

TITLE : Disability, mental disability (Schizophrenia and Affective Disorders), Stigma and multidimensional Poverty in India. A pilot study

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Description: We aim at providing knowledge to the Government of India to better address the needs of people with a mental health condition. We would like to understand what are the difficulties you and your family face in everyday life. Therefore we are seeking help from persons diagnosed to have Schizophrenia or severe affective disorders.

You are invited to participate to the study along with 2000 other heads of family and caregiver of persons with either Schizophrenia or severe affective disorders. If you agree we will administer a questionnaire about the following: family composition and characteristics, disability status of some members, access to employment, construction of your house, empowerment issues, health behaviour and access to services, stigmatisation. Risks and benefits Risks: There is no risk involved for you. There is no administration of treatment, drug or vaccine of any kind.

Benefits: There is no direct benefit for you or your family from the study. However, this research may yield important information to better address the needs of people with a mental health condition.

Witness Initials _____

Subject's initials _____

New information: If any new information relevant to your decision to participate becomes available during the course of this study, you will be informed.

Costs and Payments: Through this consent form I understand that it will not cost me anything to take part in this study. I will not be paid to participate in this study. No material of this study is of commercial value and will be sold.

Compensation for illness or Drawing injury: interviewing patients carries no risk of hazard. Yet, in the unlikely event of distress linked to the interview, the interviewer will stop the interview and you will be referred for treatment free of charge at Dr Ram ManoharLohia Hospital, New Delhi. I will not claim or receive any additional compensation from University College London or Dr R.M.L. Hospital or the investigators jointly or independently as the result of the distress.

Confidentiality: It has been explained to me that all personal information is kept strictly confidentially. All information about me and my family will be coded and kept in locked files. The information provided by me will be kept separate from the medical record of the patient from my family. My identity on record and sample will be indicated by a case number. My research results will not be provided to any third party including my relatives or my personal physician. No person or family will be identified in any report or publication from the study. My identity or that of my family will not be revealed in any description or publication of the study. Therefore I consent to publication for scientific purpose. I do understand that my research records, just like hospital records, may be subpoenaed by court order or may be inspected by government regulatory authorities. Right to Withdraw: I understand that I have the right not to be in the study or to stop at any time and that my decision will not adversely affect my care or cause a loss of benefit to which I might otherwise be entitled. If I withdraw from the study, all my information will be destroyed.

Voluntary consent: I certify that I have read the preceding or it has been read to me and that I understand its contents. Any question I have pertaining to the research have been and will be answered by the research assistant working on the project or by the investigators. Any questions, difficulties, grievance I have concerning my rights as a research subject may be answered by Dr Smita N Deshpande, Senior psychiatrist, Department of Psychiatry or Chairman, Ethics Committee of Dr R.M.L. A copy of this consent form will be given to me. My signature below means that I have freely agreed to participate in this pilot study.

Consent to re-contact : If a second round of study is decided, the investigators may wish to obtain further relevant information from you. I give permission to be re-contacted. I understand that the study will then be explained to me and separate informed consent will be requested.

Date _____

_____ Subject Signature

_____ Witness

Participant's Statement (the person answering the questions is the caregiver of the patient or the respondent him/herself when the person belongs to the control group)

I _____ (name) and ID number patient control

Section 1: Profile of the Key Informant – Interview Details

Q.No	Question	Response Categories		Instructions
101	State (code)	Andhra Pradesh	1	
		DelhiUnion	2	
102	District name and code		<input type="text"/> <input type="text"/>	See list of districts
103	Village area: Sub-District (Taluka) name and code		<input type="text"/> <input type="text"/>	See list of sub-districts
104	Village name and postal code		<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
105	Urban area: colony name and postal code		<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
106	Name of head of the household			
107	Name of caregiver			Only for patient interview
108	Household address with landmark			
109	Patient name and ID number		1 <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
110	Control name and ID number		2 <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
111	Date of Interview	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Day Month Year		
112	Language of interview	Telegu	1	
		Urdu	2	
		Hindi	3	
		Other (specify) _____	4	
113	Starting Time of Interview	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Hrs Mts		
114	Ending Time of Interview	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Hrs Mts		
115	Name of the Interviewer		<input type="text"/> <input type="text"/>	
116	Name of the Supervisor		<input type="text"/> <input type="text"/>	
117	Back Checked	Yes	1	
		No	2	
118	Accompanied	Yes	1	
		No	2	
119	Result of the interview	Complete	1	If refused please specify why below
		Incomplete	2	
		Refused	3	
		_____ _____ _____		

Supervisor/Editor Details

	Supervisor	Field Editor	Office Editor	Data Entry
Name	_____	_____	_____	_____
Date	_____	_____	_____	_____

Section 2: Details of the members of the household(ask to caregiver or control or another adult member in HH)

