

THE IMPACT OF A CHILD WITH AUTISM ON THE BRUNEIAN FAMILY SYSTEM**Kathleen J. Tait***Hong Kong Baptist University***Lawrence Mundia***University of Brunei Darussalam*

An investigation of parents' perspectives on family life with a child with autistic spectrum disorder (ASD) in Negara Brunei Darussalam (Brunei) and the socio-cultural context in which these families function was conducted. It has been suggested that the impact of a child with a developmental disability, like autism spectrum disorder, on the family appears to be related to demographic; child and parent characteristics (Dur-Vila, Dein, & Hodes, 2010). Thirty sets of Bruneian parents with children with ASD aged between 4 – 12 years were surveyed regarding the impact of having a child with autism on family functioning. The investigator found that based on the results from the Impact on Family Scale (Stein & Reissman, 2004) that the financial situation, social interaction within and outside the home, and the subjective distress felt by the parents were found to be high on impact. Content analyses of the narrative data indicated that parents' Islamic faith influenced their coping with rearing a child with ASD in Brunei. This study highlights the need for further investigation of parent adjustment in terms of Islamic cultural influence, the context, help seeking and support service uptake.

Parents of children with autism or autistic spectrum disorder (ASD) frequently turn to service delivery systems to access supports designated to help adapt to the challenges of having a child with a life-long impairment. ASD is a pervasive developmental disorder (PDD) defined by abnormal development in social interaction, impairments in communication, and a restricted repertoire of interests and activities (Diagnostic and Statistical Manual – fourth Edition – Text Revision [DSM-IV-TR]; American Psychiatric Association, 2000). Gardner, Grant, and Webb (2001) concluded from their work that the most disabling aspect of autism was lifelong social problems and hardships. Although studies have suggested various supports and coping strategies that are effective for adapting to a family member with a PDD, few studies have examined the experience of families who live in Brunei in terms of their parents' own perceptions of needs, and whether parents felt their needs were being met. In addition, there is overwhelming evidence that leads to the conclusion that formal services and programs are very important for the successful adaptation of the family of a child with ASD (Waldman, Perlman, & Cinotti, 2009).

The present study was undertaken to investigate the effect of children diagnosed with ASD aged between four and twelve years in producing changes related to levels of stress in their immediate family in Brunei. The study was conducted in Brunei as this is a country with extremely limited educational, social and allied health services for families of children with high support needs; communication problems, hearing or visual impairments; intellectual or physical disabilities (Tait, 2008).

Despite the acknowledged importance of the family in this traditional Islamic community, relatively little is known about the functioning of Bruneian families with children with ASD. Therefore, this study was designed to underscore certain variables that are the cause of families of children with autism experiencing higher than average family stress in Brunei. Further, it was hoped that the results of this study will raise awareness for the need of further social, health and educational services for Bruneian families who are currently trying to adjust their parenting skills to cater for a family member with ASD.

The Bruneian context

Since the inception of deinstitutionalization, professionals providing services to children with disabilities have recognized the importance of addressing the needs of parents and other family members (Freedman & Boyer, 2000; Dura-Vila, Dein & Hodes, 2010). In seeking to cater for the extensive therapeutic and educational needs of children with autism, in many countries in the western world, professionals generally involve parents in program planning as well as training them to carry out intervention at home (Dempsey & Keen, 2008). However, in Brunei, only very few support services for families of children with disabilities exist. Specifically, there are currently no government services available to parents of school aged children with autism in Brunei. However, there is one non-government agency (NGO) located in the capital city of Brunei. This service is known as the SMARTER agency and it offers part time day services to children with ASD aged between four and twelve years of age.

One of the hottest current issues in the field of autism 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. The National Autistic Society in the United Kingdom estimates the possible total prevalence rate of all autistic spectrum disorders at 91 per 10,000 (Fitzgerald, 2004). Further, Sturme and Gitzer (2007) 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.

Official current statistics are difficult to come by in Brunei. For example, there is no central register of information pertaining to the incidence of children born with a disability in Brunei (Tait, 2007). However, estimates are that in 2005, Brunei had a population of approximately 348,800 (Europa World Year Book, 2005). The 2003 census, documented by the UN World Urbanization Prospects (2003), indicated that the population of the capital city of Brunei (Bandar Seri Begawan) was 60,874. At the time of the data collection for this research study, only 30 Bruneian families with children aged between (4-12 years) were accessing services for their children via the SMARTER agency which was established in 2000.

Given the above statistics, one could reasonably expect that there is a significant number of Bruneian families raising children with ASD, full-time at home without the assistance of any support service. To date, little has been reported concerning the functioning of families of children with ASD, in Brunei. When one considers the possible number of Bruneian children with autism living at home full time without any educational, health or social services, it is disconcerting that family intervention models have not been more systematically developed and implemented in this country. This lack of research with family members of children with such a high support needs disability highlights an area of great need.

Inclusion of children with high support needs in Brunei Darussalam

In stark contrast to the country's economic wealth, Brunei is very much a developing country in relation to its capacity to cater for families of children with high support needs such as ASD. Although Brunei has a long history of having students with diverse backgrounds in government schools, many students with special education needs do not succeed at school, as the education system there is strongly oriented towards academic performance (Wong, 2005). Indeed, in this country, it is not an uncommon practice for pupils with significant special education needs (such as ASD) to be kept at home due to their disabilities. Further, in the past, children have been turned away by general education schools due to the lack of special education resources to support their special learning needs (Aziz bin Taha, Yoong, & Leong, 2004).

In addition to regular, special and private schools, there are also separate Arabic schools (or Madrasahs) that provide Islamic religious education to children in Brunei. While children with SEN are exposed to religious education to the maximum extent possible, in general, children with intellectual impairments are not considered to be able to perform the necessary religious obligations of the Islamic faith (Tait & Mundia in press). Consequently, it is also unknown how many children with special needs receive instruction in these separate Arabic schools in Brunei.

However, in recent years the Ministry of Education (MOE) along with other interested parties (including the SMARTER agency), has taken various steps to develop a system that is more receptive to the educational needs of all students (Tait, 2008). As with any education system, change comes slowly when

that change requires a reform to previous systemic principles, standards and practices. Consequently, Brunei is only beginning to pave the road to inclusive education.

