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SERVICE NEEDS OF CARERS FOR PEOPLE WITH INTELLECTUAL DISABILITIES: PROFILES OF HIGH-NEED AND LOW-NEED GROUPS

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INTRODUCTION

The stress and social support profiles of families with differing service needs were explored in this study. A growing body of literature on the impact of disability on family adjustment points to the variability rather than the homogeneity of families' responses to caring for a disabled or handicapped member (e.g., Akamatsu, Stephens, Hobfoll & Crowther, 1992; Carr, 1994; Crnic, Freidrich & Greenberg, 1983; Eiser, 1990; Rolland, 1993; Sloper & Turner, 1993; Tunali & Power, 1993). Such variability may be due to differences in the type of disability and family stresses entailed by it, the resources available to families caring for their handicapped members and particular coping strategies adopted by carers for the disabled person (Sloper & Turner, 1993). While adjustment of carers for people with handicaps is typically assessed in terms of physical or psychological well-being (Crnic et al, 1983), a particularly useful index of carer adjustment for service providers may be carers' reported service needs (Bailey, Blasco & Simeonsson, 1992). In this study the reported needs of carers of people with learning disabilities were assessed with a view to identifying sub-groups of carers with differing service-need profiles. The study also aimed to identify stress and social support profiles of such subgroups.

METHOD

Participants

The primary carers of 78 people with learning disabilities living in County Kildare, Eire, were interviewed in this study. Participants were members of the Kildare Association for Parents and Friends of the Mentally Handicapped. The 78 carers constituted a non-random convenience sample drawn from a population of carers whose handicapped dependants were receiving services in nine educational and training programmes in the County. Demographic characteristics of the handicapped individuals and their primary carers who participated in this study are presented in Table 4.1. County Kildare is a predominantly rural locality with a number of small market towns.

This group studied were predominantly married women of whom almost half (48%) were in their forties. Only 10% of the handicapped people whose carers participated in this study had spent time in a residential school, group home or special hospital. Over half of the carers (51%) had only primary school education and only 7% had completed secondary education. A third of the families (33%) had no car and the average income was under IR£10,000. The mean family size was 5 children with a range from two to eight. Over a fifth of the families (22%) had more than one child with a disability. Overall, the group of carers who participated in this study were relatively socially disadvantaged.

Table 4.1. Demographic characteristics

Variable	Percentage	(N)
Carer's sex		
Male	16.7	(13)
Female	83.3	(65)
Carer's age in years		
Under 20	1.3	(1)
21-30	1.3	(1)
31-40	16.4	(13)
41-50	48.1	(37)
51-60	15.4	(12)
61-70	14.1	(11)
over 71	2.6	(2)
Carer's marital status		
Single	2.6	(2)
Married	74.4	(58)
Separated	7.7	(6)
Widowed	15.4	(12)
Net Family Income after tax		
Less than IR£10,000	70.7	(53)
IR£10,000-IR£14,000	14.7	(11)
IR£15,000-IR£20,000	9.3	(7)
IR£20,000-IR£25,000	4.0	(3)
More than IR£25,000	1.3	(1)
Handicapped person's sex		
Male	59.0	(46)
Female	41.0	(32)
Handicapped person's age in years		
Under 5	3.8	(3)
6-10	12.8	(10)
11-15	26.9	(21)
16-20	20.5	(16)
21-25	10.3	(8)
26-30	12.8	(10)
31-35	7.7	(6)
36-40	2.6	(2)
41-45	1.3	(1)
46-50	1.3	(1)
Type of handicap		
Mild	55.8	(43)

Moderate	35.1	(25)
Severe	6.5	(5)
Profound	2.6	(2)
Other medical problems		
Epilepsy	16.7	(13)
Psychiatric disorder	17.9	(14)
Epilepsy and/or psychiatric disorder	30.0	(24)

Note: For all variables except Other Medical Problems, where totals do not sum to 78, there were missing data.

