

# Estimating the direct health and broader societal costs of caring for autistic children and adolescents – Preliminary findings from a tertiary care centre in urban India

Autism

1–17

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## Abstract

Autistic individuals across the spectrum have diverse rehabilitation and support needs. Systematic data on the cost of care for autism is unavailable in low- and middle-income countries, yet such information is essential to understand the financial burden on families. The current study is a preliminary attempt aimed to estimate the cost incurred by families of autistic children and adolescents attending a tertiary care centre in urban India. The adapted Children and Adolescents Economic Resources Questionnaire was administered to 80 families seeking autism-specific services. Direct medical, non-medical costs and indirect costs, including time and productivity costs, were estimated by parent self-report. The sample consisted predominantly of preschool- and middle-childhood-aged children coming to a premier referral centre, from various geographical locations in the country and with different profiles of support needs and interventions received. Preliminary findings showed that major expenses involved diagnostic and early intervention services, schooling and centre-based rehabilitation. Among direct non-medical costs, education and childcare costs were the highest. In the absence of universal health coverage, approximately 71.25% of families exceeded the threshold of spending >10% of their monthly income on healthcare, amounting to catastrophic out-of-pocket expenditures. Our study contributes preliminary findings as a first step in the cost-of-care studies on autism in India. Future studies should include a larger sample size, robust methods of cost estimation and a mixed-methods design to capture economic impact on families.

## Lay abstract

People with autism have different needs when it comes to support and treatment. In many countries without universal health coverage, getting proper care can be expensive and difficult for families to afford. There isn't much information about how much autism care costs in low- and middle-income countries. This study looked at how much families spend on caring for their autistic children in the Indian context. The adapted Children and Adolescents Economic Resources Questionnaire was administered to 80 families of children with autism seeking services at a tertiary care centre. Results showed that families spent the most on diagnosis, early intervention, education and childcare. A significant proportion of families incurred catastrophic out-of-pocket expenditures on a regular basis. The preliminary findings highlight the financial impact on families.

## Keywords

autism, cost of care, India, out-of-pocket expenditure, universal health coverage

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## Introduction

Autistic individuals across the spectrum have diverse rehabilitation and support needs (Lord et al., 2018, 2022). Alongside the individual and family-centric approach to support and interventions, there is an increasing need to understand the financial and economic implications for the care of autistic individuals, a gap that remains unaddressed. Autistic individuals and their families incur higher healthcare costs compared to the general population, impacting employment, standards of living, family relationships and quality of life (Matin et al., 2022), and the presence of comorbid medical and psychiatric conditions significantly influences costs incurred (Peacock et al., 2012). In the United States, the lifetime costs of supporting an individual with autism and intellectual disability (ID) are estimated to be US\$2.4 million and for autistic individuals without ID to be US\$1.4 million (Buescher et al., 2014). Delays in diagnosis and initiation of interventions can increase comorbidities and, thereby, healthcare costs (Horlin et al., 2014; Malik-Soni et al., 2022; Matin et al., 2022).

The costs of care vary across the lifespan and based on support needs; in younger ages, higher costs involve healthcare, schooling, special education services, informal care and parental productivity loss, whereas in adulthood, the costs may involve residential care, individual productivity loss and healthcare expenditure (Lord et al., 2022; Rogge & Janssen, 2019). In the absence of universal health coverage (UHC), the cost of care is a crucial prohibitive factor for adequate and equitable healthcare utilization, as it results in lesser financial protection and significant out-of-pocket (OOP) expenses, especially for families with financial adversities (Divan et al., 2021). A systematic understanding of ‘costs of care’ can inform policymaking and facilitate systems-level approaches towards developing cost-effective interventions and care pathways.

The cost of care could be classified as direct medical, direct non-medical and productivity costs for autistic individuals, their families and caregivers (Lamsal & Zwicker, 2017; Rogge & Janssen, 2019). Healthcare costs are associated with the countries’ policies of mental health and disability care financing, and families may be pushed towards catastrophic OOP health expenditures in the absence of UHC (Wang et al., 2018). According to the World Health Organization’s (WHO) global monitoring report on UHC, nearly 40% of current health expenditures in low- and middle-income countries (LMICs) on average are OOP expenditures, with parents of lower socioeconomic status reporting poorer access and quality of care (De Leeuw et al., 2020; World Health Organization, 2023). Catastrophic OOP healthcare expenditures are conceptualized in different ways and thresholds, the most common being the healthcare expenditure above >10% or >25% of the total household income or expenditure (Pandey et al., 2018; Prinja et al., 2019; World Health Organization, 2023). Estimating the cost of care helps

understand different components of costs incurred, the size of the contribution of each dimension, and the direct financial impact on families.

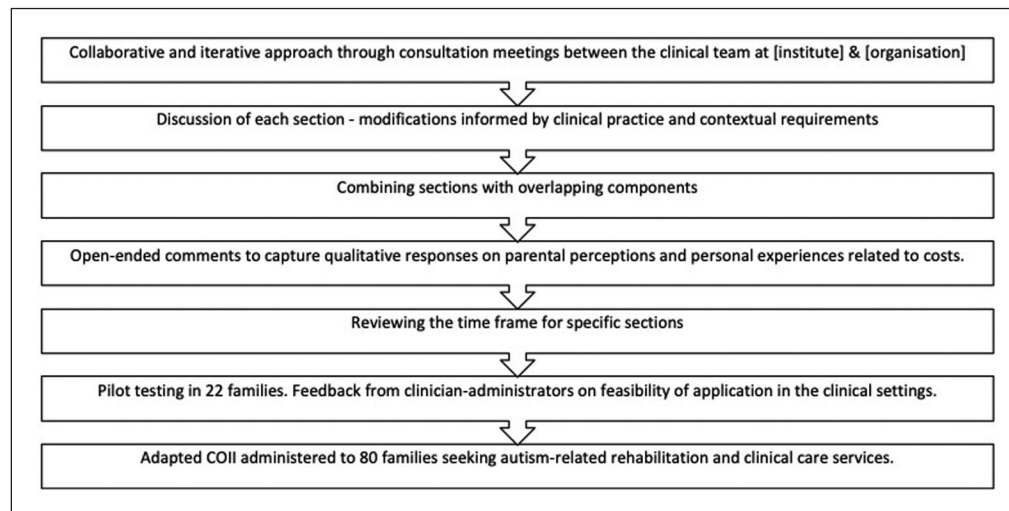
Systematic data on the cost of care for autism are largely unavailable in the LMICs (Rogge & Janssen, 2019). In India, despite increasing recognition of autism and rising prevalence estimates (Arora et al., 2018), multiple barriers continue to impede equitable access to care. The specialist models for diagnosis and individualized treatment are resource-intensive and are currently not scalable in the LMICs (Divan et al., 2021). The resource limitations in public healthcare systems and rapid expansion of private sector services, combined with the predominance of OOP expenditures, exacerbate the financial strain across socioeconomic groups (Gururaj et al., 2016). In India, health insurance schemes like the Niramaya Health Insurance Scheme (NHIS) and Ayushman Bharat have been introduced to provide affordable healthcare; however, they remain significantly underutilized (Angothu et al., 2022; Parida & Sarkar, 2021). It is crucial to understand the cost incurred towards the care of autistic individuals and the underlying complex perspectives to systematically assess the financial impact on families. The study aims to capture costs incurred by families in caring for autistic children and adolescents accessing specialized tertiary care autism services in India. One of the methodological groundings of what we have done in this pilot work is to provide a descriptive understanding of a heterogeneous population taking services from a very specific tertiary care centre.