Significance of impact

The birth of a child with any disability can have significant psychological implications. Parents may experience anger, grief and confusion (Einfeld & Emerson, 2008). Yet programs serving children with disabilities have often planned intervention with families as if they were a homogenous group, not recognizing that families differ in their ability to manage stress and in their coping styles, individual resources and needs (Dempsey & Keen, 2008). In their study of intellectual disabilities across cultures, O'Hara and Bouras (2007) found that in a state of need and emotional distress, parents and relatives may turn to religion to ease their feelings of distress and to answer questions regarding the ultimate cause of the disability. Further, there is a perspective emerging in the literature that the problems experienced by families of children with high support needs are often more related to their own resources, social supports and reaction to stress than to the child's disabling condition (Tait, 2010a; Siklos & Kerns, 2006).

The lack of research done on the impact of a child with ASD in Brunei and the subsequent needs of the family highlights this as an area in serious need of investigation. Consequently, the present study was designed to address the research question: What demographic variables, child and family characteristics contribute significantly to perceptions of Islamic family functioning and stress as measured by financial impact, disruption to social systems, general impact, coping and total impact? Specifically, what particular characteristics of these families and of the children with ASD are associated with the level of family functioning and the amount of family stress reported by these parents? It is anticipated that the results of this study will be of extreme importance for the relevant Bruneian government departments and service providers and of families of children with ASD who often experience added stress.

Method

Participants

The total sample consisted of 40 parents (10 fathers and 30 mothers) from 30 families who were rearing at least one child who had ASD between the ages of 4 – 12 years and who was attending the SMARTER Centre in Bandar Seri Begawan. The age range of the child (4-12 years) was chosen as it represents the early to middle childhood and pre-pubescent years in which increasing adjustment problems are thought to arise. At the time of the data collection, 30 families with children with ASD were being assisted by the SMARTER Centre. Therefore, the data collected in this study represents the total population attending the SMARTER Centre.

Procedure

Staff at the SMARTER Centre provided a list of all families with a child with ASD who were accessing services from this agency, who resided in the Bandar Seri Begawan metropolitan region and who were registered with this NGO. Thirty families were sent an introductory letter explaining the aims of the study and what was involved. Within two weeks, all families had agreed to be involved in the study.

Data Collection:

Data were obtained in two ways. Firstly, from an in-person, semi-structured interview and 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) (Stein & Reissman, 2004). The interview was designed to obtain general demographic information such as parents' marital status, occupation, employment status, children's ages, and parents' relationship to the child with ASD. Further information was gathered on issues such as medical, intellectual and communication problems, an index of level of dependence in activities of daily living (adapted from Breslau et al., 1982); and questions regarding therapy services, schooling, and family adjustment to living with a child with ASD were also sought via interview.

The interview was carried out by a trained Bruneian special education teacher, an experienced educationalist who could speak both English and Malay fluently. The interviewer contacted each family by telephone and arranged a mutually convenient time to visit. In all cases, the agreed upon time was after school between 5.00pm and 8.00pm. When the interviewer arrived at the family home, she introduced herself, briefly explained the format for the visit, the nature of the interview, and how to complete the IFS. 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 father? The interviewer recorded this information manually on prepared data collection sheets. Separate sheets were constructed for each family. The results/answers from the interview questions were member checked by the parent/s immediately post interview to maintain the reliability and integrity of the data.

The Impact on Family Scale (IFS)

According to Williams, et al., (2006) the 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. A paper and pencil format was used to facilitate the administration of the IFS questionnaire which was printed in English. The parents were given a letter briefly explaining the objectives of the study and the interviewer gave directions on how to complete the IFS (i.e., rate each item on a scale from 4 (strongly agree) to 1 (strongly disagrees)).

The most frequently spoken language in Brunei is Malay. While most Bruneians speak some English, proficiency in written and spoken English can vary considerably. Consequently, in case parents required any assistance in translating what was written on the IFS questionnaire, the interviewer (also a translator) was able to assist in the collection of the IFS material used in this study. The IFS was completed by all parents of children with ASD who attend the SMARTER agency in the form of a home visit with both parents where possible. Finally, in conclusion to the data collection, respondents were invited to offer a more extensive and free narrative when asked *Is there any advice that you would like to give to someone with a child like _____ [target child's name] in the family? Or do you have anything further to say about raising a child with ASD in Brunei that has not been covered tonight?* Respondents wrote their comments to these questions in a prepared open ended section at the end of the IFS questionnaire form.

Data Analysis

Information obtained from the parent demographic 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. Since the sample was non-random, it generated non-random data. In view of this, it was only possible to use non-inferential or non-parametric statistics (e.g., descriptive statistics) to analyse the data. Descriptive statistics (i.e., mean, median, and co-efficient of skewness) were used to analyse the data obtained from the non-random sample. In addition, pictorial representations were employed to visually present the data. The procedures were deemed to be adequate to meet the objectives of the study. All data analyses were done using the SPSS version 16.

Results

General description of the children with autism

In the sample (n=30) there were: (1 x 4 year olds, 1 x 5 year olds, 8 x 6 year olds, 11 x 7 year olds, 3 x 8 year olds, 2 x 9 year olds, 1 x 10 year olds, 1 x 11year olds, and 2 x 12 year olds). Twenty-four were male and six were female with a mean age of 7.4 years. Families were unsure of the term intellectual ability and most parents viewed their child as functioning as either average or below average intelligence. In this small group of children, 16 were considered to be below average intelligence and 14 children were considered to be of average intelligence. Consequently the heterogeneity of the ASD population is not illustrated in this group. Only four families indicated that their child had an additional medical, sensory or emotional problem. In their parent's opinion, 3 children had asthma and one child was considered to be hyperactive.

The birth order of the children varied. In 14 families, the child with ASD was the youngest; in 10 families they were the oldest and in 16 families, occupied a medial position. The mean ranking for birth order was 2.233. The children attend various educational venues: 9 (30%) are enrolled in their local primary school for half of the day and attended the SMARTER centre for the other half of the day, while 21 (70%) attend classes at the SMARTER centre only.

