

NIMH DISABILITY IMPACT SCALE (NIMH-DIS)

AUTHORS

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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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Mrs.Saila Kumari

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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 Disability Impact Scale (NIMH - DIS) 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). Parents and the family are known to get impacted because of having a child with mental retardation.

A need was felt to develop a culture specific tool which could be used to identify and assess;

- a) The nature and degree of impact on the parents (both positive and negative) because of having a child with mental retardation,
- b) The nature and degree of impact on the family members and the relationships within the family,
- c) The nature and degree of impact with regard to relationships outside the family,
- d) To identify thrust areas for family intervention programmes,
- e) To objectively evaluate family intervention programmes.

As part of the development of NIMH-DIS, the areas and sub areas of impact included in the scale were identified from an earlier study by Reeta Peshawaria, et. al (1995) on "parents impact" included in the second chapter of the book "Understanding Indian Families Having Persons with Mental Retardation" (NIMH Publication). The 11 areas of impact derived from the study and included in the scale are as follows:

1. Physical care
2. Health
3. Career
4. Support
5. Financial

6. Social
7. Embarrassment/Ridicule
8. Relationships
9. Sibling effect
10. Specific thoughts
11. Positive effect

Instructions were added. An open ended question leading to introducing each area in the tool was included. A quantitative scoring of 2, 1 and 0 was adopted for each of the impact areas to assess the degree of impact. To study its feasibility the developed tool was initially field tested on 30 parents (16 mothers and 14 fathers) of 30 mentally retarded individuals. Following which it was decided to retain three slots each under the item "Any other (specify)" in each area for including the unique responses, if any, of the respondents.

The pilot study using the NIMH Disability impact scale was conducted on 20 parents (12 mothers and 8 fathers) of 20 mentally retarded individuals. The sequence of areas was readjusted in the tool as was found comfortable for respondents to respond. 5 parents of mentally retarded individuals were interviewed by two raters independently using NIMH-DIS. The inter-rater reliability between the two raters was found to be ($r=0.849$; $p<0.001$). The final study is in progress under the project.

GUIDELINES FOR ADMINISTRATION AND SCORING OF NIMH-DIS

1. Interview method is preferred over self-reporting method for gathering information using NIMH-DIS.
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 - DIS.
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.
7. The items included in NIMH - DIS should be asked in the same sequential order.
8. The interview should be conducted in such a way that the interviewer does not influence the decision of the concerned respondent.
9. The interviewer should interview the respondent on each area of impact by stating the leading open question for the given area followed by stating one by one each of the sub-items listed in alphabetical order of the given area.
10. The interviewer should score each sub-item in the given area by obtaining the choice option from the concerned respondent and check for the score 2, 1 or 0 with the key given at the end of each area. Enter the score in the appropriate box given in the scale.
11. Enter the total score for each of the area as also the grand total score obtained by the respondent on NIMH-DIS at the appropriate places provided in the profile sheet. Scores should be counted separately for areas 1-10 and the area 11. The higher the grand total scores in areas from 1 to 10 the greater the negative impact. The higher the scores in area 11 the greater the positive impact.
12. Complete the NIMH-DIS profile sheets separately for both the parents after the assessment.

NIMH DISABILITY IMPACT SCALE (NIMH-DIS)

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:

Instructions

Parenting a child with mental retardation is not an easy job. Parents /other primary care givers are known to get affected in many ways because of having a child with mental retardation. We would like to know the impact your child with mental retardation is presently having on you and your family in the following areas :

1. PHYSICAL CARE

Are you experiencing difficulties/facing extra demands with physical care of your child:

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Bathing										
b) Feeding										
c) Dressing										
d) Toileting										
e) Brushing										
f) Grooming										
g) Lifting and carrying the child										
h) Medicating/giving medication										
i) Any other (specify)										
j)										
k)										
Total area score										

Scoring: 0. No Difficulty 1. Some Difficulty 2. Lot of Difficulty

2. HEALTH

Are you experiencing any health related problems like :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Asthma										
b) High Blood Pressure										
c) Sleeplessness										
d) Headache										
e) Mental worries										
f) Any other (specify)										
g)										
h)										
Total area score										

Scoring: 0. Not at all 1. Some times 2. Most of the times

3. CAREER

Are you presently making any career adjustments by :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Readjusting job timings										
b) Taking up a less paying job										
c) Unable to take up a job										
d) Seeking transfer										
e) Any other (specify)										
f)										
g)										
Total area score										

