The Impact on Family among Down syndrome Children with Early Intervention

*Azmawati MOHAMMED NAWI, Aniza ISMAIL, Syazana ABDULLAH

Dept. of Community Health, UKM Medical Centre, Malaysia

*Corresponding Author: Email: atienawi@yahoo.com

(Received 26 Feb 2013; accepted 11 July 2013)

Abstract

**Background:** Child with Down's syndrome is an individual who is suitable and eligible to receive early intervention services. This study aimed to measure the family outcome among parents of Down syndrome children, on the impact of receiving early intervention and identify the factors influencing it.

**Methods:** A cross-sectional was conducted from April 2009 until January 2010 with a total of 125 parents of children with Down syndrome. There are five domains of family outcomes that has been studied which are understanding the strengths, abilities and special needs of children, knowing the rights and talk on children behalf, assisting the child to grow and learn, having a support system and be involved in the community. Children with Down syndrome aged four to 15 years was chosen as the respondents when they were accompanying their children in seven rehabilitation centers or during house visits.

**Results:** Family outcomes among parents of Down syndrome children who receive early intervention is better, 67.3 percent, compared to parents of Down syndrome children who receive late intervention, 41.4 percent. There are significant relationship between the acceptance level of intervention, parents education level, family income and the family outcomes. Parents of children who receive early intervention were more positive in understanding the strengths, abilities and special needs of their children compared to other family outcomes.

**Conclusion:** Families whom children received early intervention had indirectly proved the importance and benefit of early intervention, not only for children with special needs, but for their family as well.

**Keywords:** Down syndrome children, intervention, special needs

Introduction

Children who were identified with development disabilities i.e Down’s Syndrome, are suitable and eligible to receive early intervention service (1). There are various definitions of early intervention. Bowe (2) defines early intervention as a service or a special program for children from newborn to age of three years old with a development problem or at risk. Meanwhile, the term early intervention according to Watts (3, 4) refers to the provision of therapy or early treatment before the age of four years old and usually begins as early as in the first 36 months of age. There are various family outcomes experienced by the family whom children received early intervention. For example, in this study, researchers use the consensus of the family outcomes and the indicators used and developed by the Early Childhood Outcomes (ECO) Center which was established on 2003 by the U.S. Department of Education, Office of Special Education Programs. There are five family outcomes identified which understand the strengths, abilities and special needs of children, knowing the rights and talk on children behalf, assisting the child to grow and learn, having a support system and be
Mohammed Nawi et al.: The Impact on Family among Down syndrome ...

involved in the community (5). Data from the National Early Intervention Longitudinal Study which assess the family outcome for children whose early intervention was terminated at the age of three years old shown that many parents feel competent in providing care of their children, advocacy in service and have support system (6). Other than that, the characteristics of the Down's syndrome children family would also affect the family outcome. Based on several researches done, there are relationship between various demographic factors of parents, children, process and the staff with services and early intervention. The Abecedarian Project (7), a supplier of early intervention services for children found that children at risk for factors such as single parents, low parental education levels and poverty will have impact on the intervention result (2,7). Indirectly, the result of early intervention which is influenced by various factors, including parental socio-demography factor will also affect the family outcomes.

This study aimed to investigate the family outcome of Down syndrome children as a result of early intervention and factors influencing it. Early intervention in this study refers to the services or special programs such as stimulation, physical therapy, occupational therapy, speech therapy and others received by the child before the age of three years old or 36 months. Hypothetically, the family outcomes would be higher for families with children who received early intervention compared to families of Down syndrome children who received later intervention. The families with these characteristics; higher income, high education and with working mothers, would yield higher family outcome.

Methods

This cross-sectional study was carried out using quantitative methods. Respondents were identified through purposive sampling of seven selected Down syndrome rehabilitation centers. Sample population were parents of Down syndrome children registered with the seven rehabilitation center. Review period is from April 2009 until January 2010. Sample size was set to 135. The sample selection criteria include parents of Down syndrome children aged between 4 to 15 years old who are registered with the rehabilitation center and can read and write in Malay fluently.

Measurements taken for the dependent variable is the family outcomes which consists five domains; understanding the strengths, abilities and special needs of children, knowing the rights and talk on children behalf, assisting the child to grow and learn, having a support system and be involved in the community. Meanwhile independent variable is the intervention received by children either late or early and family socio-demography factors such as ethnicity, marital status, education level of parents, working mothers, and family income.

