

2019

ECONOMIC IMPACT REPORT

*Financial Burdens of Pediatric
Feeding Disorder on Insured Families*



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A close-up photograph of a newborn baby lying down, being fed with a syringe. An adult's hand is visible, holding the syringe and gently supporting the baby's head. The baby is looking up towards the camera. The adult is wearing a green shirt and a blue patterned scarf. The baby is wearing a white onesie. The background is a soft, out-of-focus green surface.

Feeding Matters is the first organization in the world uniting families, healthcare professionals, and the broader community to improve the system of care for children with pediatric feeding disorder through advocacy, education, support, and research.



FEEDING IS THE SINGLE MOST COMPLEX AND PHYSICALLY DEMANDING TASK AN INFANT WILL COMPLETE DURING THE FIRST FEW WEEKS, AND EVEN MONTHS, OF LIFE.

A single swallow requires the use of 26 muscles and 6 cranial nerves¹ working in perfect harmony to move food and liquid through the body. When one or more pieces of the feeding puzzle are missing, out of order, or unclear, infants and children can have difficulty eating and drinking.

Children with pediatric feeding disorder (PFD) are more than fussy babies or picky eaters. For them, taking a single bite of food may be painful, frightening, or even impossible. As a result, they may severely limit their food choices or refuse food altogether, preventing them from getting the nutrition they need.

Applying the US Census Bureau's 2017 population reports, early findings estimate that more than 2.3 million children under the age of 5 experience severe pediatric feeding disorder in the United States each year. Additional reports estimate that up to 25% of developmentally typical children² and up to 80% of those with developmental disabilities² have feeding problems.

Yet, there had been no studies to quantify the assorted costs, medical and otherwise, incurred by families navigating PFD.

PFD is defined as impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction.³

Feeding Matters' Economic Impact Study identifies the economic burden of PFD on families who have insurance. From medicines, supplies, and expert childcare to specialized education, travel to appointments, and lost time, managing PFD can come with significant economic costs to families. Furthermore, parents and caregivers – herein referred to as “caregivers” – may experience lost or decreased income due to time required for PFD care. This study describes those costs.

OVERALL FINANCIAL BURDEN OF PEDIATRIC FEEDING DISORDER

Since its creation in 2006, Feeding Matters has witnessed many insured families spend hundreds, and sometimes thousands, of dollars out of pocket to cover non-reimbursed costs related to pediatric feeding disorder. Through a nationwide survey of insured families, Feeding Matters learned that 76% of respondents reported that PFD results in at least a moderate financial burden for their family.

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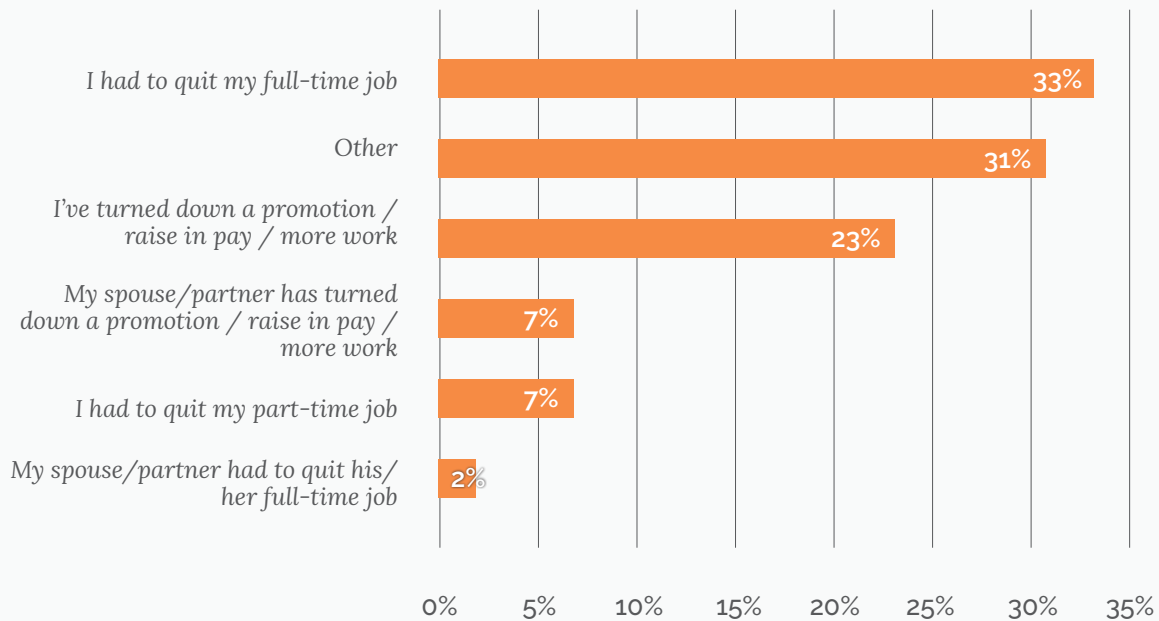
Our story is 14 years in the making. We have lost everything because PFD was not (and overall still is not) looked at as a severe issue. It is an astronomical amount of money to raise a PFD special needs child in a middle income family.”

