

Impacts of raising a child with a feeding difficulty in Aotearoa New Zealand

Stacey-Louise Corney, Givona Rush, Sarah A Taylor, Bianca N Jackson

ABSTRACT

Economic barriers to accessing support for children with paediatric feeding difficulties can have serious repercussions, including parental stress and emotional fatigue, the child developing a negative relationship with food and health risks such as undernourishment, aspiration pneumonia or choking. We explored the financial and psychological impact experienced by parents and caregivers raising a child with a feeding difficulty in Aotearoa.

Respondents were 88 parents or caregivers of a child with a feeding difficulty, living in Aotearoa. Respondents completed an online survey with 34 questions, the majority of which were multi-choice. Open-ended responses provided exemplars and detail.

The results indicate that many families (64.3%) experience a significant but small impact associated with raising a child with feeding difficulties in Aotearoa. However, 36.4% of respondents reported a moderate to significant financial impact. Barriers to working caused by feeding challenges and childcare, as well as non-medical expenses, contributed to financial strain and psychological impacts experienced by respondents. Parents struggled to find support for their own wellbeing.

Paediatric feeding difficulties (PFD) are disruptive, hindering family life and routines as well as being the cause of many health issues for children. Further, PFD cause financial and psychological stress to whānau (family, extended family connections). Feeding may be a challenge from birth, may become more difficult over time or may coincide with a period of illness.¹ Children may have chronic complex medical situations or be otherwise healthy. There is currently little research that reports on the financial and psychological impacts of having a child with a feeding difficulty from an Aotearoa perspective. There is no exact data on the prevalence of feeding problems in children in Aotearoa. Existing research focussed on the economic challenges associated with childhood disability, for whom feeding difficulties are prevalent, is commonly from Census data. Feeding difficulties are not reported on in the New Zealand Disability Survey; however, if we apply the widely accepted prevalence data of 20% of typically developing children (20% of 837,479 = 167,495.8) and 80% of children with disabilities (80% of 103,521 = 82,816.8) having a feeding difficulty (PFD), this would mean that more than 250,000 children in Aotearoa will experience PFD at some point in their childhood, with approximately 43,303 (17.3%) predicted to be Māori.

Māori are the Indigenous people of Aotearoa, and the role of kai (food) is highly important in whānau relationships. Māori and Pacific grandparents and extended whānau often care for children from birth (or soon thereafter) to the age of 3 years.² Being with whānau is an important component of Māori hauora (Māori philosophy of health).^{2,3} PFD may particularly impact on the nurturing aspect of feeding for Māori,^{3,4} and there are known barriers to accessing public health system care and support.^{2,5,6}

Extant literature does little to address the cost of PFD in Aotearoa. Canadian studies identified most families of children with disabilities were unable to engage in paid work to the same extent as families of typically developing children.^{7,8} In Australia, parents of children with intellectual disabilities faced between AUD\$15,000 and AUD\$25,000 in additional costs, depending on the severity of their child's disability.⁹ This was on top of costs associated with reduced labour, estimated to add up to around AUD\$48,000 per year. In a study focussed on PFD, Australian parents reported considerable financial impacts, including the cost of the appointment itself, the time taken to attend (at least half a day) and the associated disruption to work and other daily activities.¹⁰ These impacts are likely to be magnified for Māori.

The diverse ways that healthcare is funded internationally affects cost comparisons with Aotearoa. The 2022 Household Economic Survey¹¹ found that one in five children with disabilities in Aotearoa lived in material hardship—more than twice the rate for typically developing children. Economic barriers to accessing support and intervention for children with PFD can have serious repercussions, including parental stress and emotional fatigue, the child developing a negative relationship with food and health risks such as undernourishment, aspiration pneumonia or choking.¹² These often life-endangering risks can be avoided with appropriate multidisciplinary input.¹³

This study explored the economic costs and psychological impact associated with raising a child with PFD in Aotearoa. Furthermore, a clearer description of the financial and psychosocial consequences associated with feeding difficulties specifically would guide health professionals and service providers to more tailored support for families.

Method

This cross-sectional study had approval from The University of Auckland Human Participants Ethics Committee #22188. Data were collected via an online survey on the Qualtrics platform.

Table 1: Respondent demographics (N=88).

Variables		n (%)
Relationship to child with PFD (n=88)	Caregiver or father	10 (11%)
	Mother	78 (89%)
Region (n=81)	Upper North Island	34 (42%)
	Lower North Island	28 (35%)
	South Island	19 (23%)
Employment status (n=78)	Employed full-time (>30 hours/week)	17 (22%)
	Employed part-time	25 (32%)
	Home maker	23 (29%)
	Self-employed	6 (8%)
	Unemployed (seeking/not seeking work)	7 (9%)
Marital status (n=81)	Married/domestic partnership	70 (86%)
	Separated/divorced/single	11 (14%)
Number of adults in the home (n=86)	One	8 (9%)
	Two	67 (78%)
	Three or four	11 (13%)
Number of children in the home (n=86)	One	27 (31%)
	Two	29 (34%)
	Three or four	30 (35%)

Note: *Cell counts of less than 5 have been merged.

Thirty-four quantitative and qualitative questions covered demographic data, financial impacts and psychological impacts of raising a child with PFD (Appendix 1). The survey design was adapted, with permission, from the Economic Impact Study created by Feeding Matters.¹⁴

Demographic questions were based on Aotearoa Census classifications.¹⁵ Options for additional expenses incurred reflect the financial support offered to parents raising a child with a disability in Aotearoa (\$200 per month).¹⁶ Changes to financial providers reflect local options.

