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Support for Parents of Children with Disabilities in Malaysia

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Abstract: Parents of children with disabilities need information and practical support in order to reinforce their confidence and ability to cope with the stress of parenting their children. The objective of this study is to to gain an understanding on the availability and types of support perceived by parents of children with disabilities in Malaysia. About 20 parents of children with various disabilities were interviewed. The interviews were transcribed and analyzed for themes. Findings suggested that there is a lack of comprehensive information and support for parents of children with disabilities in Malaysia. Instead, support for parents come from informal sources, such as family, friends and other parents. Formal support from government agencies, non-governmental organizations and the private sector should be improved in order to empower parents to provide better care for their children. Suggestions on how to improve these services include getting parents input and carrying out evaluations of current services.

Key words: Parents, children with disabilities, support, stress, coping, Malaysia

INTRODUCTION

The importance of family in child development and the significance of the environment, specifically professional and social support, to strengthen family functioning has been widely accepted (Bronfenbrenner, 1979; Siklos and Kerns, 2006). When families are physically and mentally fit, they are better able to promote their child's development (Rosenbaum *et al*., 1998).

However, parents of children with disabilities face significant emotional and physical demands in order to provide care for their children (Forde *et al*., 2004). The primary carers, especially face tremendous stress from the additional duties of caring over and above normal daily family activities which may be detrimental to their mental and physical health (Burton-Smith *et al*., 2009; Hastings, 2002, 2003). Kenny and McGilloway (2007) pointed out that among the stresses faced by these parents were the difficulties they faced during daily routines, restricted social life, conflicting attitudes within the family towards issues surrounding impairment, financial strain, worries about the future and inadequate availability of formal or informal support.

Parents face barriers in accessing services, such as health, social and respite care for their children (Sloper, 1999). These difficulties in accessing services for their child and family resulted in extra stress and burden for parents. Most of the time services provided are inadequate and uncoordinated (Redmond and Richardson, 2003).

A high level of stress that a parent experiences might negatively affect the quality of interaction with their child (Lessenberry and Rehfeldt, 2004; Bor *et al*., 2002) and with other family members, leading to family maladjustment (Turnbull and Ruef, 1996). Studies that have been carried out to examine the impact of providing care for children with disabilities on parents have also shown that parents face negative effects on their career and financial well-being (Ashworth and Baker, 2000; Kenny and McGilloway, 2007; Yantzi *et al*., 2006).

However, access to personal and social resources is associated with significantly lower stress experience among parents of children with disabilities (Hintermair, 2006). A study by King *et al*. (1998) showed that support that assisted parents to better carry out their responsibilities towards their child resulted in greater satisfaction with services, less reported stress and improved well-being. Kenny and McGilloway (2007) highlighted that support from partners or other family members may lessen the strains experienced by these parents.

A study on challenges faces by parents of children with autism in Malaysia showed that these parents experienced stress related to accepting and communicating with their child. They also faced challenges in accessing information needed in order to cater to the needs of their child and finding channels where they could express their desperation at the lack of practical and emotional support they need. These parents also faced the burden of accessing appropriate education for their children with autism.

The study by Pua and Mohd Mokhtar heightened the awareness on the challenges faced by parents of children with disabilities in Malaysia, specifically those with

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autism. A study, therefore is needed to better understand the types of support available for parents of children with disabilities in Malaysia. To be more precise, the objective of this study is to investigate the type of support needed and accessed by parents of children with disabilities in Malaysia.

MATERIALS AND METHODS

Respondents for this research were 20 parents and guardians of children with disabilities in the states of Selangor and Terengganu and the Federal Territories of Kuala Lumpur and Putrajaya in Malaysia. A set of semi-structured interview questions was developed based on the literature review on previous studies on support needed by parents of children with disabilities. The set of questions consisted of 20 questions related to the support and aid needed by the parents and guardians. Where 11 of the respondents were interviewed face to face, 8 were interviewed through the telephone and 1 answered the questions through e-mail. The interviews were recorded using an MP3 and were transcribed. The data were explored for themes and coded.