OVERALL FINANCIAL BURDEN OF PEDIATRIC FEEDING DISORDER



For the vast majority of respondents, over 79% report that they or their partner have had to quit working, not take a promotion, or cut back on work hours to care for a child with PFD. On average, respondents estimate that over the years they have lost \$125,645 in income caring for their child with PFD.

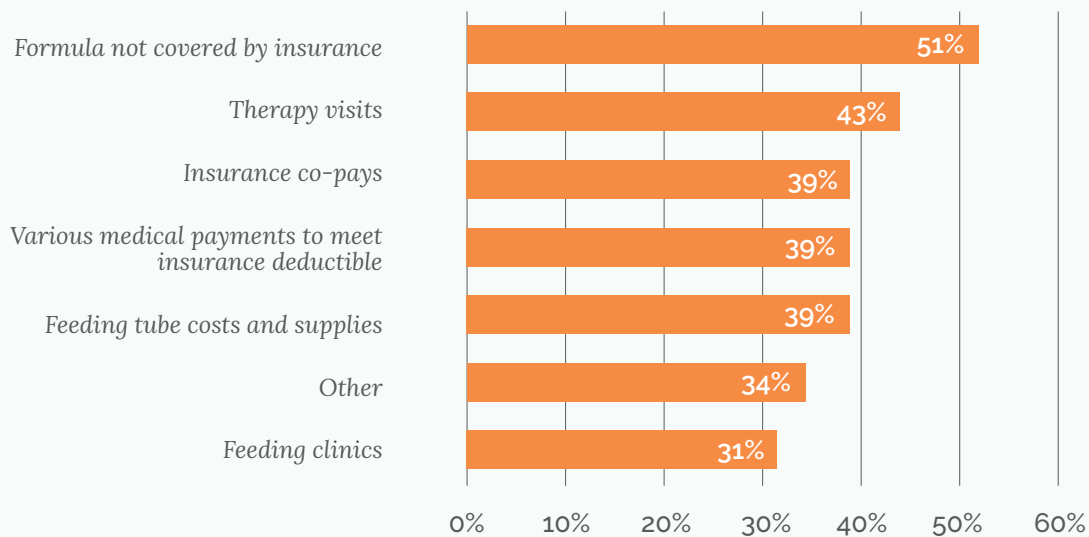
FAMILY CHANGES TO PROVIDE CARE



MEDICAL COSTS, SUPPLIES, AND SERVICES

Beyond their perceived burden, participants were asked to estimate numerous monthly costs in different categories. Responses showed that insured families spend significant amounts on uncovered or underinsured medical expenses for their child's PFD care, averaging \$353 a month.