Recruitment occurred online and in-person through advertisements in special interest groups on Facebook, and professional networks. All parents or carers of children with PFD in Aotearoa were eligible to participate. Relevant Facebook groups were identified by searching “Children with feeding difficulties Aotearoa”, “Parenting children with disabilities Aotearoa” and “Parenting support group Aotearoa” in the Facebook group search function. Respondents could enter a prize draw to win one of 10 \$50 vouchers. Data collection occurred exclusively online. Respondents accessed the survey via a link in the Participant Information Sheet on their own internet-capable devices. The survey ran from August 2021 to October 2022.

Descriptive statistics were calculated for select data using Microsoft Excel and Statistical Package

for Social Sciences (SPSS). Qualitative comments are included to illustrate the numerical findings.

Results

A total of 101 respondents began the survey, with a completion rate of 87% (n=88). Twenty-one respondents had children with PFD 12 months old or less, 66 children were older (range, 2 months–17 years). Of the 59 (67%) children who were tube-fed, 38 (43%) had a gastrostomy and 21 (23%) a nasogastric tube. Five respondents identified as Māori, two as Pacific peoples and 70 as Pākehā. Respondents were able to identify with more than one ethnicity. Demographic information is shown in Table 1.

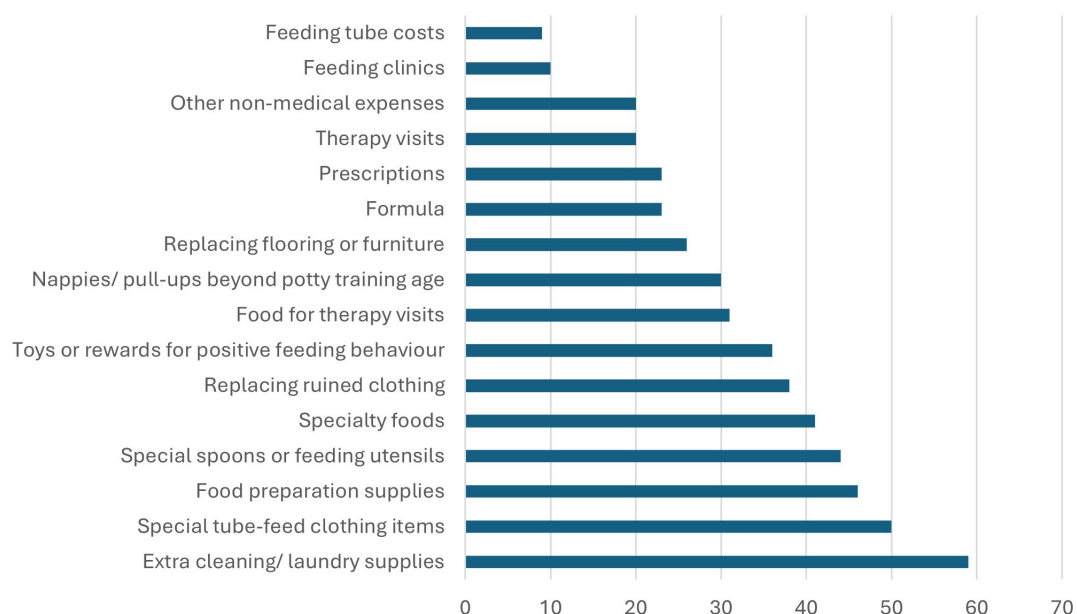
Levels of reported financial strain

A majority of respondents (n=73, 82%) reported their income was at least enough to meet their needs and a majority (n=68, 80%) experienced at least minor financial strain, with 15 (18%) respondents reporting significant strain. Chi-squared between perceived income sufficiency and financial strain was not statistically significant ($\chi^2[9]=13.565, p=.139$).

Expenses incurred by parents/caregivers of a child with PFD

Almost half of respondents (n=39, 45%) have

Figure 1: Medical and non-medical expenses related to child’s PFD paid for out-of-pocket by whānau (n=88).



not had to pay for any medical expenses out-of-pocket. However, all respondents in the survey reported paying for at least one non-medical expense out-of-pocket, with the most common expense being extra cleaning/laundry supplies due to reflux and/or vomiting (Figure 1).

Thirty-two percent of respondents indicated they were not experiencing extra travel costs because of their child's PFD: 70% reported they did not travel extensively to appointments, 48% indicated they spent \$1–200 per month and 20% spent over \$200 on travel costs. Over 50% of respondents spent additional money each month on childcare related to their child's feeding difficulties (up to \$200 n=24 [27%], more than \$201 n=23 [26%]).

Several parents reported a significant loss of earnings due to extra time spent looking after children at home or in hospital: "... *There is a financial burden as I didn't qualify for maternity leave and planned to be back at work after 4 months. At 10 months I am still not able to return to work*" – P12; "*I've been unable to work due to my youngest's issues, yet there is no other funding or help available*" – P23; "*We live in a small community, and I haven't been able to go back to work, our small daycare has only just agreed to take her. Financially we have run out of savings*" – P56.