Patient (1+number) or Control (2+number) ID

ID of the main Respondent (see HH grid)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Ask the following questions and code in the Household Rooster Grid			
Q.No	Question	Response Categories	Instructions
201	Can you please tell me the name of all the members in your household in decending order of age?	Fill the Table form. Start with head of household. Then his wife and children by order of age (from the oldest). Then parents, brothers and sisters with their own children, and last other members of family and friends.	
202	What is NAME relationship with the head of household?	Head	01
		Spouse	02
		Son/Daughter	03
		Son in law/Daughter in law	04
		Grandchild	05
		Parent	06
		Parent in law	07
		Brother/Sister	08
		Brother in law/ Sister in Law	09
		Other relatives	10
		Adopted/Foster/Stepchild	11
		Servant/employees/other non-relatives	13
Visitors	14		
203	Can you tell me NAME gender?	Male	1
		Female	2
204	Can you tell me NAME's age as on his/her last birthday?		Code in completed years
205	What is the current marital status of NAME?	Unmarried	1
		Married	2
		Separated	3
		Divorced	4
		Widow/widower	5
206	What is NAME's level of education?	Not literate	01
		Literate without any formal schooling	02
		Literate but below primary, not completed	03
		Primary School completed	04
		Middle School	05
		Secondary school	06
		Higher secondary	07
		Diploma/Certificate course	08
		Graduate	09
		Post graduate and above	10
Too young to go to school	11		
Ask 207 to 211 for all children below age of 17 years			
207	What is NAME's current grade in school?	Grade:	Record 00 for Preschool and Nursery. Record 97 for not going to school and go to 209
208	What kind of school does NAME attend?	Formal Government	1
		Formal Private	2
		Informal	3
209	Has NAME ever attended a special school for disabled people?	Yes	1
		No	2
210	Why NAME is not going to school?	We cannot afford school fees	1
		He/she has to work	2
		School is too far away	3
		Because of his/her physical or mental condition	4
		Other reason, specify:_____	5
211	Why does this difficulty prevent him/her from going to school?	Other children in school would be mean to him/her	1
		He/she cannot learn	2
		He/she cannot get into or to the school	3
		We do not want him/her to be seen by others	4
		No school will enrol him/her	5
		6. Other reason:_____	6

MISPI survey main questionnaire

Ask 212 to all HH member above age of 5 years				
212	What is the usual primary activity of NAME?	Works on own farm	01	<p>Go to next member except for answer 13 go to 213.</p> <p>Answer 13 only if answered at least ONE YES to the questions in the disability module 7 below and go to 213</p>
		Self-employed (home-based work)	02	
		Self-employed (work place outside home)	03	
		Works as regular wage/salaried employee	04	
		Works as casual agricultural labourer	05	
		Works as casual worker (non-agricultural)	06	
		Does not work due to sickness though have regular work (any kind)	07	
		Does not work due to other reasons though have regular work (any kind)	08	
		Does not work but was seeking and/or available for work	09	
		Working and attending educational institutions at the same time	10	
		Not working, attending Educational Institutions	11	
		Attending to domestic duties including caring for others at home	12	
		Not able to work owing to disability/physical or mental condition	13	
		Retired	14	
		Too young	15	
		Does not want to work	16	
		Others, Specify _____	17	
213	why does this condition prevent him/her from working?	People would be mean to him/her	1	For response 13 to 212
		He/she cannot do any of the jobs available in the community	2	
		He/she cannot get into or to the workplace	3	
		We do not want him/her to be seen by others	4	
		No employer will hire him/her	5	
		Other reason: _____	6	
Ask 214 to 225 if coded 1 to 9 in 212				
214	In what sector is NAME's primary activity?	Agriculture	1	
		Other Primary (Animal Husbandry, Non-timber forest produce collector, etc)	2	
		Secondary (Manufacturing, mining, construction, etc)	3	
		Tertiary (Services, Government, Trade, retail, etc)	4	
215	At what age did NAME start working for pay?	Age:	Record age in completed years	
216	If there have been breaks of more than 6 months in NAME's work during their life, how long have they not worked?	No Breaks/less than 6 months	1	
		6-12 months	2	
		1-2 years	3	
		2-3 years	4	
		3-5 years	5	
		More than 5 years	6	
217	How many hours a day does NAME usually work?	Record completed hours		
218	How many days a month does NAME usually work?	Record completed days		
219	Does the number of days per month vary across the year?	Yes	1	Go to 222
		No	2	
220	In which months it is the maximum? How much is it?	Month: Number of days:	Record January as 01, February as 02, etc. December as 12	
221	In which months it is the minimum? How much is it?	Month: Number of days:		
222	How much does NAME usually earn per month?	Record in Rupees		
223	Does this earning vary across the year?	Yes	1	Go to next member
		No	2	
224	In which months it is the maximum? How much is it?	Month: Income:	Record January as 01, February as 02, etc	
225	In which months it is the minimum? How much is it?	Month: Income:		