## Methodology

The study methodology is described under the following sections: ‘Adaptation of the Children and Adolescents Economic Resources Questionnaire’, ‘Method of cost estimation’, and ‘Estimation of the Cost of Care’.

### *Adaptation of the Children and Adolescents Economic Resources Questionnaire*

The Cost of Illness Inventory (COII)<sup>1</sup> (Chaudhary et al., 2022) was developed by Sangath, India, as part of the Communication-centred Parent-mediated treatment for Autism Spectrum Disorder in South Asia (COMPASS) trial (Roy et al., 2023). Sangath is a leading research non-governmental organization (NGO) dedicated to advancing child mental health, development and well-being. The COII, now renamed as the Children and Adolescents Economic Resources Questionnaire (CAER-Q), is a measure developed to comprehensively assess the cost incurred by families towards the care of their autistic child in the sociocultural context. The original tool was developed by an interdisciplinary team of professionals, including public health experts, health economists, implementation



**Figure 1.** Study process flow.

scientists, developmental paediatricians, occupational therapists and paediatric neurologists. The tool's administration time was 35–40 min and was primarily concerned with the context of care for younger autistic children within a trial setting.

The tool was adapted to improve scalability in clinical and community settings and expand its scope to cover service utilization by autistic individuals during childhood, adolescence and young adulthood. The adaptation was carried out as a collaborative work between Sangath and a team of child psychiatrists from the National Institute of Mental Health and Neurosciences (NIMHANS), India, a tertiary care centre catering to the therapeutic and rehabilitation needs of autistic individuals and their families from diverse regional and socioeconomic backgrounds nationwide and across the lifespan. Six meetings were conducted between the Sangath and NIMHANS teams to understand the tool's initial development for the COMPASS trial and adaptations required for considering costs from a comprehensive clinical and societal perspective (see Figure 1). Each section of the tool and its items were discussed and adapted in an iterative manner based on contextual requirements and consensus between the teams.

The modifications were practice-informed, based on experiences of working with families of autistic children with high rates of healthcare utilization and co-occurring developmental and psychiatric conditions. The costs related to therapeutic services, specific medical evaluations guided by recent developments in the field, and informal care for autistic children and adolescents were included. Sections with overlapping components, such as support and care, relocation and occupational adjustments, were combined. Table X (Supplementary Table) reports the final domains and respective cost categories included in the adapted CAER-Q.

Open-ended questions related to socioeconomic comments, experiences with autism-specific services,

availability of services in their locality/district, felt needs and facilitators/challenges in optimum service utilization due to prohibitive costs were added. The focus of the study was to capture quantitative data on costs. While qualitative data were not captured using in-depth interviews with parents, open-ended responses related to the nature of incurred costs were intended to capture insightful qualitative data that would complement and contextualize the quantitative cost data.

### Method of cost estimation

**Cost estimates: parent report.** The information on family income was collected on an interval scale, aligning with survey practices. The method of estimation of the costs in the current study is 'self-report' (parent-report in this case). While the patient self-report forms a pragmatic approach to cost estimation, it is of variable accuracy, prone to missingness and influenced by recall bias (Bhandari & Wagner, 2006; Franklin & Thorn, 2019; Janssen et al., 2021). In the Indian context, currently, there is a lack of linkages between administrative data and healthcare records. This is prohibitive to comparing the accuracy of estimates between the patient/self-reported cost estimates versus providers' reports available from administrative data (Patel et al., 2005; Van Den Brink et al., 2004). Given the above, the self-report method was chosen as the preferred and best possible solution, despite its limitations.

The direct costs were reported by parents as costs incurred in Indian Rupees (INR), price year 2024, for various services – for example, medications, outpatient consultations, transport and lodging. Wherever possible, the parent reports were verified by the clinician administrators using the doctor's prescription, pharmacy bills and hospital bills in case of inpatient care. Indirect costs attributable to the productivity loss for the parents due to caregiving needs of their autistic child were calculated using the

human cost method/human capital approach by multiplying the number of work days lost with the average daily wage. Owing to the unavailability of reliable data on national or regional average income, average daily wage estimates were derived from parent self-report.

**Recall period.** The recall period for the incurred costs on the CAER-Q was 6 months, except for non-recurring costs such as certification, purchase of therapeutic equipment, and costs incurred when parents attended workshops or training programmes, and costs related to relocation and occupational adjustments. Literature on health economics and cost estimation suggests that there is no ideal recall period (Clarke et al., 2008; Janssen et al., 2021). The recall period should be long enough to cover all types of resource use; however, a too-long recall period could decrease the accuracy of the responses, with a greater margin of potential variability. Factors such as frequency of resource use can lead to both overreporting and underreporting. While this would theoretically favour a narrower/shorter recall period, a recall period that is too narrow can lead to leaving out infrequent but important and expensive events. Also, shortening the recall period cannot fully prevent recall bias (Janssen et al., 2021). Hence, for the final version of the adapted CAER-Q, the recall period was finalized based on expert consensus to capture the best possible cost estimates with a reasonable margin of potential variability.

**Estimating resource use.** The frequency of resource utilization refers to the number of times a particular service was availed by participants during the recall period. These are recorded as ‘number of observations’. For example, if a participant had availed 10 outpatient consultations during the 6-month recall period, this will be recorded as 10 observations contributing to the dataset. The unit of analysis is the cost incurred per service or consultation.

### *Estimation of the cost of care*

**Site.** The study was conducted at the Department of Child and Adolescent Psychiatry, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India, both in the inpatient and outpatient settings. The study was approved by the Institutional Ethics Committee (No. NIMHANS/40th IEC (BEH. SC.DIV.) 2023).

**Study participants.** Participants of the study involved caregivers of children/adolescents aged < 18 years, with a primary diagnosis of Autism Spectrum Disorder (ASD), as per the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association [APA], 2013), and had at least three consultations during the study period. Participants were not excluded based on the presence of neurodevelopmental and psychiatric

comorbidities, as it is representative of a clinical sample. Diagnosis of ASD and comorbid disorders, such as ID, was established based on a comprehensive clinical evaluation by trained child and adolescent psychiatrists and was available from clinical records. Requiring a minimum of three consultations ensured that clinical care was prioritized while also balancing the time commitment needed for participation in a hospital-based research study.

In the pilot phase, the adapted CAER-Q was administered to 22 families to determine its administration feasibility within clinical settings. Based on the feedback provided by the clinicians and the families, minor revisions were made iteratively to develop the final version. Minor revisions included the addition of information on availing autism-specific health insurance support, waiting time for consultation, and thereby delay in initiation of treatment, if any, from a healthcare accessibility and utilization perspective. Feedback from clinicians indicated the feasibility of administration within the clinical settings. The adapted CAER-Q was translated into Hindi, and the final version of the bilingual tool was approved by H.M. and R.R., senior members of the adaptation process. The tool was integrated into Research Electronic Data Capture (REDCap) for digital data capture, an innovation to address time and human-resource constraints. The administration time of the adapted CAER-Q was about 15 min, a 57% time reduction compared to the original tool.

**Sampling strategy and sample size.** Following the pilot phase, participants were recruited using a convenience sampling strategy over a 6-month period. The sample size ( $n=80$  families) was determined based on the average number of children with a diagnosis of autism who attended the child psychiatry services and were available for at least three consultations during the study period. This pragmatic approach was chosen to ensure the feasibility of conducting research within a clinical setting, allowing researchers to approach families who were already engaged in ongoing clinical care. However, participant recruitment and data collection could have been influenced by practical constraints such as participants’ availability and limited time, which may have introduced selection bias and affected the representativeness of the sample. As this is a preliminary study, both the sampling strategy and sample size were determined by convenience.