RESULTS

Respondents' demography: Among the parents and guardians of children with disabilities interviewed, 5 were male and 15 were females. About 17 of the respondents were Malays, 2 were Chinese and 1 was Indian. About 9 of the respondents were government workers, 2 worked in the private sector and the rest were housewives. About 4 of the respondents were below the age of 30 years old, 4 between the age of 31-35, 2 between the ages of 36-40, 4 between the ages of 41-45 and 5 between the ages of 46-50.

The range of the ages of the respondents' children was between the ages of 6-20 years old. The majority of them (13) were between the ages of 6-10 years old. And 16 of these children were boys while the rest were girls, 8 of these children have been diagnosed with autism, 4 with Down's syndrome, 1 each with learning disability and cerebral palsy. While 4 respondents reported that their children have ADHD and/or autism. This unclear diagnosis is due to the lack of appropriate instruments and well-trained personnel to carry out diagnostic assessments. As for educational placements, 3 of these children attended community based rehabilitation centers, 9 attended private schools, 6 attended government schools and 2 did not attend any schools. Table 1 shows the demography information of the parents, guardians and their children involved in this study.

Source of information: Based on the interviews, most of the respondents expressed an urgent need for information regarding their children's disabilities. Respondents report that they especially need this information during the early stage of their children's diagnosis as they especially need the knowledge on the needs of their children and how to care for them. Most of the respondents reported that they received the initial information that they need through the doctors who diagnosed and provide treatments for their children. P9 was one of those parents who received support in the form of information from the doctor who treats her child:

Table 1: The demography information of the parents,guardians and their children involved in this study

Respondents	Age	Race	Sex	Relationship	Employment	Interview method
P1	31	Malay	Male	Father	Statutory body officer	Face to face
P2	22	Malay	Male	Brother	PDK staff	Face to face
P3	23	Malay	Female	Aunt	PDK staff	Face to face
P4	42	Malay	Male	Father	University staff	Face to face
P5	40	Malay	Female	Mother	Manager	Phone
P6	45	Malay	Female	Mother	Teacher	Phone
P7	44	Malay	Female	Mother	Housewife	Phone
P8	49	Chinese	Female	Mother	Housewife	Phone
P9	48	Indian	Female	Mother	Housewife	Phone
P10	47	Malay	Male	Father	Manager	Phone
P11	30	Malay	Female	Mother	Housewife	Phone
P12	29	Malay	Female	Mother	Teacher	Face to face
P13	34	Malay	Female	Mother	Teacher	Face to face
P14	35	Malay	Female	Mother	Teacher	Face to face
P15	37	Malay	Female	Mother	Housewife	Email
P16	40	Malay	Female	Mother	Housewife	Face to face
P17	50	Malay	Female	Mother	Housewife	Face to face
P18	56	Malay	Female	Mother	Housewife	Face to face
P19	35	Malay	Female	Mother	Teacher	Phone
P20	47	Chinese	Female	Mother	Housewife	Face to face

> I felt relieved because the doctor helped me a lot in giving information on my child. He informed us that our child was 2 years behind in terms of his social, cognitive and communication development

Other parents of children with similar disabilities are also another source of information on their children's disabilities. Apart from information, they also provide emotional support to each other. This is exemplified by the following statement of P7:

> I received a lot of information from the parents who have the same child as mine. They help a lot, we share our feelings and knowledge in managing our children. Of course as a housewife, if I have time, I will search for information on autism in newspapers...

However, a majority of them reported that information on disabilities is very limited in Malaysia, especially in Malay as there is a dearth of local publications on this topic. Therefore, most parents have to resort to looking for information on their children's disabilities via the internet. Parents such as P5, P13 and P15 reported that they gained a lot of information through the internet. In fact, they also found other parents who could share ideas and together search for information that could be used to educate their children. The following is a statement by P13:

> I get information from the internet. There is not enough information on autism in Malaysia. In fact, the sources from abroad help us a lot. And finally, I understand his behaviour. Besides that, I share information with parents who are having the same child as us and learn how to manage my child. We share our problems. I feel relieved when I am able to share my feelings with other parents...

Other respondents also reported that they relied on the internet and for information regarding their children's disabilities. The following is a statement by P5:

> I knew my child has autism through my neighbor. He described autism and it was similar to my child. He asked me to bring my child to the hospital. It took a month to do the assessment. I have no idea what autism is. We search via the internet...

