

# Development of a cost of illness inventory questionnaire for children with autism spectrum disorder in South Asia

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## Supplementary material

### Literature search results

Economic Evaluation Studies	
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4.	Lavelle TA, Weinstein MC, Newhouse JP, Munir K, Kuhlthau KA, Prosser LA. Economic Burden of Childhood Autism Spectrum Disorders. <i>Pediatrics</i> . 2014 Mar 1;133(3):e520–9.
5.	Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. <i>Autism</i> . 2009 May;13(3):317–36.
6.	Roddy A, O’Neill C. The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed? <i>Autism</i> . 2018 Oct 1;1362361318801586.
7.	Patel V, Weobong B, Nadkarni A, Weiss HA, Anand A, Naik S, et al. The effectiveness and cost-effectiveness of lay counsellor-delivered psychological treatments for harmful and dependent drinking and moderate to severe depression in primary care in India: PREMIUM study protocol for randomized controlled trials. <i>Trials</i> . 2014 Apr 2;15(1):101.
Pathways to Care Studies	
1.	Chakraborty S, Kommu JVS, Srinath S, Seshadri SP, Girimaji SC. A comparative study of pathways to care for children with specific learning disability and mental retardation. <i>Indian Journal of Psychological Medicine</i> . 2014 Jan 1;36(1):27.
2.	Juneja M, Sairam S. Autism Spectrum Disorder - An Indian Perspective. In [cited 2018 Dec 12]. p. 15. Available from: <a href="http://www.smgebooks.com/autism/chapters/AUT-18-12.pdf">http://www.smgebooks.com/autism/chapters/AUT-18-12.pdf</a>
3.	Divan G, Vajaratkar V, Desai MU, Strik-Lievers L, Patel V. Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. <i>Autism Res</i> . 2012 Jun;5(3):190–200
4.	Daley TC. From symptom recognition to diagnosis: children with autism in urban India. <i>Social Science &amp; Medicine</i> . 2004 Apr;58(7):1323–35.
5.	Anand P, Sachdeva A, Kumar V. Pathway to care and clinical profile of children with attention-deficit hyperactivity disorder in New Delhi, India. <i>J Family Community Med</i> . 2018;25(2):114–9.
6.	Rudra A, Belmonte MK, Soni PK, Banerjee S, Mukerji S, Chakrabarti B. Prevalence of autism spectrum disorder and autistic symptoms in a school-based cohort of children in Kolkata, India. <i>Autism Research</i> . 2017;10(10):1597–605.
7.	Desai MU, Divan G, Wertz FJ, Patel V. The discovery of autism: Indian parents’ experiences of caring for their child with an autism spectrum disorder. <i>Transcult Psychiatry</i> . 2012 Jul 1;49(3–4):613–37.
Others	
1.	McDaid D, Byford S, Sefton T. Because it's worth it: a practical guide to conducting economic evaluations in the social welfare field: Joseph Rowntree Foundation; 2003.
2.	Beecham J, Knapp M. Costing psychiatric interventions. <i>Measuring mental health needs</i> . 2001;2:200–24.
3.	Reinap M, Lai T, Janno S, Tamme T, Tamm M. Cost-effectiveness of mental health interventions in Estonia. <i>Healthcare Society in Estonia</i> . 2005.
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7.	Parsonage M, Fossey M. Economic evaluation of a liaison psychiatry service: Centre for Mental Health London; 2011.
8.	Lamsal R, Zwicker JD. Economic Evaluation of Interventions for Children with Neurodevelopmental Disorders: Opportunities and Challenges. <i>Appl Health Econ Health Policy</i> . 2017;15(6):763–72.
9.	Shearer J, McCrone P, Romeo R. Economic Evaluation of Mental Health Interventions: A Guide to Costing Approaches. <i>Pharmacoeconomics</i> . 2016 Jul 1;34(7):651–64.
10.	Luyten J, Naci H, Knapp M. Economic evaluation of mental health interventions: an introduction to cost-utility analysis. <i>Evidence Based Mental Health</i> . 2016 May;19(2):49–53.
11.	Green J, Charman T, McConachie H, Aldred C, Slonims V, Howlin P, et al. Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. <i>Lancet</i> . 2010 Jun 19;375(9732):2152–60
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13.	Rahman A, Divan G, Hamdani SU, Vajaratkar V, Taylor C, Leadbitter K, et al. Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial. <i>Lancet Psychiatry</i> . 2016 Feb;3(2):128–36.