Informed consent (digital) was obtained from the study participants. The data were collected by clinician-researchers trained in the CAER-Q. Figure 1 depicts the study process flow.

### **Community involvement**

The initial COII (renamed CAER-Q) measure was developed with extensive community involvement, including parents and other stakeholders (domain experts). Parents

of autistic children provided feedback on the relevance and comprehensiveness of the adapted CAER-Q.

## Data analysis

The data were analysed using the STATA software (Version 17). Descriptive statistics were performed to summarize the sociodemographic characteristics of participants. The data were then categorized by the type of cost, specifically direct medical and direct non-medical. This segregation allowed for a detailed analysis of the financial burden on families. As the data on costs followed a non-parametric distribution (right-skewed), the costs are represented as medians and interquartile ranges, in addition to means, standard deviation and 95% confidence intervals (CIs). Furthermore, direct medical and non-medical costs were analysed across two clinical subgroups: autistic children with and without comorbid ID. This approach enabled a nuanced understanding of how clinical factors such as comorbidities influenced the cost burden. The preliminary inferential statistics comparing the group differences are reported; however, the significance values are not interpreted, given the small 'n' in the subgroups. When 95% CIs were estimated using parametric methods, it occasionally resulted in lower negative bounds. As negative values for costs are not meaningful, the lower bound negative values are truncated at zero to improve interpretability.

Catastrophic healthcare expenditure (CHE) was estimated as >10% of healthcare expenditure of the total household income/expenditure, aligned with previous studies (Hogan et al., 2018; Pandey et al., 2018; Prinja et al., 2019; Raban et al., 2013). CHE was calculated using interval-censored income data, in line with common survey reporting practices and recommendations in the health economics literature (Nguyen et al., 2023; Wijesundera et al., 2012). While not ideal, and this approach does not allow for the precision of fully observed and accurate income variables, the decision to use interval-censored data was made to maximize the available information and minimize bias. The approach reflects real-world constraints and is endorsed in the literature (Wijesundera et al., 2012). CHE was calculated as a ratio of OOP expenditure and mid-point income, available from interval income data.

The qualitative data collected as part of the study are nested within the CAER-Q. The data do not lend itself to comprehensive qualitative analytical methods; however, it provides important insights that are not captured by quantitative data. A content analysis of the qualitative responses was done by the clinician-researchers (child psychiatrists). Given the limitations in methodological rigour, qualitative data are not analysed here.

## Results

Table 1 presents the sociodemographic characteristics of the study participants. The sample was male-predominant ( $n=64$ , 80%) with an average age of 7.10 (3.75) years. Among the 80 children, 63 children (78.7%) belonged to the preschool or middle childhood age range (<10 years). Comorbid ID was noted in 14 children (17.50%) of the sample. A predominant proportion of the families had the head of the family who was educated at least until graduation or more (65 families, 80%); 40 of them (50%) were employed in professional occupations.

Table 2 outlines the direct medical costs incurred by the families over the past 6 months, which include consultation fees for outpatient and inpatient care, medication, emergency/accidents and diagnostic investigations. The tables also indicate the number of observations (obs), representing the frequency at which each service was utilized and the associated costs. For example, one family taking 'n' outpatient consultations over the 6-month recall period contributed 'n' observations to the dataset, with costs recorded per consultation. All families received services from multiple providers. Outpatient consultations represent the most common (100%) and highest frequency of service utilization, followed by medications for the management of comorbid conditions. Overall, 16 families (20%) received inpatient care for parent training for implementing parent-mediated early interventions and management of comorbid psychiatric disorders. This pattern of service utilization indicates the clinical profile of children receiving hospital-based services and care pathways.

Table 3 summarizes direct medical expenditure incurred by families of autistic children with and without comorbid ID, highlighting medical costs incurred across clinical subgroups. Comparing children with and without comorbid ID, inpatient treatment (14.29% vs. 21.21%), medications (42.86% vs. 63.64%) and investigations (14.29% vs. 25.76%) were utilized by a comparatively higher proportion of families of children without comorbid ID. Table 4 summarizes direct non-medical expenditures, including costs related to education, childcare, transportation, food and lodging during medical/service visits and others, which differ across families based on their individual circumstances. Apart from travel, food and lodging costs related to outpatient consultations, education-related costs were among the most frequently encountered costs in the sample (83.8%).

Sixteen families (20%) had relocated to a different city to ensure autism-specific services were available and accessible. Three families (3.75%) had international relocation (back to India) in view of concerns related to the challenges in accessing services in the countries they had immigrated to. The costs related to relocation included shipping household goods, labour, brokerage, travel costs

**Table 1.** Sociodemographic description.

Variable	No. of participants <i>n</i> (%)
Child's sex and age	
Female	16 (20.00%)
Male	64 (80.00%)
Average age of children (at the time of assessment)	7.10 (3.75) Range (2–16.5)
Age < 10 years	63 (78.75%)
Ages 10–18	17 (21.25%)
Comorbid intellectual disability (ID)	
Yes	14 (17.50%)
No	66 (82.50%)
Male with comorbid ID	11 (78.57%)
Female with comorbid ID	3 (21.43%)
Male without comorbid ID	53 (80.30%)
Female without comorbid ID	13 (19.70%)
Mean age of children with comorbid ID	9.30 (3.00, 5.72–16.48)
Mean age of children without comorbid ID	6.64 (3.75, 0–16.27)
Education of head of the family	
Primary school	1 (1.25%)
High school	9 (11.25%)
Intermediate/diploma	5 (6.25%)
Graduate	30 (37.50%)
Professional degree	35 (43.75%)
Family monthly income (INR)	
<7,315	2 (2.50%)
7,316–21,913	5 (6.25%)
2,194–36,526	8 (10.00%)
36,527–45,588	8 (10.00%)
45,589–54,650	11 (13.75%)
59,252–63,853	6 (7.50%)
63,854–68,454	1 (1.25%)
68,455–73,053	8 (10.00%)
73,054–100,579	12 (15.00%)
109,580–146,103	7 (8.75%)
>146,104	12 (15.00%)
Occupation of the head of the family	
Unemployed	3 (3.75%)
Elementary occupation	2 (2.50%)
Craft and related trade workers	1 (1.25%)
Skilled agricultural and fishery workers	1 (1.25%)
Skilled workers, shop and market sales workers	15 (18.75%)
Clerk	1 (1.25%)
Technicians/associate professionals	17 (21.25%)
Professional	35 (43.75%)
Legislator, senior officials, managers	5 (6.25%)

(site visits and shifting), temporary accommodations, etc. Since the study's focus is on costs incurred towards the care of autistic children/adolescents in the Indian context, the cost of care incurred in countries outside of India was not collected. The relocation costs were included only if the relocation was for reasons related to accessing better therapeutic care for their child, which was true for all the families. Sixteen families (20%) also incurred expenditure

on religious visits, reflecting families' explanatory models and care-seeking patterns.

Table 5 summarizes the direct non-medical costs incurred across the subgroups of families of children with and without comorbid ID and frequencies (number of observations) of service utilization. The service utilization for direct non-medical costs was comparable across the subgroups of children with and without comorbid ID.

