

**The Economic and Social Effect of
a Disabled Child on the Family**

M. Kandanathan

Discussion Paper No. 91

**Kerala Research Programme on Local Level Development
Centre for Development Studies
Thiruvananthapuram**

**The Economic and Social Effect of
a Disabled Child on the Family**

M. Kandamuthan

English
Discussion Paper

Rights reserved

First published 2004

Editorial Board: Prof. S. Neelakandan, Prof. P. R. Gopinathan Nair, H. Shaji

Printed at:

Kerala Research Programme on Local Level Development

Published by:

Dr K. N. Nair, Programme Co-ordinator,

Kerala Research Programme on Local Level Development,

Centre for Development Studies,

Prasanth Nagar, Ulloor,

Thiruvananthapuram

Cover Design: Defacto Creations

ISBN No: 81-87621-94-X

**Price: Rs 40
 US\$ 5**

KRPLLD

2004

0500

ENG

Contents

1. Introduction	5
2. Review of Literature	7
3. Research Questions	9
4.Objectives	10
5. Methodology	11
6.Outcome Measurements	14
7. Analysis	15
8. Results	16
9. Determinantas of Family Expenditure	23
10. Policy Implications	25
11. Summary and Conclusion	26
References	27

The Economic and Social Effect of a Disabled Child on the Family

M. Kandamuthan

1. Introduction

Illness or disablement of a child may affect the economic functioning of a family as it alters the employment pattern and earnings of parents. It creates special demands on the income of the family. Children with disabilities are more likely to need continuous care and supervision of the parents. Effort and resources are required for contacting the hospitals, housing, clothing, and diet may be more for the disabled children. Most of the previous studies have found that the employment patterns of both women and men are affected adversely by disablement in a child. However, a study by Piachaud, et al, cast considerable doubt on the hypothesis that disablement in a child is typically affected with loss of parental employment.

Measuring the financial effect of disablement could be done subjectively by asking the concerned families to estimate any losses of income or extra costs; or objectively, by comparing income and expenditure data from similar families with or without a disabled child. Subjective data may be very unreliable. Comparative data are more reliable but often difficult to interpret. Most of the previous studies on this topic have relied on subjective data except the study by Piachaud, et al, and Sally Baldwin, et al, who have compared the data on hours of work of men and women or on their earnings or on family incomes. The present study is designed to overcome the methodological weakness of previous studies.

Childhood disability

A disabled child has been defined as one “who is unable to ensure by himself, wholly or partially, the necessities of a normal individual or social life including work, as a result of deficiency whether congenital or not, in his physical or mental capabilities”.

It was estimated that in India in 1981, the number of disabled children consisted of 250 thousand blind, 250 thousand deaf, 500 thousand with severe orthopaedic disability and two

ACKNOWLEDGEMENTS: *This research was supported by the Kerala Research Programme on Local Level Development. I am grateful to Dr K. N. Nair, Programme Co-ordinator, KRPLLD for his sincere co-operation and help in the implementation of this research project. I would like to thank Professor & Head and Social Scientist of the Department of Physical Medicine and Rehabilitation for permitting me to use the available data for undertaking this research project. I express my sincere thanks to Dr Sara Varghese, Administrative Medical Officer, Medical College Health Unit, Pangappara and other field staff of this Health unit for all their help for identification of study subjects in the area. I would also thank the field staff of Mar Gregorious Rehabilitation and Training Centre, Vattiyookavu for providing the list of disabled children in the area and also for locating the houses of these children. I gratefully acknowledge my research assistants Manoj and Bindu and doctors Smita. V and Subitha K, who were involved in the collection of data for this research project.*

M. Kandamuthan is Associate Professor of Biostatistics, Medical College, Thiruvananthapuram.

to three million mentally retarded, which figure included cases due to iodine deficiency. In 1994, the prevalence of total blindness among children in the rural areas of India was 1264 per 100,000 and in the urban areas 1325 per 100,000. In the same year the prevalence rate of physical impairment was 1149 for rural areas and 878 for urban areas. In Kerala, the rate of disabled per 1000 children was 23.3. Disability mainly occurred in the age group 1-4, and speech and hearing was the most common type of disability.