OUT-OF-POCKET MEDICAL EXPENSES

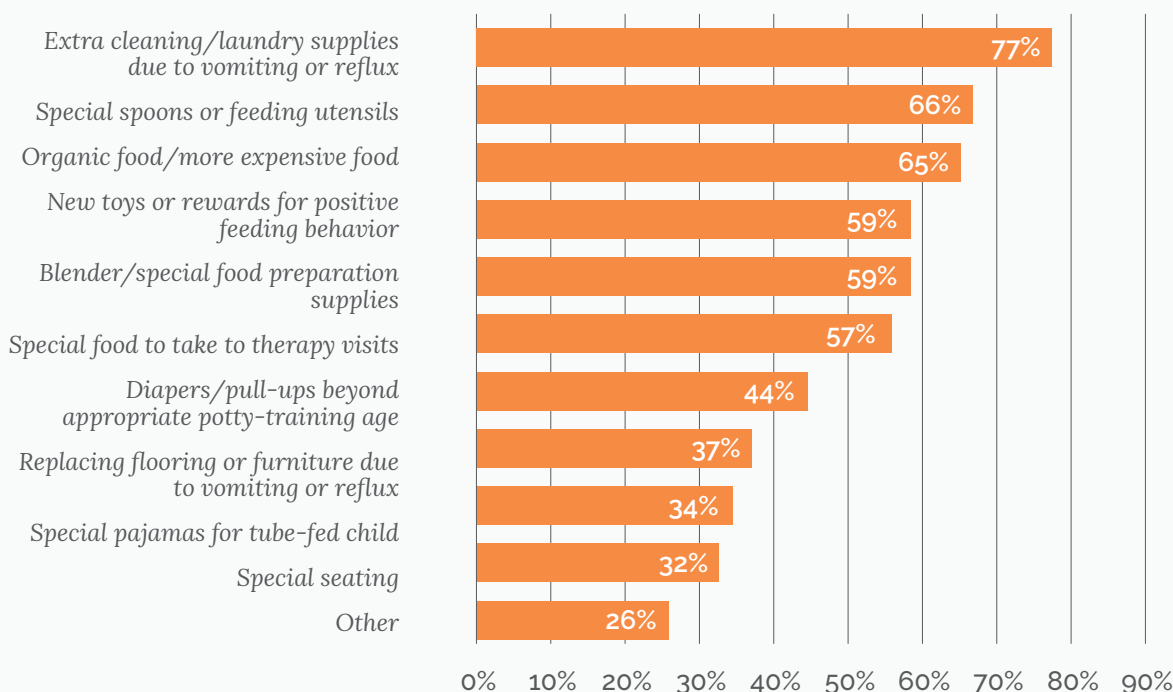


Responses showed significant spending on supplies related to their child's PFD, averaging \$170 on goods in a typical month. As a result of accommodating their child's PFD, over two-thirds of respondents (70%) spend money on convenience food they normally wouldn't have purchased –adding up to \$200 more than their normal food budget per month.

“

We have to purchase a new recliner every 6 months for safe feeding positioning that gets ruined by reflux and feeding accidents. Bed covers, bed positioning slabs, pillows every 2-3 months.”

OUT-OF-POCKET COSTS FOR SUPPLIES



Participants were asked to estimate the extra amount they spend on childcare beyond typical costs, including supplemental care for their children without PFD. One in four respondents (25%) pay additional fees or rates on specialized supervision for their child with PFD, estimating they spend an extra \$153 on specialty childcare in a month beyond typical care costs for their child with PFD.

In response to childcare for their children without PFD, 14% of respondents hire supplementary

childcare so they can provide attention to their child with PFD. Moreover, almost one in four respondents (23%) hire additional childcare for their children without PFD while they attend appointments for their child with PFD.

A small number of respondents (17%) pay extra for private school or education services to accommodate their child's PFD. In an average year, this costs these parents or caregivers an additional \$8,575.