**Table 2.** Direct medical expenditure in the last 6 months ( $n=80$ ).

Domain <sup>a</sup>	Number of participants availing the service	No. of obs	M	95% CI <sup>b</sup>	Range	
					Min	Max
Outpatient consultation fees	80 (100.00%)	220	452.74	[379.79, 525.69]	0	4,000
Medication	48 (60.00%)	54	8,151.48	[4,449.30, 11,853.66]	40	75,000
Inpatient treatment	16 (20.00%)	16	13,810.94	[7,458.34, 20,163.54]	0	35,000
Emergency/ Accidents	1 (1.25%)	1	700.00	NA	NA	NA
Investigations	19 (23.75%)	30	9,065.00	[0, 19,109.37]	0	150,000

<sup>a</sup>The recall period for reporting direct medical expenditure was 6 months.

<sup>b</sup>Lower confidence interval bounds were truncated at zero in the case of negative values.

Figures 2 to 5 represent the costs incurred by families of children with and without comorbid ID in the domains of outpatient consultation fees, food, travel and lodging.

Table 6 presents the indirect costs, which account for the caregiver's lost income, including daily and the last monthly salary drawn before stopping work to care for a child with autism. About 27 parents from 80 families (34%) incurred income loss as they made accommodations at their workplace to be available for childcare support, specific to the needs of their autistic child. Seventeen parents (21.2%) who previously held a full-time job had to quit, the majority being mothers. On average, caregivers lost approximately Rs. 2,000 per day and up to Rs. 70,000 per month due to the reduction or cessation of employment caused by their caregiving responsibilities for the autistic child.

Only eight families (10%) reported having insurance coverage or receiving rebates through government schemes linked to parental employment status, while the remaining 90% incurred expenses out of pocket. Despite seeking services from multiple providers, most families were unaware of the existing insurance schemes in the government and the private sector. Table 7 summarizes the proportion of families who incurred catastrophic health expenditure considering the mid-point income on interval data.

## Discussion

Cost of care studies have been conducted predominantly in high-income or Western countries (Horlin et al., 2014; Malik-Soni et al., 2022; Matin et al., 2022; Rogge & Janssen, 2019). However, these findings are not generalizable to LMIC, given the wide variations in the healthcare systems and policies, socioeconomic differentials and uneven access to healthcare. This article presents preliminary findings on the direct and broader societal costs associated with caring for autistic children and adolescents receiving services at a tertiary care centre in urban India.

Cost evaluation of illnesses and interventions often involves perspectives of the payer (direct costs, indirect costs including costs of treatment as well as lost wages and

pension benefits), healthcare providers, healthcare sector, health systems, societal perspective (impact on non-health sectors) and patient perspectives in terms of adjustments due to the illness (Culyer et al., 2018; Sittimart et al., 2024). Cost estimation requires the collection of health resource use data through healthcare databases or self-report measures and the valuation of the identified health resource use in terms of monetary value to each consumed health item. Western studies on the cost of care are largely based on a combination of information available in insurance or service databases and patient-reported outcomes. The method of estimation of the costs in the current study is 'self-report' (parent). While the patient self-report forms a pragmatic approach to cost estimation, the reported cost estimates are 'crude' in nature, prone to variable accuracy, missingness and influenced by recall bias (Bhandari & Wagner, 2006; Franklin & Thorn, 2019; Janssen et al., 2021).

Unlike in the global north, administrative data/databases on healthcare costs are not available in the LMICs. When such measures are not available, self-report of cost estimates with periodic assessments to prevent memory bias/risk of missing data is the best possible approach (Franklin & Thorn, 2019; Goossens et al., 2000; Roukas et al., 2023; Short et al., 2009). Information related to days of loss of work from administrative databases provides insights into costs incurred due to illness-related absenteeism. However, indirect costs related to loss of productivity are complex costs that are often difficult to capture. Given that this method of data collection involves a great degree of uncertainty, the 'best-case estimate' is often used in valuation (Fautrel et al., 2020). Against the background of these systemic and contextual limitations, the adapted CAER-Q provides a valuable framework for economic evaluations of autism-related care in LMICs, with cost estimates considered preliminary.

The preliminary findings from our study demonstrated that the cost of care has largely involved diagnostic and early intervention services and school and centre-based rehabilitative services. Among direct non-medical expenditures, the average costs for education and childcare were

**Table 3.** Direct medical expenditure of participants with and without comorbid ID.

Domain	Number of participants availing the service		Costs incurred										t	p
	Comorbid ID		Comorbid ID					No comorbid ID						
	n (%) N=14	No comorbid ID n (%) N=66	No. of obs	M (SD)	95% CI	Mdn (range)	No. of obs	M (SD)	95% CI <sup>a</sup>	Mdn (range)				
Outpatient consultation (n=220)	14 (100%)	66 (100%)	27	433.70 (462.65)	[250.68, 616.72]	110 (0–1,500)	193	455.40 (561.04)	[375.75, 535.06]	200 (0–4,000)	0.19	.848		
Medication (n=54)	6 (42.86%)	42 (63.64%)	6	2,730.00 (3,725.02)	[0, 6,639.17]	1,500 (80–10,000)	48	8,829.17 (14,204.34)	[4,704.66, 12,953.68]	4,000 (40–75,000)	1.03	.303		
Inpatient treatment (n=16)	2 (14.29%)	14 (21.21%)	2	30,000.00 (7,071.06)	[0, 93,531.02]	30,000 (25,000–35,000)	14	11,498.21 (10,680.08)	[5,331.72, 17,664.71]	8,750 (0–35,000)	-2.33	.034		
Emergency/accidents (n=1)	0	1 (1.52%)	0	NA	NA	NA	1	700.00	NA	NA	NA	NA		
Investigations (n=30)	2 (14.29%)	17 (25.76%)	3	3,883.33 (2,919.04)	[0, 11,134.65]	3,300 (1,300, 7,050)	27	9,640.74 (28,336.65)	[0, 20,850.34]	3,100 (0–150,000)	0.34	.731		

<sup>a</sup>Lower confidence interval bounds were truncated at zero in the case of negative values. The value in bold indicates p <0.05.

**Table 4.** Direct non-medical expenditure (n=80).

Domain	No. of participants availing service	No. of obs	Mean	95% CI <sup>a</sup>	Range	
					Min	Max
Education	67 (83.75%)	75	33,270.00	[25,794.57, 40,745.43]	0	175,000
Education travel	67 (83.75%)	75	2,213.33	[1,414.61, 3,012.06]	0	24,000
Childcare	9 (11.25%)	8	39,250.00	[11,347.33, 67,152.67]	12,000	108,000
Childcare travel	9 (11.25%)	8	125.00	[0, 420.58]	0	1,000
Outpatient travel	80 (100.00%)	215	3,918.60	[2,162.22, 5,674.97]	0	120,000
Outpatient food	80 (100.00%)	216	435.28	[253.94, 616.62]	0	10,000
Outpatient lodging	80 (100.00%)	210	617.43	[288.64, 946.22]	0	15,960
Inpatient travel	16 (20.00%)	14	24,314.29	[8,563.58, 40,064.99]	0	10,000
Inpatient food	16 (20.00%)	15	7,780.00	[2,931.95, 12,628.05]	0	30,000
Inpatient lodging	16 (20.00%)	15	6,066.67	[0, 12,944.58]	0	40,500
Relocation	16 (20.00%)	16	101,750.00	[28,143.85, 175,356.20]	0	500,000
Religious visits	16 (20.00%)	20	15,525.00	[5,419.83, 25,630.17]	2,000	80,000
Equipment	22 (27.50%)	34	2,896.47	[1,070.61, 4,722.33]	200	30,000
Workshops/ training/ conferences	7 (8.75%)	8	23,350.00	[2,018.43, 44,681.57]	700	63,100
Certification	12 (15.00%)	12	316.67	[0, 703.70]	0	2,000

<sup>a</sup>Lower confidence interval bounds were truncated at zero in the case of negative values.

the highest. The majority of children (78.7%) were under 10 years of age, of whom 20% were below 5 years. The distribution of study participants across age bands reflects predominant patterns of service utilization and, thereby, associated direct costs.