MISPI survey main questionnaire

	201	202	203	204	205	206	207	208	209	210	211	212
ID No	Name	Relationship	Gender	Age	Marital Status	Education	Current Grade	Type of School	Special School	Why no school	No school because difficulty?	Primary Activity
01	N M DWARY	01										
02	KRISHNA DEVI	02										
03	NEEL MANI	03										
04	NEELU	04										
05	MADHAV	05										
06	KESHAV	05										
07	GOPAL MANI	03										
08	GUNJA	04										
09	RAGHAV	05										
10	RAJA MANI	06										
11	S DEVI	06										
12												
13												
14												
15												
16												
17												
18												
19												
20												

MISPI survey main questionnaire

ID No	215	216	217	218	219	220		221		222	223	224		225	
	Age of working	Breaks in work	Hours of work/day	Days of work in a month	Variation across the year	Maximum	Amount	Minimum	Amount	Wage in a month	Variation across the year	Maximum	Amount	Minimum	Amount
01															
02															
03															
04															
05															
06															
07															
08															
09															
10															
11															
12															
13															
14															
15															
16															
17															
18															
19															
20															

Section 3: Household characteristics(ask to caregiver or control or another adult member in HH)

Patient (1+number) or Control (2+number) ID
ID of the main Respondent (see HH grid)

Q. No	Question	Response Categories		Instructions	
301	What is the religion of the household?	Hindu	1		
		Muslim	2		
		Christian	3		
		Sikh	4		
		Buddhist/Neo Buddhist	5		
		Jain	6		
		Others, Specify_____	7		
		No Religion	8		
302	Is this a scheduled caste, a scheduled tribe, other backward caste, or none of them?	SC	1		
		ST	2		
		OBC	3		
		None of them	4		
		DK/CS	9		
303	Does your household have either	AntyodayaAnnaYojana ration card	1		
		Below Poverty Line (BPL) ration card	2		
		Above Poverty Line (APL) ration card	3		
		Annapoornaration card	4		
		Other ration card, specify:_____	5		
		No ration card	6		
If you have a Job Card, adult members of your household are entitled to work under the National Rural Employment Guarantee Act (NREGA).					
304	Does your household have a Job Card?	Yes own Job Card	1	If answered 1, 2 or 3 go to Q. 305, if answered 4 or 5 go to Q. 309.	
		Yes but joint with some other household	2		
		Yes several Job Cards	3		
		No	4		
		Not applicable, urban area	5		
		Don't know/refuse to answer	88/99		
If possible, ask to see and please note the Job Card number below, in full. Job Card Number: /___/___/___/___/_____/_____ (state) (district) (block) (GP) (household)					
305	How many adults are listed on the Job Card(s)?	Females	<input type="checkbox"/> <input type="checkbox"/>	"Adult" means someone aged 18 or above today (not at the time of issuing of Job Card)	
		Males	<input type="checkbox"/> <input type="checkbox"/>		
306	How many days of NREGA work has been done during the last 12 months by <u>all</u> Household members?	Specify number of days	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Number of days worked by all household members together	
307	Do you feel that NREGA has brought any significant change in your life or your family's life?	Yes	1		
		No	2		
		Don't know/refuse to answer	88/99		
308	Does working on NREGA have helped you or your family...		YES	NO	Please read the different options to the respondent and ask her/him to choose Yes=1 or No=2
		to avoid going hungry	1	2	
		to avoid migration	1	2	
		to send children to school	1	2	
		to cope with someone's illness	1	2	
		to repay our debts	1	2	
		to give up work we didn't want to do (e.g. because it was demeaning or hazardous)	1	2	
or resulted in the creation of useful assets in the village.	1	2			