Twenty-three children (76.6%) had received some form of therapy during their life at either the SMARTER centre or the Government Hospital. It should be noted that there is very little consistency in the provision of therapy as a support service in Brunei. There are no private clinics, no education dept therapists etc, only government hospital departments. Some families had only accessed Hospital therapy when the child was very young (birth to two years and prior to diagnosis) but after diagnosis the families

were offered no more therapy at the hospital. One family told the investigator that upon receiving their child's diagnosis, a hospital social worker gave them a brochure to read on autism, and they were told to take their child home. That was the extent of the support service that they were ever offered by the Bruneian Government.

None of the children with ASD in this study had access to any therapy or educational services until they were enrolled at the Smarter Centre. Also, families were confused as to exactly what type of program was being offered by the SMARTER centre. Some families indicated that their child did receive therapy at the Smarter Centre. While others families seemingly unsure, indicated that their child attended the Smarter Centre, but also checked the box that indicated that their child did not get any therapy there. According to the staff at the Smarter Centre, if the child attends the Smarter Centre, the children do get therapy (of a sort). Consequently, the position is not clear.

General description of the families

Specific characteristics investigated in relation to the composition of the families involved in this study were: marital status, the relationship of the child with the disability to his/her caregivers, the relative size of the family, the socio-economic status of the family (determined by the father's occupation) and the age of the parents. An over view of these families' social networks is also presented.

In 100% of the families, the parents were married, this being their first marriage. With regard to the parent-child relationships: in all cases (n=30, 100%) the child with ASD was the mother's own child, with 100% of the cases (n=30) being the father's own child. Only three children were Brunei Nationals. In the majority of cases (n= 24), the children were of Malaysian descent, two children were Chinese and one child was Indonesian. Family size varied from one to seven members with a mean of 3.63. In the majority of cases (n=14, f=47%) there were three or four children.

Socio-economic status was estimated from the father's occupation according to Jones' Scale of Occupational Prestige (1989). The majority (n=22, f=73%) fell into categories 3 and 4, the middle level occupations, designating these families as lower to upper-middle class. Five fathers (16.6%) held positions categorized as lower class (e.g., hospital attendant, prison warder, technical assistant, etc.), while only three fathers, a Managing Director, a University Lecturer, and an accountant) were considered to hold an upper class position). Eight (26.6%) of the mothers were occupied with full time home duties: 21 (70%) had full time positions (e.g., teacher, nurse, government officer, religious officer, etc); while only one mother (3.3%), a Director, was considered to hold an upper class position.

The maternal age ranged from 23 years to 45 years with the mean age of mothers at the time of the birth of the child with ASD being 30.5 years. The paternal age range was similar to the mothers, being 23 years to 44 years with the mean age of fathers being 32.1 years at the time of the birth of the child with ASD.

Family Functioning Measures

The main findings from the Financial Impact, Disruption of Social Relationships, General Impact, Coping and Total Impact scales are summarized in Table 1. Following on from this, there are brief explanations of each of these five variables and an explanation of the findings of this study.

Table 1. Descriptive statistics on the five scales of the Impact on Family Scale

Variable	Scale	Mean	Median	SD	Skewness
1	Financial Impact	5.43	6.00	1.69	-.61
2	Disruption of Social Relationships	20.70	21.00	3.87	-.76
3	General Impact	25.77	27.00	5.14	-1.39
4	Coping	6.30	6.50	1.78	.06
5	Total Impact	49.63	52.00	9.32	-.97

Financial Impact

The Financial Impact (FI) score is the factor which measures financial burden. There was a high adverse financial impact on most families with a child with autism (see Table 1 for all five variables). Half of the families scored above the median (6.00) which was higher than the mean (5.34). This finding is further

supported by the negative coefficient of skewness (-.61) and the left skewed figure (histogram with a line graph) for the Financial Impact variable.

The birth of any child requires a relocation of finances (Parette, Meadan, & Doubet, 2010). However, expensive care is a common problem for families with a child with a disability. This impact is mentioned by a number of writers in this field (Magana, Schwartz, Rubert, & Szapocznik, 2006; Skinner & Weisner, 2007). In the case of this investigation, all families needed to earn a living and to subsequently decide how best to spend the income according to each family's individual requirements. The presence of the child with ASD may have created an economic need, increasing the family's consumptive demands. Due to this excessive economic impact, parents may have perceived the family sacrificing the expenditure of the family income in favour of the child's disability.

Another possible reason for high family impact results is lack of government funds. In Brunei, there is no financial assistance for the services required by children with ASD and so the cost of care is not covered. The parents must pay a small tutorial fee for their child to attend the Smarter Centre. The monthly tuition fee costs less than \$400 Bruneian dollars. Yet, for low income families in Brunei, it was a significant expenditure. Many parents mentioned the impact of the cost of the Smarter Centre fees and the fact that there was no Government subsidy. One parent indicated that she knew of families who had a child with autism who could not afford to pay for the Smarter Centre fees. Sample comments are as follows:

The SMARTER centre requires sponsoring and donation from parents and other people. Financial problem is affecting some parents. They cannot afford to send their children to SMARTER (Interviewee 1, 2010).

We need help from government in terms of financial. Autistic children does not know that when we tell them we cannot afford them some of their needs, In other countries, parents of autistic children are given allowances We don't need much, just to cover the monthly fees of attending Smarter School(Interviewee 2, 2010).

We get no help from the government. No help! In the extended family like mine it's required two domestic helpers for looking after well being of the children (Interviewee 3, 2010).