2. Review of Literature

The United Nations Expert group cited many implications of disability for family life and productivity. They postulated the possibilities of: increased personal stress, both physical and emotional, for parents and family members of the disabled. This condition of the parents reduced their ability to care for other children and/or to undertake household tasks. It also reduced time and energy available to the parents and members of the family for work, within and outside the home, both paid and unpaid. The effect of disability on family income may be doubly adverse: it may cause one of the parents of the disabled child to lose his or her income from work, and/or the need to care for the disabled child may cause one of the parents to stop working. The result of all these factors in combination may be a disruption in the economic status of the disabled family.

Creese and Fielden compared the cost of hospital and home care incurred by the severely disabled in London. This study revealed a preference for home care of the disabled because of an existent supportive household income and the presence of a husband, wife or mother.

Susan and Maikowski surveyed the economics of disabilities. They examined the socio-economic impact of disability prevention and rehabilitation measures found in a rehabilitation international analysis of literature from about 40 countries and studies conducted by the United Nations. This study revealed that the social and economic costs of disability are enormous. The financial impact of the loss of labour power, reduced earnings of the disabled individual as well as of the family members responsible for the care are all together constituted the direct costs. The study found that disability had a significant impact on family income, particularly on those below the poverty line. The study showed that health expenditure for the disabled was three times more than that of the non-disabled. And, not only disability led to poverty, but poverty also led to disability. It also found that the children of the poor were thirteen times more likely to be disabled than those of the middle and upper classes.

Dijkstra analysed the cost and socio-economic consequences of being visibly handicapped. The hypothesis tested was that on an average, workers with a visible handicap in production organisation occupied a lower socio-economic position than their colleagues whose handicap was not visible. The results of the study showed that socio-economic position of workers with visible handicap was significantly lower than that of their colleagues whose handicap was invisible.

Shanmugham studied the socio-economic problems of the orthopedically handicapped persons. It explored the various economic, psychological, and vocational problems that influenced their treatment as applicable to the Indian conditions. Sally, Christine, and Staden tried to establish how the disablement of a child in a family in Britain affected finances of families, and to quantify any such effects and thereby provide information relevant to the formulation of criteria for new or increased cash support. The study found that the participation rates, hours, and earnings of women with a disabled child were all substantially lower than for those women in the control group. Thus the results showed that the costs in the families of disabled children were greater. The financial support should be increased to provide compensation.

Newachek conducted a study on the prevalence, severity, and access to health needs of the adolescents with special health needs in USA. The study attempted to achieve estimates of the prevalence of disabling chronic conditions of adolescents between 10 to 18 years, to describe the severity of the disabling chronic conditions, compare the health service use patterns between disabled and non-disabled, adolescents and to describe and emphasise the importance of health insurance for the disabled adolescents.

Khan and others framed ten questions to provide a rapid and culturally useful tool for detecting several types of disability in two to nine year old children. Research perspectives in investigating chronic illness and disability in Britain were examined by Harper. Historical research conceptualisations in childhood disability were reviewed and newer contexts for evaluating disorder were presented by him. Kothari and Gulaty tried to analyse the limitations of the concept of Disability Adjusted Life Years (DALY) and the implications of adopting DALY as a policy guide in the pursuit of health care objectives in the context of developing country like India.

Though various national as well as international studies have shown that there is a significant relationship between socio-economic factors and handicapped children, the impact of childhood disability on the economic status of their families has not received adequate attention. So, the present study is expected to be useful to fill up this lacuna.

3. Research Questions

The study aims at finding answers for the following two questions.

Primary question

Does the severe disablement in a child in Kerala have a significant impact on the family finances of their parents?

Secondary question

Does the childhood disability in Kerala have a significant effect on the occupational and social status of the families?

4. Objectives

The overall aim of the study is to establish whether, and how, severe disablement in a child affected finances of their families; to quantify any such effects; and to provide information relevant to the establishment of criteria for new or increased cash support.

The specific objectives are:

1. To estimate the strength of association between childhood disability and the economic status of the family.
2. To estimate the cost of caring for the disabled child at home, in hospitals and institutions.
3. To estimate the effects of childhood disability on the occupational and social status of the family.
4. To find out the relative importance of socio-economic variables on the expenditure of the family with a disabled child, and of the family with a normal child.