MISPI survey main questionnaire

309	How many kilometers away is your house from the nearest bus stand?	[][] . [][]		Code in kilometers	
310	What is the condition of the road which connects your house to the bus stand?	Kuchcha (raw)	1		
		Semi Pucca (semi-finished)	2		
		Pucca (finished)	3		
311	How many kilometers away is your house from nearest primary school?	[][] . [][]		Code in kilometres	
312	How many kilometers away is your house from nearest functional government health facility? What type of facility is it?	[][] . [][]		Code in kilometers	
		Sub Centre (SC)	1		
		Primary Health Centre (PHC)	2		
		Community Health Center (CHC)	3		
		Government Dispensary	4		
		Government Hospital	5		
Others, Please specify _____		7			
313	Did anyone from your household vote in the last Gram Panchayat election or in the municipal election?	Yes	1	Go to 315	
		No	2		
314	Who voted in the last Gram Panchayat or in the municipal election?	Name	Id No.	Write the name and post code the Respondent Id from Household Rooster. For urban areas consider municipal election.	
			[][]		
			[][]		
			[][]		
			[][]		
			[][]		
			[][]		
315	Did anyone from your household attend the last Gram Sabha or ward committee meetings?	Yes Gram Sabha	1	Go to 318 for rural area and section 4 for urban area	
		Yes ward committee meetings	2		
		No	3		
316	Who attended the last Gram Sabha or ward committee meeting from your Household?	Name	Id No. in grid section2	Spoke in GS	Write the name and post code the Respondent Id from Household Rooster
			[][]	1 2 88..99	
317	Did they speak in the this last Gram Sabha/ward committee meeting? Yes 1 No 2 Don't know 88 No answer 99		[][]	1 2 88..99	
			[][]	1 2 88..99	
			[][]	1 2 88..99	
The Mahatma Gandhi National Rural Employment Guarantee Act (NREGA) aims at enhancing the livelihood security of people in rural areas by guaranteeing hundred days of wage-employment in a financial year to a rural household whose adult members volunteer to do unskilled manual work					
318	To your knowledge, has the selection of NREGA works been discussed in any Gram Sabha meetings in this Gram Panchayat during the last 12 months?	Yes	1		
		No	2		
		N.A. urban area	3		
		Don't know	88		
		Refuse	99		

Section 4: Dwelling Characteristics and Asset Ownership (ask to caregiver or control or another adult member in HH)

Patient (1+number) or Control (2+number) ID
 ID of the main Respondent (see HH grid)

Q.No	Question	Response Categories			Instructions
401	Can you tell me about the ownership of this dwelling?	Owned by household member	1		
		Owned by a HH member's relatives	2		
		Rented by HH members	3		
		Rented by a HH member's relatives	4		
		Government housing	5		
		No dwelling, in the street	6		
		Other (specify)	7		
For 402, Observe the construction of the dwelling used for living by the household and record in the Grid					
402		Kuchcha	Semi Pucca	Pucca	
	Walls	1	2	3	
	Roof	1	2	3	
	Floor	1	2	3	
403	Does this dwelling have telephone connection?	Yes	1		
		No	2		
404	How many members of the Household own a mobile phone?		Specify number based on HH roster grid		
405	What is the primary source of cooking fuel?	Wood	1		
		Coal/charcoal	2		
		Gas	3		
		Dung	4		
		Kerosene	5		
		Straw/Shrubs/Grass/Agricultural crop	6		
		Other, specify	7		
406	What is your primary source of lighting?	Electricity (Grid)	1		
		Generator	2		
		Kerosene lamp	3		
		Petromax	4		
		Candle	5		
		None	6		
		Others, specify	7		
407	What type of toilet facilities do you use when at home?	Open field	1		
		Flush toilet	2		
		Pit/latrine	3		
		Improved ventilated pit	4		
		Public	5		
		Other, specify	6		
408	What is the estimated covered area of the dwelling?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Record in Square feet. Include the covered area used by the household excluding cowsheds etc.		
409	Does your household own any land for cultivation?	Yes	1	Including land in your village if you live in town	
		No	2	Go to 411	
410	How many acres of land does your household own?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> . <input type="checkbox"/> <input type="checkbox"/>	Record in acres		
411	Do you lease <u>in</u> any land?	Yes	1		
		No	2	Go to 417	
412	How many acres of land do you lease in?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> . <input type="checkbox"/> <input type="checkbox"/>	Record in acres		
413	Ask only if coded 1 in 409/411 Do you lease <u>out</u> any land?	Yes	1		
		No	2	Go to 416	
414	How many acres of land do you lease out?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> . <input type="checkbox"/> <input type="checkbox"/>	Record in Acres		
415	How much do you earn per month from leasing out your land?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Record in Rupees		
Ask 416 to 417 if coded 1 in 409/411/413					