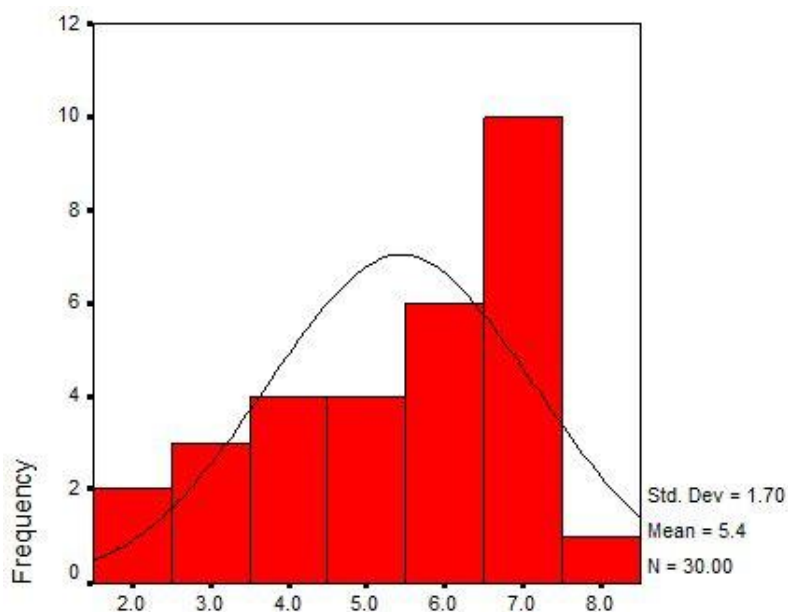


Figure 1. Financial Impact

Disruption of Social Relations

The Disruption of Social Relations (DSR) score is a familial-social support factor which addresses the social interactions both within and outside the family. Evidence from Table 1 indicates that most families with a child with ASD experienced a disruption of social relationships and hence scored high on the DSR scale (see negative skewness and a median higher than the mean in Table 1). This claim is visually

illustrated by the left skewed figure for the DSR variable. All these pieces of evidence suggest that having a child with ASD highly disrupted the social relationships of the family.

The fact that the child with ASD can sometimes require almost constant attention from a parent is one of the major factors in preventing a parent's involvement in social activities. Parents may find themselves spending the bulk of their time in the home, physically apart from friends and family not residing with them. They may be overly busy with the child, embarrassed by the stigma of the disability, of fatigued from frequent or lengthy medical/therapy visits, complex feeding, dressing, bathing and toileting routines. Many family members have reported feelings of loneliness, social isolation or distance from friends and neighbours, relatives and their communities (Katbamna, Bhakta, & Parker, 2000). Another reason for the disruption of social relations may be seen in the friends, neighbours' and relatives' feelings of discomfort and lack of knowledge about appropriate ways to interact with the child with autism and his/her family.

Aspects of social relations that were potentially affected by social curtailments included the parent's job schedule or occupational choice, church (or mosque) attendance, vacations, hobbies and general social events (Buntinx & Schalock, 2010). Families of children with Down's syndrome were found to partake in fewer holidays, outings and visits with grandparents than were families of non-disabled children (Cheng & Tang, 1995). Sample parent comments were:

As a parent, we should not be ashamed of them as I understand it, a lot of other family tried to hide it (Interviewee 4, 2010).

Problems – if he doesn't attend school and preoccupied most of the time, he is getting more hyperactive. His toilet habit (pee) particularly seems to be out of control and timeless (Interviewee 5, 2010).

There is not much support from society in Brunei. The community as a whole does not understand what autism is, so people tend to laugh or just find them troublesome or 'weird'. Even my closest family do not given enough support (Interviewee 6, 2010).

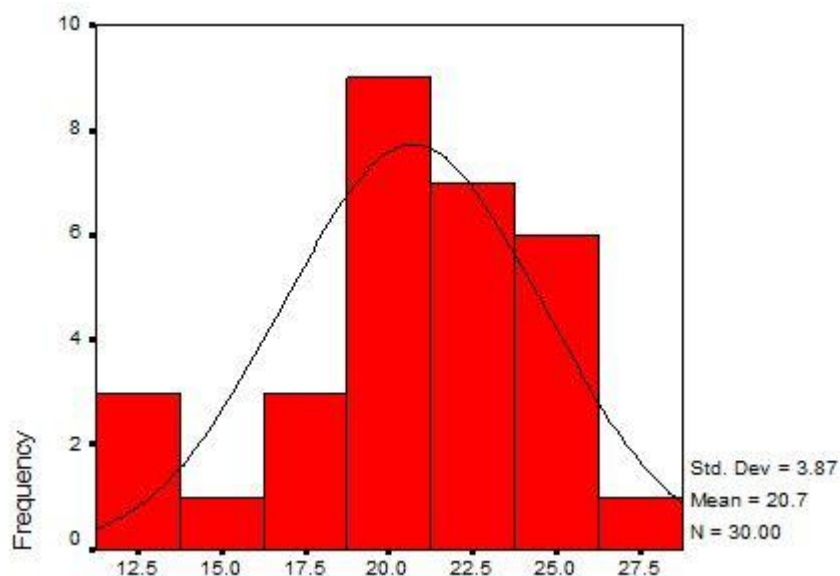


Figure 2. Disruption of Social Relationships

General Impact

The General Impact (GI) score is a personal strain factor that measures subjective feelings of a family's stress. In general, the presence of a child with autism in the family tended to have had a negative impact on the normal functioning of the family (see descriptive statistics in Table 1 and the left skewed pictorial representation for the General Impact variable).

Caretaking demands of children with ASD often exceed those of the non-disabled child. In general, children with ASD require that their parents do many things for them, such as feed them, toilet them, dress them etc. While some normally developing children also require this care, the quantity and longevity of the non-disabled child's care requirements are usually less intensive.

A frequent emotional problem associated with the impact of a child with a disability on the family is parental depression (Tait, 2010b). Some time ago, Olshakky (1991) described a process that he called ‘chronic sorrow’ in which parents carried feelings of sadness throughout their lives. Arney and Scott (2010) report feelings of hopelessness in parents of children who are developmentally delayed. Increased rates of suicide are also reported, although much less frequently than milder depressive reactions (Berman, 2003).

Thus, while the nature and severity of a child’s disability condition may affect the family response; other factors, particularly the parental perception of the difficulty, may moderate or exacerbate the difficulties. For example, parents could be better able to respond positively to the child if they did not define the disability as an unmanageable strain or hardship. If the parents see the child’s condition as a fateful occurrence to be dealt with adaptively or as a fact of life that they can handle together, their adjustment capability could be better than if they interpreted the disability as a family disaster or an insurmountable problem (Skinner & Weisner, 2007).

However, while parents of normally developing children know that their children will ultimately become self-sufficient adults, parents of some children with ASD may always be burdened by unrelenting demands and dependency. Feelings of uncertainty of what the future holds can increase the stress already felt by parents of children with a disability. Ageing parents particularly become increasingly stressed by concern for the care and placement of their child with a disability when they are too old to look after them.