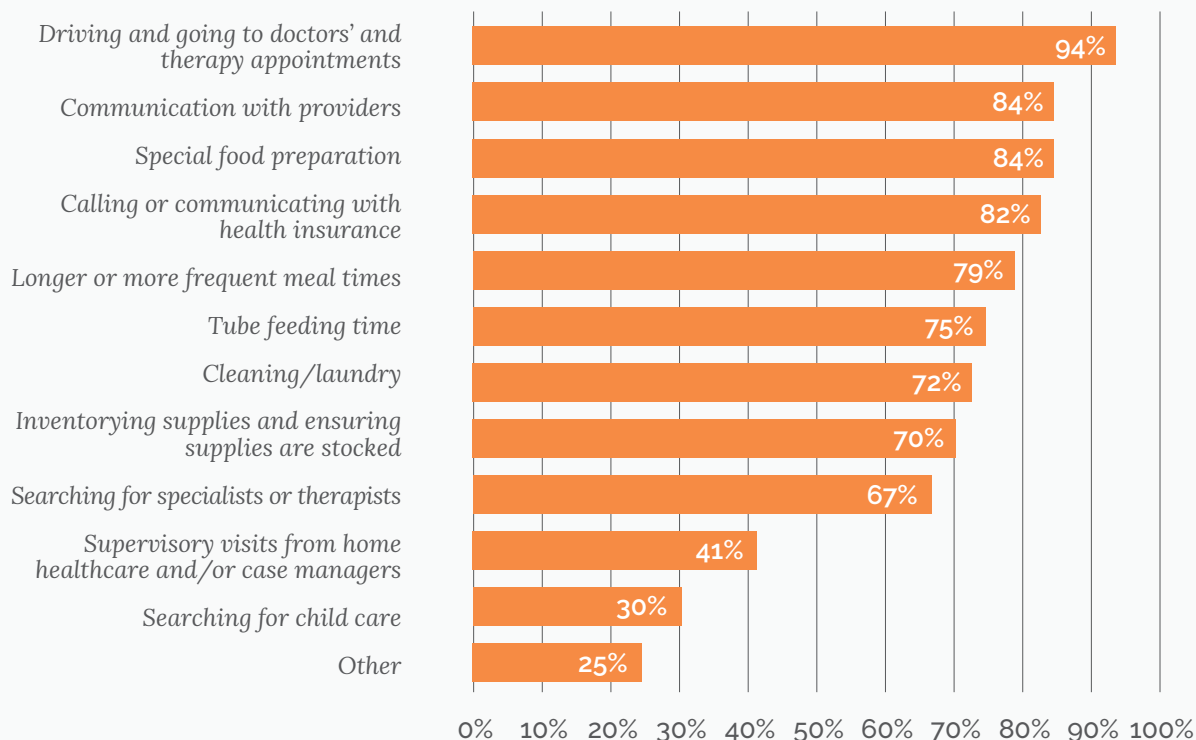
A young child with dark hair and a joyful expression is jumping in the rain. The child is wearing a bright green hooded raincoat with a small cartoon character on the chest, dark pants, and red rubber boots. Raindrops are visible as white streaks all around the child. The background is a soft-focus green, suggesting a park or garden.

“

I am killing myself trying to work full-time to support my daughter as a single parent. My parents had to move from out of state to help, and even with them here I am exhausted from trying to coordinate supplies, therapy, and her care while maintaining full-time employment. I want to quit and give up every day, but I can't. It is maddening.”

TIME & TRAVEL

ACTIVITIES REQUIRING EXTRA TIME



Caregivers of children with PFD spend an enormous amount of time on things that require extra attention, such as communication with medical providers, driving to appointments, special food preparation, and longer or more frequent meal times. On average, respondents estimate they spend an extra 83 hours a month on PFD-related activities.

When asked about their expenses for travel related to PFD care, three out of four respondents (75%) reported in-town travel for appointments – estimating 193 miles of in-town travel per month, on average.

Over half of respondents (55%) travel out of town for their child's PFD care. For these caregivers, they estimate that out of town travel costs add up to over \$2,822 in a typical year.