Assessment Protocol

Family needs. Carers' perceptions of family needs for a variety of internal and external resources and services were evaluated using a 34 item Family Needs Scale which was based on the Family Needs Survey (Bailey et al, 1992). For all items, three point response formats were used (1 = do not need help, 2 = unsure, 3 = need help) and item scores were summed to give scale and subscale totals. The overall scale contained eight subscales which assessed needs for familial social support, help explaining the condition to others, assistance with meeting the handicapped members leisure needs, extrafamilial social support, financial assistance, service information, child management information and respite care with counselling. These eight subscales were identified by conducting a principal components analysis with varimax rotation on a pool of 42 items some of which were drawn from Bailey's original scale and some of which were generated by the research team. Thirty four items with loadings greater than .4 on eight interpretable factors were entered into a second similar principal components analysis. The eight factor solution from this analysis was used to construct the eight family need subscales. Items with factor loadings above .4 on a given factor which did not load more substantially on another factor were included in the subscale based on that factor. Alpha reliability coefficients were calculated for all eight subscales and these ranged from .72 to .87 with an overall scale reliability of .93.

Behaviour problems and skills. A 22 item scale was used to evaluate carers' perceptions of handicapped persons' conduct problems and difficulties in developing life skills. For all items, two point response formats were used (1= yes, has skill or lacks problem, 2 = lacks skill or has problem). The overall scale comprised five subscales which assessed the presence of behavioural problems and skills required for self-care, independent living, safety, and grooming. The same statistical procedures that were employed in developing the family needs scale were used to develop these subscales. Reliability coefficients for the skills deficits and behaviour problem subscales ranged from .64 to .91 and the overall reliability for the scale was .91.

Perceived social support scale. This 20 item measure of perceived social support was developed from Dahlem, Zimet and Walker's (1991) 12 item scale which assesses perceived support obtained from family, friends and significant others. Additional items were written to assess perceived social support from the carer's spouse and professionals involved in providing services for the handicapped person. A principal component analysis of 20 items yielded a five factor structure. Scales based on these factors assessed perceived social support from Dahlem et al's three sources and the two additional sources for which the new items were written. Reliability coefficients for subscales ranged from .83 to .97 and the overall scale reliability was .89. For all items, responses were coded on seven point scales where 1 = very strongly disagree; 4 = not sure; and 7 = very strongly agree. Subscale scores are based on item totals.

Family stress. The stresses and strains associated with caring for a handicapped family member were assessed with Friedrich's short form of the Questionnaire on Resources and Stress (QRS-F) (Friedrich, Greenberg & Crnic, 1983). This 52 item scale has 4 subscales which assess (1) family problems associated with the index child, (2) carer's pessimism about the index child's future adjustment, (3) the carers' perception of the handicapped person's social skills deficits and (4) the carer's perception of the handicapped person's motor skills deficits and incapacities. A true/false response format was used for each item. Responses were coded so that high scores reflected a high level of stress. Subscale scores were based on subscale item totals. The factor structure of the QRS-F is well established so Friedrich's original scales were used in the present study. In this paper only the scores from the first two subscales are reported since constructs measured by the third and fourth subscales are more comprehensively assessed by the behaviour problems and skills scale described earlier.

Dissatisfaction with leisure-time arrangements. The degree of dissatisfaction with leisure-time arrangements for both carers and people with disabilities was the second index of stress used in this study. To assess carers' dissatisfaction with the way they spent their leisure time and handicapped persons' leisure time arrangements, carers indicated the *actual frequency* of certain leisure activities and the *desired frequency* for the occurrence of these activities. For all items, responses to the *actual frequency* of the activity and the *desired frequency* of the activity were given on three point scales (1= yes/frequently 2 = somewhat/occasionally, 3 = no/never). Dissatisfaction item scores were calculated by subtracting the *desired frequency* score from the *actual frequency* score and adding a constant of 3 to avoid negative values. Principal components and reliability analyses were conducted on dissatisfaction item scores in a similar manner to those conducted for the Family Need Scale. Four subscales comprising 18 items emerged from these analyses. These subscales assessed dissatisfaction with the carer's weekly leisure arrangements, the carer's annual leisure arrangements, the handicapped person's weekly leisure arrangements and the handicapped person's annual arrangements. Weekly arrangements refer to various forms of socializing and recreation such as going out at night. Annual arrangements refer to holidays and weekend trips. Subscale scores were obtained by summing dissatisfaction item scores. An alpha reliability coefficient of .85 was obtained for the overall scale and those for the four subscales ranged from .70 to .85.

Psychometric data on the scales used in this study are given in appendices 4A-4D.

Procedure

Assessment protocols, which contained the instruments described above along with a demographic information sheet, were completed in participants' homes with informed consent and a guarantee of confidentiality. Most participants filled out the questionnaires unaided. Others completed the questions in an interview format. Protocol completion took between 80 and 100 minutes

Item scores from completed protocols were entered into the mainframe computer at University College Dublin. Routines from the Statistical Package for the Social Sciences (SPSS) (Norusis, 1990) were used for data verification, item analysis, scale construction and all statistical procedures reported here.