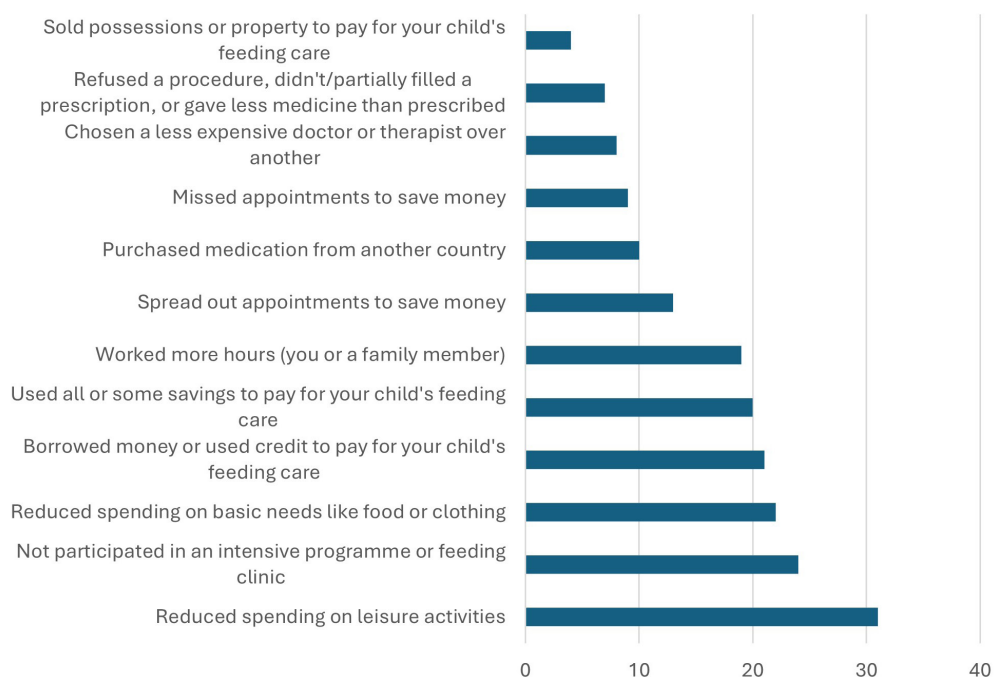
Money saving strategies

Respondents were using a wide range of strategies to save money on costs related to their child's feeding difficulty (Figure 2). The most common strategies included reducing spending on leisure activities (n=27, 42%), reducing spending on basic needs (n=18, 28%), working more hours (n=18, 28%) and not participating in a treatment programme due to cost (n=18, 28%).

Psychological impacts

Most whānau said their relationship with food or mealtimes had changed because of their child's feeding difficulty. Most respondents (94.4%) reported feeling stressed about their child's feeding. Typically, mealtimes were more complex: "*Very stressful environment around mealtimes. We are unable to all eat the same meal and eat as a family*" – P22. Parents reported differing significance of feeding difficulties, which frequently co-occurred with other needs: "*Although my child has general special needs, it is the tube feeding and feeding difficulty which causes the most strain on our day to day lives by far!*" – P60, whereas P57 commented "*They do correspondence school. This is in part due to feeding issues but also in part due to anxiety etc. Also, marriage issues and stress cannot be entirely blamed on feeding issues, but it's played a part.*"

Figure 2: Strategies employed by whānau to save money on costs related to their child's feeding difficulty (n=63).



Parents reported PFD resulted in them experiencing depression (n=46, 52%), anxiety (n=62, 70%) and relationship struggles with their spouse/domestic partner (n=36, 41%), as well as disconnection from their community (n=39, 44%). Some (n=13, 15%) noted challenging relationships between other siblings, particularly resentment over “special treatment”: “I feel like my other kids resent him for always having special things” – P23; “My older son ... resents his brother terribly and it’s causing all sorts of problems” – P14.

Supportive people, groups or organisations for parents

Most respondents were able to identify at least one person or organisation that was helpful or supportive (Table 2)—some named specific people. Forty percent had accessed free support. A minority felt whānau were supportive. Unfortunately, several felt unsupported: “None, I have tried so hard, but I can’t seem to get anywhere” – P7, “No one—I’m in this alone” – P14. Parents reported feeling judged negatively: “To be honest, no one has helped, just say I’m a bad parent [and] that he is just fussy” – P40. Others had mixed experiences with the support that was available: “Our DHB physio team have been the most helpful. Our SLT is a lovely lady—but useless. We don’t know where else to access help and can’t afford private” – P70.

There was difficulty in accessing sufficient or timely mental health support through the public health system: “I was offered six sessions of counselling via my GP but needed much more to deal with the PTSD I have from being in hospital so much with my child” – P87; “Little mental health support—took over 6 months to get any counselling” – P30.

Discussion

The aim of this study was to gain perspectives from caregivers in Aotearoa regarding the financial and psychological impact of caring for a child with PFD. Overall, results highlighted that there was a substantial experience of financial strain and little opportunity for psychological support for parents.

The majority of parents/caregivers of a child with PFD experienced some degree of financial strain. More than 60% reported feeling at least minor financial strain, with nearly 40% of respondents rating their level of financial strain as moderate or significant. This result is consistent with results of the Feeding Matters Economic Impact Study,¹⁴ as well as literature on the financial impact of raising a child with a disability.^{9,17}

There was a positive relationship between number of non-medical items purchased out-of-pocket and levels of reported financial strain.

Table 2: People or groups who have been particularly supportive or helpful (n=71).

Helpful and supportive people, groups or organisations	n (%)
Facebook groups related to tube feeding or child’s condition	17 (24)
Whānau (grandparents, extended whānau, children)	9 (13)
In-person community groups, church, friends	6 (8)
Family Centres related to child’s condition or disability	10 (14)
General Practitioner, Paediatrician, Specialist Tertiary Team, Dietitian, Physiotherapist	16 (23)
Mental Health Service, Psychotherapist, Psychologist, Counsellor	7 (10)
Nurse—community, homecare and outreach services	6 (8)
Speech-Language Therapist—community and inpatient	14 (20)
No one/none*	5 (7)

Note: Multiple responses were possible. Cell counts of less than 5 have been merged. *These respondents did not choose multiple options.