MISPI survey main questionnaire

416	What is the main source of irrigation for your land?	Bore well	1		
		River/Pond/Stream/Lake	2		
		Canal	3		
		Open well	4		
		None	5		
		Others, specify _____	6		
	Don't know/refuse to answer	88/99			
417	What are the main crops you grow on any land owned or leased by you?	Rice	1	Multiple responses possible	
		Wheat	2		
		Vegetables	3		
		Pulses	4		
		Other Food Crops	5		
		Fodder	6		
		Cash Crops	7		
		Don't know/refuse to answer	88/99		
418	What share of your household food consumption is provided from food the household produces?	All	1		
		Most (over 60 percent but not all)	2		
		Significant (40-60 percent)	3		
		Some (20 to 40 percent)	4		
		Not much	5		
		None	6		
		Don't know/refuse to answer	88/99		
419	Does your household own any of the following? (in working condition)		Yes	No	Indicate Yes=1 or No=2 for each asset
		Wooden/steel sleeping cot	1	2	
		Mattress	1	2	
		Table	1	2	
		Clock/watch	1	2	
		Charpoy	1	2	
		refrigerator	1	2	
		Radio/transistor	1	2	
		Electric fan	1	2	
		Television	1	2	
		Bicycle	1	2	
		Computer	1	2	
		Moped/scooter/motorcycle	1	2	
		Car	1	2	
		Tractor	1	2	
		Buffalo/cow/bullock	1	2	
		Goat/sheep	1	2	
		At least one pair of shoes/chappals for each member	1	2	
More than one set of clothes for each household member	1	2			
420	How many meals are usually served in your household in a day?				Indicate number of meals per day
421	Does it vary across the year?	Yes	1		
		No	2		
422	In which months it is the maximum? How many is it?	From <input type="text"/> <input type="text"/> <input type="text"/> To <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	Record January as 01, February as 02, etc	
423	In which months it is the minimum? How many is it?	From <input type="text"/> <input type="text"/> <input type="text"/> To <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>		
424	What do you typically eat for the main meal of the day?	Rice/Roti with Salt, Pickle etc	1		
		Rice/Roti with Dal	2		
		Rice/Roti Dal and vegetables	3		
		Rice/Roti, Dal and vegetables or meat	4		
		Others, specify _____	5		
425	Are you a vegetarian family?	Yes	1		
		No	2		
426	How often do you eat eggs?	Daily	1		
		2-4 times a week	2		
		Once a week	3		

MISPI survey main questionnaire

		Once a fortnight	4	
		Occasionally	5	
		Never	6	
427	How often do you eat dairy products like milk, curd, etc?	Daily	1	
		2-4 times a week	2	
		Once a week	3	
		Once a fortnight	4	
		Occasionally	5	
		Never	6	
428	What is the household's monthly expenditure on the following?	Food	<input type="text"/>	Ask what is the general pattern over the last year Record in Rupees
		Health Care	<input type="text"/>	
		Education	<input type="text"/>	
		Transport	<input type="text"/>	
		Savings	<input type="text"/>	
		Personal Care products	<input type="text"/>	
429	What is the primary source of drinking water?	Bottle water/Filtered water	1	Specify main source of <u>drinking</u> water
		Pipe water at home	2	
		Pipe outside home/public pump	3	
		Tanker truck/cart with small tank	4	
		Water from a covered well	5	
		Unprotected well	6	
		Spring/river/dam/lake/pond/stream	7	
		Other, specify, _____	8	
430	How safe is the place where you live?	Very safe	1	
		Rather safe	2	
		Rather unsafe	3	
		Very unsafe	4	
		Don't know	88	
		No answer/refuse	99	

Section 5: Health behaviour and services

Patient (1+number) or Control (2+number) ID

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

ID of the main Respondent (see HH grid)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

Q. No	Question	Response Categories	Instructions
501	Did the mother (of any child) have any difficulties in accessing pre-natal care?	Yes 1	Check for the last 36 months
		No 2	Go to 503
502	Why did she have difficulty accessing prenatal care?	No services in my area 1	Multiple responses possible
		Transportation problems 2	
		Could not afford services 3	
		Do not like the services in my area 4	
		Waiting time is too long 5	
		Providers don't treat people like me 6	
503	Was anyone in your household ill in the past 2 months?	Yes 1	Go to Section 6
		No 2	
Ask 504 with respect to all members who were ill in the last 2 months and code in the grid			
504	Who all suffered illness in the last 2 months?		Record and name of the member and the id from household roster
505	What was the type of illness?	Fever 01	Record verbatim and specify possible several responses.
		Cough and Cold 02	
		Diarrhoea 03	
		Typhoid 04	
		Jaundice 05	
		Skin ailments 06	
		Respiratory problems 07	
		Diabetes 08	
		Heart Problems 09	
		Renal Problems 10	
		Dental problems 11	
		Orthopaedic Problem 12	
		Ear Nose Throat 13	
		Eye problems 14	
		Sexually Transmitted Infection/Reproductive Track Infection 15	
		Mental illness or other mental condition 16	
		Others, Specify 17	
506	Did the ill household member use health services when ill?	Yes 1	Go to 511
		No 2	
507	What type of services did you/the ill household member receive?	Medical Check Up 1	Multiple responses possible
		Medical Check up and medication 2	
		Medication for ongoing condition 3	
		Pathological tests, X ray etc 4	
		First Aid or Emergency Care 5	
		Hospitalization 6	
		IV treatment 7	
		Surgery 8	
		Others, Specify 9	
508	From what type of health care provider did the member receive services?	Public health facility - Allopathic 1	Multiple responses possible
		Public health facility - Traditional 2	
		Private health facility - Allopathic 3	
		Private health facility - Traditional 4	
		Faith healer, tantric, or astrologer 5	
		Other Specify 6	
509	What was the approximate cost of treatment during the episode?		Record in Rupees. Code 8888/9999 for DK or NA
510	What was the duration of the episode of illness?	Cured 1	Record in Days Code 88/99 for DK or NA
		Still Continuing 2	
511	Why did you not receive the services you desired?	No services in my area 1	Multiple responses possible
		Transportation problems 2	
		Could not afford services 3	
		Do not like the services in my area 4	
		Waiting time is too long 5	