RESULTS

To identify subgroups of carers with differing need profiles, a cluster analysis was conducted on the 78 cases. Cases were clustered on the eight family need variables and scores on these variables were transformed to z-scores for the clustering procedures. There were two stages to the analysis. First a hierarchical cluster analysis was conducted. Then, a non-hierarchical cluster analysis was conducted in which the standardized means of clusters identified in the hierarchical analysis were used as seed points.

Table 4.2. Analysis of agglomeration coefficients for the final five steps of the hierarchical cluster analysis

Step	No of Clusters	Agglomeration coefficient	Change in agglomeration coefficient to next level	Percentage Change in agglomeration coefficient to next level
73	5	288.18	36.8	12.7
74	4	324.98	50.9	15.6
75	3	375.90	54.3	14.4
76	2	430.24	185.9	43.2
77	1	615.89	____	____

This two-stage approach allows meaningful clusters to first be identified and then for the membership of these clusters to be fine-tuned (Hair, Anderson, Tatham & Black, 1992, p. 284). For the first stage, Wards' hierarchical agglomerative procedure was employed with squared Euclidean distances summed over all variables as the distance measure (Norusis, 1990, p.364; Hair et al, 1992, p. 277). With this method, each case begins as its own cluster. In subsequent steps the within cluster sum of squares is minimized for all clusters by combining two clusters from the previous stage. At each step, it is the smaller clusters that tend to be combined, rather than the larger ones. Ward's algorithm tends to lead to solutions where clusters contain similar numbers of cases.

Changes in the agglomeration coefficient, an index of the homogeneity of clusters being merged, was used in selecting a cluster solution for further refinement through non-hierarchical cluster analysis (Hair, 1992, P.281). The final steps of the agglomeration schedule are presented in Table 4.2. From this table it may be seen that the small changes in the agglomeration coefficients at steps 73, 74 and 75 of the clustering procedure indicated that relatively homogeneous clusters were being combined. It was inferred that these five, four and three cluster solutions, therefore, contained a number of relatively homogeneous groups. The particularly large percentage change in the agglomeration coefficient from step 76 to 77 indicated that the two cluster solution contained relatively dissimilar groups. Seed points from this two group solution were therefore chosen for the non-hierarchical cluster analysis.

Cluster centres of all eight family need variables for both the hierarchical and non-hierarchical cluster analyses are presented in Table 4.3. Little change occurred in cluster membership across the two procedures, indicating that a relatively robust cluster solution had been identified.

Table 4.3. Standardized cluster means on eight need variables for the hierarchical and non-hierarchical cluster analyses

Variable	**Stage 1 Hierarchical cluster analysis**		**Stage 2 Non-hierarchical Cluster analysis**	
	Group 1 N=29	**Group 2 N=49**	**Group 1 N=26**	**Group 2 N=52**
Familial social support	.793	-.469	.865	-.432
Help explaining the condition	.682	-.402	.809	-.403
Leisure activities for child	.720	-.425	.919	-.459
Social support	.755	-.446	.914	-.456
Financial needs	.676	-.401	.487	-.244
Service information need	.581	-.344	.654	-.327
Child management information	.547	-.325	.675	-.338
Respite care and counselling	.863	-.511	1.020	-.512

Note: Cluster means are z scores.

The solution from the non-hierarchical cluster analysis was selected for further profiling. It comprised one group of 26 cases which obtained higher mean

