

NIMH FAMILY SUPPORT SCALE (NIMH-FSS)

AUTHORS

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NATIONAL INSTITUTE FOR THE MENTALLY HANDICAPPED

(Ministry of Social Justice and Empowerment, Govt. of India)
MANOVIKAS NAGAR P.O., SECUNDERABAD - 500 009. A.P. INDIA.

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PROJECT TEAM

TITLE OF PROJECT

Family Intervention and Support Programmes for
Persons with Mental Retardation (1998-2003)

PRINCIPAL INVESTIGATORS

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(February 2000 - continuing)

Mrs.Saila Kumari
(February 2000 - continuing)

Mr.Arul Raj
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IDENTIFICATION DATA SHEET

Name of the interviewer : Family No:

Position held :

Name of the Institute :

Date :

CHILD CHARACTERISTICS

Name :

Age :

Sex :

Level of mental retardation and associated conditions (if any) :

FAMILY CHARACTERISTICS

Total family income :

Type of family : nuclear/non nuclear

Family status : intact/broken

Address and Telephone No :

INTRODUCTION

NIMH Family Support Scale (NIMH - FSS) has been developed as part of the research project on "Family Intervention and Support Programmes for persons with mental retardation" funded by the US-India rupee fund (1998-2003).

Having a child with mental retardation generates a number of additional needs for the family which require to be met in order to cope with this special situation. One of the known factors for effective coping is the support available to the family. A need was felt to develop a culture specific tool:

- a) To identify and assess the quantity and quality of support available to the families,
- b) To assess the need for more support to the families,
- c) To identify the thrust areas of family intervention,
- d) To objectively evaluate the family intervention programmes.

NIMH-FSS though has been developed to be used with parents of mentally retarded individuals, it can also be used with other significant adult members of the family.

As part of the development of this tool a study was conducted on a sample of 52 parents (28 fathers and 24 mothers) of 52 mentally retarded individuals. Only one of the parents of each of the mentally retarded child was interviewed. A semi-structured interview schedule was developed for the purpose. Each of the parents was interviewed individually using open ended questions followed by probes as follows:

- a) Because of having (name of the child with mental retardation) you might be having some special needs. Could you please help us to understand what those present needs are?
- b) From whom do you normally seek the support to fulfill each of these needs?
- c) How satisfied are you with the support you are getting to fulfill each of your need?
- d) Which more sources of support you think you require to meet the identified needs?

The analysis of the data obtained helped to identify :

- a) the areas in which the parents need support,
- b) the various sources of support which are used by the parents,
- c) to develop a quantitative scoring system and assign numerical scores to measure the quantum of support available and further needed by the family.

Following were the six areas identified for support which got included in NIMH-FSS. All the six areas have been defined in the tool:

1. Personal
2. Financial
3. Technical
4. Recreation
5. Emotional
6. Material

Following were the sources of support which got included in NIMH-FSS. (The first ten are in relation the index individual with mental retardation).

1. Spouse
2. Mother
3. Father
4. Siblings
5. Paternal Grandfather
6. Paternal Grandmother
7. Maternal Grandfather
8. Maternal Grandmother
9. Paternal Aunt/Uncle
10. Maternal Aunt/Uncle
11. Friends
12. Neighbours
13. Organisations/Agencies
14. Boss/Co-workers
15. Doctor
16. Other professionals
17. Religious/support group
18. Any other

Briefly the results of the study are shown at Table:1

AREAS AND SOURCES OF SUPPORT (PARENTS n=52)

Sl. No	SOURCES OF SUPPORT	AREAS FOR SUPPORT								TOTAL
		PHY-SICAL	FINAN-CIAL	TECHNI-CAL	INFORM-ATION	RECREA-TION	EMOTI-ONAL	MATE-RIAL	OTHERS	
1	MOTHER	21	4	-	3	15	7	1	-	51
2	FATHER	3	22	4	3	2	10	8	-	52
3	SIBLINGS	3	2	-	-	1	-	-	-	6
4	PATERNAL GRANDFATHER	-	1	1	1	-	-	-	-	3
5	PATERNAL GRANDMOTHER	10	1	-	-	2	6	-	-	19
6	MATERNAL GRANDMOTHER	5	3	-	1	1	5	1	-	16
7	MATERNAL GRANDFATHER	-	3	-	7	-	-	-	-	10
8	PATERNAL AUNT/UNCLE	-	3	1	4	1	1	1	-	11
9	MATERNAL AUNT/UNCLE	1	5	12	-	2	-	3	-	23
10	FRIENDS	-	2	-	12	1	4	-	-	19
11	NEIGHBOURS	-	1	2	2	-	3	-	-	8
12	INSTITUTIONS SPL.SCHOOL	-	-	9	5	2	1	4	-	16
13	DOCTOR	-	-	9	7	-	-	-	-	16
14	OFFICIALS/BOSS	-	-	-	-	-	-	-	3	3
15	OTHERS	2	-	1	1	1	-	1	-	6