In our sample, 17.5% of the autistic children had comorbid ID, with moderate-to-profound impairment in intellectual and adaptive functioning, and their service utilization patterns involved outpatient consultations, inpatient admissions and medication management for comorbid disorders. Studies have reported higher costs of care for individuals with high support needs and medical and psychiatric comorbidities (Barrett et al., 2012; Horlin et al., 2014; Matin et al., 2022; Raz et al., 2013; Van Steensel et al., 2013). However, our preliminary findings do not align with these reports, likely because the subgroups in our sample are too small for direct comparison. Moreover, our sample is predominated by young children, and the costs related to the management of medical and psychiatric comorbidities may not have fully emerged and are likely to increase over the course of development. In addition, parents' responses to open-ended questions reflect a lack of availability of appropriate education and rehabilitation services for children with comorbid ID in comparison to those without. Consequently, the observation on costs incurred may reflect limited access to appropriate services rather than lower need. Similar challenges in accessing services for autistic children with high support needs have been reported in the Indian context (Manohar et al., 2025). Finally, the prevalence rates of comorbid ID in our sample are much lower compared to rates reported in other studies, particularly in the LMIC

region (Abubakar et al., 2016; Balachandar et al., 2021; Kommu et al., 2017; Mpaka et al., 2016), which could be attributed to a predominance of young children in our sample.

Inpatient care in our tertiary Child and Adolescent Mental Health Services (CAMHS) contributes to higher direct medical costs than outpatient consultations alone. Apart from indications such as the management of acute psychiatric, behavioural and medical emergencies (Cervantes et al., 2019; Righi et al., 2018; Thom et al., 2020), inpatient admissions for the provision of parent training on parent-mediated intervention models are a common practice in tertiary care CAMHS in India, given that many families have travelled to the city for accessing specialized services (Girimaji, 1999; Krishnan et al., 2016; Manohar et al., 2019). The brief inpatient admission is family-centric, in spaces conducive to milieu-based learning; intervention programmes are individualized and are based on principles of naturalistic developmental and behavioural interventions. The costs related to inpatient care are specific to specialized settings and may not reflect service models or costs across other healthcare systems in India.

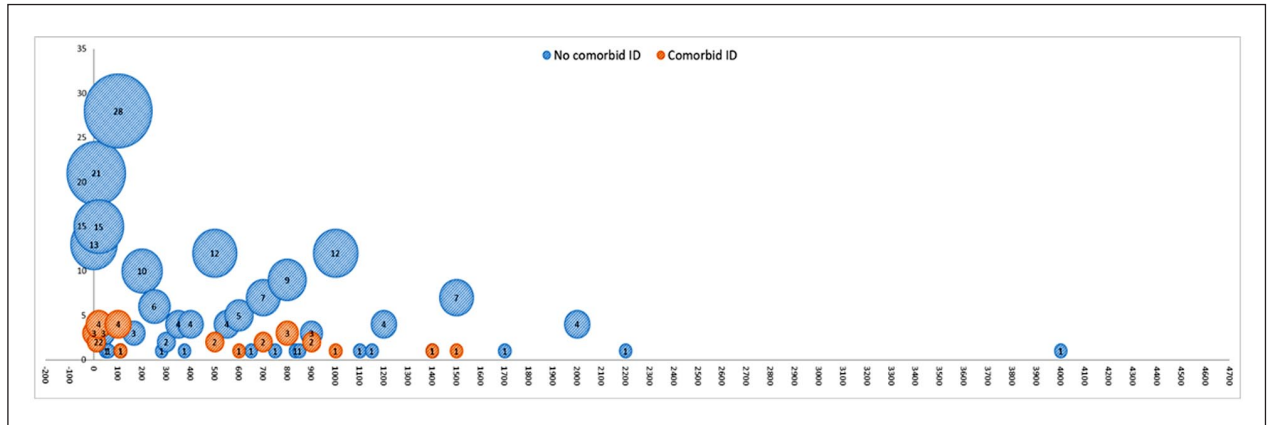
This study did not compare direct medical costs incurred across public and private sector services. Most families in our sample utilized a combination of services from both sectors, likely influenced by accessibility and affordability considerations. While public sector services are largely subsidized and involve minimal costs, private sector services operate within a market-based economy, substantially increasing expenditures. Hence, the actual direct medical costs for families relying primarily on private care may be considerably higher than reflected here.

