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Exploring the Feeding Skill Domain of the Paediatric Feeding Disorder Framework in a Child Development Service: Speech-Language Therapist and Caregiver Perspectives

A thesis presented in fulfilment of the requirements of the degree of

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Abstract

Paediatric Feeding Disorder (PFD) Framework (Goday et al., 2019) is increasingly used to understand the multifactorial complexities of children's feeding difficulties. Most research in PFD has been done in the Medical and Psychosocial Domains. However, there is a small amount of research within the Nutrition and Feeding Skill Domains. There is even less research in PFD for children with other disabilities, and the impact within the Aotearoa New Zealand population is not well understood. Speech-Language Therapists (SLTs) are one of the main professionals supporting these children's feeding skills. Caregivers are managing their children's feeding skill differences several times a day.

This two-phase convergent mixed-methods study explored the feeding skills of children within a Child Development service (CDS) through the lens of SLTs and caregivers. Data was obtained from retrospective chart review of the SLT clinical notes of 10 children, and subsequently nine caregivers of these children were interviewed. Data from each phase was analysed separately, then integrated and reported together.

Mapping both these perspectives onto the PFD Framework revealed individualised differences in Feeding Skill Impairment and Feeding Skill Dysfunction for all children. The children met the criteria for PFD within the Feeding Skill Domain. Caregivers shared experiences of Feeding Skill Dysfunction impacting participation and safety at mealtimes.

This research captured the feeding skills of children from a disability service provider within an Aotearoa New Zealand context, bringing together perspectives from SLTs and caregivers. The integration of perspectives provided a richer, everyday understanding of the children's feeding skills.

This study highlights the need for further research in all four domains of the PFD Framework. Moreover, it suggestions the need for additional research within the Feeding

Skill Domain for children with disability, particularly in Aotearoa New Zealand. Other studies should consider gathering a range of caregiver perspectives, measure variables influencing PFD and engage in longitudinal data collection. Literature within these areas may support funding, awareness and access to services for children with PFD and the workforce supporting them.

The clinical implications of this study highlight the importance of adopting the PFD Framework for all professionals, and the Framework being part of the thorough assessment of children's feeding skills by SLTs specifically. Additionally, professionals should prioritise caregiver perspectives, since they provide contextual insight into their child's PFD profile. Finally, the emphasis on interdisciplinary collaboration may encourage use of shared PFD terminology and increase PFD awareness.

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I would like to thank my supervisors, Associate Professor Sally Clendon and Dr Emily Jones for their support and nurturing of my skills. Sally, for her academic expertise which pushed me to places that felt unimaginable and for keeping me on track. Emily, for her knowledge of the topic, her teaching style and gentle guidance. I feel privileged to have worked with and be inspired by the families who participated in my study; to have heard their stories from a different perspective and for their contribution to raising PFD awareness.

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Ehara taku toa i te toa takitahi, engari kē he toa takitini.

My success is not that of an individual, but that of many.

During the preparation of thesis, ChatGPT (OpenAI, 2026) and Copilot (Microsoft, 2026) were used for brainstorming, sentence structure improvement and reference list cross-checking. AI tools were not used to generate research content or sections of text, analyse data, interpret findings, or develop conclusions. All content remains my original work.

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List of Abbreviations

ARFID	Avoidant Restrictive Food Intake Disorder
ASD	Autism Spectrum Disorder (Takiwātanga)
CDS	Child Development Service
CGA	Corrected Gestational Age
DD	Developmental Disability
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSS	Disability Support Services
DTF	Developmental Texture Framework
FEES	Flexible Endoscopic Evaluation of Swallowing
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health – Children and Youth
IRAG-M	Interim Research Advisory Group – Māori
MUHEC	Massey University Human Ethics Committee
NHI	National Health Index
NZDep	New Zealand Index of Deprivation
PAH	Potentially Avoidable Hospitalisations
PFD	Paediatric Feeding Disorder
RCR	Retrospective Chart Reviews
SLT/s	Speech-Language Therapist/s
VFSS	Videofluoroscopic Study of Swallowing

Chapter One: Introduction

Introduction

Due to limited research, undefined diagnostic criteria consensus and the heterogenous nature of this population, it is difficult to determine prevalence. However, the best current available research indicates that feeding difficulties are present in 25 to 45% of typically developing children (Lukens & Silverman, 2014; Manikam & Perman, 2000). In children with developmental delay, this increases to 80 to 90% (Manikam & Perman, 2000; O'Regan Kleinert, 2017). Mealtimes occur several times a day and, if difficulties with feeding skills are present, this results in significant challenges. The impact of feeding skill difficulties is an important consideration and remains an area with limited research.

Paediatric Feeding Disorder Framework

The Paediatric Feeding Disorder (PFD) Framework was released in 2019 by expert consensus (Goday et al., 2019). The World Health Organization (2001) established the International Classification of Functioning, Disability and Health (ICF) to provide a unified, standard language for health and health-related states, such as defining components of well-being. The ICF forms the foundation for the PFD Framework, as it recognises both the impairment and the dysfunction components. The dysfunction components are the impact on activities and participation in everyday life due to limitations and restrictions. The PFD Framework acknowledges the complexity and multifactorial components of paediatric feeding difficulties (Goday et al., 2019). Use of the Framework establishes common terminology to determine prevalence and support advocacy (Goday et al., 2019), which has been missing in paediatric feeding research. With limited representation in the United States, one in thirty-seven children under 5 years of age receive a diagnosis of PFD (Kovacic et al., 2021). Moreover, (Kovacic et al., 2021) found the prevalence for PFD in children under

5 years of age with other chronic diseases is one in five children. There is currently no data on the prevalence of PFD in Aotearoa New Zealand. Presently, there is limited research on children over the age of 1 month and children aged 2 to 9 years with PFD (Estrem et al., 2022).

Feeding Skill Domain

The Feeding Skill Domain of the PFD Framework has received limited research, unlike the Medical and Psychosocial Domains (Estrem et al., 2022). In Aotearoa New Zealand, the Ministry of Health funds Child Development Services (CDS), who provide support for children who are at risk of, or have a disability following criteria from the Disability Support Services (DSS). CDS often has Speech-Language Therapists (SLTS) who have specialist skills for paediatric feeding, and may provide part of the management of feeding skills for these children. However, there is limited research in speech and language therapy focused on children with PFD in Aotearoa New Zealand, particularly children with disabilities and PFD. The Feeding Skill Domain is the basis for this study.

Disability Service in Aotearoa New Zealand

Children meeting established criteria are defined by the DSS definition of disability and are under 16 years of age. In the most recent Disability Survey in 2023, the disability rate in Aotearoa New Zealand was 10% for children under the age of 15 (Statistics New Zealand, 2025). Furthermore, the disability rate was higher for Māori Children at 14% (Statistics New Zealand, 2025). Statistics New Zealand (2025) grouped functional domains of disability rates for children. Within these groups, 3% of childhood disability was categorised ‘other’, which included intellectual disability and developmental delays, while 3% was categorised ‘cognition’ which included learning and concentration.

In the 2013 Disability Survey prior, findings showed over half of all children with a disability aged 0 to 14 years of age, had more than one type of impairment (Statistics New Zealand, 2014). With increasing prevalence of disability and the new consensus PFD Framework, it is important that research is done in Aotearoa New Zealand.

Caregiver Perspectives

There is significant stress reported by caregivers of children with PFD (Muldoon et al., 2022). However, there is limited literature provided on caregivers' perspectives of their child's feeding skills, and the resulting impact on everyday life for the child. Therefore, caregiver perspectives provide lived insight into the dysfunction of feeding skills in an everyday setting.

Researcher Positionality

I completed my undergraduate degree in South Africa. Thereafter, I worked as a clinician in a range of settings including health, education and private practice, which provided me with a wide array of experiences of feeding/eating and drinking concerns by caregivers. Moving to Aotearoa New Zealand several years ago, I gained more insight working with young people who had disabilities. As a clinician, I am frequently asked by caregivers, "Are there other children with these difficulties?"

One of my siblings requires extra support and adaptations. Through this personal connection, I observed situations with my sibling and others with disability, who encounter participation barriers and the impact thereof. Both my professional and personal life experiences led me to advocating for children and supporting caregivers understanding of the varied journeys surrounding PFD. In exploring feeding skills of children within a CDS, I am hoping to gain information to share with caregivers and the PFD community of Aotearoa New Zealand as a whole.

Study Aims

The aim of this study is to the explore the Feeding Skill Domain of the PFD Framework for children between 1 month to 3 years of age in a CDS, through the lens of SLT and caregiver perspectives. This aim is further defined by the following objectives:

- Describe the feeding skills of children with disabilities from SLT perspectives using clinical notes.
- Investigate the feeding skills of children with disabilities from caregiver perspectives using interviews.
- Integrate the Feeding Skill Domain findings from both perspectives, and determine the most prevalent sub-domains for children in a CDS in the Hutt Valley area of Aotearoa New Zealand between January 2021 and December 2024.

Thesis Structure

This chapter provided an overview of this study's key constructs and aims. Chapter Two provides a detailed review of literature about paediatric feeding and PFD, specifically research within the Feeding Skill Domain for children from various perspectives. Chapter Three outlines the study design and methodology used, including data collection and analysis. Chapter Four presents the participant demographics, as well as the study results, using the Feeding Skill Impairment sub-domains and Feeding Skill Dysfunction categories to integrate SLT and caregiver perspectives. Chapter Five discusses key findings from both perspectives in relation to available literature. Chapter Six outlines considerations taken to ensure trustworthiness as well as the limitations of the study. Additionally, Chapter Six concludes this study and provides the implications for future research and clinical practice.

Chapter Two: Literature Review

Introduction

The aim of this literature review is to outline and discuss the historical definition of feeding difficulties, the PFD Framework and the Feeding Skill Domain thereof. Thereafter, this chapter examines research related to children's feeding difficulties and PFD from professional and caregiver perspectives. While exploring this literature, gaps in PFD-specific research are highlighted. With the recent PFD Framework, and greater awareness of developmental disability (DD), there is a need for more research within this area and specific to Aotearoa New Zealand. The study's research objectives and conclusion complete the chapter.

Search Strategy

A systematic search strategy was used to identify relevant studies. Electronic databases were accessed through Massey University library's Discover Tool (including ERIC and SCOPUS), PubMed and Google Scholar were searched between July 2023 and February 2026. These databases provided a range of coverage between disciplines. Search terms were developed, based on key concepts related to the research question, such as "Paediatric", "Pediatric", "Children", "Children with Developmental Delay", "Children with Disability", "Feeding Difficulties", "Feeding Disorder", "Paediatric Feeding Disorder" and "Pediatric Feeding Disorder". Boolean operators (AND, OR) and truncation were applied to search terms. Filters were also applied, limiting results to peer-reviewed material. Reference lists of relevant studies were reviewed to identify additional studies. Appropriate studies were exported and managed in EndNote (Clarivate, 2023).

History of Feeding Difficulties

Within this section, the historical background of feeding difficulties is discussed. The medical, psychiatric and speech-language therapy viewpoints are explored. This is followed by discussion of the multidisciplinary viewpoint leading to a consensus framework for PFD.

Studies have shown that 25 to 45% of typically developing children have feeding difficulties (Lukens & Silverman, 2014; Manikam & Perman, 2000). These figures indicate the likelihood of these difficulties being experienced in childhood. However, the range of values also reflects the need for a unifying definition of feeding difficulties. Historically, feeding difficulties were viewed by individual medical disciplines separately (Pergeline et al., 2025). There was variability in how single professions defined feeding difficulties, making classifying and treating them holistically challenging. Furthermore, there is no evidence to suggest whether feeding difficulties resolve, and if they do, how long it could take (Taylor & Taylor, 2021).