Note: (Sl.No.1 to 9 are in relation to the index child with mental retardation)

The study helped to format NIMH-FSS. In order that the NIMH-FSS helps in providing directions for family interventions the dimensions such as "utilisation", "level of satisfaction" and "need for more support" was retained in the tool, the dimension on "Rank order utilisation" was added to find out the rank of the sources of support utilized from most helpful to least helpful. However, it was agreed to consider the scores on "utilization" and "level of satisfaction" only for computing the overall "family support score". Another source of support "spouse" of the mentally retarded individuals got added. The area of support 'Technical' and 'information' were clubbed under 'Technical'. As the next step NIMH-FSS was field tested on 20 parents (10 mothers and 10 fathers) of 10 mentally retarded individuals to find out the feasibility of the tool. It was decided to add 3 slots under item "Any other" in each area of NIMH-FSS to elicit unique responses, if any, from the respondent.

The inter-rater reliability was established by having two raters from the research staff independently assessing same 5 parents of mentally retarded individuals using NIMH-FSS. The inter-rater reliability for NIMH-FSS was found to be $r=0.9776$; $p<0.001$. The final study is in progress under the project.

GUIDELINES FOR ADMINISTRATION AND SCORING OF NIMH-FSS

- 1) Interview method is preferred over self-reporting method for gathering information using NIMH-FSS.
- 2) The scale should be used by a person trained in interview method.
- 3) The interviewer should go through the scale and get familiarised with the items in the scale before using it.
- 4) The interviewer should be familiar with the family members of the index child with mental retardation to be interviewed to an extent that the respective family members feel comfortable to share their concerns with the interviewer. Hence adequate rapport with the family members is essential before starting to use NIMH - FSS.
- 5) The interviewer must take consent before using the scale with each of the parent. The scale should be used separately for both mother and father and as far as possible use the scale for both mother and father at the same session one after the other or interview both mother and father at the same time using separate interviewers.
- 6) Read the 'Instructions' paragraph to the respondent and ensure that he/she has understood the intentions of the assessment. Also, read the introduction/explanation paragraph for each area to the respondent before eliciting information on each area of support.
- 7) Make sure that the information elicited for items that is, sources of support from 1 to 10 under each area of support is in relation to the person with mental retardation.
- 8) For each item under "sources of support" ensure that you obtain choice option from the respondent and give score of 2, 1 or 0 on all the three dimensions, that is "utilization", "level of satisfaction", and "need for more support"
- 9) After obtaining the information/responses from the respondent on "utilization", "level of satisfaction", and "need for support" for all the items

in the given area of support, then collect information on the “rank order utilization” of the sources of support reportedly being used by the respondent starting from the most helpful to the least helpful. Follow the same procedure for gathering information for each area of support.

- 10) The interview should be conducted in such a way that the interviewer does not influence the decision of the concerned respondent.
- 11) Enter the total score for each area as also the grand total score obtained by respondent on NIMH-FSS for both “Utilisation” and “Level of Satisfaction” at the appropriate places provided in the profile sheet.
- 12) Complete the NIMH-FSS profile sheets provided at the end of the tool after the assessment for both parents separately on “utilisation” and “level of satisfaction” of support. Information obtained from “need for more support and “rank order utilisation” could also be compiled separately for understanding and helping the families.
- 13) NIMH-FSS indicates that the higher the scores on “Utilization” greater the quantity/amount of support available to the family. The higher the scores on “Level of satisfaction” the greater the quality of support available to the family.
- 14) The grand total scores on “Utilization of support” and “Level of satisfaciton” of support are added to calculate the total “Family Support Score”. The higher the score the greater is the family support.

NIMH FAMILY SUPPORT SCALE (NIMH-FSS)

Client Name:
(person with mental retardation)

Interviewer's Name:

Date:

Family No:

Baseline:

Respondent's Name:
Mother/Father (Tick)

1st Assessment:

2nd Assessment:

3rd Assessment:

4th Assessment:

Mother/Father (tick)

Instructions:

In our society people help each other at various times in various ways. Please mention about those people, who are providing help to you in your day to day life as well as in managing your child with mental retardation. Kindly report which of the following source of support (from item no.1-10 in relation to the mentally retarded individual) you have utilized in the past six months or are currently utilizing and place them rank order; to what extend you are satisfied and if not satisfied then what kind of support do you require.