**Table 5. Direct non-medical expenditure of participants with and without comorbid ID.**

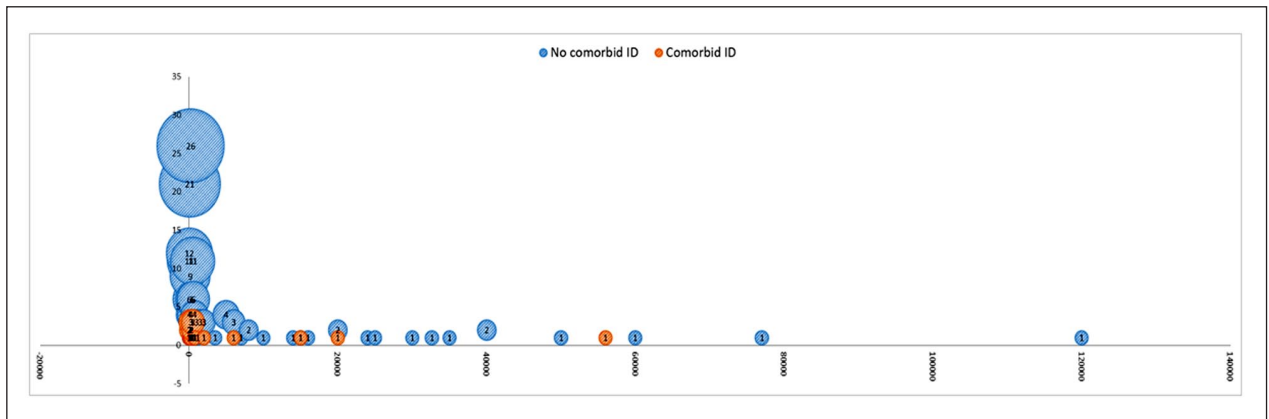
Domain <sup>a</sup>	No. of participants availing services (%)										Costs incurred										t	p																																																																																																																																																																																											
	Comorbid ID					No comorbid ID					Comorbid ID					No comorbid ID																																																																																																																																																																																																	
	Recall period	N (%)	N (%)	N (%)	N (%)	Recall period	N (%)	N (%)	N (%)	N (%)	Recall period	N (%)	N (%)	N (%)	N (%)	Recall period	N (%)	N (%)	N (%)	N (%)			Recall period	N (%)	N (%)	N (%)	N (%)																																																																																																																																																																																						
Education (n=75)	6 months	13 (92.86%)	54 (81.82%)	15	29,086.67 (39,685.71)	[7,109.45, 51,063.88]	12,500 (0-150,000)	60	34,315.83 (30,736.75)	[26,375.69, 42,255.98]	27,400 (0-175,000)	0.55	.580	Education travel (n=75)	6 months	13 (92.86%)	54 (81.82%)	15	3,533.33 (6,222.73)	[87.30, 6,979.37]	1,200 (0-24,000)	60	1,883.33 (2,318.03)	[1,284.52, 2,482.15]	1,000 (0-12,000)	-1.66	.100	Childcare (n=8)	6 months	1 (7.14%)	8 (12.12%)	1	18,000.00	NA	18,000	7	42,285.71 (34,836.35)	[10,067.46, 74,503.97]	25,000 (12,000-108,000)	NA	NA	Childcare travel (n=8)	6 months	1 (7.14%)	8 (12.12%)	1	0	NA	NA	7	142.86 (377.96)	[0, .492.42]	0 (0-1,000)	NA	NA	Outpatient travel (n=215)	6 months	14 (100%)	66 (100%)	25	4,160.26 (11,850.74)	[0, 9,052.01]	257.38 (0-56,000)	190	3,886.80 (13,245.53)	[1,991.27, 5,782.33]	200 (0-120,000)	-0.09	.921	Outpatient food (n=216)	6 months	14 (100%)	66 (100%)	27	285.18 (1,020.06)	[0, 688.71]	0 (0-5,000)	189	456.72 (1,394.00)	[256.69, 656.74]	0 (0-10,000)	0.61	.538	Outpatient lodging (n=210)	6 months	14 (100%)	66 (100%)	27	488.89 (1,951.20)	[0, 1,260.76]	0 (0-10,000)	183	636.39 (2,482.22)	[274.35, 998.44]	0 (0-15,960)	0.29	.768	Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA
Education travel (n=75)	6 months	13 (92.86%)	54 (81.82%)	15	3,533.33 (6,222.73)	[87.30, 6,979.37]	1,200 (0-24,000)	60	1,883.33 (2,318.03)	[1,284.52, 2,482.15]	1,000 (0-12,000)	-1.66	.100	Childcare (n=8)	6 months	1 (7.14%)	8 (12.12%)	1	18,000.00	NA	18,000	7	42,285.71 (34,836.35)	[10,067.46, 74,503.97]	25,000 (12,000-108,000)	NA	NA	Childcare travel (n=8)	6 months	1 (7.14%)	8 (12.12%)	1	0	NA	NA	7	142.86 (377.96)	[0, .492.42]	0 (0-1,000)	NA	NA	Outpatient travel (n=215)	6 months	14 (100%)	66 (100%)	25	4,160.26 (11,850.74)	[0, 9,052.01]	257.38 (0-56,000)	190	3,886.80 (13,245.53)	[1,991.27, 5,782.33]	200 (0-120,000)	-0.09	.921	Outpatient food (n=216)	6 months	14 (100%)	66 (100%)	27	285.18 (1,020.06)	[0, 688.71]	0 (0-5,000)	189	456.72 (1,394.00)	[256.69, 656.74]	0 (0-10,000)	0.61	.538	Outpatient lodging (n=210)	6 months	14 (100%)	66 (100%)	27	488.89 (1,951.20)	[0, 1,260.76]	0 (0-10,000)	183	636.39 (2,482.22)	[274.35, 998.44]	0 (0-15,960)	0.29	.768	Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA														
Childcare (n=8)	6 months	1 (7.14%)	8 (12.12%)	1	18,000.00	NA	18,000	7	42,285.71 (34,836.35)	[10,067.46, 74,503.97]	25,000 (12,000-108,000)	NA	NA	Childcare travel (n=8)	6 months	1 (7.14%)	8 (12.12%)	1	0	NA	NA	7	142.86 (377.96)	[0, .492.42]	0 (0-1,000)	NA	NA	Outpatient travel (n=215)	6 months	14 (100%)	66 (100%)	25	4,160.26 (11,850.74)	[0, 9,052.01]	257.38 (0-56,000)	190	3,886.80 (13,245.53)	[1,991.27, 5,782.33]	200 (0-120,000)	-0.09	.921	Outpatient food (n=216)	6 months	14 (100%)	66 (100%)	27	285.18 (1,020.06)	[0, 688.71]	0 (0-5,000)	189	456.72 (1,394.00)	[256.69, 656.74]	0 (0-10,000)	0.61	.538	Outpatient lodging (n=210)	6 months	14 (100%)	66 (100%)	27	488.89 (1,951.20)	[0, 1,260.76]	0 (0-10,000)	183	636.39 (2,482.22)	[274.35, 998.44]	0 (0-15,960)	0.29	.768	Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																												
Childcare travel (n=8)	6 months	1 (7.14%)	8 (12.12%)	1	0	NA	NA	7	142.86 (377.96)	[0, .492.42]	0 (0-1,000)	NA	NA	Outpatient travel (n=215)	6 months	14 (100%)	66 (100%)	25	4,160.26 (11,850.74)	[0, 9,052.01]	257.38 (0-56,000)	190	3,886.80 (13,245.53)	[1,991.27, 5,782.33]	200 (0-120,000)	-0.09	.921	Outpatient food (n=216)	6 months	14 (100%)	66 (100%)	27	285.18 (1,020.06)	[0, 688.71]	0 (0-5,000)	189	456.72 (1,394.00)	[256.69, 656.74]	0 (0-10,000)	0.61	.538	Outpatient lodging (n=210)	6 months	14 (100%)	66 (100%)	27	488.89 (1,951.20)	[0, 1,260.76]	0 (0-10,000)	183	636.39 (2,482.22)	[274.35, 998.44]	0 (0-15,960)	0.29	.768	Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																										
Outpatient travel (n=215)	6 months	14 (100%)	66 (100%)	25	4,160.26 (11,850.74)	[0, 9,052.01]	257.38 (0-56,000)	190	3,886.80 (13,245.53)	[1,991.27, 5,782.33]	200 (0-120,000)	-0.09	.921	Outpatient food (n=216)	6 months	14 (100%)	66 (100%)	27	285.18 (1,020.06)	[0, 688.71]	0 (0-5,000)	189	456.72 (1,394.00)	[256.69, 656.74]	0 (0-10,000)	0.61	.538	Outpatient lodging (n=210)	6 months	14 (100%)	66 (100%)	27	488.89 (1,951.20)	[0, 1,260.76]	0 (0-10,000)	183	636.39 (2,482.22)	[274.35, 998.44]	0 (0-15,960)	0.29	.768	Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																								
Outpatient food (n=216)	6 months	14 (100%)	66 (100%)	27	285.18 (1,020.06)	[0, 688.71]	0 (0-5,000)	189	456.72 (1,394.00)	[256.69, 656.74]	0 (0-10,000)	0.61	.538	Outpatient lodging (n=210)	6 months	14 (100%)	66 (100%)	27	488.89 (1,951.20)	[0, 1,260.76]	0 (0-10,000)	183	636.39 (2,482.22)	[274.35, 998.44]	0 (0-15,960)	0.29	.768	Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																						
Outpatient lodging (n=210)	6 months	14 (100%)	66 (100%)	27	488.89 (1,951.20)	[0, 1,260.76]	0 (0-10,000)	183	636.39 (2,482.22)	[274.35, 998.44]	0 (0-15,960)	0.29	.768	Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																				
Inpatient travel (n=14)	6 months	2 (14.29%)	14 (21.2%)	2	9,000.00 (8,485.28)	[0, 85,237.23]	9,000 (3,000-15,000)	12	26,866.67 (28,691.12)	[8,637.20, 45,096.14]	18,500 (0-100,000)	0.84	.412	Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																		
Inpatient food (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	4,000.00 (1,414.21)	[0, 16,706.20]	4,000 (3,000-5,000)	13	8,361.54 (9,300.50)	[2,741.31, 13,981.77]	5,000 (0-30,000)	0.64	.532	Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																																
Inpatient lodging (n=15)	6 months	2 (14.29%)	14 (21.2%)	2	0.00	[0, 0]	0 (NA)	13	7,000.00 (13,148.57)	[0, 14,945.60]	0 (0-40,500)	0.72	.478	Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																																														
Relocation (n=16)	NA	3 (21.43%)	13 (19.7%)	3	46,666.67 (47,258.16)	[0, 164,062.40]	30,000 (10,000-100,000)	13	114,461.50 (150,150.80)	[23,726.31, 205,196.80]	35,000 (0-500,000)	0.75	.462	Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																																																												
Religious visits (n=20)	NA	1 (7.14%)	15 (22.7%)	1	12,000 (NA)	NA	12,000 (NA)	19	15,710.53 (22,166.86)	[5,026.44, 26,394.61]	7,000 (2,000-80,000)	NA	NA	Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																																																																										
Equipment (n=34)	1 year	4 (28.57%)	18 (27.3%)	4	2,800.00 (1,973.15)	[0, 5,939.73]	3,000 (200-5,000)	30	2,909.33 (5,545.86)	[838.48, 4,980.19]	1,000 (230-30,000)	0.03	.969	Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																																																																																								
Workshops/training/conference (n=8)	NA	1 (7.14%)	6 (9.09%)	1	700 (NA)	NA	700 (NA)	7	26,585.71 (25,726.15)	[2,792.99, 50,378.43]	18,000 (2,000-63,100)	NA	NA	Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																																																																																																						
Certification (n=12)	NA	1 (7.14%)	11 (16.7%)	1	0.00 (NA)	NA	0 (NA)	11	345.45 (630.26)	[0, 768.87]	50 (0-2,000)	NA	NA																																																																																																																																																																																																				