Medical Viewpoint

Feeding difficulties were initially defined using an organic and non-organic dichotomy (Goday et al., 2019), with many children's difficulties stemming from organic causes. Organic causes were defined by identifiable medical conditions such as reflux, while non-organic causes included behavioural, environmental and parent-child interaction difficulties impacting a child's feeding (Kerzner et al., 2015). Using this dichotomy did not properly define the impact of the feeding difficulties and the children's trajectory of skill progression. Moreover, it minimised challenges resulting from the feeding differences. It assumed once the organic cause was remediated, difficulties no longer persisted (Goday et al., 2019). However, feeding difficulties often persist once organic causes are remediated.

It was believed that non-organic causes were a result of maternal or environmental barriers. However, oral motor dysfunction was found in infants studied by Mathisen et al. (1989). This study reiterated the importance of assessing function, since the infants had functional difficulties, including differences in oral tone and movement, and texture progression, despite being diagnosed from a group characterised by non-organic failure to thrive (Mathisen et al., 1989). In addition, the group of children with non-organic feeding difficulties were found to have several underlying functional factors causing their feeding difficulties (Marshall et al., 2016).

A narrative review completed by Veiga et al. (2023) showed a child's linear growth as a multisystem outcome as opposed to solely a nutritional or biological cause, aligning with the multidomain definition of feeding difficulties. This study concluded children's growth outcomes are reflected by several layers of interacting sub-systems occurring prior to birth and between child, family, community, country and culture. Growth was narrowly defined and not reflective of feeding skills or mealtime behaviours (Veiga et al., 2023). Additionally, most of the studies reviewed were cross-sectional with participant representation from countries including Brazil, Ethiopia, India, Mexico and China.

Despite revisions of worldwide classification systems, such as the World Health Organization's (2019) International Classification of Diseases, 11th Revision (ICD-11), following revisions to the psychiatric viewpoint and the inclusion of Avoidant Restrictive Food Intake Disorder (ARFID), the diagnostic criteria continued to reflect the same historical dichotomy, making it challenging to utilise in clinical practice (Pergeline et al., 2025).

Psychiatric Viewpoint

Feeding difficulties have been viewed from the psychiatric lens with a behavioural or eating-disorder focus. Later diagnosis was viewed to include ARFID. The Diagnostic and

Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR) by the American Psychiatric Association (2000) defined feeding difficulties through a diagnosis of Feeding Disorders of Infancy and Early Childhood. This only partly addressed the relational and multisystemic nature of feeding difficulties (Davies et al., 2006), as it focused on the failure to eat in conjunction with a negative impact on weight gain. Exclusionary criteria included parent-child-centred or environmental-centred causes (Davies et al., 2006), and reduced feeding difficulties to unilateral management (Goday et al., 2019). Therefore, this limits feeding difficulties to existing solely with the child, and with an implied but undefined context (Davies et al., 2006).

In 2013, ARFID was categorised as its own diagnosis which replaced prior definition (American Psychiatric Association, 2013). The American Psychiatric Association (2022) further expanded on the ARFID definition in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition, text-revision (DSM-5-TR). ARFID is defined as an eating or feeding disturbance resulting in inadequate nutrition and eating behaviours, such as food selectivity, poor appetite, or fear/anxiety about eating in the absence of cultural norms, food scarcity, body-image perceptions or concurrent medical or mental conditions (American Psychiatric Association, 2022). However, ARFID diagnostic criteria reduce the role of medical and psychological comorbidities (Milano et al., 2019) and developmental skill-related difficulties associated with paediatric feeding (Estrem et al., 2025; Goday et al., 2019).

Speech-Language Therapy Viewpoint

Speech-Language Therapists (SLTs) have historically viewed feeding difficulties with a dysphagia focus, through the impairment in swallowing or eating/feeding mechanism. Feeding difficulties related to swallowing occur across oral, pharyngeal and oesophageal phases. Sensory and motor differences may be present in the oral and pharyngeal phases of

swallowing. Difficulties in any of these phases are described through clinical characteristics (Groher & Crary, 2021). While SLTs specialised in feeding and eating assess the clinical characteristics, they may not fully capture the functional impact of swallowing difficulties on activities of daily living for the child and others experiencing mealtimes with the child.

Using existing literature, Duncan et al. (2024) aimed to provide condition-based estimates of the incidence and prevalence of dysphagia in Aotearoa New Zealand. Through their limited paediatric-specific estimation, findings indicated that there was a small and constant annual increase in the number of paediatric cases. Medical conditions such as Cerebral Palsy, Craniofacial Disorders, Autism Spectrum Disorder (ASD) and Down Syndrome were recorded within the studies used. Although this study grouped children and working-age adults under 65 years of age, it confirmed that dysphagia in the younger population is present. In addition, it highlighted the research gap between paediatric and adult dysphagia research.

Multidisciplinary Viewpoint

Feeding is a multifaceted process that is impacted by a variety of factors, making it important to apply wide definitions to include a broad range of difficulties (Milano et al., 2019). Feeding difficulties identified by a behavioural perspective may impact their identification, understanding of their complexity and management (Estrem et al., 2016; Uher & Rutter, 2012). The historical unilateral approach to feeding difficulties may have provided single profession advancements. However, it limited the multidisciplinary advancements required to support the complexities of paediatric feeding (Sharp et al., 2022). Gradually, empirical research relevant to the relationship between feeding difficulties and the multiple contributing factors is gaining recognition.

Paediatric Feeding Disorder

As previously discussed, the need for a multidisciplinary cross-domain framework was required. Therefore Goday et al. (2019) proposed the unifying diagnostic PFD Framework formed from the basis of the ICF Framework. There is some overlap between ARFID and PFD in the Psychosocial Domain. Consistent with the ICF, the PFD Framework provides recognition of psychosocial factors across developmental, behavioural, social and environmental influences (Estrem et al., 2025). Additionally, the introduction of the PFD Framework expanded on difficulties not previously accounted for regarding nutritional complications, while incorporating medical and developmental-feeding-skill dysfunction (Sharp et al., 2022). In this section, the ICF principles are outlined, followed by the background of the PFD Framework. The diagnostic criteria, the four domains of the PFD Framework and the Feeding Skill sub-domain are also explored in more detail.

International Classification of Functioning, Disability and Health

The World Health Organization (2018) defines disability as any difficulty encountered in three interconnected areas of: body function/structure, limitations/difficulties executing activities and restrictions to participation. In 2001, the World Health Organization (WHO) developed the ICF, which is applicable in a host of contexts as it was developed and tested based on a wide range of people, including professionals and people with disability (World Health Organization, 2001).

The World Health Organization (2012) merged the ICF and International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) as the original ICF lacked child-specific developmental nuances. This recognised that children develop in the context of their families, with participation changing based on the child's lifespan, as well as developmental changes in participation and the impact of DD on function (Kostanjsek, 2011;

World Health Organization, 2007). A child's disability is shaped by multidimensional concepts, including health, functions, activities, participation, environmental and personal factors (Akin et al., 2021; World Health Organization, 2001). ICF usage across the lifespan improved with the merging of the ICF and ICF-CY (World Health Organization, 2012).

The Medical and Social models of disability form the foundation of the ICF. The Medical model assumes disability as a problem of the individual directly caused by health conditions, and requiring healthcare support. The Social model reframes disability as a socially created problem and a complex collection of conditions created by the social environment, requiring modification from society to allow participation (World Health Organization, 2018). Integration of these two models with recognition of the interrelatedness of biological individual and social perspectives of disability are useful. The ICF intends to classify functioning, as opposed to describing the person with a disability (World Health Organization, 2018). The ICF is the foundation of the diagnostic criteria for the PFD Framework focusing on the functional impact of feeding difficulties (Goday et al., 2019).

Background of Paediatric Feeding Disorder

Due to the historical definitions and diagnostic systems separating organic and non-organic feeding differences, and with limited representation of functional implications thereof, a new definition of paediatric feeding was required (Goday et al., 2019). The PFD Framework recognises feeding as multifaceted, involving complex skills. Use of single professional diagnostic models resulted in children being treated in isolation with contributing factors not addressed, resulting in incomplete treatment plans and inconsistent or delayed referrals between professionals (Goday et al., 2019).

Use of the PFD Framework strengthens advocacy efforts and training opportunities to ensure children with PFD receive access to the range of specialists required in optimal

management of PFD (Goday et al., 2019). Use of this diagnostic term is easier to apply to clinical practice and includes different dimensions of feeding difficulties (Pergeline et al., 2025). Additionally, a unified definition aims to support consistency in research and advancement in healthcare policy (Goday et al., 2019). A standardised functional definition of PFD may lead to better improved recognition, consistency in diagnostic practice and access to service (Goday et al., 2019).

Being a relatively new diagnostic definition, prevalence data using the PFD Framework is limited. In several regions of the United States, the annual prevalence is one in five children under 5 years of age with chronic health conditions receives a diagnosis of PFD (Kovacic et al., 2021). Feeding difficulties are not uncommon, and potentially more common than previously recognised. This prevalence finding from Kovacic et al. (2021) was based on ICD-10 code claims from private health insurance and limited public health insurance. Therefore, these findings may provide limited representation of the United States and the international community.

Diagnostic Criteria of Paediatric Feeding Disorder

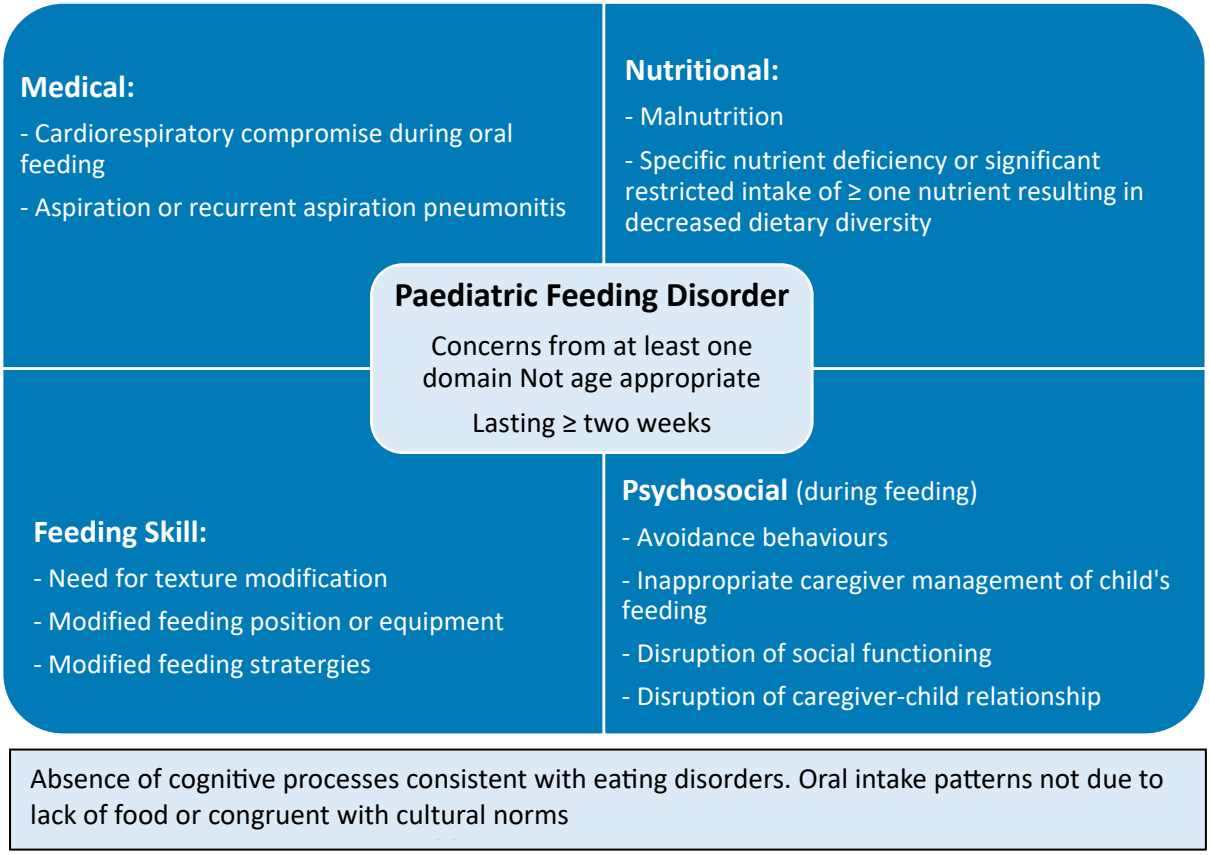
The diagnostic criteria of PFD materialised from available evidence and expert opinion (Goday et al., 2019). PFD is defined as impaired oral intake that is not age appropriate, and is impacted by at least one of the following domains: Medical, Nutritional, Feeding Skill, and/or Psychosocial (Goday et al., 2019) as seen in Figure 1. PFD is classified as acute (>2 weeks) and chronic (≥3 months), and diagnosed in the absence of body-image disturbances, with oral intake that is not appropriate, and the feeding difficulties present daily (Goday et al., 2019).