5. Methodology

This was a case-control study. The design of the study is described below:

Design

Both comparative and subjective data were collected. The study contained three discrete elements:

1. Comparisons of income and expenditure patterns of families with, and without, a disabled child.

A sample of 300 families with a severely disabled child drawn from the register of ongoing Community Based Rehabilitation Programme in Pangappara and Vattiyoorkavu PHC area. These data were compared with data from a control group of 300 families with normal children matched for age, sex of the disabled child, and occupational status of the parents.

2. A supplementary survey of families with a disabled child.

A supplementary survey was carried out to collect information on important topics not covered in the questionnaire. To guide the interpretation of the comparative data, parent's views on the effect of the disabled child on family finances was also sought.

3. A case study.

A general survey of the samples was followed by an in-depth study using semi-structured interviews on 10 percent of the families with a disabled child.

Sampling frames

From a total of 1400 disabled children below 15 years from the Pangappara and Vattiyoorkavu area, a sample of 300 severely disabled children below 15 years was selected by the stratified sampling procedure with proportional allocation. Stratification was done according to the type of disability condition. By ensuring the minimum sample size within each stratum should be 12, the number of cases selected for study for each type of disability is given below.

Locomotor disability: 116; Disability of speech: 25; Disability of hearing: 57; Visually impaired: 17; Mental retardation: 53; Mental illness: 22; and Other types of disabilities: 10.

An interview with the head of the household, or mother of the child, was made in which details of income and certain regular expenditures were collected. A diary record of all household expenditure in the 14 days after the interview was maintained. In the course of the study, detailed information on each child's condition including disease or disorder, disabilities and handicaps were collected from the parents.

Sample cover and size

To reduce variations due to factors other than type of disablement, the sample of families with a disabled child was matched at the design stage itself on the basis of regional distribution to age, sex of the child, and occupation of the parents and the timing of the field work was modified to suit the collection of data on that basis. Further matching was carried out in the stage of analysis. The final sample of families with disabled child was 300. The control group with normal children also contained 300 families.

The important components of income earnings and social security payments were examined separately. Differences in participation rates, days of work, and earnings were examined in relation to women and subsequent to men. Consideration was also given to the part played by the disability benefits in making good any loss of earnings. Finally, to assess the final impact of the child's disablement, family's total income and expenditure was compared. The cost of disability was estimated from the families of disabled children included in the study. The kinds of costs involved include the following:

Direct cost

This refers to the specific cost of disability related expenditure. The basic expenditure for disability prevention and rehabilitation services included the cost of specialised health service, counselling and hire or purchase of technical equipment, specialised nursery programme, resource classes and educational programme for disabled children such as centre for vocational training and retraining.

Extra cost

Disabled people and their families experienced extra cost as a result of disability. Extra cost also includes the cost of travel, domestic help, medical care, and other forms of daily living assistance.

Health care expenditure included the spending on physician services, dentistry, drugs, and others.

Sample specification

A sample of 300 severely disabled children of the total of 1400 disabled children below 15 years who were registered under the Community-based rehabilitation programme at the Department of Physical Medicine, Medical College, Thiruvananthapuram and residing at the Pangappara and Vattiyoorkavu area was included in the study group. An equal size sample of normal children matched for age and sex of the study group was enrolled in the control group from the houses next to that of cases selected. The incomes and regular expenditure pattern for families with and without a disabled child was compared. A supplementary survey of the families with a disabled child was done to obtain the parent's views on the effect of having a disabled child on family finances. All the families with and without a disabled child

was followed up by an in-depth study to estimate the money spent by these parents on the children for medical care, and loss of earning of the parents. This helped to estimate the additional economic burden to the family due to the disability of the child in the family.

6. Outcome Measurements

The main outcome expected from the study is the estimation of average expenditure of the families with and without disabled children and from that to estimate the money lost due to the presence of a disabled child in the family. Women's paid work and earnings, men's paid work and earnings, social security benefits, family incomes, and income related to need were all estimated. Income related to need was the additional income earned by the parents by the overtime work to meet the extra need of their disabled children like travel, domestic help, needed care and other forms of necessities. The percentage of social contribution by the parents, interaction of family members with the society, friends, relatives, and co-workers was estimated and compared with the families of normal children. Participation rate in social gatherings was estimated. The extent of the disability condition of a child in the family becoming a barrier for the marriage of family members, reduction in status of the family in the society, social stigma, isolation from the society, and reduced educational opportunities to the child and siblings were estimated.