The questionnaire consists of three parts which have been translated into the Malay version. Parts A and B are related to respondents' background and personal information of their children. Part C is used to obtain information on the family outcomes. Family outcomes are measured using the Family Outcomes Scale, FOS (5), which contains 15 items. Each question was given the code according to the Likert scale which is very low, low, high and very high for the nine items (questions 1,2,3,4,5,6,7,8,9), while no, less frequently, often, very often were coded for the next six items (questions 10,11,12,13,14,15). Score range is between 15 and 60. According to Bailey et al. (5) higher the score indicates better family outcome. Median score of 43 points is taken to compare the positive or negative family outcome based on the calculated mean. Five domains of the family were evaluated based on Family Outcomes Scale, FOS, which is to understand the strengths, abilities and special needs of children, knowing the rights and talk on children behalf, assisting the child to grow and learn, having a support system and be involved in the community. There are three items added to this section to assess parental perceptions on benefits of early intervention. The advantage of early intervention is measured by scores on three related questions. Each question has been coded according to Likert scale which is poor, moderate, good and very good. Three related questions are to what extent does early inter-
vention help the family to know and understand your child, to what extent does early intervention help the family to state your child’s needs effectively’ and ‘to what extent does early intervention allows your family to help your child grow and learn. The questions raised in the questionnaire survey were made prior to the pre-test on 11 respondents in the National Center Kiwanis Down Syndrome Foundation of Malaysia. Results from pre-test were used to refine the questions that have been formed. Overall, no major changes made. Analysis of the questionnaire used in this study has shown high reliability. The FOS shows the reliability coefficient Cronbach’s α 0.92 for overall scale, while reliability coefficient Cronbach’s α between 0.73 to 0.87 for the scale of each of the five domains. Reliability coefficient Cronbach's α more than 0.6 is considered to have high reliability. Several ethical matters has been considered upon completing this research including obtaining permission from the institution in accordance with the procedures and ethic of conduct, also to assure confidentiality to the respondents and voluntary basis in the study. Sampling and data collection was directly done either in the seven rehabilitation centers or during house visit. A name list of children who met the entry criteria was obtained from registration records at the rehabilitation center. A total of 135 parents of Down syndrome children between rehabilitation centers were chosen as the sample frame. These parents have been approached personally and have voluntarily answered the questionnaire. They have been given the opportunity and sufficient time to fill out the questionnaires before they surrendered to the researchers. The researchers also offered guided interviews to assist parents who needs help answering the questions. In cases where parents are unable to be at the rehabilitation center, they still have the opportunity to answer the questionnaire during house visit by researchers and staff of the rehabilitation centers. Data analysis was done with SPSS statistical software package version 16.0. Initially, data were analyzed using descriptive statistics. Factors that have a relationship with the family outcomes were studied using statistical tests such as independent t test, chi square test and Pearson correlation.

**Results**

A total of 125 questionnaires were returned from 135 questionnaires that were distributed in seven selected rehabilitation centers which is 92.6 percent complete. Age of parents involved in the study was between 31 years to 57 years. More than half of respondents were mothers of Down syndrome children which is 77.6 percent, while the remaining 22.4 percent were fathers. Majority of parents, 61.6 percent were Malays and the remaining were Chinese and Indians. In terms of marital status, 92.0 percent of parents are still married and only 8.0 percent are single parent. The study also found that 51.2 percent of these parents are colleges or universities graduate, 32.0 percent completed secondary school and the last 16.8 percent completed primary school. It was also found that 72.0 percent of the Down syndrome children mothers are working, while the remaining 28.0 percent were full-time housewife. Financially, 33.6 percent of these Down syndrome children families have an average income above RM3001, 48.8 percent makes between RM3000-RM1001 and the remaining 17.6 percent of the families have an average income of RM1000 and below per month. Majority of children with Down syndrome fall between ages 4 to 15 years old. 61.6 percent of the Down syndrome children were boys while the remaining were girls. In terms of participation in early intervention, a total of 56.0 per cent of children in the study participated at the age of above 37 months. Meanwhile 24.0 percent had an early intervention at the age of 25 to 36 months, 16.0 percent at the age of 13 to 24 months and 4.0 percent at the age of 12 months and below. Children with Down syndrome who received early intervention which is before the age of 36 months is lesser than those who received late intervention, 44.0 percent and 56.0 percent respectively.