MISPI survey main questionnaire

		Providers don't treat people like me	6	
		Other specify _____	7	

History of the Illness and Treatment in the Household for last 2 months

504		505		506	507	508	509	510		511
Id No	Name	Type of illness		Use of health services	Type of health service received	Type of Provider	Cost	Duration		Ask if coded 2 in 506 Reason for not receiving
		Verbatim	Code					1	2	
				1 2	1 2 3 4 5 6 7 8 9 88 99	1 2 3 4 5 6 88 99		1 2		1 2 3 4 5 6 7
				1 2	1 2 3 4 5 6 7 8 9 88 99	1 2 3 4 5 6 88 99		1 2		1 2 3 4 5 6 7
				1 2	1 2 3 4 5 6 7 8 9 88 99	1 2 3 4 5 6 88 99		1 2		1 2 3 4 5 6 7
				1 2	1 2 3 4 5 6 7 8 9 88 99	1 2 3 4 5 6 88 99		1 2		1 2 3 4 5 6 7
				1 2	1 2 3 4 5 6 7 8 9 88 99	1 2 3 4 5 6 88 99		1 2		1 2 3 4 5 6 7
				1 2	1 2 3 4 5 6 7 8 9 88 99	1 2 3 4 5 6 88 99		1 2		1 2 3 4 5 6 7

Section 6: Disability

Patient (1+number) or Control (2+number) ID
ID of the main Respondent (see HH grid)

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

		1. Locomotor/physical						2. Sensory			
	601	602	603	604	605	606	607	608	609	610	611
ID No	Name	Age	Does (name) lack part of one or more limb?	Is (name) partially or totally paralysed?	Is (name) unable to move part or entire body?	Does (name) often have any difficulties walking/ moving around or climbing steps?	Does (name) have a part of the body that looks different from the other persons of the family?	Does (name) have difficulty or need assistance taking care of themselves, such as bathing, getting dressed, or going to the toilet?	Does (name) have any difficulties seeing even if wearing glasses?	Does (name) have any difficulties hearing, even if using a hearing aid?	Does (name) unable to talk, or has difficulties saying words?
N° in HH grid	Please copy the name from the Household form	What is the age of (name)?	4 = YES, two or more limbs	4 = YES, totally paralysed	4 = YES, unable	4 = YES, unable	2 = YES	4 = YES, constantly /always	4 = YES, cannot see at all	4 = YES, cannot hear at all	4 = YES, cannot talk at all
			3 = YES, one limb	3 = YES, half paralysed	3 = YES, a lot of difficulty	3 = YES, a lot of difficulty	1 = NO	3 = YES, often	3 = YES, a lot of difficulty to see, needs glasses	3 = YES, a lot of difficulty to hear, needs a hearing aid	3 = YES, a lot of difficulty to talk, pronounce words
			2 = YES, part of one limb	2 = YES, less than half body paralysed	2 = YES, some difficulty: move slowly	2 = YES, some difficulty: move at a slow pace		2 = YES, sometimes	2 = YES, some difficulty to see, needs glasses	2 = YES, some difficulty to hear	2 = YES, some difficulty to talk, pronounce words
			1 = NO	1 = NO	1 = NO difficulty to move the body at all	1 = NO difficulty to move or climb steps		1 = NO, never	1 = NO difficulty to see at all	1 = NO difficulty to hear at all	1 = NO difficulty to talk at all
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MISPI survey main questionnaire

3. Learning/Developmental							
	612	613	614	615	616	617	618
ID No	Was (name) later than the others beginning to walk?	Was (name) later than the others beginning to talk?	Does (name) have more difficulty or are you slower than others in learning things (change in routine for example cooking things in a different way)?	Do people think or say that (name) acts or behaves much younger than his/her own age? How often they think s/he do?	Does (name) have difficulty in understanding what people are telling you? How often?	Do people have difficulty understanding what s/he is trying to tell them? How often?	Does (name) have difficulty concentrating or remembering recent things? How often?
N° in HH grid	4 = YES, several years	4 = YES, a lot late, more than 5 years	4 = YES, cannot learn or with very high difficulty	4 = YES, constantly/always	4 = YES, constantly/always	4 = YES, constantly/always	4 = YES, constantly/always
	3 = YES, more than a year	3 = Yes, rather late between 3 and 5 years	3 = YES, have some difficulty to learn and to do things	3 = YES, often/ many times	3 = YES, often	3 = YES, often	3 = YES, often
	2 = YES, but less than a year	2 = Yes, slightly late about 1 year	2 = Little difficulty to learn and to do things	2 = YES, sometimes/few times	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes
	1 = NO	1 = NOT late at all	1 = NO difficulty to learn and do things at all	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never
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MISPI survey main questionnaire