This could be due to Health New Zealand – Te Whatu Ora funding, whereby financial support is not provided for items costing less than \$50, nor for toileting products if the child is younger than 4.5 years.¹⁸ This correlation suggests that the lack of funding for smaller items specifically related to feeding and swallowing, like special feeding utensils, food preparation supplies, bibs and nappies, are having a significant impact on the cost of raising a child with PFD.

Medical expenses, as opposed to non-medical expenses, do not appear to be a major source of financial strain for the respondents. This contrasts with the findings from the original Economic Impact Study.¹⁴ Some Aotearoa respondents reported having to pay for prescriptions, therapy visits, formula and feeding tube costs; however, a third of respondents reported that they were not paying for any medical expenses related to their child's PFD. Further investigation is required to determine why some whānau are paying for medical expenses that should be covered by Health New Zealand – Te Whatu Ora, such as formula feeds for children over 1 year old. Respondents were paying for a maximum of two medical expenses, and up to 10 non-medical expenses. Unfunded costs such as additional kitchen utensils, formula feed and extra laundry can make healthcare unaffordable.⁶ Children's healthcare visits and prescriptions are currently free in Aotearoa, and some feeding difficulties have funded medical expenses (e.g., tube feeding costs, formula prescriptions). It is positive that medical expenses are not a major source of financial strain. The lack of travel expenses for around half the families is consistent with the health professionals being community-based, and increasingly using telehealth methods of service delivery.

Respondents reported a wide range of money-saving strategies they used. These strategies can be broadly classified into three groups: saving money on household expenses, seeking extra money and saving money on healthcare expenses related to their child's feeding difficulty. Respondents reduced spending on both basic needs like food and clothing, as well as on leisure and community activities. Findings suggest the financial strain is leading to a reduced quality of life for the entire whānau.¹⁷ Lastly, while the known impacts of credit card debt are variable, medical debt may lead to a cycle of poverty, including poorer physical and mental health and disruption to whānau life.¹⁹⁻²¹

The burden of hospital stays and reduced opportunity for working was a reported cause of

stress for many families. Rather than additional expenses, a lack of income due to not being able to work was a substantial cause for parents' concern. For many, partner and spousal relationships were impacted, along with relationships between parents and children who were typical feeders. Whānau were a source of support for only a few families, which may reflect the mainly Pākehā demographic. Māori and Pacific whānau were under-represented in this study and are likely to experience greater whānau support. Previous studies show high levels of stress and increased risks of anxiety and depression in parents of children with feeding difficulties, with impacts on relationships with spouses, wider social relationships and employment.¹² Parents commented that it was difficult to access mental health support when they needed it, with a small number indicating they were under care of local Maternal Mental Health services. Approximately one third of families/whānau spent money to address psychological issues arising from the stress of their child's PFD.

Our sample mainly captured the perspectives of Pākehā whānau in Aotearoa. Overall, 38% of respondents indicated they were not employed outside of the home and 14% were not in a relationship. Further, one third of our sample paid out-of-pocket to access psychological support (broadly construed).²² The sample population was strongly tauīwi. An online survey may not adequately capture voices of Māori or Pacific whānau, due to accessibility, or the lack of kanohi ki te kanohi (face-to-face) recruitment or delivery. Further qualitative research with a Kaupapa Māori approach is needed; a notable example is a recent paper focussing on Māori experiences of treatment and recovery from eating disorders.²³

For Māori, we also acknowledge the impact of colonisation on health outcomes, and the current systemic and institutional biases in the healthcare system that act as barriers to accessing care.²⁴ Especially for PFD, there are few and inconsistently funded services, and none that are designed by Māori or involve a Kaupapa Māori approach.

There are many informal networks accessed by whānau and families to mitigate stress and fulfil a need for advice and support when caring for a child with a feeding difficulty. This, however, does not replace the medical advice and assistance needed for whānau and families to safely care for children with feeding difficulties alongside very complex health needs and medical challenges. Overall, the results indicate that for most families

there is a substantial financial burden posed from raising a child with PFD. Parents/caregivers reported experiencing financial strain, but psychological impacts were more emotive,

and further consideration should be given to a whānau-centred approach, addressing the mental wellbeing of the whole whānau where there is a child with a feeding difficulty.

COMPETING INTERESTS

Nil. This work was funded by The University of Auckland.

AUTHOR INFORMATION

Stacey-Louise Corney: Speech-language Therapist, School of Psychology, The University of Auckland, Auckland, New Zealand.

Givona Rush: Speech-language Therapist, School of Psychology, The University of Auckland, Auckland, New Zealand.

Dr Sarah A Taylor: Board Certified Applied Behaviour Analyst & Senior Lecturer, School of Psychology, The University of Auckland, Auckland, New Zealand.

Dr Bianca N Jackson: Speech-language Therapist & Research Fellow, School of Psychology, The University of Auckland, Auckland, New Zealand.