<sup>a</sup>Recall period for education, childcare, travel, food and lodging expenses was 6 months; costs incurred towards equipment purchase over the last 1 year; Costs incurred towards certification, relocation, attending workshops/training/conferences did not have a specified recall period, as these costs are usually incurred during the initial years of the diagnosis and are infrequent. The tables also indicate the number of observations (obs), representing the frequency at which each service was utilized and the associated costs. For example, one family taking 'n' outpatient consultations over the 6-month recall period will be considered as 'n' observations and costs incurred per observation are included.

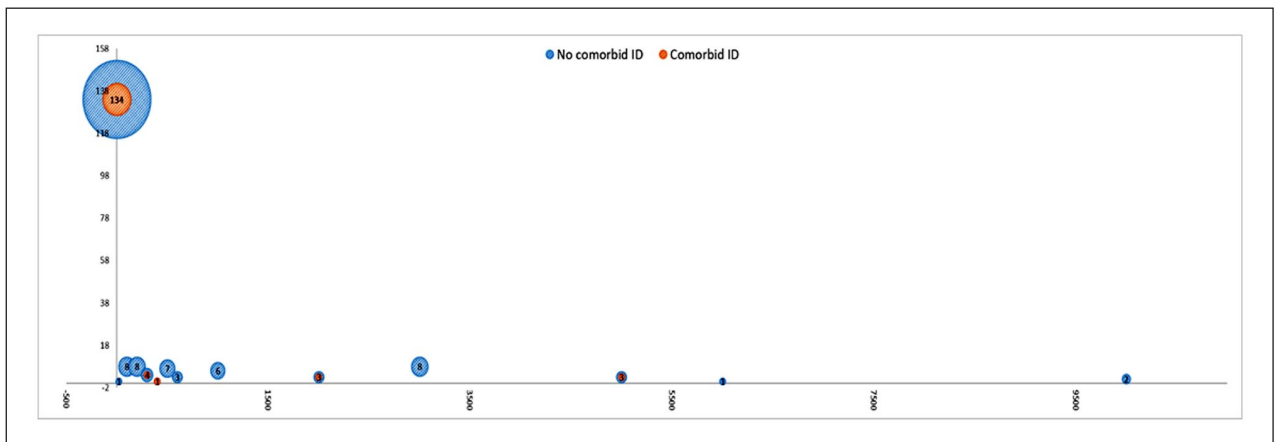
<sup>b</sup>Lower confidence interval bounds were truncated at zero in the case of negative values.



**Figure 2.** Outpatient consultation fees for participants with and without comorbid ( $n = 220$ ).



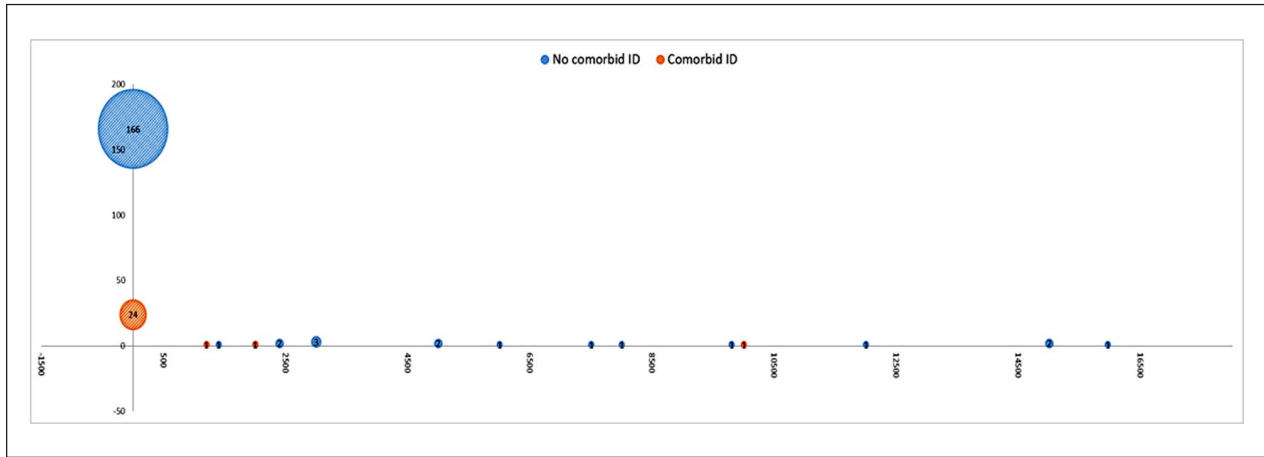
**Figure 3.** Outpatient travel costs for participants with and without comorbid ( $n = 196$ ).



**Figure 4.** Outpatient food costs for participants with and without comorbid ( $n = 196$ ).

Among direct non-medical expenditures, the average costs for education and childcare were highest. Although childcare costs were incurred by a small proportion of families (11.25%), this was reported as a significant and

prohibitive cost. Paid childcare support was sought for reasons related to providing a therapeutic environment at home, while parents were at work, and also to support mainstream school integration (paid support for a shadow



**Figure 5.** Outpatient lodging costs for participants with and without comorbid ( $n = 196$ ).

**Table 6.** Indirect cost: additional potential income if continued to work full-time, if autism were not a factor.

Variable	Proportion of participants ( $n$ %)	$M$	$SD$	$Mdn$	Min	Max
Additional potential income/day	19 (23.75%)	2,472.81	3,492.95	1,200.00	100.00	15,000.00
Additional potential income/month	17 (21.25%)	70,117.65	80,355.37	40,000.00	3,000.00	300,000.00

**Table 7.** Proportion of families incurring catastrophic health expenditure.

% of healthcare expenditure of the total income	Proportion of families ( $n = 80$ )
<10%	23 (28.75%)
10%–24%	10 (12.5%)
25%–49%	14 (17.5%)
>50%	33 (41.25%)

teacher). Given the gaps in systemic support, the onus of responsibility for childcare and support for integration in schools is on the parents. In our study, reported travel costs for healthcare services were considerably high, largely influenced by a few extreme outliers. The centre serves families from across the country, with no geographical limitations on its catchment area, which contributes to a wide variation in travel expenses. Although travel represents a significant cost, in a country like India – with wide socioeconomic disparities – the skewed distribution of travel, food and lodging expenses likely reflects individual families' choices rather than comparable costs across households. This highlights the importance of interpreting mean travel costs with caution and considering median summaries when analysing the cost of care.