If a disabled child exists in a family with a boy or girl of marriable age, people will be hesitant to seek alliance for marriage of the boy or girl from that family as they presume that the disability condition is genetically inherited. Existence of a disabled child in the family becomes a burden to the family and the society as such view this family involved with social and economic problems. This in turn leads to reduction in the status of the family in the society. Due to the disability conditions like mental retardation and locomotor disability of the child, social stigma is likely to develop which results in the isolation of the family from the society. Children with deaf and dump, mental retardation or locomotor disability have to be admitted in the special schools which limit their opportunities for higher studies like professional education and this also became a barrier for the education of their siblings due to financial difficulties.

Methods of outcome measurement

A diary record of all household expenditure in the 14 days after the interview was made from both groups. The condition of the child including the nature and type of disease or disorder, the type of disabilities, and degree of handicaps was collected from the parents. Differences in participation rates, hours of work, and earnings in relation to men and women were examined. Part played by disability benefits in making good any loss of earnings was collected. Comparison of families' total income was made and the regular expenditure on the family was made. Comparison of income related to need was made by taking into account of additional income earned by the parents for the special care needed to the disabled children when compared to the normal children.

7. Analysis

Analysis of main outcome

The main outcome of interest is the comparison of the average expenditure of families with disabled children and without disabled children.

As the main outcome is the continuous data, the comparison of the outcome measurements was analysed and tested by the students 't' test.

Discriminant analysis was made to find out the effect of socio-demographic variables on the disability condition of the children.

Data handling and collation

All information about the study subjects was recorded on data sheets. They were counterchecked by the principal investigator to ensure that there was no missing information. The data were subjected to computerised statistical analysis.

8. Results

Of the 300 disabled children studied, 31.3 percent were in the age group of 0-4, 29.3 percent in the 5-9 years and 39.4 percent in 10-14. Of the disabled children, 52 percent were males and 48 percent females and in the case of normal children 56 percent were males and 44 percent females. Table 8.1 shows the type disability of the disabled children according to sex.

Table 8.1 Type of disability of the children

Type of disability	Male	Female	Number	Per cent
Speech	13	12	25	8.3
Hearing	30	27	57	19.0
Visual	6	11	17	5.7
Locomotor	62	54	116	38.7
Mental retardation	24	29	53	17.7
Mental illness	14	8	22	7.3
Others	6	4	10	3.3
Total	155	145	300	100

It was noted that the locomotor disability accounted for the highest proportion of cases. Hearing disability was found in 19 percent of the cases and mental retardation accounted for 18 percent. It was noted that mental retardation was found more among females whereas mental illness was more among male children. The nature of disability showed that disability was hereditary in 45 percent of the cases while the rest 55 percent were with developmental delay. A considerably high percentage of the total disabled cases were hereditary, and most cases had chances of curability. When there are more chances of curability, more amount has to be spent on them.

Table 8.2 Educational level of father

Education of father	Disabled		Normal	
	No.	%	No.	%
No schooling	4	1.4	2	0.7
Lower primary	24	8.6	5	1.7
Upper primary	72	25.7	68	23.7
High school	129	46.1	151	52.6
College	30	10.7	34	11.8
Technical	8	2.9	13	4.5
Graduate	11	3.9	13	4.5
Post graduate	2	0.7	1	0.3
Total	280	100	287	100

$$\chi^2 = 16.81, P = .019$$

Table 8.2 reveals that 10 percent of the fathers of disabled children were either with no schooling or with lower primary education as against 2.4 percent in the corresponding case of normal children. The association between education level of father and disability of the children ($\chi^2 = 16.81, P = .019$) indicates that association between these attributes was not a causal association but a non-causal association. This indicates that the educational level of parents cannot be attributed as a significant causative factor for the occurrence of disability condition of the children though low educational level of fathers was found to be more among the disabled children than that of the normal children. There was no significant difference in the educational level between the mothers of disabled and normal children.