CORRESPONDING AUTHOR

Dr Bianca N Jackson: Speech-language Therapist & Research Fellow, Private Bag 92019, Auckland 1142, New Zealand. E: bianca.jackson@auckland.ac.nz

URL

<https://nzmj.org.nz/journal/vol-137-no-1596/impacts-of-raising-a-child-with-a-feeding-difficulty-in-aotearoa-new-zealand>

REFERENCES

- Morton K, Marino LV, Pappachan JV, Darlington AS. Feeding difficulties in young paediatric intensive care survivors: A scoping review. *Clin Nutr ESPEN*. 2019;30:1-9. doi: 10.1016/j.clnesp.2019.01.013.
- Graham R, Masters-Awatere B. Experiences of Māori of Aotearoa New Zealand's public health system: A systematic review of two decades of published qualitative research. *Aust N Z J Public Health*. 2020;44(3):193-200. doi: 10.1111/1753-6405.12971.
- Stevenson K. A consultation journey: Developing a Kaupapa Māori research methodology to explore Māori whānau experiences of harm and loss around birth. *AlterNative*. 2018;14(1):54-62. doi: 10.1177/1177180117744612.
- Moeke-Pickering T, Heitia M, Heitia S, et al. Understanding Māori food security and food sovereignty issues in Whakatāne. *MAI Journal*. 2015;4(1):29-42.
- Cormack D, Harris R, Stanley J, et al. Ethnic bias amongst medical students in Aotearoa/New Zealand: Findings from the Bias and Decision Making in Medicine (BDMM) study. *PloS One*. 2018;13(8):e0201168. doi: 10.1371/journal.pone.0201168.
- Paine S-J, Li C, Wright K, et al. The economic cost of Indigenous child health inequities in Aotearoa New Zealand—an updated analysis for 2003–2014. *N Z Med J*. 2023;136(1568):23-45.
- Burton P, Chen K, Lethbridge L, Phipps S. Child Health and Parental Paid Work. *Rev Econ Househ*. 2017;15(2):597-620. doi: 10.1007/s11150-014-9251-z.
- Burton P, Phipps S. Economic Costs of Caring for Children with Disabilities in Canada. *Can Public Policy*. 2009;35(3):269-90. doi: 10.3138/cpp.35.3.269.
- Doran CM, Einfeld SL, Madden RH, et al. How much does intellectual disability really cost? First estimates for Australia. *J Intellect Dev Disabil*. 2012 Mar;37(1):42-9. doi: 10.3109/13668250.2011.648609.
- Raatz M, Ward EC, Marshall J, et al. "It takes a whole day, even though it's a one-hour appointment!" Factors impacting access to pediatric feeding services. *Dysphagia*. 2021;36(3):419-29. doi: 10.1007/s00455-020-10152-9.
- Perry B. Child poverty in New Zealand: MSD Child Poverty Report 2022 [Internet]. Wellington (NZ): Ministry of Social Development; 2022 [cited 2024 May]. Available from: <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/research/child-poverty-in-nz/2022-child-poverty-report.pdf>
- Backman E, Granlund M, Karlsson AK. Parental Perspectives on Family Mealtimes Related to Gastrostomy Tube Feeding in Children. *Qual Health Res*. 2021;31(9):1596-608. doi: 10.1177/1049732321997133.
- Soar N, Birns J, Sommerville P, et al. Approaches to eating and drinking with acknowledged risk: A systematic review. *Dysphagia*. 2021;36(1):54-66. doi: 10.1007/s00455-020-10107-0.
- FirstEval LLC, Feeding Matters. 2019 Economic Impact Report: Financial Burdens of Pediatric Feeding Disorder on Insured Families [Internet]. Phoenix, Arizona (US): Feeding Matters; 2019 [cited 2024 May]. Available from: <https://www.feedingmatters.org/wp-content/uploads/2019/07/Economic-Impact-of-PFD.pdf>
- Statistics New Zealand Tatauranga Aotearoa. 2018 Census 2020 [Internet]. Wellington (NZ): Stats NZ; 2020 [cited 2024 May]. Available from: <https://www.stats.govt.nz/2018-census#methods>
- Work and Income Te Hiranga Tangata. Child Disability Allowance [Internet]. Wellington (NZ): Ministry of Social Development; 2023 [cited 2023 Jun 10]. Available from: <https://www.workandincome.govt.nz/products/a-z-benefits/child-disability-allowance.html#null>
- Stabile M, Allin S. The Economic Costs of Childhood Disability. *Future Child*. 2012;22(1):65-96. doi: 10.1353/foc.2012.0008.

18. Whaikaha – Ministry of Disabled People. Equipment available to loan or buy [Internet]. Wellington (NZ): Whaikaha – Ministry of Disabled People; 2024 [cited 2023 Jun 10]. Available from: <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/equipment-and-modifications-disabled-people/equipment-disabled-people>
19. Goode J. Brothers are doing it for themselves?: Men's experiences of getting into and getting out of debt. *J Soc Econ*. 2012;41(3):327-35. doi: 10.1016/j.socsec.2012.02.001.
20. Marshall GL, Kahana E, Gallo WT, et al. The price of mental well-being in later life: the role of financial hardship and debt. *Aging Ment Health*. 2021;25(7):1338-44. doi: 10.1080/13607863.2020.1758902.
21. Białowolski P, Węziak-Białowolska D, VanderWeele TJ. The impact of savings and credit on health and health behaviours: an outcome-wide longitudinal approach. *Int J Public Health*. 2019;64(4):573-84. doi: 10.1007/s00038-019-01214-3.
22. Jeffreys M, Ellison-Loschmann L, Irurzun-Lopez M, et al. Financial barriers to primary health care in Aotearoa New Zealand. *Fam Pract*. 2023:cmad096. doi: 10.1093/fampra/cmad096.
23. Clark MTR, Manuel J, Lacey C, et al. 'E koekoe te Tūi, e ketekete te Kākā, e kuku te Kererū, The Tūi chatters, the Kākā cackles, and the Kererū coos': Insights into explanatory factors, treatment experiences and recovery for Māori with eating disorders - A qualitative study. *Aust N Z J Psychiatry*. 2024;58(4):365-372. doi: 10.1177/00048674231207583.
24. Hobbs M, Ahuriri-Driscoll A, Marek L, et al. Reducing health inequity for Māori people in New Zealand. *Lancet*. 2019;394(10209):1613-4. doi: 10.1016/S0140-6736(19)30044-3.