Support from extended family: Support from extended family members plays a vital role to strengthen parents in nurturing their children with disabilities. Most of the respondents felt grateful for having families who understand and accept their child. Extended family members also provide encouragement and support to them in raising their child with disabilities. P12 shared his/her relationship with his/her extended family with regards to their having a child with a disability:

> My family or my husband's family has never looked down on our special child. In fact, I am really grateful because they understand the situation and accept things as they are

Apart from understanding and acceptance, some extended family members also provide practical support. A good example is the support that P2 received from her cousin:

> I feel grateful because my family understands our situation. They are okay. They never isolate our son. My cousin is a pediatric nurse, so she helps me a lot. She is the one who suggested that I took my child to a specialist hospital. She helps me a lot in terms of information and moral support...

Support from the community: Findings from this study showed that the respondents received a mixture of support from their neighbors, ranging from positive support to indifference. P4, P5, P9 and P15 were those who received positive support from their neighbors. They felt lucky for having understanding neighbors who never looked down or isolate their child. The neighbors also are really caring and also provide information to them. P9 shares her family's experience:

> My neighbours are very kind. They have no problem in helping us. They knew that my child has issues since he was small. They always ask about his well being. Some of them even help us find places for treatment. It is really touching...

P12 also reported an excellent relationship with her/his neighbours who were very supportive of her child:

> I am really grateful, they care for her. My neighbours all know my child. Whenever my child goes missing, they would help us go look for her. They know she is an orphan with no father. They always look after her. I have never felt isolated...

Another respondent, P5 stated that the neighbors were very understanding and never isolate her child. They even asked her child to join playing together with them. On the other hand, P2, P5, P13, P15 and P19 reported that they do not receive any supports from their neighbor or community in terms of moral or practical support. Respondent P19 stated that:

> No problem. Only some of them do not know about our child. Our child is not like theirs. My family, in laws parents and relatives are very understanding. They are our main supporters...

However, according to the respondents, community members who do not know the family proved to be quite a challenge. According to P5, whenever she took her child to public places, they would be stared at rudely the public. Some community members even make unkind remarks either about their children with disabilities or the parents themselves. Respondent P5 shares his/her feelings regarding these negative treatments:

> Sometimes I feel tired handling the community who is unwilling to understand our child and throw nonsense words to us. For me and husband, it does not matter. Let it be...

Respondent P13 stated that these unkind behaviours toward themselves and their children with disabilities reflected the fact that the society in Malaysia lacks awareness on disabilities:

> I never care about what they say. They do not feel what we feel. Anyway, if the society outside there does not understand, I am not angry with them. It is because our government does not take any initiative to raise society's awareness about our children (with disabilities)...

Support from other parents of children with disabilities: All respondents, except for P17 and P18 agreed that they received great support from other parents of children with disabilities. According to them, they used to share views, techniques on caring for their children, ideas on appropriate education and development of their children. This support helped to improve their morale and self-confidence in caring for their children. It also helped to reduce their stress and strengthen their relationship with each other. Respondent P11 shared her experience of receiving this support from other parents:

> Parents who have children with disabilities share their stories and knowledge with us. We keep exchanging and sharing tips to educate our child at home. Their stories motivate me and make me feel grateful that my child is still able to learn even though he is not as smart as other kids...

Respondent P16 also shared her experience of receiving support from other parents:

> We share a lot of information and tips on how to manage our children's behavior. I am always at my child's school so I meet other parents there. We share a lot feelings. They are just the same as me. If there is anything that they are not satisfied with, I will try to bring it forward to teachers and school...

Although according to P15, there were parents who were not comfortable to share stories about their child. Respondents P17 and P18 reported that they had never received any support from other parents of children with disabilities. Respondent P17 reported that she felt ashamed to face the community to share stories of her child. While P18 said hers was the only family with a child with Down Syndrome in her area. She had nobody to share her feeling and problems with.

Support from teachers: About 11 of the respondents reported that they had a good relationship with the teachers at their children's school. They reported that they were happy that the teachers took the effort and time to discuss their children's development. Furthermore, the teachers also provided them with guidance on how to manage their children's behavior and educate their children at home. The following is a statement by P10:

> It was almost a year since we kept searching for suitable places to send our child. I am satisfied with the training and education provided here. He changed a lot, especially in his speech and behavior. Thanks to the teachers who are able to modify his behavior. We really appreciate it...