Table 4.4. Profiles of high-need and low-need groups on all scales

Variable	High-Need Group N=26		Low-Need Group N=52		t	r_{xx}
FAMILY NEEDS						
Familial social support	9.16	(3.93)	5.19	(1.05)	5.06***	.92
Help explaining the condition	10.38	(4.32)	6.41	(1.20)	4.61***	.87
Leisure activities for child	12.07	(3.36)	6.70	(2.70)	6.69***	.85
Social support	9.58	(3.67)	5.48	(1.09)	5.57***	.84
Financial aid	6.19	(2.40)	4.67	(1.71)	2.88**	.74
Service information	10.19	(1.87)	7.57	(2.58)	5.09***	.70
Child management information	5.88	(2.25)	3.79	(1.58)	4.26***	.75
Respite care and counselling	7.03	(1.99)	3.71	(1.18)	7.87***	.72
Total family need	70.50	(11.57)	43.82	(5.31)	11.18***	.93
HANDICAPPER PERSON'S BEHAVIOUR PROBLEMS AND SKILLS						
Behavioural problems	5.53	(1.21)	4.76	(1.02)	2.79**	.64
Safety skills deficits	4.96	(1.08)	4.17	(1.26)	2.87**	.78
Self-care skills	6.23	(0.59)	6.65	(1.91)	1.46	.91
Independence skills	10.00	(2.77)	9.23	(3.57)	1.05	.89
Grooming skills	3.65	(1.02)	3.71	(1.13)	0.23	.82
Total deficits and problems	30.38	(4.37)	28.54	(7.33)	1.39	.91
PERCEIVED SOCIAL SUPPORT						
Friends	17.92	(7.25)	23.31	(5.53)	3.28**	.94
Professionals	18.23	(6.37)	22.92	(4.56)	3.35**	.91
Family	22.42	(5.41)	24.63	(3.69)	1.88	.86
Spouse	22.38	(7.09)	19.25	(10.79)	1.53	.97
Special person	22.73	(5.63)	24.35	(4.00)	1.31	.83
Total social support score	105.04	(22.09)	114.46	(18.95)	1.83	.89
FAMILY STRESS						
Family problems (QRS)	26.16	(4.40)	23.09	(2.48)	3.24**	.81
Carers pessimism (QRS)	17.84	(2.75)	16.33	(2.93)	2.25*	.78
Dissatisfaction with carer's weekly arrangements	16.69	(4.37)	13.71	(2.53)	3.22**	.78
Dissatisfaction with Carer's annual arrangements	11.73	(2.59)	10.19	(2.34)	2.55*	.72

Dissatisfaction with Han.Per.weekly arrangements	21.65	(4.04)	17.76	(4.91)	3.72***	.84
Dissatisfaction with Han.Per.annual arrangements	11.42	(2.76)	9.65	(2.17)	2.86**	.73
Total dissatisfaction with leisure arrangements	61.50	(9.28)	51.33	(8.06)	4.76***	.85

Note: Values in table are means based on raw scores with standard deviations in brackets.
t=value from t test. rxx = alpha reliability coefficient for the scale. Han. Per. = handicapped person.
*p<.05, **p<.01, ***p<.001.

scores on all family need variables in comparison with the second group which contained 52 cases. These clusters were termed high-need and low-need groups.

The two groups were compared on fifty two variables, 11 of which were demographic, and 28 of which were derived from the psychosocial scales, i.e. the Family Needs Scale, the Behaviour Problem's and Skills Scale, the Perceived Social Support Scale, the Questionnaire on Resources and Stress, and Dissatisfaction with Leisure-time Arrangements Scale. These 28 variables are listed in Table 4.4. For categorical variables, chi square tests were used to compare the groups. t-tests were used for comparisons on interval scale variables. p values for two-tailed, rather than for one-tailed tests are reported below since the comparisons were essentially exploratory. To deal with the problem of Type 1 error associated with making 39 comparisons a p-value of .01 was set as the significance level for inferring intergroup differences on each variable.

The high-need and low-need groups were demographically similar. They did not differ significantly on the following nine demographic characteristics: the age of the carer, the sex of the carer, the income of the carer, the age of the handicapped person, the severity of the handicapped person's disability, the number of disabled people with epilepsy and the number with a psychiatric disorder. The groups also had comparable numbers of children in the family and comparable numbers of children in the family with disabilities .

While the groups did not differ on any demographic variable at the .01 level, differences on two variables at the .05 level occurred. These differences were for the sex of the handicapped person (Chi square (1, N=78)= 4.48, $p <.05$) with more females (58%) in the high need group compared to the low need group (32%) and the marital status of the carer (Chi square (3, N=78)= 8.69, $p <.05$)

with over a fifth (23%) of the carers in the low need group being widowed compared with no widows in the high need group.