Appendices

Appendix 1: Whānau of children with feeding difficulties in Aotearoa survey

2. Are you the parent or caregiver of a child or children with a feeding difficulty?
 - Yes
 - No
3. Please state which best describes you:
 - Mother of a child with feeding difficulty
 - Father of a child with feeding difficulty
 - Caregiver of a child with feeding difficulty
4. How many adults (18 years or older) live in your household, including yourself?
5. How many children (under 18 years old) live in your household?
6. How old is your child (in years and months) with the feeding difficulty? If more than one of your children has a feeding difficulty, please just focus on the oldest child with a feeding difficulty.
7. Which of the following diagnoses/challenges does your child face?
 - Autism spectrum disorder
 - Fear of choking
 - Cleft palate or velopharyngeal insufficiency
 - Colic
 - Dysphagia
 - Food allergies
 - Gastrostomy-tube fed
 - Gastrointestinal condition (e.g., reflux, short gut syndrome, esophagitis, gastritis, etc.)
 - Head or neck abnormalities
 - Heart condition
 - Medications that cause decreased appetite
 - Nasogastric tube fed
 - Nervous system disorder (e.g., cerebral palsy, encephalopathy, etc.)
 - Oral motor dysfunction
 - Premature/low birth weight
 - Reflux
 - Respiratory difficulties
 - Vomiting
 - Other diagnosis or challenge not listed here (please enter details)
8. Are any of your child's feeding expenses covered by any financial provider?
 - Yes—private health insurance
 - Yes—carer support (Ministry of Health)
 - Yes—ACC
 - No
 - Unsure/rather not say
 - Yes—other (please name)
9. Which of the following medical expenses have you or anyone in your whānau had to pay for because of your child's feeding difficulty? Check all that apply:
 - Feeding clinics

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

- Feeding tube costs
 - Formula
 - Prescriptions
 - Therapy visits
 - Other medical costs not listed here (please specify):
 - We have not had to pay for any medical expenses
10. Which of the following non-medical supplies have you/your whānau purchased to care for your child with a feeding difficulty and not been reimbursed for? Check all that apply:
- Special food preparation supplies
 - Special clothing items for tube-fed child e.g., clothing, bibs, etc.
 - Special spoons or feeding utensils
 - New toys or rewards for positive feeding behaviour
 - Organic/speciality food
 - Food to take to therapy visits
 - Extra cleaning/laundry supplies due to vomiting or reflux
 - Replacing flooring/furniture due to vomiting or reflux
 - Replacing ruined clothing due to vomiting or reflux
 - Nappies/pull-ups beyond appropriate potty-training age
 - Other supplies not listed here (please specify):
11. Do you or anyone in your whānau pay additional rates or fees for childcare and/or babysitting due to the special needs surrounding your child's feeding difficulty?
- Yes—we pay extra
 - No—we don't pay extra
 - There are no suitable services for my child, so we don't use paid childcare or babysitting
 - Other—please tell us how you and your family organise childcare
12. Have you or anyone in your whānau ever used any of the following strategies to help cope with the costs of your child's feeding difficulty? Check all that apply:
- Missed appointments to save money
 - Spread out appointments to save money
 - Not participated in an intensive programme or feeding clinic due to cost
 - Reduced spending on basic needs, like food or clothing, in order to pay for your child's feeding care
 - Reduced spending on leisure activities, like vacations, eating out, or going to the movies, in order to pay for your child's feeding care
 - Chosen a less expensive doctor or therapist over another
 - Refused a procedure or test for your child because of cost
 - Gave your child less than the prescribed amount of medicine to make it last longer
 - Didn't fill or partially filled a prescription for your child's feeding care because it cost too much
 - Purchased medication from another country
 - Worked more hours (you or a family member) to help pay for your child's care
 - Sold possessions or property to pay for your child's feeding care
 - Took out a second mortgage on your house to pay for your child's feeding care
 - Used all or a portion of your savings to pay for your child's feeding care
 - Borrowed money or used credit to pay for your child's feeding care
 - Other (please specify):

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

13. Overall, to what degree have the costs of your child's feeding difficulty been a financial strain for you or your whānau?

- Not a financial strain at all
- Minor financial strain
- Moderate financial strain
- Significant financial strain
- I'm not sure

14. When thinking about your household income, which of the following statements best describes your situation?

- My household income is more than enough to meet mine and my whānau's needs
- My household income is enough to meet mine and my whānau's needs
- My household income is just enough to meet mine and my whānau's needs
- My household income is not enough to meet mine and my whānau's needs
- Prefer not to answer

15. Do you or anyone in your whānau travel extensively for doctor or therapy appointments for your child with feeding difficulty?

- Yes
- No

16. How much extra, beyond typical childcare costs or sitter costs, do you or anyone in your whānau spend due to the special needs of your child with a feeding difficulty? Please estimate your extra costs in a typical month.