4. Behavioural patterns										
	619	620	621	622	623	624	625	626	627	628
ID No	Do people think or say that (name) behaves in a strange manner? (for example in interactions with others)	Does (name) think that people want to hurt him/her, or say bad things about him/her, even though family and friends say this isn't true?	Does (name) see or hear things and when s/he share this with other people they do not believe her/him? How often?	Does (name) talk aloud to him/herself (more like having a conversation ? How often?	Does (name) feel good making the same gestures over and over again like rocking (show how), biting your arm, swinging your head? How often?	Is (name) afraid when s/he is touched or hears a noise that s/he does not like? How often this happens?	Does (name) feel better when s/he hit her/his head against the wall, or when s/he pull her/his hair when s/he is upset, sad or angry? How often does s/he do it?	Does it make (name) upset, sad or angry when things are not the same or when someone changes things around her/him? How often does it make her/him upset, sad or angry?	How often does (name) prefer to be alone rather than with family or other people?	Are you angry with other people and want to fight with them but they don't understand why you are angry? How often are you angry with people?
N° in HH grid	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always
	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often
	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes
	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never
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MISPI survey main questionnaire

5. Mood/Affect							6. Neurological			
ID	629	630	631	632	633	634	635	636	637	
No N° in HH grid	Does (name) feel happy, and then immediately sad, or happy and then immediately angry (one moment s/he is happy and one moment s/he is sad or angry)? How often s/he feels like that?	Does (name) want to or like (prefer) moving around and hate keeping still or sit in one place for long? How often does this happen (in comparison with people in a similar position to him/her)	Does (name) not feel worried or sad when someone close to you is hurt, upset or sad? How often does this happen?	Does (name) not notice when someone is speaking to her/him, or is not aware of the presence of others? How often does this happen?	Does (name) feel afraid for no reason or feel easily scared? How often does this happen?	Does (name) have trouble getting along with other people of the same age? <i>For children below 15 only</i>	Has (name) fainting in the past 3 months? How often did this happen?	Does (name) experience sudden jerking of the (parts of) body with loss of consciousness during the last 3 months? How often did this happen?	Does (name) bite his/her tongue or froth at the mouth on occasions in last 3 months? How often did this happen?	
	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always	4 = YES, constantly /always , almost daily	4 = YES, constantly /always I fainted daily or almost every day	4 = YES, constantly, almost daily	
	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often	3 = YES, often, once a week	3 = YES, often, once a week	3 = YES, often, once a week	
	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes	2 = YES, sometimes, 1 to 2 times	2 = YES, sometimes, 1 to 2 times	2 = YES, sometimes, 1 to 2 times	
	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	1 = NO, never	
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6.38 Does he/she not go to school because of the difficulty reported above?						Yes	1	For children under 15 who reported earlier that they do not go to school (question 207)		
						No	2			
6.39 Does he/she not work because of the difficulty reported above?						Yes	1	For people above 14 who reported earlier that they do not go to		

MISPI survey main questionnaire

	No	2	school (question 212)
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Section 7: Disability, prejudice and social participation (asked only to caregiver of patient or to control)

Patient (1+number) or Control (2+number) ID
 ID of the main Respondent (see HH grid)

Q.No	Question	Response Categories			
		Yes	No	NA	
701	When a decision that concerns the house is taken, does the head of household take into consideration opinions or feelings of...	His wife	1	2	3
		His adult child	1	2	3
		His child under 18	1	2	3
		His father	1	2	3
		His mother	1	2	3
		You (the control or the person with mental illness)	1	2	3
		Other member of the household	1	2	3
		Everyone in age to express opinion	1	2	3
702	Are women in your household allowed to go to the market?	On her own	1		
		With someone else only	2		
		Not at all	3		
		Only certain women, specify _____	4		
		Don't know	88		
	No answer/refuse	99			
Ask the caregiver about the patient or the control		Always/ almost always	Sometime	Never	Don't know/refuse
703	Are people with disability included in community activities like festivals and religious celebrations?	1	2	3	88/99
704	Should people with disability be included in community activities like festivals and religious celebrations?	1	2	3	88/99
705	Are people with disability included in political activities like taking part in gram sabhas, local associations of farmers, other local association in urban areas etc.	1	2	3	88/99
706	Should people with disability be included in political activities like taking part in gram sabhas, local associations of farmers, other local association in urban areas, etc.	1	2	3	88/99
707	A child with a disability can participate in a regular school effectively, if they are:				
	Locomotor disabled	1	2	3	88/99
	Low vision or Blind	1	2	3	88/99
	Deaf or Dumb	1	2	3	88/99
	Mentally ill	1	2	3	88/99
708	A child with a disability can participate in a special school effectively, if are:				
	Locomotor disabled	1	2	3	88/99
	Low vision or Blind	1	2	3	88/99
	Deaf or Dumb	1	2	3	88/99
	Mentally ill	1	2	3	88/99
709	People with a disability can be successfully employed, if they are:				
	Locomotor disabled	1	2	3	88/99
	Low vision or Blind	1	2	3	88/99
	Deaf or Dumb	1	2	3	88/99
	Mentally ill	1	2	3	88/99
710	Women with disabilities are capable of having and caring for children if they are:				
	Locomotor disabled	1	2	3	88/99
	Low vision or Blind	1	2	3	88/99
	Deaf or Dumb	1	2	3	88/99
	Mentally ill	1	2	3	88/99
711	It is acceptable for a person with disability to marry?	1	2	3	88/99
712	If a person with disability wished to marry a person without, would the size of the dowry have to be adjusted?	1	2	3	88/99
713	Do you think people become disabled as the result of a curse or because of God's will?	1	2	3	88/99