The status of the two groups on the Family Needs Scale, the Behaviour Problem's and Skills Scale, the Perceived Social Support Scale, the Questionnaire on Resources and Stress, and Dissatisfaction with Leisure-time Arrangements Scale is presented in Table 4.4. From this table it may be seen that the psychosocial profiles of carers in the high-need and low-need groups were distinctly different. In comparison with the low-need group, carers in the high-need group reported greater needs for familial social support; more help explaining their child's handicap to others; greater assistance with leisure activities for their handicapped member; more extrafamilial social support; greater financial assistance; more information on services for families with a handicapped member; more information on child development and management; and greater access to respite care and counselling. In comparison with the low-need group, carers in the high-need group reported that the handicapped people for whom they cared had more safety skills deficits and behavioural problems. Carers in the high-need and low-need groups differed significantly in the levels of social support from both professionals and friends that they reported to be available to them with the high-need group reporting less support. Carers in the high-need group reported more family-based stress than those in the low-need group. Compared with carers in the low-need group, those in the high-need group reported more family problems and pessimism on those subscales of the QRS which assessed these constructs. The two groups also differed in their responses to the Dissatisfaction with Leisure-time Arrangements Scale. Carers in the high-need group reported greater dissatisfaction with weekly and annual leisure-time arrangements for themselves and the handicapped people for whom they cared.

DISCUSSION

Two distinct subgroups of carers characterized by unique service need profiles were identified in this study. While the high- and low- need groups were demographically similar and the handicapped people for whom they cared did not differ in their overall level of intellectual disability or life skills, there were a number of important psychosocial differences between the two groups. First, the high-need carers reported that the handicapped people for whom they cared had more behaviour problems and poorer safety skills. Second, the high-need carers reported less social support than their low-need counterparts. Third, they reported more stress associated with caring for handicapped family members. In this context stress referred to family problems associated with the burden of care, greater pessimism about the future and greater dissatisfaction with leisure arrangements. A summary of the profiles of the two groups is presented in Table 4.5.

Table 4.5. Summary of characteristics of high and low service-need groups

CHARACTERISTIC	HIGH-NEED GROUP	LOW-NEED GROUP
PERCEPTION OF HANDICAPPED PERSON	**High Demand** Aggressive Unsafe	**Low Demand** Not Aggressive Safe

PERCEIVED SOCIAL SUPPORT	Low Support	High Support
PERCEIVED FAMILY STRESS	High Stress	Low Stress

These profiles suggest hypotheses about two distinct patterns of adaptation which characterize carers in the high- and low-need groups. In the low-need group, carers perceive the handicapped person for whom they care to have few behaviour problems and few safety skills deficits and therefore to place relatively low demands upon them. They also perceive friends and professionals to be offering them a relatively high level of social support. Given this low-demand, high-support situation, they perceive less family stress associated with caring for the person with the intellectual disability and so report fewer service needs.

The second pattern of adaptation, suggested by the results, is shown by carers who report high service needs. These carers perceive the behavioural problems and safety skills deficits of the handicapped person for whom they care to place high demands upon them. Furthermore, they perceive a low level of support to be available to them from friends and professionals. This high-demand, low-support situation underpins their perception of high levels of family stress associated with caring for the handicapped person and so they report high service needs.

The results of this study are consistent with two of the main findings in the international literature. First, the relationship between level of disability and carers' reported service needs is not simple. Second, multifactorial models of stress, coping and social support are probably the most useful way to conceptualize the impact of caring for a person with a disability on the family (Scott, 1994). For, example, Frey, Greenberg and Fewell (1989) found that social support, utilitarian resources, problem solving skills, belief systems, and morale all contributed to carer's adjustment.

The study reported here had a number of methodological shortcomings. First, a non-random convenience sample was used which was relatively socially disadvantaged. Thus it is difficult to say the degree to which the results may be generalized. Second, a limited range of variables was tapped by our assessment protocol. Important variables such as carer's self-efficacy beliefs about their caring abilities were not included. Third, there was an exclusive reliance on self-report instruments. Carer's actual service-using behaviour was not observed and independent ratings of the handicapped persons' behaviour problems or other psychosocial variables were not obtained.

In the light of the shortcomings of the present study, our view is that future research using representative samples of carers should include an assessment protocol which taps a wider range of variables. It would also be desirable to include both self-report instruments and independent ratings of certain variables, particularly those in the domains of service use and behavioural problems.

SUMMARY

A cluster analysis of responses of 78 carers of people with learning disabilities to service needs scales identified high- and low-need groups, each with distinct profiles. In comparison with the low-need group, the high-need group reported

greater needs for familial social support; help explaining their child's handicap to others; assistance with leisure activities for their handicapped member; extrafamilial social support; financial assistance; information on services for families with a handicapped member; information on child development and management; and respite care and counselling. Those in the high-need group perceived the handicapped person for whom they cared to have more behavioural problems and safety skills deficits. The carers in the high-need group also had lower levels of perceived social support and higher levels of family stress. Although high- and low-need groups displayed these disparate psychosocial profiles, they were demographically similar and did not differ in terms of the level of disability of the handicapped people for whom they cared.