# Final COII (English)



## Cost of Illness Inventory (COII)

ENGLISH

Section A: Assessment Information		Variable Names
A.1. Participant ID	<input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	participant_id
A.2. Research Associate Code	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	racode
A.3. COII completed	1. Yes (Go to A.7) 2. No	coii_complete
A.4. Reason COII not completed	1. Child unavailable 2. Caregiver unavailable 3. Child unwell/irritable 4. Caregiver unwell 5. Unforeseen events causing disruption 6. Uncomfortable responding to item(s) in instrument 7. Consent withdrawal - bad past experience	coii_notcompletereason
A.5. Rescheduled Date	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/>	coii_rescheduledate
A.6. Rescheduled Time	<input type="text"/> : <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> AM PM	coii_rescheduledtime
A.7. COII - date	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/>	coii_date

### Script for the Interviewer

- The purpose of this questionnaire is for us to understand the amount of time and money that you had to invest in [Child's Name].
- We are interested in all expenses including those spent on doctor's visit, hospital admissions and tests, medicines, education and caretaking for [Child's name].
- This questionnaire usually takes 15 minutes. I will be asking you questions and it would be really helpful if you could keep any medical file/ papers that you have for [Child's Name] ready so we can refer to it. You can also show me any medicines that you are giving to [Child's Name] – so that I can accurately record the names.
- I am interested in all the information you can give me which pertains to the past **6 months**.
- If you are not able to understand the questions I am happy to clarify it for you.
- We can take a break in between whenever you feel necessary.

**C.1 EDUCATION**

Can you tell me if [Child's Name] has used any education services over the last 6 months? For example

Circle response	
YES	NO

Table 1	
Code	Name
1	Mainstream Nursery/ School
2	Special Nursery/ School
3	Resource Room in Mainstream School
4	Home tutor (Specify)
5	Others (Specify)

If NO skip to C.2

For YES refer Table 1 – inquire further in Table 2

Instruction – Mention all responses before selecting

Table 2					
S. No		C.1.1	C.1.2	C.1.3	C.1.4
C.1.a	Code (Refer Table 1)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.1.b	Name of School/ Subject (If Others Specify)				
C.1.c	Private Service provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Government Service Provider (use appropriate code)				
C.1.d	What was the total cost in last 6 months? (Rs.)				
C.1.e	Who paid the fees? (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.1.f	If fees paid by others specify				
C.1.g	How much time did [Child's Name] spend with the Service provider in a day? (Include travel time) (Hours : Minutes)	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.1.h	How much time did you spend with [Child's Name] while he/ she was attending these services in a day? (Hours : Minutes)	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.1.i	How many days in a week did [Child's Name] attend these services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.1.j	How many months did [Child's Name] attend these services in the last 6 months?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C.1.k	What was the travel costs involved (Both ways) per month? (Rs.)				
C.1.l	Who paid for the travel expense? (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.1.m	If travel cost paid by others specify				

**C.2 CHILDCARE**

Now I will be talking about childcare services. Have you used any of these forms of childcare for [Child's name] in the last 6 months?

Circle response	
YES	NO

Table 3	
Code	Name
1	Part time Nanny/ maid
2	Full time Nanny/ Childminder
3	Daycare/ Crèche
4	Others (Specify)

If NO skip to C.3

For YES refer Table 3– inquire further in the Table 4

Table 4					
S. No		C.2.1	C.2.2	C.2.3	C.2.4
C.2.a	Code (Refer Table 3)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.2.b	If any other services used specify				
C.2.c	Private Service provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Government Service Provider (use appropriate code)				
C.2.d	What was the total cost in last 6 months? (Rs.)				
C.2.e	Who paid for the services? (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.2.f	If Others specify				
C.2.g	How much time did [Child's Name] spend with the Service provider per day? (Include travel time) (Hours : Minutes)	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>

