

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>	<p>Combined these two questions for brevity.</p>
<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>	<p>This question was made multi-choice to make it easier for participants to answer accurately.</p>
<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 	<p>Added in more options to reflect the importance of whānau, community and personal identity.</p>
<p>Do you spend money to address these psychological costs, for example, on therapy, self-care, etc?</p>	<p>Added a question regarding participants' use of the free mental health support options available in New Zealand.</p>

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>
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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.