Sample comments were:

I don’t know what will become of my son when he is 18 years old. I’m not sure if he will be accepted to work or not be taken advantage of. I pray and hope things will be better and people will be kinder to him (Interviewee 7, 2010).

What we are worried and afraid about is the future of our child with autism. We are hoping that our children with autism will receive an allowance from the government so that they can be independent in the future if parents or guardians are no longer alive (Interviewee 8, 2010).

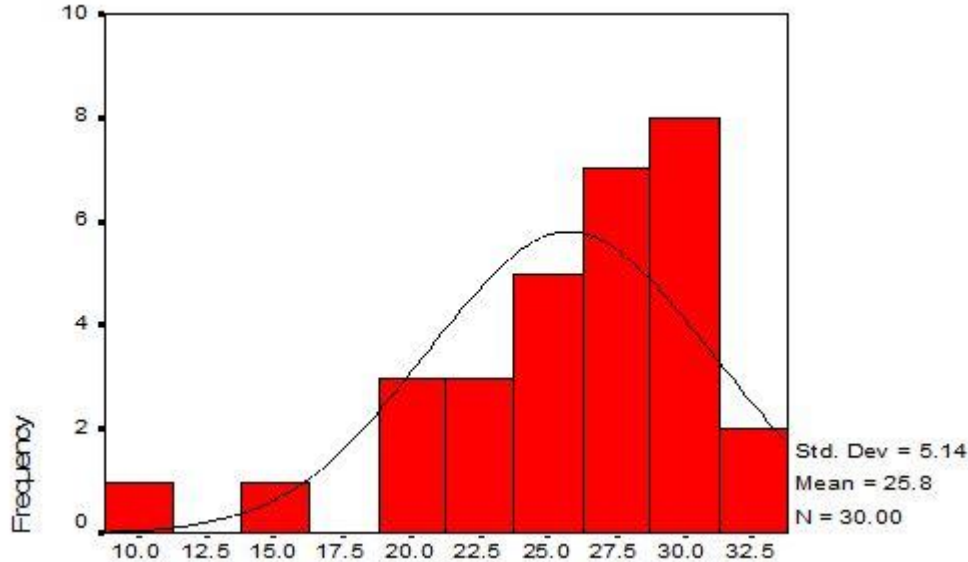


Figure 3. General Impact

Coping

The final individual score for family functioning is a positive one, Coping (CP) which addresses the change in a parent’s sense of mastery over the management of his/her child with a disability. From the values in Table 1 and the almost norm curved histogram and line graph for the Coping variable, it seems that nearly a half of the families in this study might be coping reasonably with the distress of living with a child with ASD. However, it also appears that the other half may be incapacitated by this situation.

DeFrain, Asay, and Geggie (2010) found that an individual’s conceptions of the world and the cosmos, his or her place in it, and one’s belief system influenced coping. *In particular*, the past several years have seen a virtual explosion of research in the area of religion, spirituality, and coping, (Gall,

Charbonneau, Clarke, Grant, & Shouldice, 2006). In a study undertaken by Thomas, Dowling, and Nicoll (2004), the findings stressed that spirituality could play an important role for many parents in their grieving process after the birth or diagnosis of a child with a disability and in their ways of coping and sense of well being. All of the parents in the present study were followers of the Islamic faith, and fourteen families in this study spontaneously mentioned their religion in their final interview response. Brunei is a traditional Islamic state. There are five public calls to prayer each day. It may well be that having a strong religious belief system to rely on is the main mechanism for coping to the adjustment of rearing a child with ASD by these Muslim parents. Specifically, 47% of the parents in the present study reported that having faith in *Allah* served as a means for interpreting and giving meaning to their child's disability. Sample comments were:

This child is a test that we can accurately say is from Allah the Almighty to our family. This is for us to be more patient when faced with other challenges (Interviewee 9, 2010).

A child is a responsibility given by Allah the Almighty. Look after him/her well and God willing, you will be blessed by this test. Amen (Interviewee 10, 2010).

Parents should not worry if they have a child with autism because the child is special. Autistic child is a gift child (Insyah Allah) (Interviewee 11, 2010).

Thus for some of the Muslim parents of children with ASD in Brunei, the birth of their child became a reaffirmation of their Islamic beliefs. That is, their child's disability was proof to them of Allah's purpose and faith in them as parents.

For these parents, their child's diagnosis has clearly evoked positive attributions. Their perception was that their child with ASD was a test or a divine blessing from Allah to their family. It has been suggested by Dura-Vila, Dein, and Hodes (2010) that a strong religious faith (as is the case in Brunei which is a culture that supports a traditional and very public Islamic way of life), might attribute ASD to external causes. Such faith provides a sense of meaning, resulting in greater acceptance of children with disabilities, and lowering the levels of parental stress and self-blame. Several parents of children with ASD in this study used their religious socio-culture as a way of making sense of why disability has happened to their children, and to come to an understanding about themselves, and their child's disability through their Islamic beliefs.

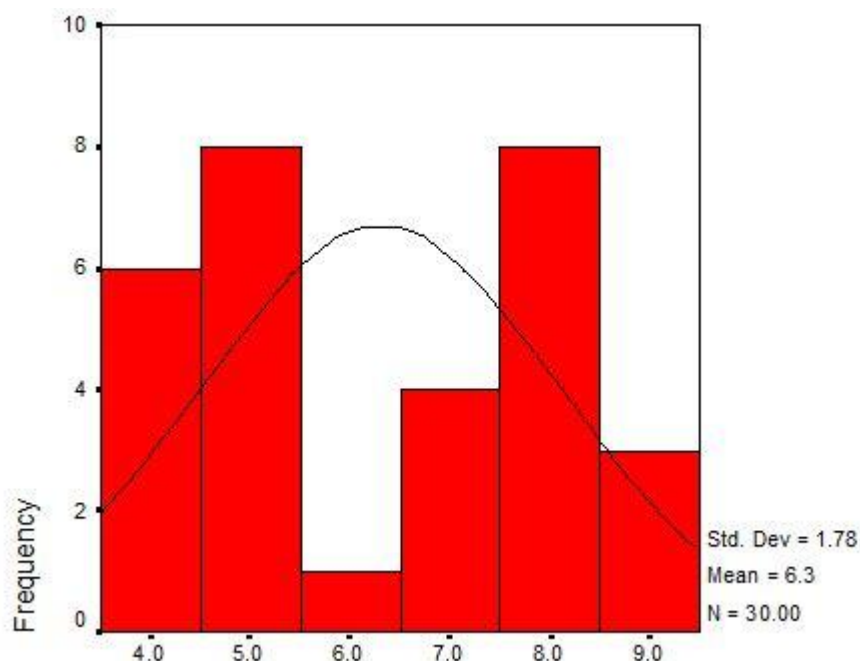


Figure 4. Coping

On the other hand, there may be some families in this country who experience a challenge to their Islamic faith. The comment below hints at a weakening of faith.

