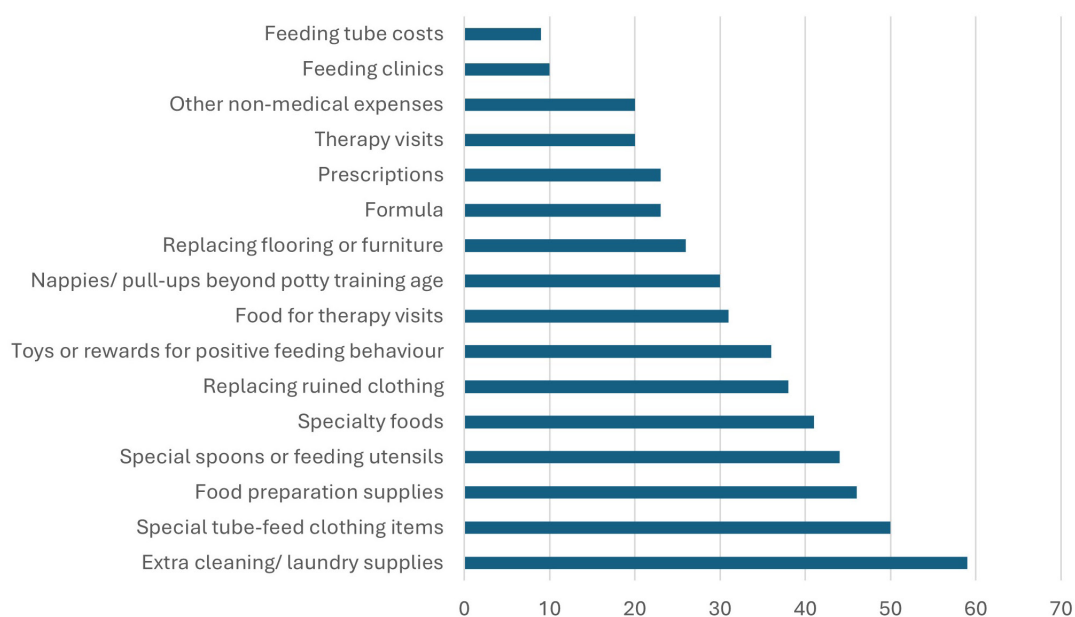


**Table 1:** Respondent demographics (N=88).

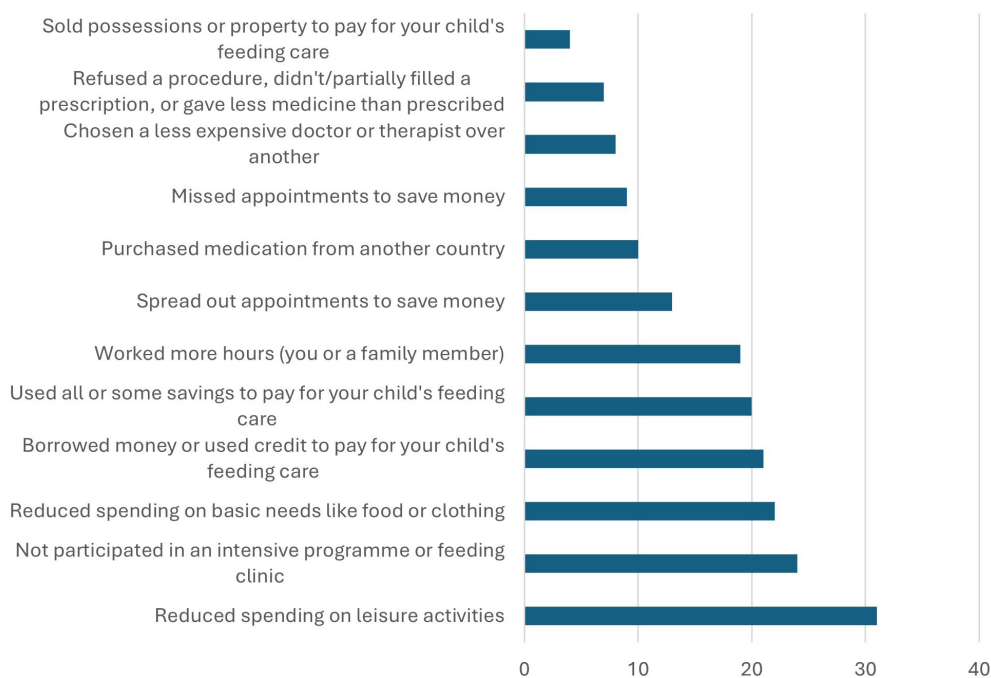
Variables		n (%)
Relationship to child with PFD (n=88)	Caregiver or father	10 (11%)
	Mother	78 (89%)
Region (n=81)	Upper North Island	34 (42%)
	Lower North Island	28 (35%)
	South Island	19 (23%)
Employment status (n=78)	Employed full-time (>30 hours/week)	17 (22%)
	Employed part-time	25 (32%)
	Home maker	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.

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



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



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

<b>Helpful and supportive people, groups or organisations</b>	<b>n (%)</b>
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.