However, P15 and P16 expressed their dissatisfactions towards special education teachers. According to P15, special education teachers in Malaysia were not well-trained and lacked the commitment to teach children with disabilities. Both these respondents complained that their children's teachers often have to leave the class to attend seminars or meetings. These teachers were replaced by para educators, who were inexperienced. The following is a statement by P16:

> I am very disappointed with my child's school. I rather resign to teach my child. I have been teaching him until he is able to manage himself and read. I do not mind if the teachers pinch or cane my son for the purpose of teaching but instead, they spent their time talking and selling merchandise in school. I felt really sad. I lodged a report to the State Education Department. The officers came to observe but the teachers were good in concealing their activities. I felt dissatisfied with this situation so, we moved our child to another school. For the time being, everything is quite okay...

Support from employers and colleagues: Employer and colleagues are also a source of support for parents.

Respondents P4, P12 and P13 felt grateful for having employers who understand the difficulties that they faced as parents of children with disabilities. The following is a statement by P4:

> I could say that I have the support of 80% of my colleagues. I need to take my child for treatment 3 times per week, they take over my responsibilities. They helped a lot. Same goes to my boss. For example, if there is a meeting, he will try to end it as quickly as he can because he knows that I have to drive my son for a therapy. My wife has equally supportive colleagues. When our child was in a critical condition and it was hard for her to accept the situation, most of her colleagues supported her. There was a colleague who helped us look for treatments. There was also another colleague who helped us to look for funding for our child's treatments. The moral support given really helped us, especially my wife...

Support from the government: Government support is vital but overwhelming bureaucracy problems deters parents of children with disabilities from seeking the services needed for their children. Here 7 of the respondents reported that their children with disabilities received a monthly allowance, people with disability identification card and special education. Respondent P20 was thankful to the government for the special allowance given to her child and the opportunity to learn in a good school with good teachers and facilities. However, respondent P17 faced problems to send his child to school:

> I knew the government provides special education but the school is far away from our home. Due to this logistic problem, my child does not go to school. His brother is a teacher. So, he teaches our child. Once, there was a nurse who came to our house when our child was a baby. She told us a lot about Down Syndrome. But I did not go to school, I came from the village. I did not really understand about Down Syndrome...

Support from the government was difficult to access due to bureaucracy. Respondent P19 described the bureaucratic difficulties that he had to go through when dealing with a government agency:

> It was hard to get the People with Disability card. When people said there was a lot of bureaucracy, I did not believe them. But when I went through it, only did I believe. At the end of the day, this card was not really that useful...

Respondent P7 stated that she felt ashamed to ask for any aids from the government. In fact, she was grateful for being able to raise her child without having to ask for any aids from the government. For P15, the services provided by the government, especially in the medical sector were not satisfactory:

> There are only 2 occupational therapists while the clients have reached to 100. Therefore, the clients have to wait for a long queue to get the next appointment. This kind of situation should not happen because each therapy needs to be consistent if not, the child's development will regress. The location is also not accessible to the public and children with disabilities due to the lack of adequate parking spaces...

A number of respondents were aware of the acute shortage of professionals, such as psychiatrists, psychologists, speech therapists, occupational therapists and physical therapists. P20 suggested that the government should increase the number of these for the sake of children with disabilities in this country.

Support from Non-Governmental Organizations (NGO): Respondents P5 and P19 reported that they received support from a Non-Governmental Organization (NGO). According to P5, she and her husband attended parenting talks organized by an NGO. P19 described the support that she received from an NGO:

> There was an NGO which gave us information on autism. The staff there helped us a lot...

According to P11 and P15, they had never received any support from any NGOs. However both these respondents, P11 and P15 pointed out that there were NGOs and private companies that were providing good programs which could be emulated by the government:

> Please see the examples of early intervention centers which are organized by the NGOs in Malaysia such as the National Autism Services of Malaysia (NASOM) and a private center called. The government should take the initiative to deliver these services and not only leave it to the NGOs and the private sector because not all citizens are able to pay for their child's education in a private school or center...

Perceived needs: The respondents strongly stated that steps need to be taken in order to ensure that children with disabilities receive the vital services that they need, especially from the government. Most of the respondents hoped that the government would place a greater emphasize on early intervention program and education of children with disabilities. They hoped that all children with disabilities would be given the opportunity enroll in schools regardless of their level of disabilities.