An important consideration in the diagnostic criteria is the recognition of the domains' relatedness, with one domain potentially impacting another (Pergeline et al.,

2025). Utilising diagnostic criteria, supports the use of clear and consistent terminology to advance clinical practice, research and health policy for this group of children (Cohen & Dilfer, 2022; Goday et al., 2019). At the time of publication of the PFD consensus, Goday et al. (2019) provided supplementary tables with more clarity, defining each of the four domains. These supplementary tables provide examples within an impairment and dysfunction layout for each of the four domains. The final supplementary table provides a description of the interdisciplinary team members and roles.

Figure 1

Diagnostic Criteria of Paediatric Feeding Disorder



Note. Adapted from Table one of Paediatric feeding disorder: Consensus definition and conceptual framework, by Goday et al. (2019). https://doi.org/10.1097/mpg.0000000000002188

PFD was later defined by Dodrill (2021) using the terms 'mild' (difficulties in one or more areas and generally growing sufficiently), 'moderate' (difficulties across several areas

and insufficient growth without nutritional supplementation), and 'severe' (difficulties across all areas and insufficient fluid, energy, and nutritional requirement, requiring enteral tube feeding). The Feeding Skill Domain will be discussed in more detail in the next section.

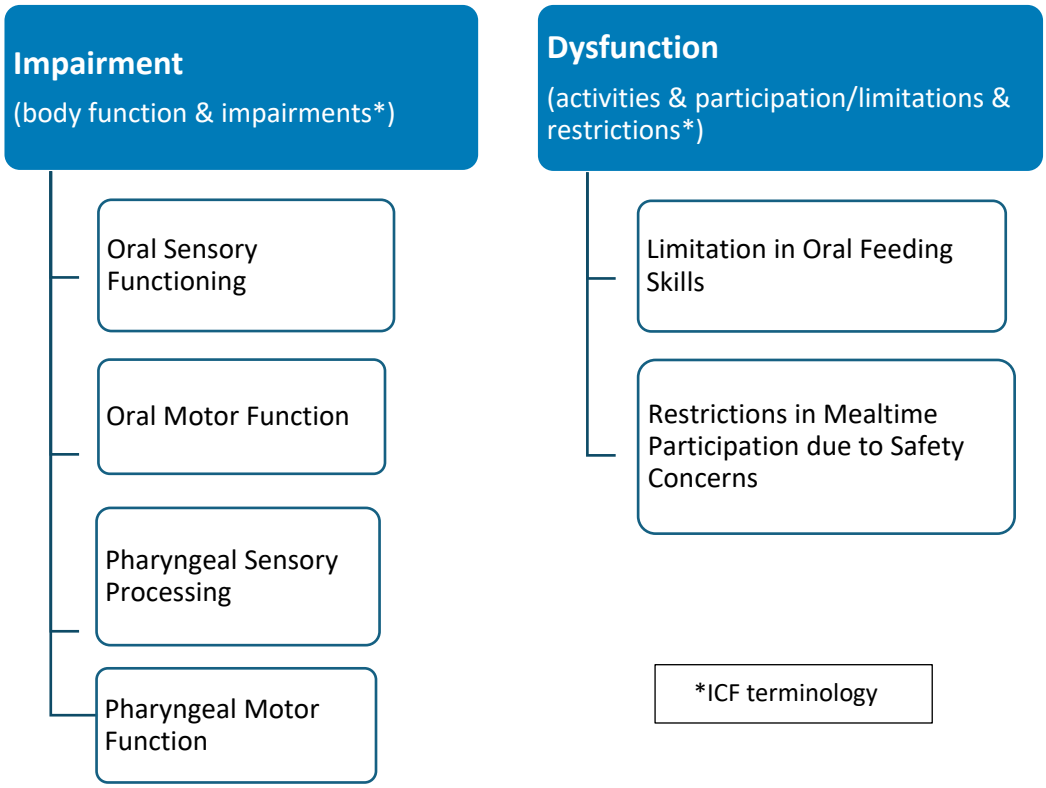
Feeding Skill Domain

The Feeding Skill Domain consists of two main areas: impairment and dysfunction, which are further broken down into sub-domains (see Figure 2). Sub-domains in the feeding skill impairment areas include: oral sensory function, oral motor function, pharyngeal sensory processing and/or pharyngeal motor function. Sub-domains in the Feeding Skill dysfunction areas include: limitations in oral feeding skills and restrictions in mealtime participation due to safety concerns. Further examples of Feeding Skill Domain impairment and dysfunction were provided in the Supplementary Table Three (Appendix A). In children, difficulties with feeding skills impacting function are described to result in unsafe oral feeding, delayed feeding skills and inefficient oral feeding (Goday et al., 2019).

PFD affects multiple areas of child development (Cohen & Dilfer, 2022). Feeding experiences altered by illness, injury or DD may lead to differences in feeding skills (Goday et al., 2019). SLTs assess and treat feeding difficulties considering the impairment and dysfunction. Currently, the PFD Framework is suitable as it includes both children with organic and non-organic aetiologies. Additionally, the Framework considers body function and limitations/restrictions to participation, with recognition of the complexity of feeding skills and the impact on others. The Feeding Skill Domain is the basis for this study.

Figure 2

Feeding Skill Sub-domains of the Paediatric Feeding Disorder Framework



Note. Adapted from Supplementary table three of Paediatric feeding disorder: Consensus definition and conceptual framework, by Goday et al. (2019). https://doi.org/10.1097/mpg.0000000000002188

Research Since the Paediatric Feeding Disorder Framework

Since the unifying PFD diagnosis, there has been some research to understand feeding difficulties using this viewpoint. Currently, PFD-specific research is heavily represented by Western countries, with the majority coming from the United States (48%), United Kingdom (7.7%), and Australia (7.5%) according to Estrem et al. (2022). There is limited published data for the diverse population of Aotearoa New Zealand.

To understand the risks of prolonged feeding difficulties, Taylor and Taylor (2021) completed a retrospective chart review (RCR) with clinical intake summaries for 42 children from Aotearoa New Zealand and Australia. Broad consequences were associated with feeding difficulties for each child. The authors found nutritional deficiencies and growth

problems to both be evident in over half the group of children. In their study, supplementary feeding was high with one third of the children requiring formula due to impacted nutrition and growth and a larger proportion had feeding tubes. Constipation, dental health and sleep disruptions were identified amongst the children. Feeding skill deficits (86% of children), particularly oral motor differences were observed. All caregivers reported impacts on community inclusion and family life, such as participation limitations at school, in eating establishments and at events. Moreover, all caregivers identified stress related to their children's feeding difficulties including concerns about other people's judgement and views on their parenting approach (Taylor & Taylor, 2021).

Utilising quantitative methods through a secondary analysis of cross-sectional nationwide data, Okada et al. (2022) investigated the financial impacts of children with feeding difficulties in the United States. Feeding difficulties were based on caregiver reports from caregivers who completed the National Survey of Children's Health (Okada et al., 2022). By statistically adjusting for some variables, including household income, child's age and the presence of special health care needs, the authors found that children with feeding difficulties were more likely to have financial impacts and utilisation of community resources than children without. Furthermore, of the 1.7% children under 5 years old with identified feeding difficulties, their caregivers were three times more likely to have left their jobs due to their child's health, compared to caregivers of children without feeding difficulties. The findings of this study show that there may be some association between environmental factors and feeding difficulties. However, this study reused data collected for another purpose and data taken at one time point, resulting in the impact of feeding difficulties over time being unclear. Additionally, further restrictions included a limited response rate from caregivers for the survey and an inability to determine formal diagnosis of PFD (Okada et al.,

2022). Therefore, there may be an underestimation, with in fact a higher prevalence of PFD. Financial impacts of children with PFD have not yet been researched in Aotearoa New Zealand.

In the United States, there are barriers reported for comprehensive support for PFD in early intervention (Cohen & Dilfer, 2022). In a clinical focus article reviewing the definition of PFD and Early Intervention, Cohen and Dilfer (2022) reported barriers to support including variation in eligibility guidelines, as many programs do not recognise exclusive feeding-related diagnosis, and provider training standards. The authors suggested a universally approved feeding-specific tool to assess feeding-related concerns, to improve consistency of eligibility standards to influence early access to support.

As a relatively new framework, there is limited research within domains of the PFD Framework (Muldoon et al., 2021) and guidelines in literature are not uniform (Pergeline et al., 2025). A scoping review done by Estrem et al. (2022), identified major gaps in study disciplines. There was under-representation within the Nutrition and Feeding Skill Domains by first-authored researchers (Estrem et al., 2022). Findings by these authors suggest this under-representation was potentially due to authors within the domain being in supporting roles for study authorship, or past availability of research training for professionals working within the two domains. Most literature available on PFD focuses on children under 1 month of age, or between 2 to 9 years of age. This means that children between 1 month and 2 years of age have limited representation, with a significant gap in research at a critical oral-skill period in child development (Estrem et al., 2022).

To explore the Nutritional Domain of the PFD Framework, Drayton et al. (2023) investigated nutrient deficient diets of children with severe food selectivity through RCR. Data collected included anthropometrics, three-day food records and laboratory tests, which

were used to complete a nutrient assessment for each child. Results suggested that despite the children maintaining adequate growth, they had multiple micronutrient deficiencies. Of the 13 children, six were typically developing while the remaining seven had ASD. This indicated that the risk of nutritional differences may be present in all children with PFD, not just those with DD. Remarkably, subtle oral motor differences, potentially unnoticed by family members and healthcare providers was mentioned by Drayton et al. (2023). Additionally, the authors found that none of the children met the daily fibre intake recommendations. These Feeding Skill and Medical Domain components attest to the multifactorial complexity of PFD and the need for an interdisciplinary approach. Generalisability is a consideration for this study's outcomes, given the small sample size and participants recruited, through an intensive inpatient paediatric feeding programme.

Research was completed by Brown et al. (2025) to analyse the nutrient data of children with PFD. Findings of this RCR indicated that 49% of the 89 children analysed were at risk of five or more nutrient-group inadequacies. This study did not use laboratory findings for nutritional analysis, and may not represent a range of ethnicities or less-severe PFD. With the research on the Feeding Skill Domain being under-represented (Estrem et al., 2022) and caregivers playing a vital role in mealtimes, PFD research specific to this domain and caregiver perspectives will be explored in the next section. This is followed by PFD research specific to children with disability and, lastly, PFD research in Aotearoa New Zealand.