Section 8: Stigma(asked *only* to caregiver of patient or to control)

Patient (1+number) or Control (2+number) ID
ID of the main Respondent (see HH grid)

Sub-section A: vignette

Here is a short account of a person who became ill. Please answer the questions about him.

This young man is twenty years old. He is not married and lives with his parents. He is friendly and hard working. He works in a local factory. One day he becomes ill and starts imagining things that are not true. He cannot do his job properly and eventually loses it. He spends a lot of time by himself. He hears people talking about him when there is no one there. His parents not become anxious but he does not get better. He starts shouting at the voices which he hears, and he tells his family that they themselves are trying to hurt him. On one occasion he hits his father.

The family are very distressed and frightened and do not know what is happening. They ask their neighbours: nobody thinks this is any sort of religious experience. The family take him to the local doctor who tells them the young man is ill, and gives him some tablets. The tablets do not help him. He does not eat properly. He seems puzzled by what is happening. He does not dress himself properly and is often dirty. He wanders about saying embarrassing things to people whom he meets in the streets.

His parents do not know what he is talking about. His doctor sends him to hospital where he stays for two months. He gets better on some new tablets but he still needs to take them when he leaves hospital. He does not hear the voices any more, nor does he have the strange ideas, but he is very quiet and stays alone for much of the time. He occasionally talks to himself but is usually polite to his family. He goes often to see his doctor to get his tablets, and wishes to go back to work.

Sub-section B: questions

Here are some questions about this person. Each one must be answered by whether you agree with the question. Remember this is not a test of knowledge but about how you really feel personally.

		Yes, very much	Yes, a little	No, not much	No, not at all
801	Would you be frightened if this man came to live next door to you?	1	2	3	4
802	Would you be content if he was to work together with you in your workplace? (If you do not have a job, answer as if you did).	1	2	3	4
803	Do you think he will get ill again even if he takes the doctor's medicine?	1	2	3	4
804	Should he take part in meetings of his family which are to make important decisions?	1	2	3	4
805	Would you be happy if he married your sister?	1	2	3	4
806	Could he suddenly become physically violent?	1	2	3	4
807	If he was your brother would it be important not to let other people know that he had been ill, to avoid shame for your family?	1	2	3	4
808	If your local hospital opens a clinic for people like him in your neighbourhood would you hope the local council would object?	1	2	3	4
809	Is the cause of this sort of illness something passing down in the family?	1	2	3	4
810	Should the doctors tell him not to have any children in case he passes the illness on to them?	1	2	3	4
811	Should the doctors have let him out of the hospital?	1	2	3	4
812	Is his illness something he might have brought on	1	2	3	4

MISPI survey main questionnaire

	himself?				
813	Should the doctors only let him leave hospital on condition he goes to see them regularly?	1	2	3	4
814	Do you think a sympathetic family and friends can stop him becoming ill again?	1	2	3	4
815	Will a sympathetic family be more help to him than regularly taking medicine?	1	2	3	4
816	Would it be wise for this man to inherit his parents' property?	1	2	3	4
817	If he becomes ill again do you think it would be better to call the police first rather than the doctor?	1	2	3	4
818	Would you be happy if this person became the teacher of your children?	1	2	3	4
819	Will he be able to return to a completely normal life?	1	2	3	4
820	Should he stay in hospital for his whole life?	1	2	3	4
821	Would you eat food which he has cooked?	1	2	3	4
822	Would you avoid talking to him if possible?	1	2	3	4
823	Might he have any special powers (to heal, to predict future events, to cause illness)?	1	2	3	4
824	Could this illness be caused by some spirits or an enemy harming him?	1	2	3	4
825	Has any person you know personally ever had a similar illness?				
				Yes	1
				No	2
826	Could you give a name to this illness?				

Thank you for your help. Please thank the respondent for her/his contribution to this survey.