C.2.h	How much time did you spend with [Child's Name] while he/ she was attending these services in a day? (Hours : Minutes)	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.2.i	How many days in a week did [Child's Name] attend these services?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.2.j	How many months did [Child's Name] attend these services in the last 6 months?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.2.k	What was the travel costs involved (Both ways) per month? (Rs.)				
C.2.l	Who paid for the travel expense? (Refer COII Code Sheet - Table G)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.2.m	If Others Specify				

**C.3 OUT PATIENT CONTACTS**

I would now like to know more about your use of outpatient and clinic based services for [Child's Name] in the last 6 months. Please do not include any instances of accidents/ emergency and inpatient contacts. We will talk about it later.

Instruction – Read out whole list before recording response in Table 6 and Table 7

Codes	Name
01	Community Doctor
02	Hospital Doctor
03	Pediatrician
04	Neurologist
05	Psychologist
06	Speech Therapist
07	Occupational Therapist
08	Physiotherapist
09	Homeopath
10	Ayurvedic
11	Others (Traditional healers, Religious healers, other branches of medicine)

S. No		C.3.1	C.3.2	C.3.3	C.3.4	C.3.5
C.3.a	Code (Refer to Table 5)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.3.b	Health Care Provider (Details) (If others Specify)					
C.3.c	Visits Probe: How many visits did you make to this provider in the last 6 months?					
C.3.d	Private Service provider	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	Government Service Provider (use appropriate code)					
C.3.e	Accompanying person Probe: What was the relationship of the accompanying adult(s) with [Child's Name]? (Refer COII Code Sheet - Table A)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	Mode of Transport (Refer COII Code Sheet Table B)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.3.g	Travel Time Probe: How much time did it take you to reach the service provider when going and coming back; per visit? (Hours : Minutes)	Going	Going	Going	Going	Going
		<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
		Coming Back	Coming Back	Coming Back	Coming Back	Coming Back
C.3.h	Travel Cost/ Distance Probe: How much money did you spend on traveling both ways per visit? Probe: How far you had to travel to visit the care provider? (In case using private modes of transport and cannot estimate cost on fuel note distance) (Specify value Rs. OR kms)	Going	Going	Going	Going	Going
		Rs. Kms	Rs. Kms	Rs. Kms	Rs. Kms	Rs. Kms
		Coming Back	Coming Back	Coming Back	Coming Back	Coming Back
		Rs. Kms	Rs. Kms	Rs. Kms	Rs. Kms	Rs. Kms

C.3.i	<b>Waiting Time</b> (Hours : Minutes) Probe: Waiting time to be seen by the provider?	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.3.j	<b>Time spent with the provider</b> (Hours : Minutes)	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.3.k	<b>Consultation fees paid per visit</b> (Rs.) Instruction - Exclude any costs of tests or medicines					
C.3.l	<b>Who paid for the consultation?</b> (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.3.m	<b>If consultation fees paid by others specify</b>					
C.3.n	<b>Food Expense</b> (Rs.) Probe: Did you have to spend money on lunch/ dinner during this visit or food was bought at home from outside? What was the average amount spent per visit?					
C.3.o	How many times did you have to incur expenses on food while visiting the healthcare provider?					
C.3.p	<b>Comments</b> (In case multiple healthcare providers visited in one visit) (In case tests and medicine are included in the consultation costs and cannot be clearly differentiated.)					

		Table 7				
S. No		C.3.6	C.3.7	C.3.8	C.3.9	C.3.10
C.3.a	<b>Code</b> (Refer to Table 5)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.3.b	<b>Health Care Provider</b> (Details) (If others Specify)					
C.3.c	<b>Visits</b> Probe: How many visits did you make to this provider in the last 6 months?					
C.3.d	Private Service provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Government Service Provider					
		<i>(use appropriate code)</i>				