Limited Research in the Feeding Skill Domain

As previously discussed, there is limited representation of the Feeding Skill Domain in existing research. However, in the United Kingdom, the lack of formal classification contributes to PFD being frequently underdiagnosed, according to Morris et al. (2026). Using

retrospective data analysed against PFD diagnostic criteria, 51 children with PFD aged 1 to 16 years were identified. All children exhibited feeding skill-based difficulties, while 96% presented with medical conditions, 51% had psychosocial diagnosis and 20% had documented nutritional deficiency. Within the Feeding Skill Domain, all children presented with over- or under sensory responsivity. Sensory-based motor difficulties were present in 92% of the children, and 57% were observed to have oral motor-skill impairments. For this study, oral motor-skill impairments that parents reported included: delayed texture progression, chewing difficulties, food pocketing, gagging and spitting. These parental reports had not been previously diagnosed, indicating a high prevalence of undiagnosed oral motor-skill impairments. The results of this study were drawn from a single specialist centre for children (a United Kingdom-based charity for PFD), who were referred due to severe feeding difficulties, which may impact the generalisability of the findings. Furthermore, comorbid health conditions were identified from prior assessments by a range of external health professionals, resulting in variability in reporting, which may result in diagnostic bias (Morris et al., 2026).

To explore Feeding Skill Dysfunction through the PFD Framework, Galai et al. (2022) conducted a cross-sectional case-control study. Findings of this study indicated that 32% of the 254 children between the ages of 9.5 months and 33 months had feeding skill differences, meeting the criteria for PFD. In this study, medical records from a specialised multidisciplinary feeding-disorder clinic at a tertiary-care hospital in Israel, and a control group (recruited via social media from the general population), were used. The findings revealed that children diagnosed with PFD had a higher risk for lower socioeconomic background, low birth weight and lack of breastfeeding when compared to the control group. Moreover, Galai et al. (2022) found higher numbers of divorced or single parents and

higher total number of siblings in the experimental group, in comparison to the control group. The authors supported use of the PFD term as the study found similar risk factors and the functional symptoms within domains stemming from the feeding difficulties (Galai et al., 2022). A constraint of this study was that the participants used may not reflect a broad paediatric representation, as the study group was accessed at a specialised clinic. Additionally, the control group consisted mainly of caregivers of healthy age, and sex-matched children recruited via a social media platform, which may be less comparable to the study group. To date there is no prevalence data or information on the Feeding Skill Domain for Aotearoa New Zealand.

Caregiver Perspectives on Feeding Difficulties

Feeding involves more than the action of eating, with mealtimes being a social time (Dodrill, 2021) that often include other people and external factors, such as behaviours while eating, interactions with food, and a willingness to sit and eat. In addition, feeding is a considerable contributor to quality of life for children and their families (Estrem et al., 2016). Davies et al. (2006) highlighted that a caregiver and child join feeding environments with predispositions and skills moulded further by each feeding instance, making a triad between caregiver, child and mealtime. Therefore, difficulties with mealtimes can impact the desire and ability to participate in everyday routines, and may increase caregiver stress.

Behaviours associated with mealtimes often fall within the Feeding Skill Dysfunction section of the Supplementary Table Three, and include Limitations in Oral Feeding Skills and Restrictions in Mealtime Participation due to Safety Concerns (Appendix A). A pertinent component of PFD for families are variables such as the impact of PFD on the family, and child-parent quality of life (Estrem et al., 2022). Information on these variables is best received directly from caregivers and family members. Despite this, caregivers' viewpoints

on the definition of feeding difficulties have been missing (Estrem et al., 2016; Estrem et al., 2018). Classification of feeding difficulties should incorporate family perspectives, as caregivers are central in shaping a child's feeding environment multiple times each day (Estrem et al., 2016).

To explore the significance of childhood feeding for caregivers, a study was completed by Wright et al. (2007). During this study, the authors explored caregiver feeding concerns through parent-reported questionnaires of typically developing children aged 30 months, with no illness likely impacting feeding behaviour (*N* = 455). Parents reported their child's feeding was a concern to them (20%) and they had sought professional help (13%). Greatest concerns reported by parents included their child's limited variety of foods (eating a median of 44 foods) and that their child preferred drinks to food (specifically drinking more milk), resulting in difficult mealtime behaviours (Wright et al., 2007). Parents reported their children's most disliked food types were "slimy" (46.7%) and "unfamiliar" (30.5%).

The introduction of the PFD Framework has been beneficial in acknowledging that feeding difficulties in children are complex and multifaceted, and require input from a multidisciplinary team (Goday et al., 2019). The multifactorial aspects involved in feeding difficulties have been reinforced through research. Hasbani et al. (2023) conducted an observational cross-sectional study with mothers and fathers of 1- to 7-year-old children displaying less severe illness in the emergency room of a hospital in Brazil. There was a positive association between children's feeding difficulties, and female children (parents expressing greater concerns about weight and nutrition for their daughters than sons), parents with a feeding difficulty history themselves (parents may limit a child's exposure, and provide reduced role-modelling experiences for non-tolerated foods), and greater frequency of parents' behaviour of offering several food options to their child. This study

was not specific to children with PFD or related diagnoses, but rather caregivers' perceived feeding difficulties. Furthermore, based on the type of study, causality cannot be asserted (Hasbani et al., 2023).

As a result of the limited caregiver viewpoints, Estrem et al. (2016) conducted a secondary analysis of caregiver interview data of children between 6 months and 5 years of age. Twelve parents representing nine families of children with feeding problems described characteristics of feeding difficulty, including problematic feeding behaviours and selective or restrictive eating. Caregivers characterised their children's feeding difficulties as a journey that unfolds with time (Estrem et al., 2016). Some effects of their child's feeding difficulties included adaptations required by parents, feeding tubes and the impact on caregivers and family. While Estrem et al. (2016) provided valuable insight into caregiver perspectives of paediatric feeding difficulties, some limitations include a small sample size and secondary interview data, which may constrain the complexity and over-representation of feeding difficulties based on more severe cases from a specialty feeding clinic.

Estrem et al. (2018) followed these findings with a descriptive study, using semi-structured interviews to describe caregiver perspectives of family management of feeding in a group of children with significant feeding difficulties. In this study, caregivers described their child's life to be organised around their feeding needs, and functionally linked to other conditions, with feeding often described as the most difficult daily challenge (Estrem et al., 2018).

A qualitative study by Simione et al. (2020) explored 30 caregiver perspectives of children's feeding difficulties. The study revealed that 22 caregivers had high levels of stress, as well as challenges balancing the needs of their child and other responsibilities, such as personal, family and work. Challenges in activities of daily living and participation at school,

as well as school outings were reported by 26 caregivers. Caregivers found access to healthcare, support from other caregivers in similar situations and community inclusion as important to achieving outcomes. They identified time, access, knowledge and financial barriers as hindrances. The children discussed in the interviews were between 2 and 5 years of age, and received medical intervention for a diagnosed feeding disorder using ICD-10 codes, which had been defined as impaired oral intake (Simione et al., 2020).

An interpretative phenomenological study of 16 mothers' perspectives of support for their children with feeding difficulties in Australia, was completed by Tan et al. (2022). Using the Bronfenbrenner's Ecological Framework (Bronfenbrenner, 1979), the authors revealed gaps in support at five of the Framework's levels for the mothers, including the compounding lack of support resulting in conflict, marginalisation and feelings of limited understanding and care by others (Tan et al., 2022). Furthermore, mothers in the study reported a reduction in their own participation, and indicated that their children's feeding difficulties affected family routines and community engagement. These findings may support understanding of how environmental factors influence the outcome of a disability. Moreover, this study reiterated the action of eating and drinking being more than an impairment itself, as it presented functional complexities (Tan et al., 2022). A limitation to this study included limited variation in participant ethnicity. Furthermore, mothers' experiences cannot be generalised to other family members (Kyzar et al., 2012), therefore more research from other family members' perspectives would be beneficial.

Recently, Aotearoa New Zealand-based researchers Erlam et al. (2025) applied the Te Whare Tapa Whā Model and provided examples viewed with a PFD lens. The examples included a child's ability to participate in important family practices (spiritual health), behaviours around food/drink (psychological health), the impact on family routines (family

health), and the child's health being intrinsically linked to their PFD (physical health). The authors acknowledged differences in caregivers' priorities, which may differ from clinicians working in a medical model in management of a child with PFD. Caregivers' focus may be more on the psychological or spiritual aspects of health (Erlam et al., 2025). Moreover, caregivers' priorities may be heightened due to stress and anxiety related to their child's chronic PFD.

Disability in Aotearoa New Zealand

Disability is an impairment that has a long term (>6 months) limiting effect (restriction) on a person's ability to conduct day-to-day activities (Statistics New Zealand, 2014). People with disability are part of human diversity (World Health Organization, 2023) and having a disability refers to something outside an individual that impacts on them and their participation (Ministry of Social Development, n.d).

Statistics New Zealand (2014) found that in 2013, 1.1 million people in Aotearoa New Zealand identified themselves in the Disability Survey as having disability, and within the Wellington region there was a 22% disability rate, while children under 15 years of age with a disability, made up 11% of the population. Findings from Statistics New Zealand (2014) indicated that Māori children (15%) had higher than average disability rates compared to other ethnicities (9%), specifically Māori boys (19%) had a higher rate of disability than Māori girls (10%). Additionally, Pacific children faced a higher-than-average disability rate, with Pacific peoples' overall disability rate at 19% according to the findings from Statistics New Zealand (2014). Intellectual disability was the most common disability in children in Aotearoa New Zealand, with a higher likelihood in males (Statistics New Zealand, 2014). The top three disabilities in children were: learning, psychological and speaking, and 48% of children had multiple disabilities (Statistics New Zealand, 2014). The Disability Survey

indicated that children with disabilities were less likely to take part in social activities (Statistics New Zealand, 2014). Similarly, in 2023, 10% of children had a disability while for Māori children, 14% had a disability (Statistics New Zealand, 2025). Within Aotearoa New Zealand, a CDS receives funding to support children at risk of/with a disability meeting the specific criteria.

Paediatric Feeding Disorder and Children with Disabilities

Children with developmental delays may have feeding skills at the level of their development and not their age (Goday et al., 2019). Feeding difficulties are shown to be prevalent between 80 to 90% in developmentally delayed children (Manikam & Perman, 2000; O'Regan Kleinert, 2017). In some states of the United States, one in thirty-seven children under 5 years of age have a diagnosis of PFD (Kovacic et al., 2021). While the annual prevalence increases to one in five children under 5 years of age with other chronic diseases such as respiratory, gastrointestinal, and prematurity related conditions (Kovacic et al., 2021). Feeding is a crucial part of parenthood and seen as a measure of successful child rearing (Davies et al., 2006). For children with DD, support is positively related to family outcomes (Kyzar et al., 2012).

There is minimal research on PFD related to children with disabilities. Akin et al. (2021) conducted a cross-sectional study of children with Organic Academias (a specific rare inherited metabolic disorder). These authors found that most children in the study did not participate in regular activities, such as playing with friends or going to the playground. Moreover, of the 22 children who had developmental difficulties, 64% had feeding difficulties. Interestingly, the group of children with DD and feeding difficulties scored significantly lower on adaptive functioning tests (p = .01*)* compared to children who did not have a Feeding Disorder diagnosis (Akin et al., 2021). These findings suggest differences in

participation for children with disabilities. Moreover, they highlight the need for caregiver and peer support, due to the children's limited ability to function at independent levels when they have developmental and feeding difficulties.