Order of birth of the children was found associated with the disability of the children ($\chi^2 = 9.49, P = 0087$). It is seen from Table 8.3 that the order of birth of 6.7 percent of the disabled children were 3 and above when compared to only 1.7 percent of the normal children, who belonged to the corresponding order of birth of 3. This indicates that higher order of birth of the children are likely to have a higher risk for disability of the children when compared to normal children as odds ratio (O.R) = 4.2. This indicates that higher order of birth of the children is likely to produce a higher risk for disability of the children when compared to normal children, as odds ratio is equal to 4.2. Odds ratio is a measure of the strength of the association between risk factor and outcome. Here, odds ratio of 4.2 indicates that the children of order of birth of 3 and above showed a risk of having 4.2 times risk of developing disability than that of normal children.

Table 8.3 Order of birth of children

Order of birth	1	2	3	4	Total
Disabled No.	164	116	17	3	300
%	54.7	38.7	5.7	1.0	100
Normal No.	169	126	5	-	300
%	56.3	42.02	1.7	-	100

$\chi^2 = 9.49, P = .0087; O.R = 4.2$

Table 8.4 shows that when the whole population is considered, the incomes of father, mother and other family members of disabled children are not affected significantly by the occurrence of disabled child in the family.

As regards the family monthly income of the study groups, it was seen that income of 9 percent of the families with disabled children was less than Rs 2000 per month as against 4 percent in the control group. It may be seen from the table that the association between total family incomes with the disability condition is found to be not significant ($\chi^2 = 8.9, P = .06$). Moreover, the Median income of the study group was found to be same for both groups (Rs 2500).

It was also found that the Median monthly expenditure for the family of the disabled child was Rs 3250, whereas the Median monthly expenditure of the normal child was Rs 3000. The difference between expenditure is statistically not significant ($P > .05$).

child. Table 8.6 shows that 29 percent of the families with disabled children spent more than Rs 1000 per month exclusively for their children whereas only 1 percent of the families of normal children spent such high amount for their children. The difference between these percentages is statistically significant ($\chi^2 = 93.9, P = .0001$). The mean money spent on the disabled child was Rs 852 whereas for the normal child it was only Rs 389. The difference between these values is statistically significant ($t = 16.86, P = .00001$).

Table 8.6 Money spent for the child

Rupees	Disabled		Normal		Total	
	No.	%	No.	%	No.	%
Less than 1000	214	71.3	298	99.3	512	85.3
1000-2000	79	26.3	2	0.7	81	13.5
2000-3000	7	2.3	-	-	7	1.2
3000-4000	300	100	300	100	600	100

$\chi^2 = 93.9, P = .0001$

Mean: 852 389 $t = 16.86, P = .00001$

S.D: 428 207

Median: 800 350

It was noted that the income lost by the parents of disabled child due to not working was Rs 795 per month whereas none of the parents of normal children lost income by not working. Parents spent Rs 176 per month for the transportation of the disabled children (with S.D of 202), whereas the corresponding mean money spent for the transportation of normal children was only Rs 24 (with S.D of 44). The difference between these values is statistically significant ($t=12.7, P = .00001$).

As regards the medical expenditure, the mean expenditure for the disabled children was Rs.362 per month (S.D = 340), whereas for the normal children it was only Rs 66 (S.D = 61). Median expenditure for the disabled child was Rs 290 and for the normal child it was Rs 50. The difference between the mean medical expenditure of these two groups is statistically significant ($t = 14.81, P = .00001$).

Other expenses for the disabled child was found to be significantly higher (Mean = 270, S.D = 166) than that of the normal child (Mean = Rs. 256, S.D = 104), ($t= 2.65, P = .008$).

We now turn to the issue of social security payments received by the disabled children. It was found that only 9.7 percent of the disabled children were in receipt of social security payments. The mean annual social security payment received was Rs 8280 with standard deviation of Rs 4501. Median social security payment received was Rs 10000. The data collected from the parents of the disabled children revealed that 40.2 percent of their children did not get any social security payments. Those who received social security payments, 9.2 percent received it through government sources and only 0.5 percent received from other sources like NGO or public assistance programme. None of these parents who got the social security payment were satisfied with the amount they received. They stated that the amount they received was insufficient. The average additional amount they demanded as social security payment was Rs 9050 per year.

The person who actually takes care of the disabled/normal child is shown in Table 8.7. It is seen that 86.7 percent of the disabled children are looked after by the mothers as against 76 per cent in the case of normal children. 8.3 percent of the disabled children are looked after by the relatives or others whereas in the case of normal children the corresponding percentage is only 0.3. This indicates that for the caring of disabled child, the help of relatives like grand parents, aunt or uncle or servants is essential in 8 percent of the cases.