C.3.e	<b>Accompanying person</b> Probe: What was the relationship of the accompanying adult(s) with [Child's Name]? (Refer COII Code Sheet - Table A)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.3.f	<b>Mode of Transport</b> (Refer COII Code Sheet Table B)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.3.g	<b>Travel Time</b> Probe: How much time did it take you to reach the service provider when going and coming back; per visit? (Hours : Minutes)	<b>Going</b>	<b>Going</b>	<b>Going</b>	<b>Going</b>	<b>Going</b>
		<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.3.h	<b>Travel Cost/ Distance</b> Probe: How much money did you spend on traveling both ways per visit? Probe: How far you had to travel to visit the care provider? (In case using private modes of transport and cannot estimate cost on fuel note distance) <i>(Specify value Rs. OR kms)</i>	<b>Going</b>	<b>Going</b>	<b>Going</b>	<b>Going</b>	<b>Going</b>
		Rs. <input type="text"/> Kms <input type="text"/>	Rs. <input type="text"/> Kms <input type="text"/>	Rs. <input type="text"/> Kms <input type="text"/>	Rs. <input type="text"/> Kms <input type="text"/>	Rs. <input type="text"/> Kms <input type="text"/>
C.3.i	<b>Waiting Time</b> (Hours : Minutes) Probe: Waiting time to be seen by the provider?	<b>Coming Back</b>	<b>Coming Back</b>	<b>Coming Back</b>	<b>Coming Back</b>	<b>Coming Back</b>
		<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.3.j	<b>Time spent with the provider</b> (Hours : Minutes)	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.3.k	<b>Consultation fees paid per visit</b> (Rs.) Instruction - Exclude any costs of tests or medicines					
C.3.l	<b>Who paid for the consultation?</b> (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.3.m	<b>If consultation fees paid by others specify</b>					
C.3.n	<b>Food Expense</b> (Rs.) Probe: Did you have to spend money on lunch/ dinner during this visit or food was bought at home from outside? What was the average amount spent per visit?					

C.3.o	How many times did you have to incur expenses on food while visiting the healthcare provider?				
C.3.p	Comments (In case multiple healthcare providers visited in one visit) (In case tests and medicine are included in the consultation costs and cannot be clearly differentiated.)				

**C.4 INPATIENT CONTACTS**

Did [Child's Name] had to stay for a night/ multiple nights in a hospital/ nursing home in the last 6 months?

Circle response	
YES	NO

Code	Name
1	Nursing home
2	Hospital

For YES refer Table 8– inquire further in the Table 9  
If NO -> SKIP to C.5

**Instruction - Note all follow-up visits related with inpatient contacts in section C.3 (Outpatient contacts)**

S.No	C.4.1	C.4.2	C.4.3
C.4.a	Code (Refer to Table 8)		
C.4.b	Private Service provider	1	
	Government Service Provider (use appropriate code)	2	
C.4.c	Reason for admission		
C.4.d	Name of Hospital/ Nursing Home		
C.4.e	Accompanying person (Caretaker) Probe: What was the relationship of the accompanying adult(s) with the child? <u>Exclude visitors.</u> (Refer COII Code Sheet - Table A)		

C.4.f	<b>Number of Nights</b> Probe: How many nights did your child stay in the hospital/ nursing home?			
C.4.g	<b>Total Cost (Rs.)</b> Probe: Total cost which may include doctor's fees, bed charges, medicines, ambulance charges, test's, travel costs and food costs			
C.4.h	Comments			

**C.5 RELOCATION**

In the last 6 months did you have to relocate to another place of residence because of [Child's Name]?  
Probe- To be closer to school or other supportive services.

Circle response	
YES	NO

If NO -> SKIP to C.6  
If YES continue and explore further

S.No	Title	Total Cost (Rs)	Paid by (Refer COII Code Sheet - Table G)	If Others Specify
C.5.1	If YES, how much was your approx. expense? Probe: Include shipping household goods, labor, brokerage, travel costs (site visits and shifting), looking at other properties			

**C.6 EMERGENCY/ ACCIDENTS**

In the last 6 months, did you incur expenses on any emergencies or accidents for [Child's Name]?