- \$1–200
- \$201–401
- \$401 or more
- No extra cost

17. Please estimate your/your whānau's mileage (in kilometres) for these appointments in a typical month.

18. Please estimate your/your whānau's additional expenditure on costs related to travelling for appointments (e.g., hotel, airfare, gas, food costs while travelling, parking, etc.) in a typical month.

- \$1–200
- \$201–400
- \$401 or more
- No extra cost

19. Do you pay extra for private school or education services necessary to accommodate your child's feeding needs?

- Yes
- No

20. Please estimate your additional education expenditures in a typical month.

- \$1–200
- \$201–400
- \$401 or more

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

- No extra cost
21. Do you or anyone in your whānau feel that your relationship with food or mealtimes has changed because of your child's feeding difficulty?
- Yes
 - No
22. Do you/your whānau feel stress over your child's feeding difficulty?
- Yes
 - No
23. Has the stress resulted in any health problems for you or anyone in your whānau?
- Yes
 - No
24. Have you, or anyone in your whānau, experienced an increase or development of the following because of your child's feeding difficulty? Check all that apply:
- Depression
 - Substance use
 - Substance abuse
 - Anxiety
 - Relationship struggles with spouse/partner
 - Separation from spouse/partner
 - Divorce
 - Relationship struggles with PFD children
 - Relationship struggles with children who are typical feeders
 - Relationship struggles with wider family
 - Disconnection from community
 - Loss of personal identity
 - Other (please specify):
25. Do you or your whānau spend money to address these psychological costs (e.g., on therapy, self-care, etc.)?
- Yes
 - No
26. Please estimate how much you/your whānau spend on care for these psychological costs in a typical month.
- \$1–200
 - \$201–400
 - \$401 or more
 - We do not spend money on psychological costs
27. Have you accessed any free support systems for psychological support (e.g., Healthline, Lifeline, depression.org.nz, CALM app)?
- Yes
 - No

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

- Prefer not to say
28. Please tell us about any people or groups who have been particularly supportive or helpful in helping you or your whānau care for your child.
29. Have you or anyone in your whānau gained any beneficial knowledge and/or experiences through raising your child with a feeding difficulty?
- Yes (please comment):
 - No
 - Unsure
30. What do you and your whānau enjoy doing together with your child with a feeding difficulty?
31. What does your child particularly enjoy doing?
32. Thank you for your responses. Is there anything else you want to tell us?
33. What ethnicity do you most identify with?
- Māori
 - Pacific
 - Asian
 - Middle Eastern/Latin American/African
 - NZ European or European
 - Other
34. What is your marital status?
- Married/domestic partnership
 - Single
 - Divorced
 - Widowed
 - Separated
 - Prefer not to answer
35. Which region of New Zealand do you live in?
- Northland/Te Tai Tokerau
 - Auckland/Tāmaki Makaurau
 - Waikato
 - Bay of Plenty/Te Moana-a-Toi
 - Gisborne/Tūranganui-a-Kiwa
 - Hawke's Bay/Te Matau-a-Māui
 - Taranaki
 - Manawatū-Whanganui
 - Wellington/Te Whanganui-a-Tara
 - Tasman/Te Tai-o-Aorere
 - Nelson/Whakatū
 - Marlborough/Tauihu
 - West Coast/Tai Poutini
 - Canterbury/Waitaha
 - Otago/Ōtākou
 - Southland/Murihiku
 - Prefer not to answer

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

36. What is your employment status?

- Employed full-time, 30 hours a week or more
- Employed part-time, less than 30 hours a week
- Unemployed and seeking work
- Unemployed and not seeking work
- Student
- Self-employed
- Homemaker
- Retired
- Prefer not to answer

37. Would you like to be entered into the prize draw or receive a summary of the results at the end of the project?

- Yes (you will be redirected to a new survey where you can enter your details NOTE: these details will not be linked to the answers you provided in the main survey) Please click on this link to prize draw entry and/or register to receive to a summary of the results.
- No (you will end the survey at this point and your answers will be submitted)

Appendix 2: Changes made to the original Feeding Matters Economic Impact survey (2019)

Original Feeding Matters Economic Impact survey*	Modifications to the questions
<ul style="list-style-type: none"> • What gender is/are your child(ren) with the PFD? • Please estimate the dollar amount you spend on medical expenses related to your child(ren)'s PFD in a typical month. • Please estimate the dollar amount you spend on these supplies related to your child(ren)'s PFD in a typical month. • Have you or your spouse or partner had to quit working, not take a job or promotion, or cut back on work hours in order to care for your child(ren) with PFD? • If you can, please estimate your total lost income due to caring for your child(ren) with PFD. • How much extra, beyond typical childcare costs or sitter costs, do you spend due to the special needs of your child(ren) with a PFD? If you can, please estimate your extra costs in a typical month. • Does your family spend more money on convenience food that you normally wouldn't have purchased as a result of accommodating your child(ren)'s PFD? • Which of the following things require your extra time due to your child(ren)'s PFD? • If you can, please estimate how much your health problems related to this stress cost you in a typical month. • What is the highest level of education that you have completed? 	<p>These questions were not included in our survey as they were either irrelevant to the research aim or would require too much effort from participants.</p>
<p>Which of the following diagnoses/challenges do/does your child(ren) face?</p> <ul style="list-style-type: none"> • Check all that apply: • Autism or autism spectrum • Choking phobia • Food allergies • Cleft palate or palate defect • Vomiting • Dysphagia 	<p>The wording of certain diagnoses was modified to reflect the terms commonly used in Aotearoa, and the "non-diagnosed" option was removed.</p>