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Appendix 4.A. Principal components analysis of the family needs scale and reliability of factor subscales and overall scale.

Factor name and Items	% Variance (factor) Factor Load (items)	Eigen Value	Mean (SD)	rxx
F1. Familial social support needs	29.8	12.5	6.48 (2.99)	.92
As a family we need to....				
1. decide on household tasks	.88			
2. support each other	.87			
3. have more time together as a family	.83			
4. discuss problems and reach solutions	.80			
5. do more recreational activities	.64			
F2. Need for help explaining the condition	9.3	3.9	7.63 (3.13)	.87
I need help in explaining N's disability to				
1. other children who know N	.85			
2. my other children	.81			
3. friends, neighbours and strangers	.74			
4. my spouse	.73			
5. parents or in-laws	.58			
F3. Leisure needs	6.3	2.6	8.69 (3.68)	.85
N Needs to get used to....				
1. being away from the family	.91			
2. being away from home for short periods	.90			
3. going out more on social outings	.54			
4. developing more leisure activities	.52			
5. making for friends who don't have disabilities	.46			
F4. Extrafamilial social support needs	5.7	2.4	6.84 (2.99)	.84
I need......				
1. to talk to a priest	.73			
2. more friends to talk to	.70			
3. someone in my family to talk to	.69			
4. more time for myself	.58			
5.to talk to other parents of children with hand,	.56			
F5. Financial needs	4.5	1.9	5.18 (2.08)	.74
I need help paying for.......				
1. therapy or day-care	.80			
2. toys	.78			
3. special equipment	.66			
4 .baby-sitting or respite care	.53			
F6. Service information needs	4.0	1.7	8.45 (2.67)	.70
I need more.....				
1. information about present services	.81			
2. information about future services	.78			
3. reading material about parents in my situation	.65			
4. information about N's condition or disability	.53			
F7. Child management information needs	3.6	1.5	4.48 (2.07)	.75
I need more.....				

1. information on how to play or talk with N	.75			
2. information about how to handle N's behaviour	.74			
3. time to talk with N's teacher and/or therapist	.47			
F8. Need for respite care and counselling	3.5	1.5	4.82 (2.17)	.72
I need......				
1. information on what to do when N's is unsafe	.67			
2. to talk to a counsellor	.59			
3. Respite-care	.43			
Total Family Needs Scale	66.8		52.59 (14.8)	.93

Note: %var = amount of variance accounted for by the factor. Factor load=factor loadings of items. rxx = alpha reliability coefficient. For all items three point scales were used (1= do not need help, 2 = unsure, 3 = need help). Subscales are based on item totals.

Appendix 4.B. Principal components analysis of skills deficits and behaviour problems scale and reliability of factor subscales and overall scale

Factor name and Items	% Variance (factor)	Factor Load (items)	Eigen Value	Mean (SD)	r_{xx}
F1. Self-care skills	40.3		8.9	6.51 (1.61)	.91
N is able to....					
1. walk		.92			
2. sit		.88			
3. feed him/herself		.84			
4. drink from a cup or glass unassisted		.81			
5. take care of all his/her toileting needs during the day		.68			
6. help with chores when asked		.64			
F2. Independence skills	12.9		2.8	9.49 (3.33)	.89
N is able to....					
1. count		.87			
2. read		.82			
3. write		.79			
4. sometimes prepare food for mealtimes		.73			
5. cross the road alone		.53			
6. set the table for meals		.51			
F3. Safety skills	8.2		1.8	4.44 (1.25)	.78
1. N understands that some situations are not safe, e.g. accepting a ride from a stranger		.76			
2. N is able to go out to parties and functions alone without an adult		.73			
3. N is able to use a public telephone		.69			
F4. Grooming skills	5.0		1.1	3.69 (1.08)	.82
1. N is toilet trained during the night		.69			
2. N can take care of his/her appearance such as brushing hair		.52			
3. N dresses self completely, including tying shoelaces and fastening all fasteners		.51			
F5. Behaviour problems	4.5		1.0	5.03 (1.14)	.64
1. N has poor eye contact		.77			
2. N teases or bullies other peers or siblings		.73			
3. N displays behaviours that are self-injurious		.66			
4. N is overly dependent on family members		.48			
Total skills deficits and behaviour problem scale	71.0			29.15 (6.53)	.91

Note: %var = amount of variance accounted for by the factor. Factor load=factor loadings of items. rxx = alpha reliability coefficient. For all items, responses are coded on two point scales (1= yes, has skill or lacks problem, 2 = lacks skill or has problem). Subscales are based on item totals.