Probe: Include the expenses incurred during time of emergency or accident i.e. doctor's fee, dressing charges, medicines, ambulance charges, travel cost, tests and food costs)

Circle response	
YES	NO

If NO -> SKIP to C.7

If YES continue, explore further in Table 10

**Instruction - Record all follow-up visits related with accidents and emergency in section C.3 (Outpatient contacts)**

Table 10					
S. No	Description	Total Cost (Rs)	Paid for by (Refer COII Code Sheet - Table G)		If Others specify
C.6.1					
C.6.2					
C.6.3					

**C.7 RELIGIOUS TRIPS\ RETREATS AND RITUALS**

In the past 6 months, have you gone to any place of worship or belief or organized any religious rituals specifically for [Child's Name]?

**Probe:** Some parents go to their hometown deities, Ajmer, Shirdi, Vaishno Devi, etc. Some go to local places like Nizamuddin Dargah, Sai Mandir, Hanuman Mandir and other places of belief.

**Probe:** Some parents organize religious rituals like feeding pundits, poor people, havans, and jaagran etc. They also donate in cash and kind at religious places for the betterment of their child's health.

Circle response	
YES	NO

If NO continue to C.8

If YES continue and explore further in Table 11

**Instruction - Includes travel costs (back and forth), extra costs for accompanying person with the child, additional food expense and other organizational expenses.**

Table 11					
S. No		C.7.1	C.7.2	C.7.3	C.7.4
C.7.a	Name of Place/ Religious Practice				
C.7.b	Number of visits/ events/ nights				
C.7.c	Total cost (Rs)				
C.7.d	Who paid for the expenses? (Refer COII Code Sheet - Table G)				
C.7.e	If others specify				

**C.8 INVESTIGATIONS (Not Admission Related)**

I would now like to know whether in the last 6 months did [Child's Name] had any of the following tests.

Circle response	
YES	NO

If NO -> SKIP to C.9

If YES continue, enter the sub category code and name explore in Table 13 and Table 14

Table 12	
Codes	Name of Test
1	X rays
2	Blood tests
3	EEG
4	ECG
5	Ultrasound
6	Scans
7	Psychological test
8	Others (Specify)

**Instruction - Include all costs associated with the tests – that is the cost of test, travel cost (back and forth), extra costs for accompanying person with the child, additional food expense.**



Table 13												
S. No	C.8.1	C.8.2	C.8.3	C.8.4	C.8.5							
C.8.a	Code (Refer Table 12)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
C.8.b	Name of Test (Description) <i>If others specify</i>											
C.8.c	<table border="1"> <tr> <td>Government Lab</td> <td>1</td> </tr> <tr> <td>Private Lab</td> <td>2</td> </tr> <tr> <td>Others*</td> <td>3</td> </tr> </table>	Government Lab	1	Private Lab	2	Others*	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Government Lab	1											
Private Lab	2											
Others*	3											
C.8.d	<i>If others specify</i>											
C.8.e	Total Cost (Rs)											
C.8.f	Who paid the expenses? (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
C.8.g	<i>If others specify</i>											

\*Includes Non-Governmental Organizations, Charitable Trusts, Free camps, CSR activities

Table 14												
S. No	C.8.6	C.8.7	C.8.8	C.8.9	C.8.10							
C.8.a	Code (Refer Table 12)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
C.8.b	Name of Test (Description) <i>If others specify</i>											
C.8.c	<table border="1"> <tr> <td>Government Lab</td> <td>1</td> </tr> <tr> <td>Private Lab</td> <td>2</td> </tr> <tr> <td>Others*</td> <td>3</td> </tr> </table>	Government Lab	1	Private Lab	2	Others*	3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Government Lab	1											
Private Lab	2											
Others*	3											
C.8.d	<i>If others specify</i>											
C.8.e	Total Cost (Rs)											
C.8.f	Who paid the expenses? (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
C.8.g	<i>If others specify</i>											

**C.9 COMPLIMENTARY MEDICATIONS (NOT ADMSSION RELATED)**

I would like to know if in the last 6 months [Child's Name] has taken any medicines which are supplementary, ayurvedic, homeopathic or traditional in nature?

