ever offered by the public hospital system. There are private therapy clinics in HK, but assessments and therapy sessions are known to be very expensive.

### Family Functioning Measures

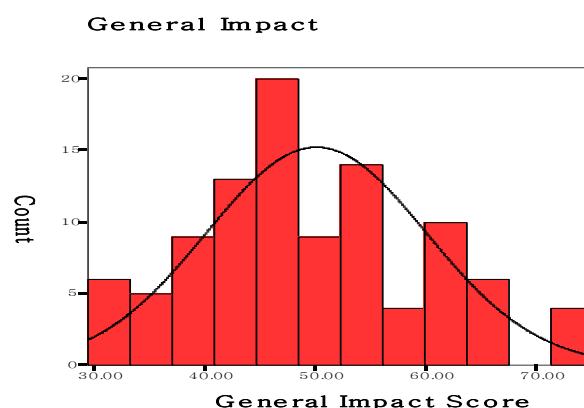
The main findings from the IFS are summarized in Table 1. In order to interpret this table, one needs to understand that, the larger the positive skewness value, the bigger the impact on the families in this study. Consequently, it would appear that the General Impact variable for this group of parents was the most severe, followed by Disruption of Social Relationships. Alternatively, the Coping variable was very strong. Brief explanations of these three variables will be followed by a summary of the findings of this study.

**Table 1: Descriptive statistics on the five scales of the Impact on Family Scale (n = 100)**

Scale	Mean	Median	S.D.	Skewness
1 Financial Impact	50.00	48.76	10.00	0.014
2 Disruption of Social Relationships	50.00	48.00	10.00	0.134
3 General Impact	50.00	48.47	10.00	0.237
4 Coping	50.00	50.06	10.00	-0.208
5 Total Impact	50.00	50.05	10.00	0.026

### General Impact

The General Impact (GI) score is a personal strain factor that measures subjective feelings of a family's stress. Fig. 1 is a visual representation of a negative general impact. Because the coefficient of skewness is positive (Skew = 0.134), this implies that the majority of the scores in the data set with high frequencies were low and concentrated in the bottom part of the distribution.



**Fig.1: General impact**

Mean: 50, Standard Deviation: 10, Skewness: 0.237

It is generally recognized that in Chinese society, parents attach a high value to the academic achievement of their children. There is no doubt that children with a moderate to severe intellectual disability (such as ASD) will face greater obstacles in the fulfillment of family expectations related to academic achievement, than will their peers with less significant disabilities. Consequently, HK/Chinese parents of children with ASD may experience even higher levels of stress than parents of children with milder disabilities. Many parents in this study spoke about their fears for the difficulties that their child would face, if they attended a local public school. In all cases, interviewed parents chose to send their child to a private special school or therapy unit. Sample comments were:

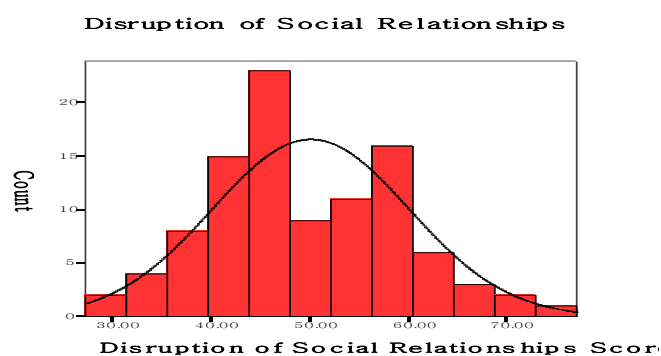
I can't imagine how normal kids would treat my boy. What is the situation like if "child" is in a normal school? The kids outside are smart. And once they know you are weak and can be a target for bullying, they will do it (interviewee no 3, 2013)

We don't want him to go to public schools because we don't want such a weak child to be bullied (Interviewee no 5, 2013).

I didn't send him to subsidized local school because I didn't think that he can fit in, That is why I have to send him to private schools. It is a better student – teacher ratio, which is better for him. But it is a lot more costly (Interviewee no 7, 2013).

### Disruption of Social Relationships

The Disruption of Social Relations (DSR) score is a familial-social support factor which addresses the social interactions both within and outside the family. There is evidence in Fig. 2 that the distress of having a child with ASD in the family tended to disrupt the family social relationships. Again, as in Fig. 1, most of the scores are low and are heaped on the lower end of the graph, indicating a right skewness.



**Fig. 2: Disruption of social relationships**  
Mean: 50, Standard Deviation: 10, Skewness: 0.134

Shek and Tsang [8] reported that approximately half of the families in their sample (N=381) never sought assistance from friends, relatives, parents, or in-laws, and about a third of this group also had never sought support from professionals in developmental disabilities (e.g., teachers, therapists, doctors). In the present study, there were similar reports of parents not attending therapy mostly due to the cost of these services. There were also comments on the difficulties of taking children on outings in HK. Parents explained that family outings were few, due to social stigma or public discrimination. Parents also spoke at length of the challenging behaviours of their children and how this reduced their desire, or ability, take their child out in public. Sample comments from parents in this study are as follows:

Taking him out is trouble (interviewee 9, 2013).