PARENT & CAREGIVER HEALTH

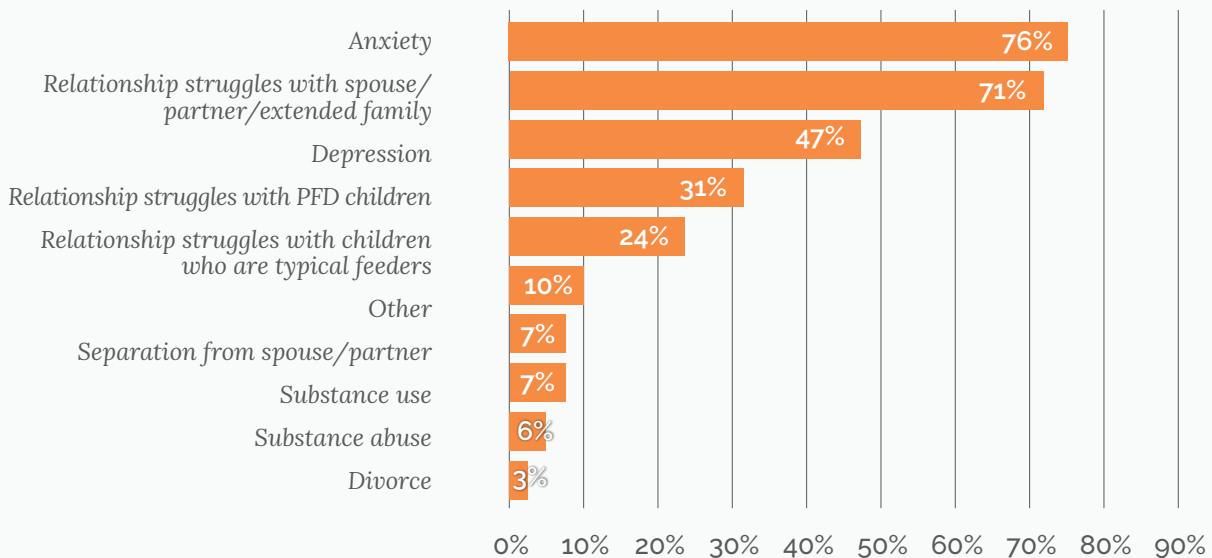
Regarding their own personal health, over 83% of respondents feel that their own relationship with food has changed as a result of their child's PFD, and not for the better. Open-ended responses to this question among caregivers included hating mealtimes, losing any sort of joy in food, and their own weight gain due to hurried eating and accommodating their child with PFD.

Unsurprisingly, over 97% of respondents feel stress regarding their child's PFD, and this

stress has resulted in health problems for 62% of respondents. In a typical month, these caregivers estimate \$189 in expenses to treat their own stress-related health problems.

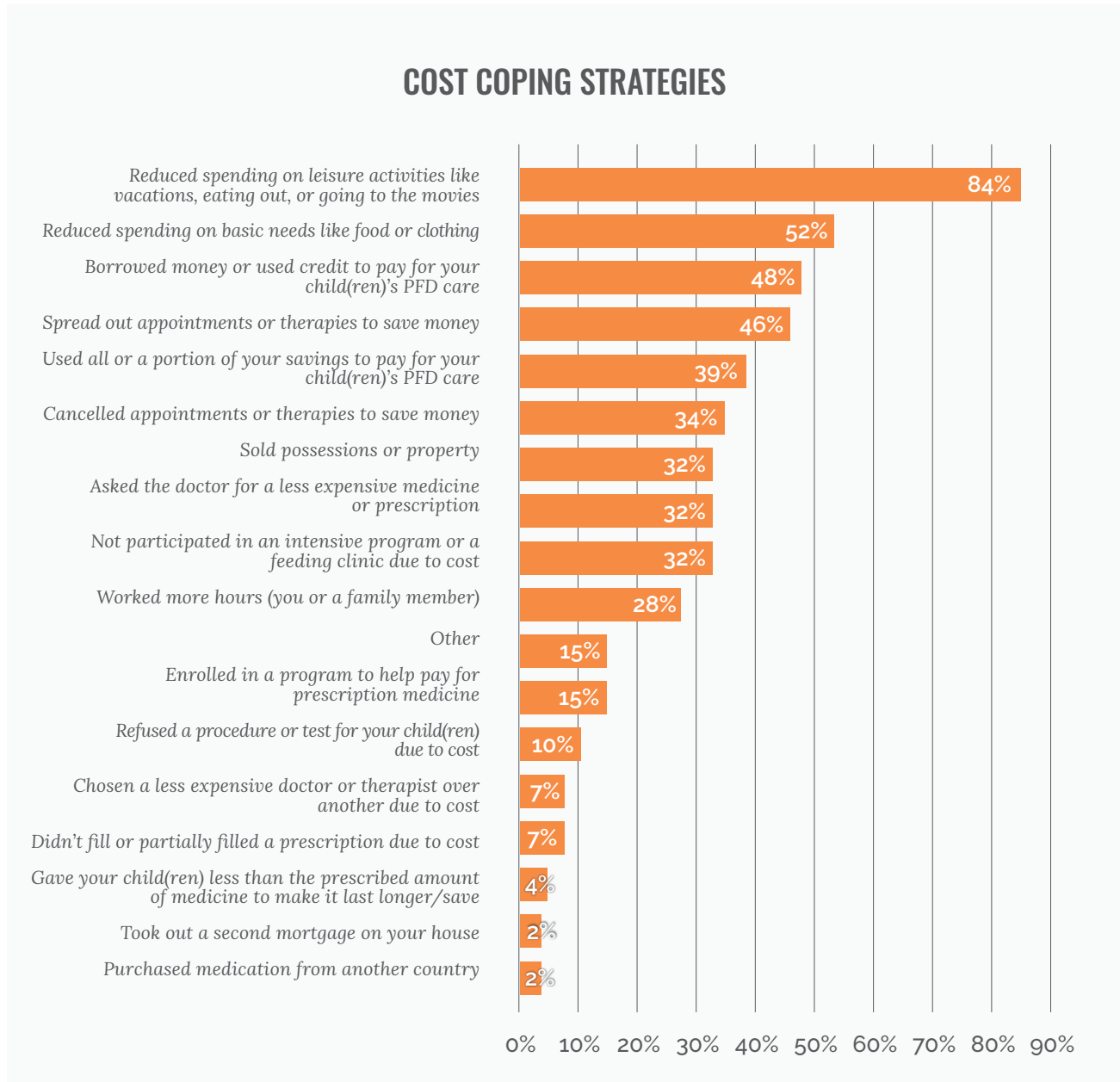
For certain, being the parent or caregiver of a child with PFD comes with a large psychological toll. And, for 41% of respondents, these psychological tolls cost them money to address, for example, on therapy and self-care. On average, these caregivers spend \$134 a month on psychological care.