Circle response	
YES	NO

If NO -> SKIP to C.10

If YES continue and explore further in Table 15 & Table 16 below

Instruction - Use codes wherever necessary

Table 15										
Q. No	S. No	C.9.1	C.9.2	C.9.3	C.9.4	C.9.5				
C.9.a	Name of Drug									
C.9.b	Brand									
C.9.c	Used to Treat (Refer COII Code Sheet - Table D)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
C.9.d	<i>If any other specify</i>									
C.9.e	<table border="1"> <tr> <td>Free medication</td> <td>1</td> </tr> <tr> <td>Paid medication</td> <td>2</td> </tr> </table> <i>(use appropriate code)</i>	Free medication	1	Paid medication	2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Free medication	1									
Paid medication	2									
C.9.f	Dosage/ Units (Refer COII Code Sheet - Table E)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
C.9.g	Value of Dose									
C.9.h	Frequency (Refer COII Code Sheet - Table F)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
C.9.i	<i>If other type of frequency specify</i>									
C.9.j	Number of days prescribed									
C.9.k	Cost per bottle/ strip/ pack									
C.9.l	Number of bottle/ strip/ pack used in last 6 months									
C.9.m	Total cost incurred in the last 6 months (Rs)									

Q. No		S. No	Table 16				
			C.9.6	C.9.7	C.9.8	C.9.9	C.9.10
C.9.a	Name of Drug						
C.9.b	Brand						
C.9.c	Used to Treat (Refer COII Code Sheet - Table D)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.9.d	If any other specify						
C.9.e	Free medication	1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Paid medication	2					
(use appropriate code)							
C.9.f	Dosage/ Units (Refer COII Code Sheet - Table E)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.9.g	Value of Dose						
C.9.h	Frequency (Refer COII Code Sheet - Table F)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.9.i	If other type of frequency specify						
C.9.j	Number of days prescribed						
C.9.k	Cost per bottle/ strip/ pack						
C.9.l	Number of bottle/ strip/ pack used in last 6 months						
C.9.m	Total cost incurred in the last 6 months (Rs)						

**C.10 MEDICATION (NOT ADMISSION RELATED)**

I would like to know if in the last 6 months [Child's Name] has taken any allopathic medicines.

Circle response	
YES	NO

If NO -> SKIP to C.11

If YES continue and explore further in Table 17 & Table 18 below

Instruction - Use codes wherever necessary

Q. No		S. No	Table 17				
			C.10.1	C.10.2	C.10.3	C.10.4	C.10.5
C.10.a	Name of Drug						
C.10.b	Brand						
C.10.c	Used to Treat (Refer COII Code Sheet - Table D)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.10.d	If any other specify						
C.10.e	Free medication	1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Paid medication	2					
(use appropriate code)							
C.10.f	Dosage/ Units (Refer COII Code Sheet - Table E)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.10.g	Value of Dose						
C.10.h	Frequency (Refer COII Code Sheet - Table F)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.10.i	If other type of frequency specify						
C.10.j	Number of days prescribed						
C.10.k	Cost per bottle/ strip/ pack						
C.10.l	Number of bottle/ strip/ pack used in last 6 months						
C.10.m	Total cost incurred in the last 6 months (Rs)						

Q. No		S. No	Table 18				
			C.10.6	C.10.7	C.10.8	C.10.9	C.10.10
C.10.a	Name of Drug						
C.10.b	Brand						
C.10.c	Used to Treat (Refer COII Code Sheet - Table D)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C.10.d	<i>If any other specify</i>					
C.10.e	Free medication	1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Paid medication	2				
<i>(use appropriate code)</i>						
C.10.f	Dosage/ Units (Refer COII Code Sheet - Table E)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.10.g	Value of Dose					
C.10.h	Frequency (Refer COII Code Sheet - Table F)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.10.i	<i>if other type of frequency specify</i>					
C.10.j	Number of days prescribed					
C.10.k	Cost per bottle/ strip/ pack					
C.10.l	Number of bottle/ strip/ pack used in last 6 months					
C.10.m	Total cost incurred in the last 6 months (Rs)					

**C.11 EQUIPMENT RECOMMENDED BY SPECIALIST**

In the last 6 months, have you purchased any equipment/ toy/ manual recommended by a specialist for [Child's Name] OR had made any major adaptations at your home for [Child's Name]?