AREA : I PERSONAL Does any one support you in doing household chores, caring and looking after your child when you are away or busy, helping you in emergencies or transporting child to school and back or other places on regular basis? **If so who?**

(Item 1 to 10 are in relation to the person with mental retardation)

Source of Support	UTILISATION					LEVEL OF SATISFACTION					NEED FOR MORE SUPPORT					RANK ORDER (UTILISATION)					
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	
1. Spouse																					
2. Mother																					
3. Father																					
4. Siblings																					
5. Paternal Grandfather																					
6. Paternal Grandmother																					
7. Maternal Grandfather																					
8. Maternal Grandfather																					
9. Paternal Aunt/Uncle																					
10. Maternal Aunt/Uncle																					
11. Friends																					
12. Neighbours																					
13. Organizations/ Agencies																					
14. Boss/ Co-workers																					
15. Doctor																					
16. Other professionals																					
17. Religious/ support group																					
18. Any other																					
19.																					
20.																					
Total Score																					

KEY : Utilisation: Using :2; Not Using :1; Not Available:0
Level Of Satisfaction: Very Satisfied:2 ; Satisfied:1; Not Satisfied:0
Need for more support : No need for more support 2; Need for more support:1

Area : II FINANCIAL Does any one support you when you have financial concerns in terms of family needs, child's medication, buying material and various other expenditures? **If so who?**

(Item 1 to 10 are in relation to the person with mental retardation)

Source of Support	UTILISATION					LEVEL OF SATISFACTION					NEED FOR MORE SUPPORT					RANK ORDER (UTILISATION)					
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	
1. Spouse																					
2. Mother																					
3. Father																					
4. Siblings																					
5. Paternal Grandfather																					
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10. Maternal Aunt/Uncle																					
11. Friends																					
12. Neighbours																					
13. Organizations/ Agencies																					
14. Boss/ Co-workers																					
15. Doctor																					
16. Other professionals																					
17. Religious/ support group																					
18. Any other																					
19.																					
20.																					
Total Score																					

KEY: Utilisation: Using :2; Not Using :1; Not Available:0
Level Of Satisfaction: Very Satisfied:2 ; Satisfied:1; Not Satisfied:0
Need for more support : No need for more support 2; Need for more support:1

AREA : III TECHNICAL Does any one help you in understanding your child's condition better, training him/her, explaining about services available, government benefits from time to time and other information about recent trends, or laws concerning mental retardation? **If so who?**

(Item 1 to 10 are in relation to the person with mental retardation)

Source of Support	UTILISATION					LEVEL OF SATISFACTION					NEED FOR MORE SUPPORT					RANK ORDER (UTILISATION)					
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	
1. Spouse																					
2. Mother																					
3. Father																					
4. Siblings																					
5. Paternal Grandfather																					
6. Paternal Grandmother																					
7. Maternal Grandfather																					
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9. Paternal Aunt/Uncle																					
10. Maternal Aunt/Uncle																					
11. Friends																					
12. Neighbours																					
13. Organizations/ Agencies																					
14. Boss/ Co-workers																					
15. Doctor																					
16. Other professionals																					
17. Religious/ support group																					
18. Any other																					
19.																					
20.																					
Total Score																					

KEY : Utilisation: Using :2; Not Using :1; Not Available:0
Level Of Satisfaction: Very Satisfied:2 ; Satisfied:1; Not Satisfied:0
Need for more support : No need for more support 2; Need for more support:1

AREA : IV RECREATION Does any one help your child in spending leisure time, playing with him/her, relaxing, accompanying for an evening walk, market, religious place, watching movie, mela, picnic etc.? **If so who?**

(Item 1 to 10 are in relation to the person with mental retardation)

Source of Support	UTILISATION					LEVEL OF SATISFACTION					NEED FOR MORE SUPPORT					RANK ORDER (UTILISATION)				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
1. Spouse																				
2. Mother																				
3. Father																				
4. Siblings																				
5. Paternal Grandfather																				
6. Paternal Grandmother																				
7. Maternal Grandfather																				
8. Maternal Grandfather																				
9. Paternal Aunt/Uncle																				
10. Maternal Aunt/Uncle																				
11. Friends																				
12. Neighbours																				
13. Organizations/ Agencies																				
14. Boss/ Co-workers																				
15. Doctor																				
16. Other professionals																				
17. Religious/ support group																				
18. Any other																				
19.																				
20.																				
Total Score																				