Life with a child with autism is very different and challenging especially for your patience and faith(Interviewee 12, 2010).

In such situations, a families' faith may not withstand the encounter with a God, who would allow such a thing to happen to their child and their family. The resulting consequence is likely to be feelings of guilt (Stubblefield, 1977), and the stress accompanying this religious adjustment is likely to be considerable.

Total Impact

The Total Impact (TI) score is a general measure of impact of disability on family functions. This score quantifies the impact of childhood disability on various components of family life: the financial situation, social interaction within and outside the home, subjective distress felt by the parent and a positive sense of mastery which may emerge from coping with stress. Overall, the total impact of having a child with ASD was devastating on most families surveyed as shown by the high values of the mean, median and negative skewness (all diagrammatically presented in the figure below).

The Total Impact measure is a composite measure of the financial impact, disruption of social relations and personal strain measures. The literature abounds with studies of the negative impact of a child with a disability on family functioning. In nearly all cases, the child with the disability is reported as affecting in a negative way some or all of the following: finances, relationships with friends and relatives, planning daily activities, or family vacations. The results of both Larson's (2010) and Demarle and Le Roux's (2001) studies of the views of parents of children with disabilities seem to confirm the findings in this investigation. In this study the parents of children with ASD in Brunei felt that there was inadequate emotional, financial and physical relief from the continuous burden of caring for a family member with a disability and that the existing educational services were considered inadequate in terms of such provisions.

There is not much support from the Government in Brunei on matters related to Autism. Most government school teachers are not trained to handle autistic children, so we need to send them to private school and to ASD centre (SMARTER) and this cost extra money and time (Interviewee 13, 2010).

Only parents that have autism children know the worry they are carrying rather than parents doesn't have autism children (Interviewee 14, 2010).

It is hard to have a child with autism. Even our family, my husband parents do not understand our child behaviour. What is the future of our child with autism? (Interviewee 15, 2010)

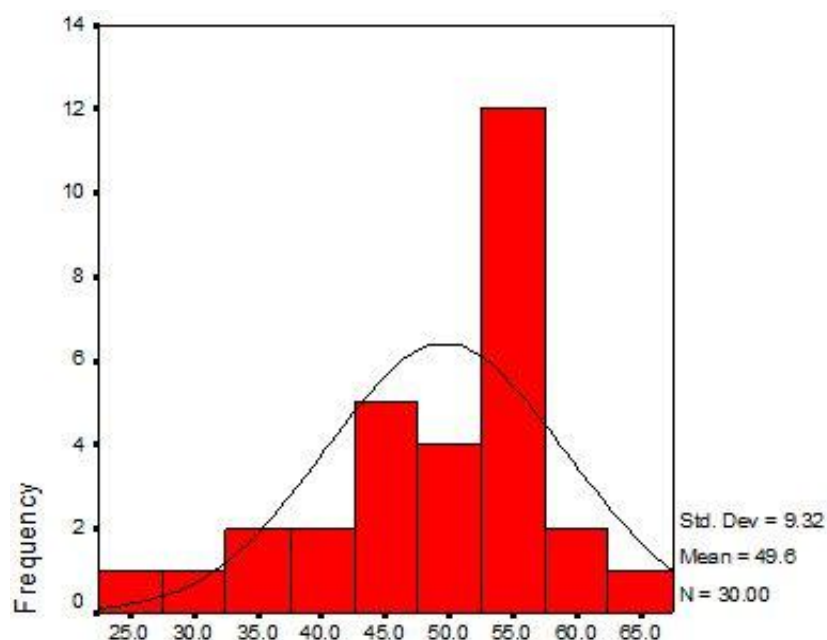


Figure 5. Total Impact

Summary of Results

The present study was undertaken to determine the effect of children with ASD aged between 4 – 12 years on their parents' perceptions of family functioning and stress. From a review of the literature, it may be concluded that the determination of patterns of impact of children with ASD on their families is extremely complex. The results indicate that the consequences of having a child with a disability in Brunei are neither unequivocally positive nor negative; Bruneian parents' reactions were influenced by the interaction of a wide range of contextual family variables.

Limitations of the Study

Sample size

A problem faced by the authors was the very small sample size being only 30 cases in total. In quantitative research it is generally desirable to have a minimum of 30 cases (McMillan, 2008). When many uncontrolled variables are present, as was the case in this study, a large random sample is the best solution since it ensures to some extent that the uncontrolled variables will themselves be operating for the different groups being studied and therefore will not have a systematic effect upon the results.

Participant sample

The sample used in this investigation may have been biased in favour of families who appear to have adjusted to some level of satisfaction to the presence of a child with ASD in the family. The major factor which contributes to this possible bias is that families who chose to be involved in this investigation had already taken the step to enrol their child to a special education facility (i.e., the Smarter Centre). Attendance at this centre automatically identifies that their child has a significant disability. Thus, these families may have differed substantially from families who are not willing to reveal that they have a child with ASD (preferring instead to hide their child at home full time).

If the act of sending their child to the Smarter Centre for their education, can be interpreted as one index of coming to terms with the reality of a child with a disability, the insights provided by these coping families could make a valuable contribution to professional knowledge concerning healthy patterns of family functioning and the mechanisms involved in coping well.