Probe: If the participant has referred to any online resource/ YouTube video was it from a specialist.

Circle response	
YES	NO

If NO -> SKIP to C.12

If YES continue and explore further in Table 19 & Table 20

Table 19						
S. No		C.11.1	C.11.2	C.11.3	C.11.4	C.11.5
C.11.a	Equipment/ Measures					
C.11.b	Estimated Cost (Rs)					
C.11.c	Paid for by (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.11.d	<i>If others specify</i>					
C.11.e	Recommended by/ source of information (Refer COII Code Sheet - Table C)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.11.f	<i>If any other source specify</i>					

Table 20						
S. No		C.11.6	C.11.7	C.11.8	C.11.9	C.11.10
C.11.a	Equipment/ Measures					
C.11.b	Estimated Cost (Rs)					
C.11.c	Paid for by (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.11.d	<i>If others specify</i>					
C.11.e	Recommended by/ source of information (Refer COII Code Sheet - Table C)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.11.f	<i>If any other source specify</i>					

**C.12 WORKSHOPS AND TRAININGS**

In the last 6 months had there been any extra costs with workshops, trainings or conferences related with [Child's Name] autism?

Circle response	
YES	NO

If NO -> SKIP to C.13

If YES continue and explore further in Table 21

Table 21						
S. No		C.12.1	C.12.2	C.12.3	C.12.4	C.12.5
C.12.a	Workshop/ Training/ Conference					
C.12.b	Time spent for the workshop (Include travel) (Hours : Minutes)	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>	<input type="text"/> : <input type="text"/>
C.12.c	Estimated Cost (Include travel) (Rs.)					
C.12.d	Paid for by (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.12.e	If others specify					
C.12.f	Recommended by/ source of information (Refer COII Code Sheet – Table C)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.12.g	If any other source specify					

**C.13 SPECIAL DIET**

In the last 6 months have you given [Child's Name] any special diet?

Circle response	
YES	NO

If NO -> SKIP to C.14

If YES continue and explore further in Table 22

Table 22				
S. No		C.13.1	C.13.2	C.13.3
C.13.a	Description			
C.13.b	Recommended by (Refer COII Code Sheet - Table C)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.13.c	If any other source specify			
C.13.d	Estimated Costs (Last 6 months) (Rs.)			
C.13.e	Paid By (Refer COII Code Sheet - Table G)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.13.f	If Others specify			

**C.14 SUPPORT AND CARE (INCLUDES ADMISSION RELATED)**

In the last 6 months, have you or any family member or a friend had to stop or reduce their regular work or activities due to [Child's Name] Autism?

Circle response	
YES	NO

If NO -> SKIP to C.15

If YES continue and explore further in Table 23

Table 23					
S. No		C.14.1	C.14.2	C.14.3	C.14.4
C.14.a	Caretaker				
C.14.b	Relationship with the child (Refer COII Code Sheet - Table A)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C.14.c	No. of days of work reduced in last 6 months Probe: Exclude sanctioned holidays				
C.14.d	Type of work reduced or stopped Probe: Exclude holidays				
C.14.e	If Applicable (Income lost per day) (Rs)				
C.14.f	No. of paid leaves				
C.14.g	No. of unpaid leaves				

**C.15 COST OF CERTIFICATION**

Did you incur any expenses getting specific certifications for [Child's Name]? (It can be before 6 months)

**Probe:** Details of the certificate and estimated cost incurred in a acquiring it (travel, registration or any other expense)

Circle response	
YES	NO

If **NO** -> SKIP to C.16

If **YES** continue and explore further

Table 24				
S. No	Description	Total Cost (Rs)	Paid for by (Refer COII Code Sheet - Table G)	If Others Specify
C.15.1			<input type="text"/>	
C.15.2			<input type="text"/>	

**C.16 OCCUPATIONAL ADJUSTMENTS**

Would you or any of your family members would have returned to work if [Child's Name] did not have Autism?