The next issue is the effect of disability on the loss of job of parents. The data reveals that 3.7 percent of the parents (6 fathers and 6 mothers) of disabled children have lost their jobs, as they have to be with the disabled child for their special care.

Data reveals specifically that disability of the child affected care of other children in 31.7 percent of the families of disabled children.

Table 8.7 Person caring the child

Person caring	Disabled		Normal		Total	
	No.	%	No.	%	No.	%
Mother	260	86.7	228	76.0	488	81.3
Father	3	1.0	-		3	0.5
Both parents	9	3.0	69	23.0	78	13.0
Sibling	3	1.0	2	0.7	5	0.8
Relative	1	0.3	-		1	0.2
Servants	3	1.0	-		3	0.5
Other	21	7.0	1	0.3	22	3.7
Total	300	100	300	100	600	100

It is seen from Table 8.8 that 60 percent of the parents of disabled children did not participate in the social organisations due to the presence of disabled child in the family whereas in the case of normal children, 32 percent of their parents did not participate in social organisations. The difference between these percentages is statistically highly significant ($\chi^2 = 47.4$, $P < .0001$; $RR = 1.76$, $C.I.: 1.57 - 2.02$). Here, social organisations included residence associations, arts and sports clubs, community clubs, women's society, cultural associations, and parent teacher associations. The implication is clear that the presence of a disabled child in the family does restrict the ability of the parents to participate in social organisations.

Table 8.8 Participation in social organisations

Participate	Disabled		Normal		Total	
	No.	%	No.	%	No.	%
Yes	121	40.3	205	68	326	54
No	179	59.7	95	32	274	46
Total	300	100	300	100	600	100

$\chi^2 = 47.4$, $P < .0001$; $O.R = 1.76$, 95% $C.I.: 1.57 - 2.02$

The reason for avoiding social functions is shown in Table 8.9, which shows that 20.3 percent of the parents of disabled child avoid the social functions only because of their disabled child whereas the corresponding percentage for normal child is only one. However, nearly 80 percent of the parents of disabled children participate in social functions. So the inability to participate in social functions might have a relationship with the degree of disability of the child.

Table 8.9 Reason for avoiding social functions

Reason as child	Disabled		Normal		Total	
	No.	%	No.	%	No.	%
Yes	61	20.3	3	1.0	64	11.0
No	239	79.7	297	99.0	536	89.0
Total	300	100	300	100	600	100

$\chi^2 = 62.5$, $P = .0001$; R.R = 2.14, C.I.: 1.99 - 2.23

It is seen from Table 8.10 that there is a significant association between disability of the child in the house and the visit of parents to the houses of friends and relatives ($\chi^2 = 81.4$, $P = .0001$; R.R = 2.15, C.I. 1.99 - 2.30). It is noted that only 69.7 percent of the parents of disabled child visit the houses of friends and relatives as against 97 percent in the case of normal children.

Table 8.10 Visiting houses of friends and relatives

Visit houses	Disabled		Normal		Total	
	No.	%	No.	%	No.	%
Yes	209	69.7	291	97.0	500	83
No	91	30.3	9	3.0	100	17
Total	300	100	300	100	600	100

$\chi^2 = 81.4$, $P = .0001$; R.R = 2.15, C.I.: 1.99 - 2.30

It may be seen from Table 8.11 that 50.7 percent of the parents of disabled children hesitate to visit other houses due to the disability of their disabled children whereas in 2 percent of the parents of normal children showed hesitation to visit other houses. The association between disability of the child and the hesitation to visit other houses is statistically significant ($\chi^2 = 183.6$, $P = .0001$; R.R = 2.87, C.I.: 2.715 - 3.0).

Table 8.11 Hesitation to visit other houses

Hesitation to visit other houses	Disabled		Normal		Total	
	No.	%	No.	%	No.	%
Yes	152	50.7	6	2	158	26.3
No	148	49.3	294	98	442	73.7
Total	300	100	300	100	600	100

$\chi^2 = 183.6$, $P = .0001$; R.R = 2.87, C.I = 2.715 - 3.0

From Table 8.12 it is noted that disability of the child became a barrier for marriage of other members of the family in 8.3 percent of the families of the disabled children.