Relocation costs were incurred by 20% of the families. The decisions for relocation were related to 'having better access to rehabilitation and therapeutic services in metropolitan cities,' 'extended family support for childcare' and

'international relocation back to India to ensure affordability and continuity of services for the child.' When available and accessible, the services were 'fragmented'. Having access to comprehensive and integrative services closer to their homes was a felt need across the majority of families.

Indirect costs in the study are estimated as lost productivity for parents and caregivers, as our study sample includes autistic children and young people (<18 years). Although the subsample reporting incurred productivity costs are relatively smaller, the average indirect costs (loss of income due to lost employment opportunity) were higher compared to direct medical and non-medical expenditure. Similar findings have been reported by (Al-Farsi et al., 2013; Horlin et al., 2014), with sample characteristics comparable to our study. Due to the small sample, the productivity costs across age groups and socioeconomic differentials are not compared. Seventeen (21.2%) families reported that one of the parents would have returned to work, 'if their child did not have autism'.

The productivity costs may be underestimates in our study, particularly for parents who quit their jobs to compensate for the time and resources required for childcare. Use of the Human Cost Method to estimate productivity loss can overestimate the cost by not accounting for compensatory mechanisms. Conversely, it can also underestimate costs by ignoring potential future productivity losses, unpaid productivity and long-term impact on career, which may not be realized.

Findings related to insurance coverage for rehabilitative interventions and challenges with OOP expenditure are comparable across studies from South Asian regions (Mosadeghrad et al., 2019; Wang et al., 2018). In countries like the United States, the affordability of private insurance is prohibitively expensive for many families, with families supported by public insurance having overall lower OOP expenditure, compared to families seeking private insurance (Parish et al., 2015). In India, it is especially concerning that insurance coverage for rehabilitative interventions is typically capped far below the actual costs, compelling families to incur substantial OOP expenses for essential services. This gap highlights a critical shortfall in financial protection and underscores the need for policy reforms to ensure equitable access to necessary care. This seems to be a recurring theme in countries with developing or mixed healthcare systems, where the burden of rehabilitation costs often falls heavily on individuals and families, pushing a higher proportion of families towards CHE. Lack of UHC has critical implications for families who cannot afford rehabilitative interventions and, in the long term, leads to suboptimal developmental outcomes and higher support needs. The key felt needs expressed by the parents included ‘need for comprehensive services in government healthcare systems’, ‘more information and awareness on systemic supports and welfare schemes’ and ‘need for inclusivity and therapeutic support in schools’. Such integrated approaches will not only make the care pathways cost-effective but also pragmatic.

Economic evaluations of the cost of care are important to understand the financial impact on autistic individuals and their caregivers. This may stimulate research to develop cost-effective interventions and systems-level changes that may further reduce the economic impact associated with conditions such as autism and other neurodevelopmental disorders.

## Strengths and limitations

This study contributes preliminary data on the cost of care for autism in the Indian context, addressing a gap in the existing literature. Adaptation of CAER-Q with clinical practice-informed modifications and data management through the use of technology to ensure wider application in the clinical and community settings outside of the research context are strengths of the study. The adapted

CAER-Q is applicable for other neurodevelopmental disorders, severe mental illnesses in childhood and adolescence, and paediatric neurological disorders where the therapeutic and care requirements are comparable.

Given that the study includes only families seeking autism-specific care at a tertiary care centre in India, the findings have limited generalizability, which represents an important limitation. The clinic-based sample represents higher severity, support needs and healthcare utilization, which may not be representative of clinical presentations across the autism spectrum. The small sample size of the study is a significant limitation. Although the convenience sampling strategy was adopted to ensure feasibility, the non-random and non-probability nature of the sampling strategy, combined with practical constraints such as participants’ availability and limited time, may have introduced selection bias and affected the representativeness of the sample.

The cost estimates were assessed at a single time point, and the absence of a test–retest assessment limits our ability to determine the reliability of these estimates. Wherever possible, the parent-reported costs were verified with other sources, such as prescriptions and hospital bills. However, conducting research assessments during outpatient visits made verification of costs incurred over a 6-month recall period from other sources challenging. The indirect costs associated with obtaining certification were not collected; this is a limitation and will be addressed in the subsequent versions of the tool.

Recall biases are inherent to assessments such as these, and there are pragmatic challenges in overcoming them. Although the assessment is likely to provide a ‘best-case estimate’ of the cost of care, the long recall period of 6 months is an added limitation. In its current form, the tool also does not cover the requirements of care for autistic adults that may include other costs, such as costs of living and productivity losses and does not assess costs incurred due to co-occurring disorders. In India, although intersectoral services are in place, healthcare is a nodal point in the pathways to comprehensive services for autistic individuals. The study has assessed costs incurred by families who continue to seek healthcare services and can potentially miss the costs of many families who are currently not utilizing healthcare services due to various reasons. Given the small sample size, subgroup analysis based on age, gender and other comorbidities was not possible. In addition, the preliminary nature of the study posed challenges for applying standard statistical approaches in health economics, limiting the scope of in-depth cost analyses. We acknowledge that truncating confidence may influence certainty of the lower bound estimates; however, this approach is commonly used in health economics analysis when distribution of cost data violates normality assumptions. Moreover, the income data are not always reported accurately by families and is one of the challenges

in conducting such research in the LMIC settings. The lack of information on the national average or average income across different geographic regions within the country limits comparison of the study participants' characteristics to those of the region or the nation. Future research from health economics perspectives could address these shortcomings. While collecting robust qualitative data was not the objective of this study, this is an important limitation and a direction for future research.

## Conclusion and future directions

Assessing costs incurred from the family's perspectives provides useful insights into direct healthcare and broader societal costs of caring for autistic individuals. The adapted CAER-Q is an important research tool for practitioners in the field of child development across various clinical, community or geographical settings. With the increasing focus on patient-centred outcomes in health policy research, more frequent use of the patient's perspective in economic studies should be advocated. Our study contributed preliminary findings as a first step in the cost-of-care studies on autism in India. Future studies should include a larger sample size, robust methods of cost estimation and a mixed-methods design to capture economic impact on families.

## Authors' note

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## Ethical considerations

The study was approved by the Institute Ethics Committee, NIMHANS, Bangalore, India [IEC approval: NIMHANS/IEC (BEH. SC.DIV.) 2023; dated February 20, 2023]. All participants provided written informed consent for participation in the study.

## Author contributions

**Kasturi Atmaram Sakhardande:** Data curation; Methodology; Writing – original draft; Writing – reviewing & editing.

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## Data availability statement

Data are available from the corresponding author upon reasonable request.

## Supplemental material

Supplemental material for this article is available online.

## Note

1. The researchers acknowledge the connotation of the term 'illness' in the context of autism. Although the initial version of the tool was named 'Cost of illness inventory', the tool is now renamed as 'CAER-Q' – Children and Adolescents Economic Resources Questionnaire.

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