Conclusion

There are clearly many issues relating to the assessment of family impact that could be addressed. The family functioning measures used in this investigation were financial impact, disruption of social relations, general impact, coping and total impact. The results of this investigation indicated that the impact of a child with ASD on Bruneian families emerged as a major factor in family functioning. These findings reveal that in a variety of ways, a child's disability poses a threat to parents' perceptions of life satisfaction and their ability to fulfil their responsibilities.

Based on the world wide incidence of ASD, one may confidently presume that there are many more families with a child with ASD living in Brunei, than the 30 families identified in this study. However, at the time of this study, there were only 30 families who had children with ASD attending the Smarter Centre. Thus, access to the total population of Bruneian families who had identified that they had a child with ASD was achieved and the details of those 30 families were reported in this investigation.

According to Tillisch (2007) lack of experimental contact with well-adjusted families can help perpetuate the myth that dysfunction is a normative pattern for families with a child with a disability. Thus, if the role of professionals is to be maximally effective there is a pressing need for research which is primarily concerned with healthy family adjustment. A comprehensive review of family functioning must encompass the entire range of possible adaptations, both positive and negative, as well as the factors that contribute to such adaptation.

Under the best circumstances, raising a child with a disability requires significant adjustment. In a state of need and emotional distress, parents and relatives may turn to religion (*It is Allah's will*), to ease the intensity of distressing feelings and to answer questions regarding the ultimate cause of the disability (O'Hara & Bouras, 2007). For many of the Muslim families in the present study, religious coping was identified as an important coping strategy. The providers of effective special educational service provision may have limited understanding of Islamic families' cultural values and communication patterns, or they may hold stereotypical views about them (Gall, Charbonneau, Clarke, Grant, & Shouldice, 2006). Such a lack of knowledge may result in educational and support service provision that do not properly address Islamic families' problems and needs. Consequently, stake holders must

understand that positive or negative personal transformations through religious beliefs do not eliminate the challenges and problems associated with taking care of a child with ASD (Skinner & Weisner, 2007).

In general, parents of children with developmental disabilities experience higher levels of parenting stress than those in families that are unaffected by childhood disability (Fidler, Hodapp, & Dykens, 2000). However, Turnbull and Turnbull (2006) have appraised some parents as responding to the emotional and caretaking challenges they face when their child has a serious disability with positive coping and resiliency. When encouraging parents' involvement in their child's educational program, professionals need to be aware of the overall effects on parents of this additional responsibility and question whether they are being unrealistic in their demands and expectations. Parents should be considered as primary caregivers first and educationalists second. Parents are not equally suited to being advocates, decision makers and teachers for their children (Tillisch, 2007). A different way of viewing parent participation is that their involvement should have positive parent outcomes reducing stress, increasing family coping and improving relationships within the family with a child with ASD.

Although several research studies have investigated parental experiences of quality of life and the impact of raising a child with a severe disability in white families (Hatton, Akram, Robertson, Shah, & Emerson, 2003), little work has focussed on the experiences of families living in remote communities such as Brunei. The present study is clearly only a preliminary starting point, and future research in this area is much needed, particularly as financial and social impact have such important long term consequences for families. However, while this study tentatively supports the idea that the basic ways in which parents adapt to a child with disabilities maybe similar across cultures, the authors also wish to point out that there may be cultural patterning in the way that these processes operate particularly when families live in a traditional Islamic state. In addition, the broad impact of socio-economic deprivation should not be lost when considering the impact of ethnicity and culture on access to educational and support services in small countries like Brunei.

The last decade of family stress research raises the exciting possibility of not only explaining and predicting family behaviour in response to a child with a disability such as ASD, but also in suggesting ways to improve it. It is obvious that documenting and evaluating family impact of raising a child with ASD in a remote community such as Brunei continues to be a complex issue.

Author note:

Approval to undertake this research was obtained by the administration of the SMARTER agency in Negara Brunei Darussalam. Further, each parent gave their written permission to be surveyed and for the authors to use the resulting data for dissemination for research purposes. The project did not receive any external funding and no restrictions have been imposed on free access to, or publication of, the research data. The authors have no financial or non-financial conflict of interests with respect to this manuscript.

References

- American Psychiatric Association . (2000). *Diagnostic and statistical manual of mental disorders (4th ed. – text revision)*. Washington, DC: Author.
- Arney, F., & Scott, D. (2010) (Eds). *Working with vulnerable families: A partnership approach*. Melbourne: Cambridge University Press.
- Aziz bin Taha, A., Yoong, W. K., & Leong, K. T., (2004). Perceptions of special education needs assistance teachers and regular teachers towards collaborative roles for delivering services to pupils with special education needs. *Brunei Darussalam Journal of Special Education*. 1. 67-84
- Berman, A. L.,(2003). An idiographic approach to understanding suicide in the young. In R.A. King & A. Apter (Eds.), *Suicide in children and adolescents* (pp. 198-210). Cambridge: Cambridge University Press.
- Breslau, N., Staruch, M., Mortimer, E. (1982). Psychological distress in mothers of disabled children. *American Journal of Disabled Children*. 136 (8), 682-686.
- Buntinx, W. & Schalock, R. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*. 7 (4). P. 283-294.
- Cheng, P., & Tang, C.(1995). Coping and psychological distress of Chinese parents of children with Down Syndrome. *Mental Retardation*. 33. 1. 10-20.
- DeFrain, J., Asay, S., and Geggie, J. (2010). Family strengths: An international perspective. In F. Arney, & D. Scott, (Eds.) *Working with vulnerable families: A partnership approach*. (pp 29-48) Melbourne: Cambridge University Press.