Table 8.12 Barrier for the marriage of family members

Barrier	Disabled		Normal	
	No.	%	No.	%
Yes	25	8.3	-	-
No	275	91.7	300	100
Total	300	100	300	100

Table 8.13 No. of families stigmatised due to the disabled child

Stigmatised	Disabled		Normal	
	No.	%	No.	%
Yes	16	5.3	-	-
No	284	94.7	300	100
Total	300	100	300	100

It is noted from Table 8.13 that 5.3 percent of the families of disabled children are stigmatised due to the presence of the disabled child in the family.

Table 8.14 shows that 12.7 percent of the families of the disabled children are isolated from the society due to the occurrence of disabled child in those families.

Table 8.14 Isolation of the family from the society

Isolated	Disabled		Normal	
	No.	%	No.	%
Yes	38	12.7	-	-
No	262	87.3	300	100
Total	300	100	300	100

Table 8.15 shows that disability of the child reduced status in the society in 45 percent of the families of disabled children.

Table 8.15 Reduction of the status of the family in the society due to the disabled child

Reduced status	Disabled		Normal	
	No.	%	No.	%
Yes	135	45	-	-
No	165	55	300	100
Total	300	100	300	100

9. Determinants of Family Expenditure

Discriminant analysis showed that money spent for the transportation of the child, medical expenditure for the disabled child, total money spent for the transportation of the child and stigma attached to the family of the disabled child was found to be significantly associated with the disability of children in the family.

Discriminant analysis

In the present study on the effect of childhood disability on the economic and social burden of the households, an analysis was made to discriminate between those households with risk factors who had a disabled child or a normal child. The types of variables used in describing differences between those two groups are measures concerning total family income, total money spent on child, medical expenditure for the child, money saved, money spent for the transportation of the child, working days lost to the mother, barrier for the marriage of other members of the family, reduced status in the society, visit to the houses of friends and relatives and various socio-economic and demographic variables.

Discriminant analysis technique is used in deciding which linear combination of those variables is most helpful in predicting whether a household with these factors belongs to the group of families of the disabled child or to the group of families of the normal child. This analysis determined whether the economic loss and reduced social status in the society to the families of the disabled child is different in any significant way from that of the families with normal children.

Discriminant analysis is a statistical rule, which is devised to decide which combination of a number of important variables enumerated above provides for the best discriminator between two defined populations. Here, there are two populations designated as study group and control group, and there are two sets of households of 300 in each group selected from each population. These are measured or observed values on a number of correlated random variables. The basic strategy in discriminant analysis is to form a linear combination of those values, which is given as

$$Z = \beta_1 X_1 + \beta_2 X_2 + \beta_3 X_3 + \beta_4 X_4$$

and then to assign a new individual household that belongs to either the study group or the control group on the basis of the value of Z obtained for that new household. In the model for the current study, the stepwise discriminant analysis was done. Examination of the classification table suggested that the model contained four variables and does a better job of classifying individual households than the model with one variable or all other variables in different combinations. The four most significant variables in the model and those, which turns out to be the best discriminator between the two populations based on the standardised canonical discriminant functions are, stigma, money spent for transportation of the child, medical expense for the child, total money spent for the child. Wilk's Lamda was obtained as 0.092 and chi-square value was 1417.46 for 4 degree of freedom, which were found to be highly significant $P < 0.0001$.

The discriminant model with standardised canonical discriminant function coefficients is $Z = 0.979$ (stigma) - $.392$ (money spent on transport) - $.28$ (medical expenditure) + $.192$ (total money spent for the child).

Classification results showed that 97.5 percent of original grouped cases were correctly classified.

10. Policy Implications

1. More social security payments and special concessions should be made available to the disabled children.
2. Institutions like non-government organisations should come forward to assist families with disabled children.
3. Medical prsonnel should create greater awareness of ways of reducing the chances of the birth of disabled child.