Having a DD may impact a child's feeding skills, as their skills are matched to their developmental level as opposed to their chronological age, leading to a diagnosis of PFD (Rohil et al., 2025). Other components impacting safe and efficient feeding, include difficulties with neurological, motor sensory and behaviour (Rohil et al., 2025). Therefore, Rohil et al. (2025) referred to children with DD being caught in a cycle where their neurological difficulties lead to feeding problems and malnutrition, which further affects their growth, brain development and cognitive function, worsening the disability. In Rohil et al.'s (2025) narrative review of 40 studies, feeding difficulties were observed in 33 to 80% of children with DD. Children with Cerebral Palsy were highly represented in this study, therefore limiting the generalisability to other groups of DD. Feeding difficulties identified from the studies included physical anomalies, swallowing dysfunction, restricted diets and socio-cultural factors, such as lack of caregiver knowledge on feeding, exclusion from society and a lack of community-based services.

Caregiver experiences of feeding their children with disabilities have been explored by Muldoon et al. (2022). This research highlighted the individualised experience faced by caregivers and their children, while also showing the commonality of significant difficulty. Muldoon et al. (2022) conducted an interpretive phenomenological analysis, with eight caregivers of children with DD and PFD providing insight on caregivers' lived experiences when feeding their children in the United States. Caregiver challenges were categorised into three themes: parenting journey (expectations and realisations of caregivers), emotions and repercussions (discord), and winging it (adaptive strategies). Many of the children's

behaviour at mealtimes was described as demanding, overwhelming, and with fixed routines that were set by the child. Additionally, according to these authors, the caregivers were aware of the significance of their child's feeding difficulties and the effects of food choices on the child; for example, on the child's social development (such as not eating at a peer's birthday party). Most participants providing perspectives were mothers, with only one participant being a father. Five children represented had a diagnosis of ASD and/or DD, and co-occurring feeding difficulty, while the remaining three children had a diagnosis of Attention-Deficit/Hyperactivity Disorder or Global Developmental Delay, and co-occurring feeding difficulty. The children were between 3 and 12 years of age. Recruitment via a university and special-education programme, and exclusion criteria including tube reliance and dependent feeding, may have resulted in the population of children with feeding difficulties and disability being under-represented. Interestingly, Muldoon et al. (2022) suggested that some caregivers interviewed had no success in finding appropriate intervention, and therefore potentially different representation would have occurred if there were caregivers in better serviced areas.

PFD paired with disability compounds effects on caregivers and whānau supporting a child with feeding difficulties. Feeding difficulties can impact other areas of development (Clawson et al., 2007; Taylor & Taylor, 2021) including cognitive delays (Sharp et al., 2017). DD is a significant predictor of stress associated with caregiver-child interactions (Silverman et al., 2021). However, there is limited research data, with the caregiver role in caring for such children being under-represented (Estrem et al., 2022). The limited evidence there is has indicated a risk of mental health difficulties and impacts on family relationships (Fernández de Valderrama Rodríguez et al., 2022) and caregivers/families feeling isolated (Estrem et al., 2018).

Paediatric Feeding Disorder in Aotearoa New Zealand

There is no specific data on prevalence of feeding difficulties for children who are typically developing or have a disability in Aotearoa New Zealand with feeding difficulties (Corney et al., 2024). In the 2013 and 2023 Census, the Statistics New Zealand (2014, 2025) Disability Survey did not include feeding difficulties or PFD (Corney et al., 2024). By applying the international prevalence data to Aotearoa New Zealand, Corney et al. (2024) estimated that more than 250,000 children would experience PFD at some stage in childhood, predicting approximately 43,303 to be Māori. To gain caregiver perspectives on financial and psychological impacts of caring for a child with PFD in Aotearoa New Zealand, Corney et al. (2024) completed a cross-sectional study. Results from this study indicated substantial financial strain and limited psychological support for parents (Corney et al., 2024). A limitation to this study was that it mainly represented perspectives of Pākehā (New Zealander of European descent) parents, and therefore cannot be generalised to the wider population of Aotearoa New Zealand (Corney et al., 2024).

In Aotearoa New Zealand, a PFD diagnosis is not yet a funded diagnosable disability, meaning children who do not have additional funded DD do not receive funding or access to support specifically for their feeding difficulties. Utilising the PFD Framework to gather information on children with feeding difficulties and disability in Aotearoa New Zealand could provide pertinent data for the Ministry of Health.

Research Aim

To address gaps in the research discussed in this literature review, this study proposed to explore the Feeding Skill Domain of children at risk of/with DD seen in a CDS context. The age range of these children aimed to be within the identified research gap. SLTs at Hutt Valley CDS support children with feeding difficulties, providing valuable information

regarding feeding skills. Caregivers are at the forefront of children's feeding journeys, providing valuable information on the impact and perspectives from everyday experiences. The research aim for this study was to integrate the Feeding Skill Domain findings of children between 1 month to 3 years of age from SLT and caregiver perspectives, determining the most prevalent sub-domains.

Summary

Previous definitions of feeding difficulties in children were mainly profession-specific and one-sided. The PFD Framework is a consensus framework released in 2019, incorporating four domains. This definition of feeding difficulties is multifactorial and considers the impact on the child, caregivers and whānau. PFD is an under-researched area, though there is some research on PFD relating to specific populations. Research is predominantly in the Medical and Psychosocial Domains. Conversely, there is less research available in the Feeding Skill Domain. Feeding Skill Dysfunction encompasses the functional impact through which feeding difficulties may present. PFD is increasingly recognised in children with other disabilities. Data related to PFD for children with disability within Aotearoa New Zealand is limited. This study aims to provide critical data regarding children with/at risk of disability with feeding-skill differences from two perspectives.

The next chapter discusses the methodology used in this study. It outlines the research design. It provides more detail about the study's participants, and outlines the procedures used for the mixed methods data collection and analysis. Lastly, the ethical considerations are discussed.

Chapter Three: Methodology

Introduction

This chapter outlines the methodological approach employed for this study. First, the mixed-method design and rationale are explained. Then, participant criteria and recruitment are outlined. Following this, the data collection methods and analysis frameworks are described. A discussion of the ethical considerations completes the chapter.

Paradigm Worldview

A worldview is the perspective brought to a study by the researcher, which is important to clarify assumptions, shape procedure formation, and inform of the researcher's stance (Creswell, 2022). Researchers may use multiple worldviews in mixed-methods studies, to allow flexibility that best fits the context of their study (Creswell & Plano Clark, 2018). As a researcher, I drew on the constructivist and pragmatic worldviews. They are complementary and may be used together to provide deep understanding of multiple perspectives in research.

The constructivist paradigm acknowledges meanings in research being varied and multiple, allowing the researcher to look for complexity of views and to rely on participants' views (Creswell & Creswell, 2023). According to Creswell (2018b), a constructivist researcher's intent is to make sense or interpret the meanings of others.

The pragmatic worldview considers there may be several philosophies and realities, allowing for inquiry and understanding through multiple approaches (Creswell, 2018b). I orientated towards a hermeneutic approach within the constructivist paradigm, which focuses on interpreting the contextual meaning of experiences to obtain an open and enduring understanding of underlying meanings and significance of lived experiences (Fairfield, 2025; Porter & Robinson, 2021). Moreover, acknowledging the researcher's

perspectives through reflexivity, the hermeneutic approach fuses the researcher's background and the context of the research question, such as historical and cultural contexts, and how these two contexts interact during interpretation (Fairfield, 2025). In this study, I collected data for both SLT and caregiver views, to provide insights of two key roles in a child's feeding journey and difficulties. Furthermore, I acknowledge my role as a researcher, providing a third perspective in interpreting the SLT and caregiver views.

Research Approach: Mixed Methods

A mixed-methods research design was employed in this study. Quantitative data were collected using retrospective chart reviews (RCR) to explore the frequency with which SLTs reported specific oral feeding skill difficulties. In addition, qualitative data were collected through interviews to gather caregivers' insights regarding the impact of oral feeding skill difficulties, eliciting rich everyday examples related to the same children.

Mixed-methods research is defined as the integration of quantitative and qualitative data collection and analysis (Plano Clark & Ivankova, 2016). This design draws on the combined strengths of the two, which accomplishes more than would be possible by using only one method (Morgan, 2014). Furthermore, use of mixed methods facilitates research that is expansive, creative, inclusive and pluralistic in answering research questions (Johnson & Onwuegbuzie, 2004). Use of some qualitative research provides humanisation in healthcare settings, providing a moral dimension, sensitisation of the topic and advocacy for people affected by the system (Morse, 2012).

Mixed-methods designs can be useful in translating research into practice for SLTs while capturing elements of PFD holistically and systematically (Thompson & Wanqing, 2020). There are currently few mixed-methods studies within SLT research areas, such as PFD (Thompson & Wanqing, 2020), and so this study added to the limited research base. For

this study, RCR intended to provide quantitative data from SLTs in which the caregiver voice could be woven into, providing functional lived examples to describe the children's oral feeding-skill difficulties.

Study Design: Convergent Approach

A convergent design was adopted for this study as the design is efficient (Thompson & Wanqing, 2020), and provides a more comprehensive understanding of the research question (Creswell & Creswell, 2023). In convergent studies, the researcher integrates data sets concurrently to provide merged findings (Creswell & Creswell, 2023). This study's design merged the two data sets, RCR and interviews.

RCR are widely used in healthcare-based disciplines (Vassar & Holzmann, 2013). Using a data collection schedule based on the Feeding Skill Domain of the PFD Framework, specific SLT notes were obtained, which provided SLT perspectives of the children. Interviews were conducted with caregivers using a semi-structured format also based on the Feeding Skill Domain. Thereafter, results from both perspectives were integrated. The study design evolved, following feedback from two ethics committees, which is discussed later in the chapter. This evolution led to each phase's data collection being done separately, with findings merged to enhance the description of oral feeding-skill difficulties thereafter.

Participants

This study obtained RCR and interview data for children who were aged between approximately 1 month to 3 years of age from Hutt Valley CDS. This age range is less researched within the Feeding Skill Domain (Estrem et al., 2022). Caregivers were invited to participate in one or both parts of the study.

Participant Criteria

Inclusion criteria for review of RCR consisted of children between approximately 1 month to 3 years of age, who received Hutt Valley CDS SLT input for feeding difficulties. Exclusion criteria included:

- Children with no email address listed in their contact details on their National Health Index (NHI).
- Children no longer living within the Hutt Valley catchment area.
- Children with isolated personal/medical conditions that did not meet DSS criteria (Whaikaha, 2012).
- Children who were seen once and/or seen only for an instrumental assessment with no clinical assessment done by a Hutt Valley SLT, for example a child coming from another funded service provider.

Caregivers of eligible children were invited for an interview. Interview criteria included caregivers over 16 years of age, who provide at least 50% part-time care to the child. Individuals in other caregiving roles for the child, including teachers or support workers, were excluded.

Participant Recruitment

Purposeful sampling was used to recruit participants. This involves the selection of carefully chosen sources for the collection of detailed information (Morgan, 2014), which are targeted specifically based on this study's aims with expectation on participants to provide unique and rich information (Etikan et al., 2015).

Recruitment began using children's NHIs on the electronic health database taken from Hutt Hospital CDS service lists, of those seen by the SLTs. Using this list of NHIs, a locality representative selected children meeting the inclusion criteria for the period January

2021 to December 2023. This enabled them to accurately identify eligible children while maintaining confidentiality. Later, an amendment request from Massey University Human Ethics Committee (MUHEC) was approved to increase the timeframe to December 2024. Due to the number of NHIs that met criteria and consideration of the possibility of many interested caregivers, an online random sequence generator was used to numerically order the NHIs of which the caregivers were emailed in five batches.