**Family Outcomes**

The study found that the family outcomes mean score is relatively high, 43.53 ± 4.65 with a range.
of scores between 31 and 55 points (Table 1). A total of 66 parents or 52.8 percent have positive family outcomes and 59 parents which were 47.2 percent parents have negative family outcomes (Table 1). Most parents scored the highest in understanding the children’s strengths, abilities and special needs with a mean of 9.10 ± 1.27. Meanwhile they scored the least on knowing the rights and talk on children behalf domain with a mean of 8.46 ± 1.37.

Table 1: Family outcomes scores (n=125)

| Family Outcomes                                      | mean  | sd   |
|------------------------------------------------------|-------|------|
| Overall Score                                        | 43.53 | 4.65 |
| Understanding the Strengths, Abilities and Special Needs of Children | 9.10  | 1.27 |
| Knowing the Rights and Talk on Children Behalf       | 8.46  | 1.37 |
| Assisting the Child to Grow and Learn                | 8.79  | 1.15 |
| Having a Support System                              | 8.50  | 1.51 |
| Overall                                              |       |      |
| Frequency (%                                          | 66    | 52.8 |
| Positive                                             | 59    | 47.2 |

Study also revealed significant differences between the mean ages of parents with a positive family outcomes, 38.7 ± 6.2 compared to 44.2 ± 8.2. Mean age of parents is lower among parents with positive family outcomes. Positive family outcomes among mothers were 57.7 percent and 35.7 among fathers. This rate difference is significant at $P<0.05$. Mothers were found to have more positive family outcomes compared to fathers. Parents who have higher levels of education were found to have more positive family outcomes than those who have lower education levels. Data also shows that the rate of positive family outcomes among working mothers is 58.9 percent, while among mothers who does not work is 37.1 per cent. This is also a significant difference. In addition, the study showed that average family household income has also influenced the family outcomes. Out of 66 parents who have positive family outcomes, 29 of them have average household income exceeding RM3001, 31 have average family income between RM1001 to RM3000 and 6 of have RM1000 or less. Other factors such as ethnicity and marital status have no significant effect on the family outcomes. (Table 2).

Table 2: Comparison of parents’ socio-demographic factors and family outcomes

| Socio-demographic Factors | Family Outcomes | Value P $(P<0.05)$ |
|---------------------------|-----------------|--------------------|
|                           | Positive (n=66) | Negative (n=59)    |
| Parents’ Age             |                 |                    |
| 31- 51 years             |                 |                    |
| mean= 38.7               |                 |                    |
| sd= 6.20                 |                 |                    |
| 31- 57 years             |                 |                    |
| mean= 44.2               |                 |                    |
| sd= 8.20                 |                 |                    |
| Relationship             |                 |                    |
| Mother                   | 56 (57.7%)      | 41 (42.3%)         |
| 10 (35.7%)               | 18 (64.3%)      |                    |
| Father                   |                 |                    |
| Ethnic                   |                 |                    |
| Malay                    | 43 (55.8%)      | 34 (44.2%)         |
| Chinese                  | 19 (48.7%)      | 20 (51.3%)         |
| Indian                   | 4 (44.4%)       | 5 (55.6%)          |

Available at:  [http://ijph.tums.ac.ir](http://ijph.tums.ac.ir)
Table 3 shows the rate of positive family outcomes among parents of Down syndrome children who receive early intervention was 67.3 percent, while for parents of Down syndrome children who receive later intervention was 41.4 percent. These figures show that parents of Down syndrome children who received early intervention found to have a more positive family outcomes than parents of children who received later intervention.