We cannot both go out because of him. People look at him with a certain kind of attitude which is quite negative. People would look at him with distain (interviewee no 2, 2013)

We cannot go out unless we have a domestic helper following him, it makes it less difficult to take him out (interviewee no 2, 2013)

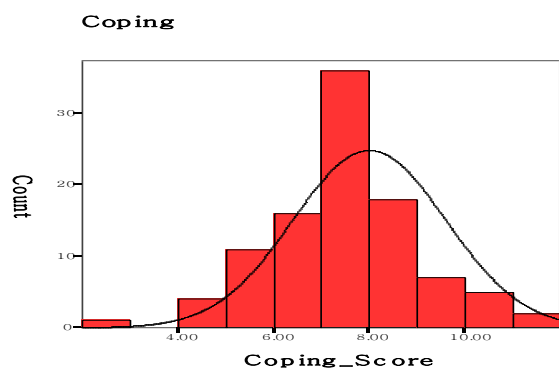
When she is not happy, so she cries, cries, cries. Oh last Wednesday was the worst day! She cried for more than 1 hour, never stop. So we carry her, walk for about 10 minutes to the Times Square, and wait there for almost half an hour. She keep crying, never stop. And she start yelling, at the top of her lungs. And then we get into the taxi and the taxi driver said "Oh it bothers me". And then we come back home. We cannot take the public transportation. Before we just go to the MTR (subway) and go. Now, we cannot (interviewee no 1, 2013).

We can't join in as many activities as other families do. It is difficult for "child" to play and have fun in a group (interviewee no 7, 2013).

### Coping

The Coping score addresses the change in a parent's sense of mastery over the management of his/her child with a disability. Despite the negative impacts depicted in Fig. 1 & 2 above, the coping scores of families of children with ASD in this study indicate that these parents have developed salient coping strategies to help them to withstand the pressure, tension, anxiety and stress associated with the task of caring for a child with high support needs. The negative skewness (Skew = 0.237) suggests that the scores

with high frequencies were mainly located in the upper tail of the graph as is graphically indicated by Figure 3. The distribution of scores for the coping variable is left negatively skewed.



**Fig.3: Coping**

Note: Mean: 7.99, Standard Deviation= 1.60

However, based on the existing literature with Chinese families with children with developmental disabilities such as ASD, avoidance appears to be the most dominant coping strategy employed [9]. When the children were young, mothers attempted to hide the disability from others to maintain face. Avoidance seemed to be the main strategy for coping with raising a child with ASD in this research group too. Sample parent comments were:

Our neighbours? No, they don't know about the situation (Interviewee no 4, 2013).

I live with my wife and my mother and they are positive about treating my child. But for the family of my wife, actually they do not know about the situation that my child have because my wife didn't want them to know about that. We can keep this secret, we only met a few times every year and they still don't know about him, the problem of my child. So yeah, that's the situation of my family (interviewee, No 6, 2013).

However as the children grew older, mothers tended to become a little more self-reliant and began to seek assistance from community support services. Nonetheless, maintaining a level of secrecy or denial to their families and friends still remained one of the most frequently employed coping strategies for these HK/Chinese families. As a result, mothers' coping resources tend to be limited. Typically the husband was the only one who knew and who could potentially provide support to the mother. Sample comments were:

My family does not know [that my child has ASD]. My family asks me "Why do you have to go to these services? So that was quite conflicting within myself, listening to all of these comments

from my family. But at the same time, I know there are problems with my son and he needs to attend (interviewee no 10, 2013).

The only support we've received is from the therapist at his school, but as to social groups and meeting friends and things like that? No. (Interviewee no 8, 2013).

I go to the trainings with my son, so that I've actually learnt more about home training, and his dad sees....he knows that I've been laborious, as I've been with him (the child) and going after him all of these years, so he has offered himself to help....like he asked me to teach him (husband) how to do the training with "Child" and he helped out also (interviewee no 10, 2013).

Shek and Tsang [8] evaluated the coping strategies of 381 parents of preschool children with intellectual impairments (II) in HK and reported that a significant proportion of the parents tended to use internal coping strategies to deal with the problems arising from taking care of their children with II. (e.g., "face the problem and devise solution", forbear and remain calm"). Parents in the present study made similar comments.

Nowadays, we know this disability is not curable. We know that. Still, we are hoping he will get better someday. We are waiting for the miracle to happen. We will not give up (interviewee no. 2, 2013).

The general public in HK, oh I think it's shocking. You know they, they don't have a tolerance for it and there is no point in trying to explain it, you just don't. I try to ignore it. I just tune everybody out basically. My priority is dealing with "child", and that's the way I deal with it (interviewee no 8, 2013).