Furthermore, children with disabilities who show good progress should be receiving inclusive education. All respondents strongly believed that with proper education, children with disabilities would be able to be independent in the future and not be a burden to anybody. The following is a statement by P13:

> Our children need support and education. For this, we need funding. In Malaysia, we are having logistic problem when school is too far and the facilities in school are left behind compared to the USA. Thus, we have to be progressive and active to develop our special education in Malaysia. We do not want our children to be left behind

Respondents also reported a need for education and counseling. Respondent P12 made a clear statement regarding this need:

> We want to be provided with workshop or training on managing children with autism. At the beginning, we do not know what to do. Training and management courses are important to us

DISCUSSION

Most of the respondents stated that they received initial information regarding their child's disability through the doctors who diagnosed their child. However after this initial stage, they were left on their own to look for information. Publications on disability, especially in the national language are scarce making it difficult to gather useful information. A majority of the respondents stated that they got most of the information from the internet and also, other parents who shared not only information but also their experiences and feelings.

Therefore, access to information for these parents is a pertinent issue that needs to be attended to so that parents have more knowledge to improve their care giving skills. Therefore, more books and websites in the national language on disabilities should be produced to facilitate the dissemination of information regarding disabilities and services. These projects should include parents of children with disabilities who have more experience as project members as they are able to provide insiders' perspectives.

Parents of children with disabilities are a major resource of support for other parents, especially those who have more experience. Government should provide grants and assistance for those who set up parents' support group. Empowered parents are excellent models for other parents to be empowered too. Furthermore, nobody understands their challenges more and therefore, they are among the best to provide support to each other by sharing experience and knowledge.

The findings, pointed out that informal support from extended family members, neighbours, employers and work colleagues towards respondents and their children in this study is favorable. Respondents reported that they receive not only acceptance for their child with disability but also practical and emotional supports. They reported that these supports had helped them to ease their stress and burden, similar to the reported findings by Hintermair (2006) and Kenny and McGilloway (2007). With the lack of a comprehensive formal support in terms of information and services from the government, these informal supports were greatly needed by these families.

However, community members who did not know these parents personally were not as receptive towards them and their children with disabilities. Parents reported that they felt that these members of the communities did not understand and were judgmental towards them. Respondents attributed these negative attitudes towards the society's lack of understanding of disabilities and the challenges faced by children with disabilities and their families. Therefore, dissemination of information regarding disabilities should not only be for parents of children with disabilities but also for members of society in general in order to heighten their awareness of disability issues. Only awareness among members of society would lead them to be more empathetic towards children with disabilities and their parents.

Responses on the support by teachers were mixed. Some respondents spoke of good teachers who not only had helped their children to develop but also was a source of information and support to them. While others reported teachers who were apathetic. Many developed countries now have implemented the family-centered approach in secial eucation (Dunst and Trivette, 2009). There teachers are trained that empowered parents provide better care giving to their child and therefore supporting parents is a part of teachers' responsibilities. Special Education in Malaysia is still very much child-centered where teachers are trained to focus on ameliorating students' weaknesses and empowering parents is not important. Therefore, it is not surprising that there are still teachers who do not provide support to parents. To overcome this issue, secial eucation teacher training in Malaysia need to include the family-centered paradigm in both inservice and preservice teacher training modules.

Majority of the respondents stated that they were not satisfied with the support from the government, especially due to the bureaucracy that they had to face. Information regarding available support and services was also difficult to access. As such, it is not surprising that quite a number of them hope for assistance and support from non-governmental organizations and private sector. Therefore, the government needs to evaluate the efficacy of current services and supports provided to children with disabilities and their parents. It is hoped that this evaluation will yield information on how to improve these services and supports.

CONCLUSION

This study showed that the support for parents of children with disabilities is important in their struggle to raise their children. In Malaysia, support in terms of information is sorely lacking, not only for the parents but also for the society in general. Parents needs information in order to access and services for their children while society need to be informed so that they are aware of issues regarding disabilities and be more empathetic to children with disabilities and their families. Families are still relying upon informal supports from family members and friends. Therefore, the government should strive to provide better services for the benefit of these children and their families.

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