Table 3: Comparisons of children factor and family outcomes

| Children Factor | Family Outcomes | Positive (n= 66) | Negative (n= 59) | Value P (P < 0.05) |
|----------------|----------------|-----------------|-----------------|-----------------|
| Age            |                | 4- 15           | 4- 14           | 0.290           |
|                |                | mean= 6.71 sd= 3.04 | mean= 7.25 sd= 2.62 |               |
| Gender         |                | Male 40 (51.9%) | Female 26 (54.2%) | 0.809           |
|                |                | (51.9%)         | (54.2%)         |                 |
| Interventions  |                | Early 37 (67.3%)| Late 29 (41.4%) | <0.05           |
|                |                | (67.3%)         | (41.4%)         |                 |

Table 4 shows the results of independent t test analysis comparing the mean of family outcomes domain against the early or late intervention on the Down syndrome children. The study found that family outcomes mean score for parents whom children received early intervention was 44.73 ± 4.73, meanwhile for the parents of children who receive later intervention was 42.59 ± 4:39. There is a significant difference, again parents of children who received early intervention have better family outcomes compared to parents of children who receive later intervention. For parents with children who received early interventions, the mean for understanding the strength, ability and special needs domain was 9.76 ± 1:40, meanwhile for the parents of children who receive later intervention, the mean was 8:59 ± 0.86. Higher mean score indicate that parents whom children received early intervention have better understandings strength, ability and special needs of their children. However other family outcomes domains does not exhibit a significant difference when comparing the effect of early and late intervention.

Factors Influencing the Acceptance of Early Intervention

Table 5 shows the results of the χ2 test analysis comparing the parents’ socio-demographic factors and the children receiving either early or late intervention.
Mohammed Nawi et al.: The Impact on Family among Down syndrome …

Table 4: Comparisons between family outcomes and intervention acceptance

| Family Outcomes                          | Intervention | t Value | Value (P < 0.05) |
|------------------------------------------|--------------|---------|------------------|
| Overall Score                            | Early mean±sd| Late mean±sd|         |
|                                          | 44.73±4.73   | 42.59±4.39| 2.62 <0.05      |
| Understanding the Strengths, Abilities   | 9.76±1.40    | 8.59±0.86| 5.79 <0.05      |
| and Special Needs of Children            |              |          |                  |
| Knowing the Rights and Talk on Children  | 8.64±1.34    | 8.31±1.38| 1.31 0.191      |
| Behalf                                   |              |          |                  |
| Assisting the Child to Grow and Learn    | 8.84±1.29    | 8.76±1.03| 0.38 0.703      |
| Having a Support System                  | 8.76±1.55    | 8.30±1.46| 1.72 0.089      |
| Involved in the Community                | 8.73±1.60    | 8.63±1.72| 0.33 0.744      |

There are significant differences on the acceptance of early intervention with parents’ education level. Among the children who received early intervention, 33 of the parents completed college/university, while those who completed secondary and primary school stood at 19 and 3 person respectively. Hence parents who have higher levels of education able to provide early intervention for their children compared to parents who have lower education levels. Other than that, average family income also has significant influence on children receiving either early or late intervention. This can be shown by the data where 25 of the parents have average family income RM3001 and above, 25 of them have between RM1001 and RM 3000 and only 5 of them have average family income of RM1000. So parents with higher average family income usually provide earlier intervention for their children compared to family with lower average income. Other factors such as ethnicity, marital status and working mothers have no significant difference in the acceptance of intervention.

Table 5: Comparisons of parents’ socio-demographic factor with children’s early or late intervention

| Socio-demographic /Factor | Intervention/Late (n=70) | Early (n=55) | Value P (P < 0.05) |
|---------------------------|--------------------------|--------------|--------------------|
| Ethnic                    |                          |              |                    |
| Malay                     | 42 (54.5%)               | 35 (45.5%)   | 0.595              |
| Chinese                   | 24 (61.5%)               | 15 (38.5%)   |                    |
| Indian                    | 4 (44.4%)                | 5 (55.6%)    |                    |
| Marital Status            |                          |              |                    |
| Married                   | 69 (60.0%)               | 46 (40.0%)   | 0.06               |
| Single                    | 1 (10.0%)                | 9 (90.0%)    |                    |
| Educational Level         |                          |              |                    |
| Completed Primary School  | 18 (85.7%)               | 3 (14.3%)    | 0.03               |
| Completed High School     | 21 (52.5%)               | 19 (47.5%)   |                    |
| College/University Graduate| 31 (48.4%)              | 33 (51.6%)   |                    |
| Working Mother            |                          |              |                    |
| Working                   | 49 (54.4%)               | 41 (45.6%)   | 0.574              |
| Not Working               | 21 (60.0%)               | 14 (40.0%)   |                    |
| Average Family Income     |                          |              |                    |
| < RM 1000                 | 17 (77.3%)               | 5 (22.7%)    | 0.02               |
| RM1001- RM 3000           | 36 (59.0%)               | 25 (41.0%)   |                    |
| > RM3001                  | 17 (40.5%)               | 25 (59.5%)   |                    |