Appendix 4.C. Principal components analysis of perceived social supports scale and reliability of factor subscales and overall scale

Factor name and Items	% Variance (factor) Factor Load (items)	Eigen Value	Mean (SD)	r_{xx}
F1. Spouse	36.3	7.3	20.29 (9.78)	.97
1. I get the emotional help and support I need from my spouse	.96			
2. My spouse really tries to help me	.95			
3. I can talk about my problems with my spouse	.94			
4. My spouse is willing to help me make decisions	.90			
F2. Friend	19.6	3.9	21.56 (6.60)	.94
1. I can talk about my problems with my friends	.91			
2. I have friends with whom I can share my joys and sorrows	.89			
3. I can count on my friends when things go wrong	.88			
4. My friends really try to help me	.83			
F3. Professional	9.8	2.0	21.36 (5.65)	.91
1. I can really rely on the professional people when things get tough	.87			
2. The professional people are willing to listen to my personal problems	.84			
3. I can really talk to the professional people about concerns and anxieties I have	.83			
4. The professional people I deal with in relation to N really go out of their way to do things to make my life easier	.77			
F4. Family	8.5	1.7	23.90 (4.43)	.86
1. I get the emotional help and support I need from my family	.83			
2. My family really tries to help me	.74			
3. I can talk about my problems with my family	.74			
4. My family is willing to help me make decisions	.73			
F5. Significant other	6.3	1.3	23.81 (4.63)	.83
1. There is a special person who is around when I am in need	.74			
2. I have a special person who is a				

real source of comfort to me	.73		
3. There is a special person with whom I can share my joys and sorrows	.73		
4. There is a special person in my life with whom I can share my feelings	.72		
Total social support	80.4	111.4 (20.36)	.89

Note: %var = amount of variance accounted for by the factor. Factor load=factor loadings of items. rxx = alpha reliability coefficient. For all items, responses are coded on seven point scales where 1= very strongly; disagree; 4 = not sure; and 7 = very strongly agree. Subscale scores are based on item totals.

Appendix 4.D. Principal components analysis of dissatisfaction with leisure-time arrangements scale and reliability of factor subscales and overall scale

Factor name and Items	% Variance (factor) Factor Load (items)	Eigen Value	Mean (SD)	r_{xx}
F1. Handicapped Persons weekly arrangements	29.9	5.3	19.06 (4.97)	.84
1. Participate in recreational activities in the community	.80			
2. Go out socially during the day	.77			
3. Develop friendships with non-disabled peers	.74			
4. Develop friendships with disabled peers	.70			
5. Go out socially during the weekend	.68			
6. Go out socially at night	.56			
7. Participate in recreational activities in the centre for the disabled	.53			
F2. Carer's weekly arrangements	16.0	2.89	14.71 (3.53)	.78
1. Go out socially at weekends	.77			
2. Go out socially at night	.76			
3. Attend social functions	.72			
4. Participate in recreational activities	.67			
5. Visit family and friends	.49			
F3. Carer's annual arrangements	8.5	1.5	10.41 (2.52)	.70
1. Entertain at home	.70			
2. Take holidays	.69			
3. Go away for weekends	.48			
F4. Handicapped person's annual arrangements	6.2	1.1	10.24 (2.51)	.73
1. Go away on holiday camps	.83			
2. Go away at weekends	.71			
3. Go on family holidays	.62			
Total dissatisfaction score	60.6		56.41(8.62)	.85

Note: %var = amount of variance accounted for by the factor. Factor load=factor loadings of items. rxx = alpha reliability coefficient. For all items, responses to the *actual frequency* of the activity and the *desired frequency* of the activity were given on three point scales (1= yes/frequently 2 = somewhat/occasionally, 3 = no/never). Dissatisfaction item scores were calculated by subtracting the *desired frequency* score from the *actual frequency* score and adding a constant of 3 to avoid negative values. Subscale scores were obtained by summing dissatisfaction item scores.