Through this rigorous process, a total of 187 potential children's NHIs were obtained. Initially, 155 potential children's NHIs (between January 2021 and December 2023) were obtained; 54 met the study criteria. Additionally, a total of 31 potential children's NHIs were obtained from the subsequent cohort (between January 2024 and December 2024); 15 of whom met the criteria. Of the 69 potential children whose caregivers were emailed, 10 provided consent to participate in both phases. One participant made no further contact during the researcher's attempts to arrange an interview. Therefore, the total number of participants for this study, with consent provided and data collected, were 10 children's SLT notes and 9 caregiver interviews (Appendix B). RCR were taken from the notes of four CDS SLTs working at Hutt Valley at the time, which made up a total of 2.0 full-time equivalent. All caregivers interviewed were mothers of the children.

The caregiver's contact details were obtained via the child's NHI primary contact information. They were approached by email invitation (Appendix C) from the researcher, using a specific research email address and sign-off from Hutt Valley Hospital. An information sheet (Appendix D) outlining the project and a consent form (Appendix E) were attached to the email invitation. An email reminder was sent approximately five days thereafter. Caregivers were invited to consent to an interview additional to the SLT notes review; they were unable to consent to an interview exclusively. An Excel spreadsheet kept

track of all information, including NHI number, contact information, email administration and consent.

Participants made voluntary contact with the researcher, and provided signed consent. After a limited response rate, an amendment was approved by MUHEC to include a video in the invitation, to captivate the audience and talk about the study, while attempting to build rapport. All caregivers who consented to being interviewed met the study's inclusion criteria.

Retrospective Chat Reviews

This section outlines the rationale for the use of clinical notes to provide the SLT perspective. The RCR data collection schedule, procedure and analysis are described.

Retrospective Chart Review Methodology

RCR uses pre-recorded, patient centred data (Worster & Haines, 2004). RCR methodology is frequently used in healthcare based disciplines to gather valuable information to direct future studies (Vassar & Holzmann, 2013). This type of data collection was chosen to examine the retrospective clinical notes written by SLTs. SLTs provide feeding support in the disability services funded by the Ministry of Health in Aotearoa New Zealand.

Speech-Language Therapists in Child Development Service

A CDS is a multidisciplinary team of Allied Health Professionals providing community-based support through assessment and management for children under 16 years of age, 'at risk of' or with a disability as specified by the DSS (Whaikaha, 2012). SLTs working within this service are specialised in child development, particularly children's communication (speech, language and social communication), and feeding/eating/drinking. Other professionals working at a CDS may include Physiotherapists and Occupational Therapists, either of which may have specialised in neurodevelopment in under 2-year-olds (referred to as Visiting

Neurodevelopmental Therapists), Dietitians, Developmental Coordinators, Social workers and Developmental Paediatricians.

There is variation in the professionals who work in a CDS across Aotearoa New Zealand. Additionally, CDS SLT resource and service specifications may vary. At Health New Zealand – Te Whatu Ora, Hutt Hospital, the CDS SLTs role includes communication assessments (as part of developmental assessments) and supporting feeding, eating and drinking through supporting oral feeding-skill development and optimising safety by decreasing the risk of choking and airway violation. The children with risk of or with confirmed airway violation, are typically on the SLTs' caseloads for longer periods of time (compared to developmental assessments), and may require more intense, frequent input.

Retrospective Chart Review Design

Initially, the RCR data schedule consisted of a table containing sections for the study's child-specific timeline to reflect 'first note', 'final note', and instrumental assessments. Each of these sections was broad, and included the primary mode of feeding at the time, clinical findings, feeding milestones and any standardised feeding assessments done, such as the Pediatric Eating Assessment Tool (Thoyre et al., 2018). Additionally, there were sections for demographics and background information that included caregiver characteristics, such as age, employment status and education level, and social/environmental characteristics, such as number of children in household, childcare hours, respite hours per week, supports accessed and if living in a rental house, Kāinga Ora house or caregiver owned house.

Feedback from MUHEC led to further refinement of this study, to focus on the PFD Feeding Skill Domain. Additionally, SLT colleague feedback, reflection and further discussion with supervisors provided valuable feedback leading to revision of the data schedule.

Two SLT colleagues were emailed the data collection schedule and asked to provide feedback, particularly regarding usability based on the electronic medical-notes system. A reminder was sent to both SLTs thereafter. One of the SLTs responded with feedback. This SLT colleague provided feedback on potential difficulties obtaining data about caregiver characteristics, and social and environmental factors, which may not be stated in the SLT notes. The SLT colleague enquired about the importance of the order of the SLT notes on feeding skills obtained, and its position on the data-collection schedule.

Upon reflection, feedback from MUHEC and SLT colleague, and further discussion with the researcher's supervisor, it was decided to focus more specifically on the Feeding Skill Domain. Therefore, caregiver characteristics, the social and environmental factors, feeding milestones and standardised feeding assessments were removed from the data-collection schedule.

For this study, along with previously mentioned children's demographic information and some variables relating to the Feeding Skill Impairment and Dysfunction centralised to the PFD Framework were documented. The two SLT notes entries acquired for each child were based on their timeline: at the beginning (note closest to January 2021 selected) and final SLT note (note closest to December 2024 selected). Additionally, SLT notes on any instrumental assessments during the timeframe, such as Videofluoroscopic Study of Swallowing (VFSS) and Flexible Endoscopic Evaluation of Swallowing (FEES) were included. The final data-collection schedule can be viewed in Appendix F.

Defining variables by turning them into measurable elements ensures clarity and consistency in research designs (Vassar & Holzmann, 2013). This was done using the PFD Framework to measure elements of oral feeding skills. Therefore, the schedule was revised by separating the oral and pharyngeal sections into oral sensory, oral motor, pharyngeal

sensory, pharyngeal motor, limitations and restrictions. This was done for consistency and later ease of analysis of the SLT notes. Distinction between liquids and solids was removed to align with the PFD Framework and the interview schedule. A pilot was completed to trial the final data-collection schedule.

Retrospective Chart Review Procedure

The researcher obtained locality approval to access the electronic medical health records specific to this study and accessed the child's SLT notes after receiving written consent from the child's caregiver. Ensuring a standardised abstraction form, electronic notes, were used for all RCR (Vassar & Holzmann, 2013). The researcher was trained in using the electronic notes system based on their role as a clinician.

SLT notes reviewed for this study were compiled into a data-collection schedule for each child. To ensure consistent procedure was used for all RCR, a written step-by-step process (Appendix G) was compiled and used by the researcher for each child's RCR data collection. The process included sectioned prompts for the researcher, as follows:

1. Prior to reviewing notes,
2. During notes review,
3. Using the data collection schedule and,
4. After reviewing the notes.

Information documented by the SLT in the specific note was used and no deductions made. Only information and clinical assessment provided by the SLT was documented, therefore documented information by caregivers reported by the SLT was not used in the data collection. This was due to the caregiver perspectives being represented in the interview phase of this study and ensuring all information in this phase represented only SLT perspectives.

A data coding manual was created after capturing the first two participants' information into the Excel spreadsheet, and after finding variations in SLT terminology/note-writing styles, impacting where within the sub-domains to place some of the findings. To ensure information was not over-represented, information from the SLT notes was coded into one of the Feeding Skill sub-domains provided in the Supplementary Table Three (Appendix A). The coded data was stored in a data coding manual (Appendix H), which was organised under the PFD Feeding Skill sub-domains and updated whenever additional SLT notes were found.

One difficulty during data collection included mapping SLT notes onto the Feeding Skill sub-domains, particularly the Oral Motor Function sub-domain. This was a result of SLT terminology or wording that could fit within several sub-domains. For example, after further discussion with the researcher's supervisor, "shallow latch" was determined to be a range of motion difficulty as opposed to a control difficulty. Moreover, information provided in the SLT notes was based on their clinical assessment during that session, meaning if the session had specific goals or focus, other areas of feeding may have not been documented. Additionally, the timepoints used for SLT notes may not reflect the child's feeding skills in detail.

Another difficulty during this phase was that some of the information in the SLT notes was difficult to map onto the Feeding Skill Domain as the researcher felt they could be placed in several areas within the sub-domains. Therefore, the researcher kept a record of enquiries and initiated a review by their supervisor if unsure of any of the raw data provided. Most of these enquiries were discussed via email. For challenging enquiries that could not be concluded via email discussion, the raw data was revisited with the supervisor at one in-person meeting and one Zoom meeting to reach a decision, and added to the data coding

manual for future data capture. Consistent with RCR, the researcher provided detailed coding situations, while regularly updating the procedure manual if unforeseen coding decisions arose (Vassar & Holzmann, 2013). Examples of enquiries from the researcher to their supervisor included documentation of pocketing of food, and the coding thereof being oral sensory and oral motor, as well as restrictions of mealtimes resulting in adverse events, such as gulping and sighing after a swallow.

Retrospective Chart Review Data Analysis

Each child's RCR schedule containing Feeding Skill sub-domain information for two sets of notes and VFSS/FEES (if applicable) was compiled into a Word document. Thereafter, each child's data-collection schedule information was transferred onto an Excel spreadsheet to compile and store the collective data obtained. Excel was used to explore frequency distributions, to understand which areas within Feeding Skill sub-domains were reported by SLTs to be present within this group of children. After broadening Feeding Skill Dysfunction categories for caregiver reports, SLT information obtained on Feeding Skill Dysfunction within the sub-domains was expanded into the three categories of unsafe oral feeding, delayed feeding skills and inefficient oral feeding.

Interviews

In this section, the rationale for using interviews to gain caregiver perspectives is outlined. The interview guide and procedure, and the data analysis process are discussed.

Interview Methodology

Using guidelines for semi-structured interviews by Galletta (2016), the schedule followed the child's feeding journey within a specific timeframe as the central story, giving interviewees direction and depth, while ensuring a standardised approach. Cultural responsiveness should be focalised in the methods to sustain equity of participants (Pasque

& Alexander, 2022). One-on-one semi-structured interviews are used when a researcher knows enough on the topic to form questions but cannot anticipate responses (Morse, 2012).

Interview Design

The interview process was documented to provide a consistent approach for the researcher to carry out interviews with caregivers (Appendix I). This had steps relating to interview preparation, process and completion. During the interview, an interview schedule ensured the interview was conducted in a standard way. Initially the interview schedule consisted of broad, open-ended questions that prompted caregivers to explain their child's feeding difficulties at that timepoint. It contained prompting questions for the researcher to use as required.

A pilot interview was completed. Feedback from the interviewee included the importance of referencing the specific timeline of enquiry, providing a detailed description of PFD and using visuals to guide the interview. Feedback was also provided to join all liquid and solid consistencies, as this may be difficult to recall retrospectively. Additional feedback was requested from two SLT colleagues, particularly regarding usability. Following a reminder to both SLTs, one responded with feedback on the process, which included considering location, minimising distractions and avoiding putting a limit to the duration of the interview. For the interview schedule, the SLT suggested using open-ended questions.

Considering these experiences, and through further reflection and discussion with the supervisors, the interview schedule and procedure documents were revised accordingly. The structure of the interview was adapted from the Supplementary Table Three (Appendix A), to ensure that both phases of data collection were aligned. This resulted in the final interview schedule consisting of three broad, overarching questions about Feeding Skill

Impairment and Dysfunction (Appendix J). This use of open-ended questions and prompts only as required, leads to greater specificity, clarification and exploration of ideas (Iyer et al., 2024).