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

<ul style="list-style-type: none"> • Oral motor dysfunction • Nervous system disorder (like cerebral palsy or encephalopathy) • Gastrointestinal condition (like reflux, short gut syndrome, esophagitis, or gastritis) • Premature/low birth weight • Heart disease • Head or neck abnormalities • Respiratory difficulties • Reflux • Medications that cause decreased appetite • Colic • NG tube fed • G-tube fed • Non-diagnosed • Other diagnosis or challenge not listed here 	
<p>What type of health insurance do(es) your child(ren) with PFD have?</p> <ul style="list-style-type: none"> • Health insurance from my employer or my spouse/partner's employer • Health insurance I purchase personally out of pocket • Medicaid/public insurance • No health insurance • Other 	<p>Modified or removed these questions to be more reflective of the variety of publicly funded financial support options for children with disabilities available in Aotearoa. Also added a free-text option for participants to enter the name of their private health insurance provider (if applicable).</p>
<p>Do(es) your child(ren) with PFD have insurance from any of the following companies?</p> <ul style="list-style-type: none"> • BCBS • Kaiser Permanente • UnitedHealthcare • Cigna • Anthem • Humana • Magellan • Aetna • None, n/a 	<p>Removed mentions of insurance in this question as health insurance is not as common in Aotearoa as it is in North America.</p>

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

<p>Which of the following medical expenses have you incurred as a result of your child(ren)'s PFD?</p> <ul style="list-style-type: none"> • Feeding tube costs • Various medical payments to meet insurance deductible • Insurance co-pays • Formula not covered by insurance • Prescriptions not covered by insurance • Therapy visits • Feeding clinics • Other medical costs not listed here 	
<p>Do you travel in town for doctor or therapy appointments for your child(ren)'s PFD care?</p> <p>And</p> <p>Do you travel out of town for doctor or therapy appointments for your child(ren)'s PFD care?</p>	Combined these two questions for brevity.
<p>If yes:</p> <p>If you can, please estimate your additional expenditures in a typical year. Please consider hotel, airfare, gas, food costs while travelling, etc.</p>	This question was made multi-choice to make it easier for participants to answer accurately.
<p>Have you or anyone in your family experienced an increase or development of any of the following as a result of your child(ren)'s PFD?</p> <ul style="list-style-type: none"> • Depression • Substance use • Substance abuse • Anxiety • Relationship struggles with spouse/partner • Separation from spouse/partner • Divorce • Relationship struggles with PFD children • Relationship struggles with children who are typical feeders 	Added in more options to reflect the importance of whānau, community and personal identity.
<p>Do you spend money to address these psychological costs, for example, on therapy, self-care, etc?</p>	Added a question regarding participants' use of the free mental health support options available in New Zealand.

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

<p>Have you ever used any of the following strategies to help cope with the costs of your child's PFD?</p> <ul style="list-style-type: none"> • Missed appointments or therapies to save money • Spread out appointments or therapies to save money • Not participated in an intensive programme or feeding clinic due to cost • Reduced spending on basic needs like food or clothing in order to pay for your child(ren)'s PFD care • Chosen a less expensive doctor or therapist over another because of cost • Refused a procedure or test for your child(ren) because of cost • Asked the doctor for a less expensive medicine or prescription • Gave your child(ren) less than the prescribed amount of medicine to make it last longer/save money • Didn't fill or partially filled a prescription for your child(ren)'s PFD care because it cost too much • Enrolled in a programme to help pay for prescription medicines • Purchased medication from another country • Worked more hours (you or a family member) to help pay for your child(ren)'s PFD care • Sold possessions or property to pay for your child(ren)'s PFD care • Took out a second mortgage on your house to pay for your child(ren)'s PFD care • Used all or a portion of your savings to pay for your child(ren)'s PFD care • Borrowed money or used credit to pay for your child(ren)'s PFD care • Other 	<p>Added an option "worked more hours (you or a family member) to help pay for your child's care".</p>
---	--

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

<p>Overall, to what degree have the costs of your child(ren)'s PFD been a financial burden for you or your family?</p> <ul style="list-style-type: none"> • Not a financial burden at all • Minor financial burden • Moderate financial burden • Significant financial burden • Catastrophic financial burden • I'm not sure 	<p>Changed the wording of the options to have a less negative connotation (changed burden to strain and removed the option for "catastrophic").</p>
<p>What race do you most identify with?</p> <ul style="list-style-type: none"> • American Indian or Alaska Native • Asian/Pacific peoples • Black or African American • White • Two or more races • None of the above/Other • Prefer not to answer 	<p>Changed to ethnicity and used the groups used in the New Zealand Census.</p>
<p>What is your employment status?</p> <ul style="list-style-type: none"> • Employed full-time • Employed part-time • Unemployed and seeking work • Unemployed and not seeking work • Student • Self-employed • Homemaker • Retired • Prefer not to answer 	<p>Defined full-time as 30+ hours, and part-time as 30 or less.</p>
<p>What is your household's annual income?</p> <ul style="list-style-type: none"> • Less than \$20,000 • \$20,000 to \$34,999 • \$35,000 to \$49,999 • \$50,000 to \$74,999 • \$75,000 to \$99,999 • \$100,000 to \$124,999 • \$125,000 or more • Prefer not to answer 	<p>Rather than ask participants to share their income, we asked participants to rate the adequacy of their household income to meet their needs.</p>

* In an email from H. Van der Molen, FirstEval Ltd (mkovacs@firsteval.com) in 2021.