Available at: [http://ijph.tums.ac.ir](http://ijph.tums.ac.ir)
Correlations of Family Outcomes and Influencing Factors

Table 6 shows that there is a moderate negative correlation between age and scores of family outcomes ($r = -0.46$). This correlation was significant and shows that parents ages are inversely related with family outcomes. Younger parents scored higher in the family outcomes. In addition, the analysis also shows that there is a moderate positive correlation between parents' education level and family outcomes scores ($r = 0.36$). This correlation was also found to be significant and shows that education level has directly influence the family outcomes. Parents with higher educational level have higher family outcomes. Correlation between the average family income and scores of family outcomes are also found to be significant but weak ($r = 0.26$). This means that the average family income has a direct relationship with the family outcomes scores. Parents with higher average family income have better family outcome. There are also negative significant correlation but weak, between the age of children receiving the intervention and the family outcomes ($r = -0.29$). This means that the family outcomes were inversely related to the age of children receiving intervention. Parents with children who received intervention earlier scores higher.

| Correlations with Family Outcomes Score | $r$   | Value $P$ ($P < 0.05$) |
|----------------------------------------|------|------------------------|
| Parents’ Age                           | -0.46| <0.01                  |
| Children’s Age                         | -0.16| 0.067                  |
| Marital Status                         | -0.08| 0.369                  |
| Mothers’ Job Status                    | 0.12 | 0.192                  |
| Educations Level                       | 0.36 | <0.01                  |
| Average Family Income                  | 0.26 | <0.01                  |
| Intervention Starting Age              | -0.29| <0.01                  |

Benefits of Early Intervention

Table 7 shows parents’ response on Down syndrome children early intervention benefit. Most parents think early intervention is very good in allowing families to assist children in growing and learning (69.1%), helping families to state child needs effectively (65.5%) and to help families understand their rights and speaks on the child behalf (3.6%).

| Rating | Poor % | Medium % | Good % | Very Good % |
|--------|--------|----------|--------|-------------|
| Benefits of Early Intervention |        |          |        |             |
| The extent of early intervention in helping your family understand your child? | - | 3.6 | 52.7 | 43.6 |
| The extent of early intervention to help your family to state your child’s needs effectively? | - | 5.5 | 29.1 | 65.5 |
| The extent of early intervention in enabling the family in helping your child grow and learn? | - | 7.3 | 23.6 | 69.1 |

Discussions

This study has found that the family outcomes improved with the acceptance of early intervention for Down's syndrome children. According to a study done by the National Early Intervention Longitudinal Study (NEILS), in respect of the families of children with disabilities who parti-
Participants in early intervention reported that 75 percent of them gained positive results, while 25 percent deemed to have less positive results (8). In the study, most parents agree early intervention has a significant influence on their families; 59 percent of them rated early intervention as very good, 23 percent said that it was good, meanwhile another 16 percent and 1 percent of them think that early intervention is moderate and does not have significant role in providing assistance and information respectively.

Researchers also found that the mean of each domain in the family outcomes studied on parents whom children received early intervention is higher than those who received late intervention. This shows that the family will have better family outcomes as a result of early intervention in many aspects. The findings of this study strengthen the findings of previous studies. Family outcomes study by NEILS found 96 percent of parents agreed their children's involvement in early intervention programs can help them to support their children to grow and learn. Similar study also found that 65 percent of parents agreed that participation in the early intervention will give them the opportunity to work with the professional and speak on behalf of their children about their needs. They are also more aware of their rights through participation in early intervention. A total of 50 percent of parents agreed that they knew what to do if their child does not get the services that they are entitled to (8).

Parents with higher education levels have a more positive result in the family outcomes. For example, the analysis performed in NEILS study found parents who take care of their children special needs positively comes from families with higher educated mothers (8). Many parents complained on their increasingly limited financial resources due to additional necessities of their special child compared to other children's need. This is the reason of their inability to fork out expenses neither to go on holiday, nor do any recreational or educational activities. Hence, the family would not have the opportunity to engage in community support systems and caused their support system to become increasingly weak. Qualitative study by Sari et al. (9), there is a parent who complained taking care of their Down syndrome children has caused their families to feel less in terms of standard of living and limited opportunities to participate in various activities.