Interview Procedure

Following consent, the researcher arranged an appointment directly with the caregiver via phone or email. Phone numbers were provided directly by the caregiver or from the child's NHI information after consent to participate was provided by the caregiver. Caregivers chose the mode (in person, phone or video), location, day and time of the interview to suit them. Caregiver availability was a challenge to setting up interviews and was arranged while children were at an education provider, or being minded by another adult. An SMS reminder was sent to each caregiver the day before the interview, to confirm suitability. Three of the caregivers postponed interviews due to childcare changes or illness. The researcher completed eight interviews in the caregivers' homes, and one interview in a café, as per their choice. Considering Massey University Safety Guidelines, the researcher informed a supervisor upon start and conclusion of an interview. An interview timetable with the researcher's whereabouts and times was available to supervisors as required.

The interviews focused on enquiries to caregivers of their child's feeding skills in the past (from January 2021 to December 2024). Interviews were conducted using a conversational style interview schedule (Iyer et al., 2024). Although the PFD Framework was used to structure the interview, there was emphasis on allowing fluidity and interviewee perspectives. The researcher's key role being an external observer, providing a comfortable environment to discuss the child's feeding and build trust (Mohammed et al., 2024).

The researcher provided a warm beverage of the interviewee's choice. At the interview, the researcher initiated the finalised interview schedule (Appendix J). This was

framed around the Hui Process (Lacey et al., 2011), and included appropriate greetings and whanaungatanga (informal conversation), explanation of the interview process, research aims and caregiver rights. Thereafter, the researcher confirmed the caregiver's consent to continue, and to take an audio recording. The researcher then started the digital recording. The interview duration from time of recording ranged from 20 to 46 minutes, with an average of 31 minutes.

During the interview, the researcher provided a visual of the child's feeding timeline being discussed. Additionally, a visual of the phases of swallowing and a table of examples for each phase were provided (Appendix J). Conversation was led by caregivers with prompts by the researcher if required. The researcher was the sole interviewer, which ensured consistency in administration of interview schedule, increasing dependability of studies (Mohammed et al., 2024).

At the end of the interview, the researcher clarified any points made that required elaboration or reflection, and closed the interview, whereby the digital recording was stopped. Thereafter, the researcher followed up with the caregiver to confirm if the discussion elicited any distress not picked up during the interview, so that a list of free and low-cost counselling services could be shared, which was not required. Lastly, a koha (informal gift) in the form of a grocery voucher was provided to the caregiver, as approved by MUHEC.

A professional transcription service was used for the interviews, and transcribers signed a confidentiality agreement to ensure participant confidentiality (Appendix K). Once the transcripts were returned as Word documents, they were reviewed and anonymised by the researcher. During review, the researcher corrected feeding terms that were missed out or misinterpreted by the transcriber. Thereafter, the transcripts were emailed by the

researcher to the caregiver, who had 14 days to edit or request changes. For the caregiver who had difficulties with reading, the researcher offered to adapt the script. No changes were made by caregivers to their transcripts.

Interview Data Analysis

Data analysis began upon completion of transcript finalisation. A data-collection schedule similar to the RCR phase, using the Feeding Skill sub-domains from the PFD Framework was considered. However, the final decision was to use NVIVO QSR International Pty Ltd (2025) to code transcripts. Codes allocate meaning to data for organising and conceptualising it, and may be adopted from other studies (Walliman, 2022). Codes created were initially open, broad and unspecific to ensure the caregiver voice came through. This resulted in many codes, some of which were outside of the Feeding Skill Domain, such as the impact of caregivers. Subsequently, codes that were not specific to the Feeding Skill Domain were removed and the relevant codes were organised into the Feeding Skill sub-domains, and broken down into oral sensory, oral motor, pharyngeal sensory, limitations in oral feeding, and restrictions in mealtime participation due to safety concerns, providing resemblance to the RCR data analysis used. This iterative process resulted in codes being refined, which is similar to suggestions of this occurring in the data-collection process by Walliman (2022).

To ensure caregivers' perspectives were coded similarly, previous code examples were reviewed while coding each transcript. Additionally, the RCR procedure manual was viewed alongside this to ensure consistency of coding sub-domain placement. This proved helpful, particularly for the oral motor sub-domain, in which caregivers gave examples of functional impact, but not of what the impairment was.

As previously mentioned, reports from caregivers about the functional impacts of their children's feeding difficulties, were initially placed into the limitations in oral feeding and restrictions in mealtime participation due to safety concerns sub-domains (Appendix A). The researcher documented enquiries about these, and email correspondence occurred with their supervisor. In some instances, excerpts from the interview were provided to the supervisor to give context. Some enquiries were less clear, therefore, following further discussion via Zoom meeting between the researcher and supervisors, it was decided that making conclusions on the caregiver's behalf using corresponding SLT information would compromise the integrity of the caregiver perspective. Consequently, codes previously completed and the enquiries within Limitations in Oral Feeding and Restrictions in Mealtime Participation due to Safety Concerns sub-domains were expanded to the three broader categories of Feeding Skill Dysfunction: unsafe oral feeding, delayed feeding skills and inefficient oral feeding (Goday et al., 2019). These categories encompassed activities and participation as well as Limitations in Oral Feeding and Restrictions in Mealtime Participation due to Safety Concerns, without making inferences.

Data Integration

Initially it was hoped to use the joint-display approach by Creswell (2022), whereby data from each method was represented and analysed to explore connections between both sources. However, due to recruitment and timing of interviews, RCR was analysed prior to interviews. Using the Feeding Skill Domain, integration occurred in a Word document whereby RCR data was described and interview data mapped onto this. Methodological triangulation by integrating SLT notes and caregiver interviews enhanced trustworthiness of the study through the process of integrating and comparing data sources (Creswell, 2018b). This process assisted comprehensive understanding of the children, as the SLT

provided a clinical perspective while caregivers described the functional impact of these differences. Additionally, the researcher's clinical experience allowed them to better understand the context and perspectives of the SLTs and caregivers. Use of the Feeding Skill sub-domains for SLT notes and software to code interviews enhanced dependability, while reflection feedback and supervisor support optimised confirmability which will be discussed in a later chapter; both of which contributed to comprehensive understanding of the research aims.

Ethical Considerations

In this section, general considerations, approval process, consent and confidentiality are addressed. Prior to participant recruitment, cultural support was sought from a Kaiakiaki Māori who was the Massey University SLT programme advisor, to mitigate generational trauma and re-traumatisation of Māori within healthcare-research themes. To prevent these, processes in this study included, voluntary participation, inclusion of the Hui Process in the interview, and the provision of counselling services details. Additionally, upon advice from the Kaiakiaki Māori and a locality cultural advisor in considering sensitive information, the researcher purposefully targeted retrospective information.

Approval Process

The study adopted Massey University's Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2017). In addition, Te Ara Tika guidelines for Māori (Hudson et al., 2010) and the Te Tiriti o Waitangi principles were considered.

The Health and Disability Ethics Committee (HDEC) screening was completed (Appendix L), with exemption given, meaning the study did not require HDEC full application. University and locality ethics approval were required. A full application was

submitted to MUHEC on 24 March 2024. MUHEC initially deferred the application on 19 April 2024 and provided feedback for consideration. Prior to changes being made, the researcher liaised with various people from Massey University and Hutt Hospital for clarification of information around data storage and informed consent for both methods. The researcher resubmitted on 22 May 2024, with approval obtained on 18 September 2024 (Appendix M).

The researcher completed an e-learning course on ICH Good Clinical Practice and attended an in-person locality researchers training prior to submitting to the locality. Following this and MUHEC ethics approval, an information letter, supporting documents and a copy of the MUHEC application were submitted to Health New Zealand – Te Whatu Ora, Capital, Coast and Hutt Valley Interim Research Advisory Group – Māori (IRAG-M), which endorsed the project on 14 October 2024 (Appendix N).

After approval by MUHEC and IRAG-M, the researcher applied for ethics approval from Health New Zealand – Te Whatu Ora, Capital, Coast and Hutt Valley Research Committee, which approved the study on 11 November 2024 (Appendix O).

This comprehensive approach to obtaining the necessary ethical approvals safeguarded participants and ensured cultural sensitivity. Following the works of Ladson-Billings (2014), culturally responsive research includes competence (including the ability to appreciate and celebrate while gaining knowledge), and sociopolitical consciousness (including using knowledge to identify and analyse problems). Culturally responsive research is a vital and iterative process (Pasque & Alexander, 2022), and PFD is impacted by culture.

Amendments were submitted for a change in supervisor, changes to timeframe to invite more participants, and the inclusion of a video explaining the study in the email invitation.

Informed Consent

To ensure autonomy and informed consent, caregivers were required to provide signed consent to review their child's SLT notes and interview, or to review their child's notes exclusively. During interviews, participants were reminded that their information remained confidential and that any shared data was anonymised, how expressed information was treated, and their right to withdraw at any point. Data collection and analysis were done in a culturally sensitive manner, with consideration of principles of Te Tiriti o Waitangi. The research received support through a cultural advisor from Massey University and hospital locality. A one-page summary of study findings was sent to participants upon completion of the study unless they requested not to receive this.

Confidentiality

Personal identifiers should be isolated from the research data set, because preventing recognition of individuals is an important consideration when using RCR (Worster & Haines, 2004). Therefore, confidentiality was of importance and consideration, and identifiable data was anonymised by the researcher, with pseudonyms during data collection of SLT notes and interview transcriptions.

The researcher and her supervisors had access to the data. Consent forms and data collection followed Massey University data-storage compliance and Health New Zealand health-data compliance. Consent forms were kept separately from data. Soft copies were stored on the researcher's password-protected Massey One Drive, on the researcher's personal password-protected laptop. The researcher will destroy all data after 5 years (from time of thesis submission).

Summary

This chapter explained and discussed the theoretical framework, methodology and methods of this study. The study's mixed methods convergent design, emphasised strengths of both quantitative and qualitative methods to merge findings, enhancing the perspectives of children's oral feeding-skills. Caregivers were recruited via email and chose if their child's SLT notes were to be accessed and/or if the caregiver wanted to participate in an interview. Detailed explanations of both phases of RCR and interview data collection and analysis were provided. Ethical considerations including the approval process by MUHEC and locality, and consent and confidentiality were outlined. The results of the study are discussed in the next chapter.

Chapter Four: Results

Introduction

This chapter presents the participant demographics and the integrated SLT and caregiver perspectives from the Feeding Skill Domain of the PFD Framework, showing prevalent sub-domains with this cohort of children. Data about the children's feeding skills were obtained from SLT notes and semi-structured interviews with caregivers. Firstly, the information in the SLT notes was mapped to the Feeding Skill sub-domains and categories. Thereafter, information obtained from caregiver interviews was grouped within the same sub-domains and categories. The collective information was integrated to describe the children's feeding skills. Results relating to the sub-domains of Feeding Skill Impairment will be outlined first, followed by the results relating to Feeding Skill Dysfunction.

Participant Demographics

The demographic information of the ten children's records reviewed in this study is provided in Table 1. Four children (40%) were female. NHI ethnicity data can list multiple ethnicities per child, and, in this study, two children identified as Māori (20%), one child as Fijian (10%), and nine children (90%) were Pākehā (New Zealander of European descent).

The New Zealand Index of Deprivation (NZDep) measures the socioeconomic deprivation of people in each small area, based on Census variables (Environmental Health Intelligence New Zealand, n.d.). Higher levels of socioeconomic deprivation are associated with higher risk of psycho-social health problems, according to Environmental Health Intelligence New Zealand (n.d.). There are low (1-3), medium (4-7) and high (8-10) deprivation indices. In this study, four children (40%) resided in areas classified as low deprivation, five (50%) in areas of medium deprivation and one (10%) in an area of high deprivation.