PSYCHOLOGICAL TOLL ON FAMILY



COST COPING STRATEGIES

Insured families and caregivers with children who have pediatric feeding disorder experience a considerable economic burden. Such families spend money on healthcare for their children and sacrifice opportunities to save money for necessities. Caregivers were asked whether they have ever used any number of creative cost-coping strategies to help with this economic burden.



CONCLUSION



To be certain, the economic burden of pediatric feeding disorder on families is immense. Data from Feeding Matters' Economic Impact Study, summarized in the table below, only tells part of the story. What cannot be captured through this dollar, mileage, and time cost exercise are the emotions tied to this economic burden.

This study provides new insight into the significant financial hardships faced by families navigating PFD. Feeding Matters' Economic Impact Study is also a unique compilation of the broad costs that insured families experience when caring for a child with a PFD. While the primary data source is self-reported, it is the only available information on PFD care-related costs. Because PFD lacks a diagnostic code, it is nearly impossible to track medical spending related to PFD, and no database of PFD costs exists.

As Feeding Matters continues its work to ignite unprecedented change to the system of care through insights, shared-collective decisions, and ideas, there will be further investigation into the prevalence of pediatric feeding disorder and the economic impact on families and the healthcare system.

MONTHLY COSTS (AVERAGE)	
Medical Costs	\$353
Supplies	\$170
Child Care	\$153
Convenience Food	\$200
Treating Personal Stress	\$189
Psychological Care	\$134
In-Town Travel	193 miles/month
Time	83 hours/month
ANNUAL COSTS (AVERAGE)	
Out-of-Town Travel	\$2,822
Education	\$8,575
LIFETIME COSTS (AVERAGE)	
Total Lost Income	\$125,645

Funding Details & Disclosure

Feeding Matters' Economic Impact Study was completed by FirstEval, LLC and supported by the Vitalyst Health Foundation and BHHS Legacy. The Vitalyst Health Foundation and BHHS Legacy had no role in study design; collection, analysis, and interpretation of the data; or the writing of the report. Feeding Matters is an author on the Economic Impact Study and contributed to the study design, access to study participants, and writing of this manuscript. Feeding Matters did not contribute to the collection, analysis, and interpretation of the data.

References

- ¹ Bass, N.H., & Morrell, R. M. (1992). The neurology of swallowing. *Dysphagia: Diagnosis and Management*, 3, 7-35.
- ² Manikam R, & Perman J.A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, 30(1), 34-46.
- ³ Goday PS, Huh SY, Silverman A, Lukens CT, Dodrill P, Cohen SS, Delaney AL, Feuling MB, Noel RJ, Gisel E, Kenzer A, Kessler DB, de Camargo OK, Browne J, Phalen JA. (2019) Pediatric feeding disorder: consensus definition and conceptual framework. *Journal of Clinical Gastroenterology*, 68(1), 124-129.



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