Raising children requires a lot of financial sacrifices especially for the families of children with special needs, which caused greater economic burden to the families. There are many studies which agreed that families who have children with disabilities need financial support from the others. Cunningham (10) found economic burden will affect family ties and increase family stress. Therefore, more efforts should be done to improve the families with disabled child upgrading the level of their education and knowledge and to improve their economic resources. The government has also approved the establishment of local training and service center for these families, namely Kompleks KASIH Keluarga who organized programs and services aimed to strengthen the family unit (11). Through this,
parents who have children with disabilities can gain more knowledge about their special children and how to handle their family through participation in programs and workshops provided by Kompleks KASH Keluarga. In addition, the Social Welfare Department and Hospital Social Work Department also provides various assistance to help families with disabled children. Indirectly, these efforts have been able to alleviate some of the economic burden for families with disabled children.

In a qualitative study in Turkey on the family experience of having Down syndrome children and its impact on family members, there is a mother who said her neighbors did not know his son has Down syndrome and he never told them so for fear of stigma against their family (9). The results from this study also support this findings where knowing the rights and to speak on behalf of their child shows the lowest family outcomes either for children receiving early intervention or not. However, the result turned out better for parents of children who receive early intervention than those receiving late intervention because of their participation in early intervention programs can be used as a medium for expressing their opinions and their children special rights. Meanwhile, the family outcomes for having a support system and be involved in the community domains were also seen weaker in this study compared to other domains. This is consistent with previous studies (12) claimed that parents tried very hard to provide care, comfort and joy as good as possible to their special children, hence they less time for themselves, less leisure and fun than other normal families. In other study (9) found that mothers of Down syndrome children have no time for themselves, where group of children aged one to three years old always require intensive care, while children in the age group of four to six years and seven to twelve years were very active.

Based on the findings of this study and previous studies, the benefit of early intervention cannot be denied, whether for the children themselves or to their immediate families. However, the involvement of children in early intervention in this study is still lower, 44 percent compared to those receiving late intervention, 56 percent. In a related study, interviews conducted during 36 months of participation in early intervention found out that only 53 percent received early intervention services, whereas for children who did not participate in early intervention is; 60 percent reported not able to adjust to the time of service, 5 percent had moved or did not get a service, 34 percent hesitates and do not need these services and other reasons such as employment barriers, program-related reasons and others. Factor that contributes to late intervention for Down syndrome children was not described accurately in previous studies. However, Fidler (13) studies on Down syndrome children concluded that children are beginning to show characteristics of behavior problems at age 45 months compared with children of other disabilities who have shown characteristics of behavioral problems at age 12 and 30 months. It is different with children of other disabilities who showed behavioral problem at an earlier stage. Parents may feel that Down syndrome child does not require intervention as early as newborn to three years old because they do not realize the needs of early intervention until their children show the characteristics of problematic behavior. Reason of late intervention among Down syndrome children may also be influenced by their health status. Down syndrome children usually dealt with various medical problems including the heart problems. Therefore, early intervention programs may be deemed inappropriate and less important to parents than their child's health condition.

In this study, factors such as parental education level and average family income has a significant relationship with the involvement of children in early intervention. Parents with higher education level and families with higher income were seen more likely to refer their children for early intervention. Lam & Mackenzie (14) reported one of the things identified in the study in Hong Kong related to Down syndrome is the lack of mothers' knowledge of the syndrome. Poorly educated parents are usually found to have less knowledge compared to those who are well educated. As such,
they are not aware about the advantages related to exposure and establishment of early intervention programs in their place. Efforts to increase awareness and early intervention programs should be implemented to provide the knowledge and exposure to the parents. Parents should be informed on factual knowledge by a physician, counselor or medical social work officer. Problems handling manual for children with special needs should be developed and distributed to parents. Low income and limited resources make it difficult for the parents to fund the services needed by their children such as early intervention services. PDK is a program provided by the Social Welfare Department to provide training and rehabilitation for special children free of charge. Children are also given special allowances per month. These efforts aim to support the participation of children with disabilities in early intervention. In addition, community-based rehabilitation program is proven to be cost effective and a better choice. Accordingly, this program should be further strengthened where the service should be extended in all small towns across the country. Establishment of children rehabilitation center to provide community-based rehabilitation program for children with quality, affordable and easy to get services should be done, especially for low-income groups in urban areas who can not afford to send their children to a child rehabilitation center run by the private sector. In addition, rehabilitation services at health clinics should be expanded throughout all health clinic in Malaysia. Some health clinics should be provided with rehabilitation equipment and physiotherapist.