Circle response	
YES	NO

If **NO** skip to C.17

If **YES** continue and explore further in Table 24

Table 25										
S. No	C.16.1					C.16.2				
C.16.a	Relationship with [Child's name] (Refer COII Code Sheet - Table A)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.16.b	Last Job title	<input type="text"/>								
C.16.c	When did you stop working? (Year)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C.16.d	Salary last drawn (per month) (Rs)	<input type="text"/>								

**C.17 GOVERNMENT REBATES/ SCHEMES**

Have you availed any rebates/ schemes from the govt. for children with autism for [Child's Name] in the last 6 months?

**Probe:** Income tax rebates, schemes by Govt. for children with Autism or any other.

Circle response	
YES	NO

If **NO** End Interview with script.

If **YES** continue and explore further in Table 25

Table 26		
S. No	Description	Total Value (Rs)
C.17.1		
C.17.2		

**End Script**

Thank you for your time. The information provided was very helpful.

**NOTES****Cost of Illness Inventory (COII)****Code Sheet**

Table A		Table B		Table C	
Codes	Relationships	Codes	Transports	Codes	Specialists
01	Father	01	Local Bus	01	Community Doctor
02	Mother	02	Metro	02	Hospital Doctor
03	Brother	03	Local Train	03	Pediatrician
04	Sister	04	Hired Cab	04	Neurologist
05	Grand Mother	05	Auto Rickshaw	05	Psychologist
06	Grand Father	06	Cycle Rickshaw	06	Speech Therapist
07	Friend (Uncle)	07	Own vehicle (4 wheeler)	07	Occupational Therapist
08	Friend (Aunty)	08	Own vehicle (2 wheeler)	08	Physiotherapist
09	Relative (Uncle)	09	Own vehicle (4 wheeler CNG)	09	Homeopath
10	Relative (Aunt)	10	Neighbours Vehicle	10	Ayurvedic
11	Neighbour	11	Employer Provided Car	11	Special Educator
12	Others	12	Walking	12	School Teacher
		13	Others	13	Others (Traditional healers, Religious healers, other branches of medicine)

Table D		Table E		Table F		Table G	
Codes	Used to treat options	Codes	Dosage/ Units	Codes	Frequency	Codes	Relationships
01	Asthma	01	Milligram	01	Once daily	01	Father
02	Eczema/ other skin condition	02	Application	02	Twice Daily	02	Mother
03	Allergies/ hay fever	03	Capsule	03	Three times daily	03	Brother
04	Anemia	04	Drop	04	Four times daily	04	Sister
05	Diabetes	05	Gram	05	Alternate days	05	Grand Mother
06	Epilepsy	06	Inhaled	06	Once a week	06	Grand Father
07	Constipation/ other bowel problems	07	Liter	07	Twice a week	07	Friend (Uncle)
08	Sleep problems	08	Microgram	08	Once a month	08	Friend (Aunty)
09	Anxiety/ depression	09	Puff	09	Twice a month	09	Relative (Uncle)
10	Hyperactivity/ inattention	10	Suppository	10	As required	10	Relative (Aunt)
11	Behavioral problems, e.g. irritability, aggression, self-injury	11	Tablespoon	11	Continuous	11	Neighbour
12	Dietary and Nutritional Supplements	12	Tablet	12	Others (please specify)	12	Employer (Reimbursed)
13	Others (Specify)	13	Teaspoon			13	Insurance (Reimbursed)
		14	Trans – dermal (patch)			14	Others (Specify)
		15	International Units				
		16	Globules				

Section B: Respondent Information		Variable Name
B.1 Visit	1. Baseline (Enrolment) 2. End line (9M) (Post-allocation) 3. Follow-up (15M) (Close-out)	coii_visit
B.2. Interactions partner the same as at baseline (Only applicable at endline)	1. Yes 2. No	coii_samerepondentbaseline
B.3. New respondent since baseline (Only applicable at endline) (Name of Respondent – Relationship with child)	<input type="text"/>	coii_newrespondentbaseline
B.4. Interactions partner the same as at 9 months (Only applicable at follow-up)	1. Yes 2. No	coii_samerepondent9m
B.5. New respondent since 9 months (Only applicable at follow-up) (Name of Respondent – Relationship with child)	<input type="text"/>	coii_newrespondent9m