Scoring: 1. Not at all 1. Some times 2. Most of the times

4. SUPPORT

Are you experiencing any loss of support from your :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) spouse										
b) family										
c) in-laws										
d) relatives										
e) friends										
f) neighbours										
g) Any other (specify)										
h)										
i)										
Total area score										

Scoring: 0. Not At all 1. Some times 2. Most of the times

5. FINANCIAL

Are you experiencing any financial difficulties because of :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Visits to Doctors & other Professionals										
b) Transportation										
c) Medical investigations										
d) Aids, appliances and equipment										
e) Visit to traditional healers										
f) Any other(specify)										
g)										
h)										
Total area score										

Scoring: 0. No Difficulty 1. Some Difficulty 2. Lot of Difficulty

6. SOCIAL

Are you feeling restricted from :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Attending social functions										
b) Pursuing leisure/recreational activity										
c) Pursuing an interesting learning opportunity										
d) Any other (specify)										
e)										
f)										
Total area score										

Scoring: 0. Not At all 1. Sometimes 2. Most of the times

7. EMBARRASSMENT/RIDICULE

Are you experiencing any embarrassment/ridicule within the :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Family										
b) Relatives										
c) Neighbourhood/colony										
d) Community										
e) Any other (specify)										
f)										
j)										
Total area score										

Scoring: 0.No Embarrassment 1.Some Embarrassment 2. Lot of Embarrassment

8. RELATIONSHIPS

How much you feel that your relationships is negatively affected with your:

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Spouse										
b) Family										
c) In-laws										
d) relatives										
e) friends										
f) neighbours										
g) Any other (specify)										
h)										
i)										
j)										
Total area score										

Scoring: 0.Not affected 1.Somewhat affected 2.Affected a lot

9. SIBLING EFFECT

Do you feel that (index child's name) siblings are being negatively affected because of :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Getting less time from you										
b) Studies getting affected										
c) Having added responsibilities										
d) Recreation needs being compromised with										
e) Being teased by the community										
f) Feeling isolated										
g) Worrying about the future										
h) Any other (specify)										
i)										
j)										
Total area score										

Scoring: 0. Not Effected 1. Somewhat Effected 2. Effected a Lot

10. SPECIFIC THOUGHTS

Do the following thoughts ever cross your mind :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) Killing the child										
b) Attempting suicide										
c) Restricting family size										
d) Separating the child so that family does not get affected										
e) Any other (specify)										
f)										
g)										
Total area score										

Scoring: 0. Not at all 1. Some times 2. Most of the times

11. POSITIVE IMPACT

Do you feel any positive effects like :

	Mother					Father				
	Baseline	1st	2nd	3rd	4th	Baseline	1st	2nd	3rd	4th
a) More patience										
b) More tolerance										
c) More empathy										
d) More sensitivity										
e) More support										
f) Better relationships (with)										
g) Any other(specify)										
h)										
i)										
Total are score										

Scoring: 2. Lot of effect 1. Some effect 0. No effect

NIMH DISABILITY IMPACT SCALE (NIMH-DIS) PROFILE SHEET

Client's Name :
(*person with mental retardation*)

Family No:

Mother's Name :

AREAS	Maximum Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score	%
1. PHYSICAL CARE	22										
2. HEALTH	16										
3. CAREER	14										
4. SUPPORT	18										
5. FINANCIAL	16										
6. SOCIAL	12										
7. EMBARRASSMENT /REDICULE	14										
8. RELATIONSHIPS	18										
9. SIBLING EFFECT	20										
10. SPECIFIC THOUGHTS	14										
GRAND TOTAL	164										
AREAS	Maximum Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score	%
11. POSITIVE IMPACT	18										

KEY : Ob score : Obtained score; % : Percentage

NIMH DISABILITY IMPACT SCALE (NIMH-DIS) PROFILE SHEET

Client's Name :
(*person with mental retardation*)

Family No:

Father's Name :

AREAS	Maximum Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score	%
1. PHYSICAL CARE	22										
2. HEALTH	16										
3. CAREER	14										
4. SUPPORT	18										
5. FINANCIAL	16										
6. SOCIAL	12										
7. EMBARRASSMENT /REDICULE	14										
8. RELATIONSHIPS	18										
9. SIBLING EFFECT	20										
10. SPECIFIC THOUGHTS	14										
GRAND TOTAL	164										
AREAS	Maximum Score	Baseline Assessment		1st Assessment		2nd Assessment		3rd Assessment		4th Assessment	
		Ob score	%	Ob score	%	Ob score	%	Ob score	%	Ob score	%
11. POSITIVE IMPACT	18										

KEY : Ob score : Obtained score; % : Percentage