There are limitations in this study where the use of Likert scale for Family Outcomes Scale questions has induced positive answer among respondents, especially to questions involving their relationship with the child. This is because of the caring culture that they live in and they are being concern when their opinions are valued. In addition, parents are more likely to answer questions based on their own opinions and perspectives rather than to assess the views of other family members as their views also represent the whole family.

Conclusions

The advantage of early intervention for children with special needs and their families cannot be denied anymore. Overall, this study showed that the family outcomes can be seen well in many aspects with early intervention for Down's syndrome children. Families of Down syndrome children receiving early intervention have more positive results compared to the families of the Down syndrome children receiving less intervention, particularly in understanding the strengths, abilities and special needs children domain. The family outcomes is also related to the initial characteristics of the Down syndrome children families. Families with lower income and poorly educated parents have shown less positive results. These groups needs more attention due to their vulnerability state when dealing with children with disabilities. Early intervention programs should be enhanced to that it would not be too costly as the number of children participating in early intervention is still low, especially from families with the low-income and low education level.

Ethical Considerations

Ethical issues (Including plagiarism, Informed Consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc) have been completely observed by the authors.

Acknowledgements

We are grateful for the cooperation given by Down syndrome Centers for allowing us to proceed with this study. A special thank to the University Kebangsaan Malaysia Medical Centre for approving the short term grant for this study FF-104-2009. The authors declare that there is no conflict of interest.

Reference

1. Majnemer A (1998). Benefits of Early Intervention for Children with Developmental Disabilities. *Seminar Pediatric Neurology*, 5: 62-69.
2. Bowe FW (2004). *Early Childhood Special Education: Birth to Eight*. 3rd ed. Clifton Park, NY: Delmar Learning.

3. Watts BH (1980). *Evaluation of early intervention programs for young handicapped children*. Brisbane: August Workshop of the Schonell Educational Research Centre.

4. Watts BH (1982). *Early Intervention Programs For Young Handicapped Children In Australia 1979-1980*. Canberra: Australian Government Publishing Service.

5. Bailey DB, Bruder MB, Hebbeler K (2006). *Guidance for States in Documenting Family Outcomes for Early Intervention and Early Childhood Special Education*. Menlo Park, CA: SRI International.

6. Bailey DB, Hebbeler KM, Spiker D, Scarborough A, Mallik S, Nalson L (2005). 36 Month Outcomes For Families Of Children With Disabilities Participating In Early Intervention. *Pediatrics*, 116: 1346-1352.

7. Martin SL, Ramey CT, Ramey S (1990). The Prevention of intellectual impairments in children of impoverished families: findings of a randomized trial of educational daycare. *Am J Publ Health*, 80(7): 844-847.

8. Bailey DB, Hebbeler K, Scarborough A, Spiker D, Mallik S (2004). Family Outcomes at the End of Early Intervention: National Early Intervention Longitudinal Study. Available from: http://www.sri.com/neils.

9. Sari HY, Baser G, Turan JM (2006). Experiences of mothers of children with Down syndrome. *Paediatric Nursing*, 18(4): 29-32.

10. Cunningham CC (1996). Families of Children with Down syndrome. *Down Syndrome Research and Practice*, 4:87–95.

11. Unit Perancang Ekonomi (2006). *Rancangan Malaysia Kesembilan (2006-2010)*. Jabatan Perdana Menteri. Putrajaya.

12. Cullen CC MacLeod JA, Williams PD, Williams AR (1991). Coping, Satisfaction, And The Life Cycle In Families With Mentally Retarded Persons Issues. *Comprehensive Pediatric Nursing*, 14(3): 193-207.

13. Fidler DJ, Most DE, Booth-LaForce C, et al. (2006). Stress trajectories in families of young children with Down syndrome. *JIDR* 50:501–514.

14. Lam I.W, Mackenzie AE (2002). Coping with a child with Down syndrome: the experiences of mothers in Hong Kong. *Qualitative Health Research* 12(2): 223-237.