11. Summary and Conclusion

There was no significant difference in the mean income of families with a disabled child and without a disabled child ($t = .5987$, $P = .55$). The mean expenditure of the families with a disabled child was Rs 852 per month, which is significantly higher than the corresponding expenditure of Rs 389 per month of families with normal child, ($t = 16.86$, $P < .00001$). Eighty-seven percent of the disabled children were looked after by their mothers and three percent by their both parents. In nine percent cases, they were looked after by other relatives. Twenty-one percent of the mothers of the disabled children were unemployed as against 12 percent in the case of normal children. The percentage of expenditure for the disabled children accounts for 23 whereas it was 11 in the case of normal children. Of the disabled children, 81 percent were not getting any social security payments and 90 percent had no special concessions for medical and other educational purposes. Average loss in terms of money by not working to the parents of disabled children was Rs 795 per month, which is an additional economic burden to the family.

In our survey, parents of disabled children demanded an average additional amount of Rs 9050 per year as social security payments from the government to meet the essential necessities of their disabled children. Parents of 40 percent of the disabled children did not participate in social functions (OR = 1.76, CI: 1.57 - 2.02) and a significant percentage of these parents attribute disability condition of their children as a reason for such non-participation (OR = 2.14, CI: 1.99 - 2.23). Disability condition of one child became barrier for the marriage of other members of the family in 8.3 percent of the cases. Parents of 50.7 percent of disabled children hesitate to visit the houses of friends and relatives (RR = 2.87, CI: 2.71 - 3.0). Families of 5.3 percent of disabled children are stigmatized due to the presence of disabled child in the family and 12.7 percent of the families of disabled children are isolated from the society due to this reason. Presence of disability condition of the child reduced status in the society in 45 percent of the families of disabled children.

The disability condition of the child postulated the possibilities of: increased personal stress, both physical and emotional, for parents and family members. This condition of the parents of disabled reduced their ability to care for other children and/or to undertake household tasks. It also reduced time and energy available to the parents and members of the family for work, within and outside the home, both paid and unpaid. Thus it reduced social contribution and interaction of the child directly affected, and, of the other close family members and friends. Disability condition of the child has reduced the status of the family in the community, possibly making it the focus of anxiety or stigma in the local community. The result of all these factors in combination was a disruption in the economic status of the disabled family. In addition to reduced earnings, there are extra costs for disabled children for travel, domestic help, medical care, and health care expenditures (hospital care, physician services, dentistry, drugs and others) for disabled individuals. A strong case could be made for improving the financial support to such families possibly through the introduction of an allowance specially to compensate for the earnings lost by parents due to the disability of their children.

References

- Atze, Dijkstra. "The Cost of being Visibly Handicapped", *International Journal of Rehabilitation Research*, 5 (4). 1982.
- Baldwin, Sally, Christine Godfrey and Francis Staden. "Child Disablement and Family Incomes", *Journal of Epidemiology and Community Health*, 37 (1). 1983.
- Creese, A.L., and R.Fielden. "Hospital or Home Care for the Severely Disabled: A Cost Comparison", *British Journal of Preventive and Social Medicine*, 31 (3). 1977.
- Hammerman, Susan and Stephen Maikowski. "The Economics of Disabilities: International Perspectives", *International Journal of Rehabilitation Research*, 5 (2). 1982.
- Harper, Dennis C. "Paradigms for Investing Rehabilitation and Adaptation to Childhood Disability and Chronic Illness", *Journal of Pediatric Psychology*, 16 (5). 1991.
- Khan, Estana, et.al. "Validity of the 'Ten Questions' for Screening Serious Childhood Disability: Results from Urban Bangladesh", *International Journal of Epidemiology*, 19 (3). 1990.
- Kothari, V. N., I. S. Gulati. "Disability-Adjusted Life Year as a Guide for Health Policy", *Economic and Political Weekly*, 31 (4). 1997.
- National Sample Survey, Government of India. *National Disability Survey 47th Round, 1991 Report*. 1994.
- Newachek, Paul W. "Adolescents with special Health Needs, Prevalence, Severity and Access to Health Services", *Pediatrics*, 84, (5). 1989.
- Piachaud D, Brandshaw J, Weale J. "The income effect of a disabled child", *Journal of Epidemiology and Community Health*, Vol. 35. 1981.
- Shanmugham, I.S. "Socio-Economic Problems of the Orthopedically Handicapped Persons", *International Journal of Rehabilitation Research*, 6 (1). 1983.
- United Nations International Children's Fund. *Childhood Disability, An Analysis of the Situation in India*, Geneva. 1984.
- United Nations Publications. *Rehabilitation for the Disabled. The Social and Economic Implications of Investments for this purpose*, New York. 1977.