- Demarle, D.J., & Le Roux, P. (2001). The life cycle and disability: Experiences of discontinuity in child and family development. *Journal of Loss and Trauma*, 6,1, 29-43.
- Dempsey, I., and Keen, D. (2008) A review of processes and outcomes in family centred services for children with a disability. *Topics in Early Childhood Special Education*. 28, 1, 42-52.
- Dura-Vila, G., Dein, S., and Hodes, (2010). Children with intellectual disability: A gain not a loss: Parental beliefs and family life. *Clinical Child Psychology and Psychiatry*. 15, 2, 171-184.
- Einfeld, S., and Emerson, E. (2008). Intellectual disability. In M.Ruter, D.V.M. Bishop, D.S. Pine, S. Scott, J. Stevenson, e. Taylor, & A. Thapar (Eds.), *Rutter's child and adolescent psychiatry* (5th ed.), (pp 820-840). Oxford:Blackwell.
- Europa World Year Book . (2005). *The Europa World Year Book Volume 1, Part one: International Organizations*. London: Routledge Taylor & Francis Group
- Freedman, R. I., & Boyer, N.C. (2000); The power to choose: Supports for families caring for individuals with developmental disabilities. *Health and Social Work*. 25, 1, 59-68.
- Fitzgerald, M., (2004). *Autism and Creativity: Is there a link between autism in men and exceptional ability?* New York: Brunner-Routledge.
- Fidler, D.J., Hodapp, R.M., & Dykens, E.M. (2000). Stress in families of young children with Down syndrome, Williams syndrome, and Smith-Magenis syndrome. *Early Education and Development*, 11, 395-406.
- Gall, T., Charbonneau, C., Clarke, N., Grant, K., & Shouldice, L. (2006). A Clinical interview assessing cancer patients' spiritual needs and preferences. *European Journal of Pain and Symptom Management* 30, 154-159 .
- Gardner, J., Grant, J., & Webb, M. (2000). (2nd ed.). *Communication for all kids: Using an exchange communication system in your classroom*. Canning Vale, WA: KLIK Enterprises.
- Hatton, C., Akram, Y., Robertson, J., Shah, R., and Emerson, E. (2003). The Disclosure process and its impact on south Asian families with a child with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. 16, 177-188.
- Jones, F.L. (1989) Occupational Prestige in Australia: A New Scale. *Journal of Sociology*. 25, 2, 187-197.
- Katbanna, S., Bhakta, P., Ahmad, W., Baker, R., & Parker, G. (2002). Supporting south Asian carers and those they care for: The role of the primary health care team. *British Journal of General Practice*, 52, 477, 300-305.
- Larson. E. (2010). Psychological well-being and meaning-making when care giving for children with disabilities: Growth through difficult times or sinking forward. *Thorofare*. 30, 2, 78-86.
- Magana, S., Schwartz, S., Rubert, M., & Szapocznik, J., (2006). Hispanic caregivers of adults with mental retardation: Importance of family functioning. *American Journal of Mental Retardation*, 111, 250-262.
- McMillan, J. (2008). *Educational Research: Fundamentals for the consumer* (5th Ed). Boston: Allyn & Bacon.
- O'Hara, J. & Bouras, N. (2007). Intellectual disabilities across cultures. In D. Bhugra & K. Bhui (Eds.), *Textbook of cultural psychiatry* (pp. 461-470). Cambridge: Cambridge: University Press.
- Olshakky (1991). Chronic sorrow: analysis of the concept. *Journal of Advanced Nursing*. 16, 11, 1311-1319.
- Parette, H., Meadan, H., and Doubet, S., (2010). Fathers of young children with disabilities in the United States: Current status and implications. *Childhood Education*. 86, 6, 382-388.
- Siklos, S., & Kerns, K., (2006). Assessing the need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders*. 36, 921-933.
- Skinner, D., & Weisner, T. S. (2007). Socio-cultural studies of families of children with intellectual disabilities. *Mental Retardation and Developmental Disabilities. Research Reviews*, 13, 302-312.
- Stein R., and Reissman, C., (2004) *Impact on Family Scale (Revised edition)*. Bronx. New York: Albert Einstein College of Medicine.
- Stubblefield, H. W. (1977). Religion, parents and mental retardation. In C. J. Drew, M.L. Hardman, & H.P. Bluhm (Eds.), *Mental Retardation. Social and educational perspectives* (pp. 32-37). Saint Louis: C.V. Mosby Company.
- Sturmey, P., and Fitzer, A. (Eds.). (2007). *Autism spectrum disorders: Applied behaviour analysis, evidence, and practice*. Austin, TX: Pro-Ed.
- Tait, K., & Mundia, L. (2012). Preparing teachers to meet the challenges of inclusive education in Negara Brunei Darussalam. In C. I. Forlin (Ed.), *Future directions for inclusive teacher education: An international perspective* (pp. 60-69). Hong Kong: Routledge/Francis & Taylor.
- Tait, K. (2010a). Developmental and physical disabilities. In V. Green & S. Cherrington (Eds.), *Delving into diversity: An international exploration of issues of diversity in education*. (pp. 123-124) New York: Nova Science.

- Tait, K. (2010b) Supporting Students with Intellectual Disability. In Hyde, M. B., Carpenter, L. & Conway, R. *Diversity and Inclusion in Australian Schools*.(pp 202-234). Melbourne: Oxford University Press.
- Tait, K. (2008) Enhancing community attitude towards children with severe disabilities. *Pendidikan, Brunei Darussalam*, 12, 53-64.
- Tillisch, D. (2007). New research provides a snapshot of parents with children who have special needs. *The Exceptional Parent*.37, 11, 43-44.
- Thomas, B., Dowling, C. and Nicoll, N. (2004). Spirituality. In B. Thomas and C. Dowling (Eds.), *Parenting a child with special needs* (pp. 167-183). London: Souvenir Press.
- Turnbull, A., and Turnbull, R. (2006). Fostering family-professional partnerships. In M.E. Snell and F.Brown (Eds.), *Instruction of students with severe disabilities* (6th ed., pp.28-61). Upper Saddle River, NJ: Pearson.
- UN World Urbanization Prospects (2003), United Nations. (1975). U.N. *Declaration on the Rights of Disabled Persons*, 1975. Retrieved from [http:// www.unhchrch/html/menu3/b/72.html](http://www.unhchrch/html/menu3/b/72.html) Accessed online on February 17th, 2011.
- Waldman, H., Perlman, S., & Cinotti, D. (2009). Living in the right state may be important if you have a child with a disability. *The Exceptional Parent*. 39, 10/11, 74-76.
- Williams, A., Piamariyakul, U., Williams, P., Bruggeman, S. & Cabanela, R. (2006). Validity of the revised Impact on Family scale. *Journal of Pediatrics* 149, 2, 257-261.
- Wong, J. (2005). Special Education in Brunei Darussalam. *Brunei Darussalam Journal of Special Education*. 2, 1-15.