KEY: Utilisation: Using :2; Not Using :1; Not Available:0
Level Of Satisfaction: Very Satisfied:2 ; Satisfied:1; Not Satisfied:0
Need for more support : No need for more support 2; Need for more support:1

AREA : V EMOTIONAL Do you have any person/s with whom you can share your deepest feelings, concerns, thoughts, emotions and for seeking hope in distress without any hesitation? **If so who?**

(Item 1 to 10 are in relation to the person with mental retardation)

Source of Support	UTILISATION					LEVEL OF SATISFACTION					NEED FOR MORE SUPPORT					RANK ORDER (UTILISATION)				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
1. Spouse																				
2. Mother																				
3. Father																				
4. Siblings																				
5. Paternal Grandfather																				
6. Paternal Grandmother																				
7. Maternal Grandfather																				
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15. Doctor																				
16. Other professionals																				
17. Religious/ support group																				
18. Any other																				
19.																				
20.																				
Total Score																				

KEY: Utilisation: Using :2; Not Using :1; Not Available:0
Level Of Satisfaction: Very Satisfied:2 ; Satisfied:1; Not Satisfied:0
Need for more support : No need for more support 2; Need for more support:1

AREA : VI MATERIAL Does any one help you in informing or getting things for your child such as play material, aids and appliances, training materials, or any others things in material form? **If so who?**

(Item 1 to 10 are in relation to the person with mental retardation)

Source of Support	UTILISATION					LEVEL OF SATISFACTION					NEED FOR MORE SUPPORT					RANK ORDER (UTILISATION)					
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th	
1. Spouse																					
2. Mother																					
3. Father																					
4. Siblings																					
5. Paternal Grandfather																					
6. Paternal Grandmother																					
7. Maternal Grandfather																					
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20.																					
Total Score																					

KEY: Utilisation: Using :2; Not Using :1; Not Available:0
Level Of Satisfaction: Very Satisfied:2 ; Satisfied:1; Not Satisfied:0
Need for more support : No need for more support 2; Need for more support:1

NIMH FAMILY SUPPORT SCALE (NIMH-FSS)

PROFILE SHEET

UTILISATION OF SUPPORT

Client's Name :
(person with mental retardation)

Family No:

Mother's Name :

AREAS	Max. Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		%	Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score
1. PERSONAL	20										
2. FINANCIAL	20										
3. TECHNICAL	20										
4. RECREATION	20										
5. EMOTIONAL	20										
6. MATERIAL	20										
Grand Total	120										

KEY: Ob score : Obtained score % : Percentage

LEVEL OF SATISFACTION

AREAS	Max. Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		%	Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score
1. PERSONAL	20										
2. FINANCIAL	20										
3. TECHNICAL	20										
4. RECREATION	20										
5. EMOTIONAL	20										
6. MATERIAL	20										
Grand Total	120										

KEY: Ob score : Obtained score % : Percentage

FAMILY SUPPORT SCORE

Assessments	UTILISATION OF SUPPORT (1)	LEVEL OF SATISFACTION (2)	FAMILY SUPPORT SCORE (1+2)
Baseline Assessment			
1st Assessment			
2nd Assessment			
3rd Assessment			
4th Assessment			

NIMH FAMILY SUPPORT SCALE (NIMH-FSS)

PROFILE SHEET

UTILISATION OF SUPPORT

Client's Name :
(person with mental retardation)

Family No:

Father's Name :

AREAS	Max. Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		%	Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score
1. PERSONAL	20										
2. FINANCIAL	20										
3. TECHNICAL	20										
4. RECREATION	20										
5. EMOTIONAL	20										
6. MATERIAL	20										
Grand Total	120										

KEY: Ob score : Obtained score % : Percentage

LEVEL OF SATISFACTION

AREAS	Max. Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		%	Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score
1. PERSONAL	20										
2. FINANCIAL	20										
3. TECHNICAL	20										
4. RECREATION	20										
5. EMOTIONAL	20										
6. MATERIAL	20										
Grand Total	120										

KEY: Ob score : Obtained score % : Percentage

FAMILY SUPPORT SCORE

Assessments	UTILISATION OF SUPPORT (1)	LEVEL OF SATISFACTION (2)	FAMILY SUPPORT SCORE (1+2)
Baseline Assessment			
1st Assessment			
2nd Assessment			
3rd Assessment			
4th Assessment			