### Summary of Parent Perception of Impact

To a point, the results of both Campbell & Uren's [10] and Demarle and Le Roux's [11] studies of the views of parents of children with disabilities seem to confirm the findings in this investigation; which is, whatever the stress incurred on the families, the caring process for children with special needs varies across families. Some families cope with their situation well. In other cases, parents have been found to never fully adjust to raising a child with ASD [12]. Yet parenting a child with ASD in HK is not as clear cut as this. In fact, for many parents, it would seem that there is a growing middle ground. Several parents in this study explained that they coped with their child's disability by living within

astriict regime. These parents knew exactly what situations were and were not, “doable” with their child and they avoided situations which might cause any negative reaction. Some comments were:

No, it’s not easy to go out. My rule is to avoid crowds. We seldom go to places with a lot of people (Interviewee no 7, 2013).

My daughter, she does not like to go out after dark. If we go out in the afternoon, we must be careful to be home before dark or she will hit and pulling at me (Interviewee no 15, 2013).

If there’s one place that we usually go for lunch, he expects to go there twice. If he doesn’t, he would scream the place down if he doesn’t get there (Interviewee no 8, 2013).

According to Mc Cubbin & Patterson [13] parenting stress is influenced by a myriad of factors including: child characteristics, family’s perception of the child, the caretaking activities, social resources, cultural impacts, discrimination and stigma. Several parents’ in this study commented on the shame and the frustration that they felt when fielding questions and comments by others.

It’s always difficult to explain to others. To explain to my family, to explain to my child’s class mate’s families, who might come and ask you, “What happens to your son?”. It’s stressful to deal with when people keep asking you “What “happened” to him?” (Interviewee no 4).

For adults, they would be like....”Don’t go near that kid, it could be dangerous!”....it happens...but it is hard to deal with that, when they mean my kid! (Interviewee no 10, 2013).

## Discussion

### The impact of traditional Chinese beliefs

Observing ‘filial piety’ towards one’s parents is a traditional Chinese virtue which includes giving gratitude and repaying kindness. According to this traditional Chinese belief, the existence of a disability is a punishment for an ancestor’s misbehavior, or the disability is due to the current family’s disregard of their obligation to honor their ancestors [13, 14]. According to research conducted by Holroyd [15], Chinese children who have disabilities represent disruptions to the flow of exchanges, in that giving good things to children who have a disability might not make life meaningful in the usual cultural sense understood by a Chinese parent. Thus, the “natural” progression of patterns of reciprocity that flow

over into ancestry and birth is neither immediate, in the form of gratitude, nor generalized, in the form of delayed care, with debts never able to be reclaimed. The care of a child with a disability strains and violates these obligations, leading to the formulation of new guidelines as a form of resistance. Accepting an ASD diagnosis is extremely difficult for many Chinese parents as a result of the influence of their traditional cultural values.

### The Impact of a Discriminating Community and Parental Lack of Faith in Local Services

The main issues of concern raised by the parents interviewed in this study were: the lack of understanding by others, the lack of free educational options, and many parents were concerned for the future care of their child due to the lack of free or HK Government subsidized support services. It is well known that Chinese parents’ hopes and expectations for their children’s educational achievements are high. While the evolution of educational opportunities for people with disabilities is a civil rights issue, there are clearly not enough suitable education options available for children with ASD in HK. In 2009, Wang & Michaels found that families of children with disabilities in HK reported a significant lack of trained professionals to support their children [16]. Little has changed in HK over the past 5 years. Teachers in HK are still not required to obtain special education training prior to being employed to teach children with disabilities in either inclusive or special schools.

In addition, attitude to inclusion is poor among HK teachers. This was another issue repeatedly raised by parents in this study. Parents worried that if they sent their child to a local school, their child would be neglected, or mistreated. This fear seems well founded, as in 2006, the Special Education Society of HK (SESHK) and the HK Primary Education Research Association (HKPERA) conducted a survey among teaching staff of local inclusive schools [17,18]. Findings showed an overall negative view toward students with special needs. In addition, discrimination such as exclusion from social activities, humiliation and neglect by teachers, teaching assistants, and the public, was not uncommon [19].

That’s why I send my child to an international school to study. Not a local school. The local school always thinking about who can get the better marks. But in an international school, they are more open about how to support him, not how to get rid of him (interviewee no 6, 2013).

Due to the expense of private special education services and the long standing Chinese etiological beliefs regarding disabilities [19], many HK/Chinese families are resistant to, or financially incapable of, accessing any adequate education for their child with ASD. This project sought the views of parents of children who were able to afford to send their children to private schools and fee incurring therapy clinics. It is extremely difficult to obtain access to HK families who have no means to fund their child's attendance at suitable inclusive education or community support services [20-25].

There are services here, as long as you can afford it. If you cannot afford it? Oh I don't know what happens to those kids (interviewee no 8, 2013).

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