The children's diagnosed health conditions were variable and included allergies, gastrointestinal, neurological, prematurity, respiratory and muscle-tone differences. The ages of children born premature, were adjusted to their Corrected Gestational Age (CGA). Children's ages ranged from less than 1 month to 50 months, with a mean age of 14 months at the initial recorded SLT note. At the last recorded SLT note, children's ages ranged from 5 months to 53 months of age, with a mean age of 26 months.

Feeding Skill Impairment

Impairment is defined by the ICF as differences in body function and structure (World Health Organization, 2001). Feeding Skill Impairment is defined by the categories of oral sensory Function, Oral Motor Function, Pharyngeal Sensory Processing and Pharyngeal Motor Function, which correspond to the impairment section of the Feeding Skill Domain (Appendix A). To present this study's findings, the examples provided within the Supplementary Table Three are used as categories to present the findings (Table 2).

Oral Sensory Function

Under/over responsive to oral sensory aspects of liquids and food textures was noted for seven children by SLTs. Caregivers mentioned children's response to oral sensory aspects. Responses inhibiting acceptance or tolerance, were mentioned by both SLTs and caregivers including taste, texture, and temperature preference and/or sensitivity. Examples of these are discussed in this section.

Table 1

Children's Demographic Information

Participant	Sex	Ethnicity	Deprivation Index	Diagnosed Health Conditions	Age at SLT Note: Initial	Age at SLT Note: Final
1	F	NZ European	Medium	Epilepsy, reflux, constipation, peanut allergy	33 months	50 months
2	M	NZ European	Low	Noisy breathing and intermittent work of breathing, low muscle tone	24 months	53 months
3	M	NZ European	Medium	Very premature[a] and associated conditions	8.8 months (38 weeks)[c]	28 months[c]
4	F	NZ European	Low	Extremely premature[a] and associated conditions	5 months[c]	19 months[c]
5	M	NZ European	Medium	Neurodegenerative condition[b] and associated conditions, Global Developmental Delay	28 months	50 months
6	F	Māori, NZ European, European other	Medium	Late prematurity[a] and associated conditions, Allergic proctocolitis, Brief Resolved Unexplained Event, cardiac murmur	8 months[c]	9 months[c]
7	F	NZ European	Medium	Intrauterine Growth Restriction	15 days	10 months
8	M	Fijian, Indian, NZ European	Low	Truncal hypotonia, suboptimal weight gain, cow's milk protein intolerance, Gastro-oesophageal Reflux/Suspected Sandifer syndrome	14 months	15 months

Participant	Sex	Ethnicity	Deprivation Index	Diagnosed Health Conditions	Age at SLT Note: Initial	Age at SLT Note: Final
9	M	Māori, Asian	High	Extremely premature[a] and associated conditions, genetic condition (bone), adrenal insufficiency	26 days[c]	5 months[c]
10	M	NZ European	Low	Dairy and egg allergies, faltering growth, eczema, Nasolacrimal duct obstruction	18 months	22 months

[a] Prematurity and associated conditions: differences with weight, respiratory (including ventilation and Chronic lung disease), gastrointestinal differences (including reflux), feeding challenges, Intraventricular haemorrhage, and hernias.

[b] Neurodegenerative condition and associated conditions: Bulbar dysfunction, and neurological condition including Evolving Spastic Quadriplegia, and non-neurological conditions including gum hypertrophy

[c] Corrected Gestational Age (age adjusted for prematurity)

Table 2

Feeding Skill Impairment Sub-domains and Categories

Feeding Skill Impairment (Body functions and impairments)	
Sub-domain	**Category**
Oral Sensory Function	• Response to taste • Response to texture • Response to temperature • Response to other sensory aspects
Oral Motor Function	• Reduced strength • Range of motion • Manipulation • Coordination • Timing • Control • Oral transit differences
Pharyngeal Sensory Processing	• Response to bolus during pharyngeal transit • Residue remaining post-swallow
Pharyngeal Motor Function	• Inhibiting efficient swallowing • Inhibiting airway protection

Note. Adapted from Supplementary Table 3 of Paediatric feeding disorder: Consensus definition and conceptual framework, by Goday et al. (2019). https://doi.org/10.1097/mpg.0000000000002188

Oral Sensory Function Category: Response to Taste. SLTs reported some children opted for sweeter flavours. Some caregivers shared that their children had preferences/sensitivities for sweeter, savoury or spicy flavours.

Caregiver 9 retold that her child only enjoyed a certain brand of banana custard by showing interest when eating it and rejecting all other brands. Reportedly, Child 9 indicated discontent whereby he would “screw his face up, sometimes poke a bit of his tongue out” for all other purees offered.

Caregiver 1 recalled that her child didn't like spicy flavours although she required foods with some flavours, including stronger flavour, or seasoning in her food in order to eat it. Furthermore, her child could identify subtle changes in flavour:

> She doesn't like spicy textures [flavours], but she has to have some flavour or something noticeable to it for her to actually eat it. She'll eat certain types of tomato sauce more than the other we've noticed. When you get the salt-reduced tomato sauce she won't eat it as much as the other. It has to have quite a strong flavour, and we noticed that we did have to add flavouring or seasoning to things, especially stuff that's more difficult [oral-skill wise]. Like a potato chip, she wouldn't eat it if you put it on a plate with no salt because she licks the salt off it and then maybe will nibble on it. But if there's no salt on it, she's just like, 'that is not worth my effort. I [child] don't want anything from this'.

Oral Sensory Function Category: Response to Texture. SLTs and caregivers noted responses to textures, including preferences and sensitivities. Some children's preference was for thicker puree or crunchy textures, while some children had sensitivities. Examples of texture sensitivity documented by SLTs included children avoiding/separating lumps in foods, requiring foods to be separated/deconstructed, and sensitivity to wet-textured foods.

Caregiver 4 described her child seeming to be scared of smooth puree at the start of her journey with solids as follows:

> Solids [first foods] introduction was rough. She was scared of the textures. She didn't want to touch them. As soon as it got to her lips or her mouth, she'd get this look of panic in her eyes, and it would just come straight back out at me.

Caregiver 7 recalled that her child tolerated all flavours of food presented only if there were no lumps in these foods. Similarly, Caregiver 2 described her child's preference for "mushy" textures and avoidance of mixed textures: "Anything that was mixed, if there were different textures, he would just refuse or struggle."

Caregiver 4 transitioned to dissolvable textures quickly as her child "could not tolerate the texture of the purees. It would just sit in the mouth and come straight back

out." Caregiver 10 shared that her child preferred crunchy and dissolvable textures, including hard biscuits, crackers and potato sticks. While Caregiver 8 commented that her child preferred a particular brand of savoury-vegetable puree, which the caregiver reported appeared to be thicker than similarly branded sweet-fruit purees.

Oral Sensory Function Category: Response to Temperature. No response to temperature was documented by SLTs. Caregiver 8 explained, however, her child's temperature preference for warm pouches. She tried to warm pouches up in other environments, but the temperature would "never quite be right" as Child 8 would only eat warm savoury pouches.

Oral Sensory Function Category: Response to Other Sensory Aspects. SLTs documented some children overfilling their mouths and pocketing food in their cheeks during eating, despite appropriate skills to chew, indicating decreased sensation. In addition, a few children reportedly inconsistently opened their mouths to the spoon despite being interested in eating, and spat out textures despite adequate oral motor skills.

Similarly, some caregivers remarked on their children pocketing, overfilling their mouths and having reduced awareness of food in/around their mouth. Caregiver 2 recalled her child often overfilling his mouth while he drank liquids. Caregiver 2 noticed her child would frequently have food around the outside of his mouth after eating, which she felt was different from his siblings, who would notice immediately and want to wipe it off. Child 2 responded that he didn't feel the food around the outside of his mouth after eating. While Caregiver 1 explained verbally checking with her child as she frequently stored foods in her cheeks and showed limited awareness of this:

> . . . "Have you finished your mouthful?" and she'd be like, "yes, I have" and she'll poke her tongue out and there is still [food], to me. "Your mouth is not empty," she'll still have bits of cracker of bits of things on her tongue. "You

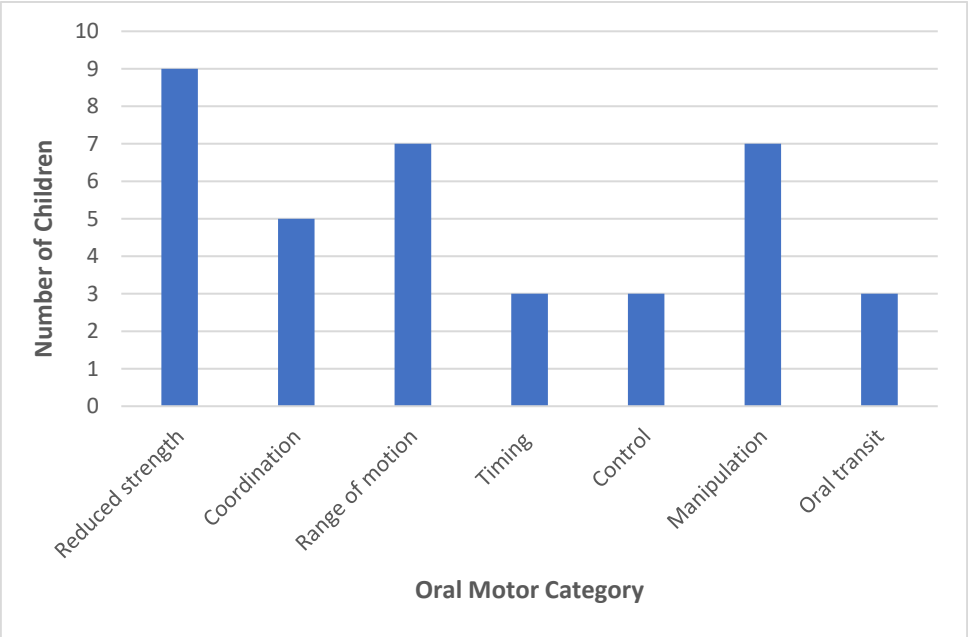
need to clear your mouth. Have a drink of water and clear your mouth." Because there is definitely still solids in her mouth.

Oral Motor Function

SLTs documented at least one Oral Motor Function difference for all children (Figure 3). Oral Motor Function differences were acknowledged by caregivers, who spoke more broadly. Some of the descriptions provided by caregivers were on the functional impact of oral motor differences, not specifically linked to an Oral Motor Function category. Therefore, some of the caregiver perspectives were coded into the Feeding Skills Dysfunction section of this chapter, where they were felt to best align. Oral Motor Function was broken down into smaller categories from the Supplementary Table Three (Appendix A), with examples from both perspectives described in this section.

Figure 3

Oral Motor Categories Noted by SLTs for the 10 Children



Oral Motor Function Category: Reduced Strength. Reduced strength was noted for nine children by SLTs. The SLTs described differences in lip seal resulting in anterior spillage, ability to bite pieces of food, sucking strength and oral residue.

Oral residue was voiced by caregivers during feeding and eating. While Caregiver 3 commented on her child's weak suck and recounted, "With the breast [feeding] we tried the nipple shield and everything, and a lot of the time it [breastmilk] would just end up sitting, pooling in the nipple shield or in his mouth." Caregiver 1 recalled, "[Child 1] collects things in the sides and then get to the point either that she had too much in her mouth so then she's gagging and spitting it all out." Caregiver 7 shared using non-nutritive exercises with the pacifier to help strengthen her infant's sucking abilities. Additionally, Caregiver 4 recounted anterior loss of liquids while her child drank water: "She started with sips of water. Initially, we started with [water], it would go in the mouth, she would dribble it out. It progressed from that to she'd have little sips and swallow."

Oral Motor Function Category: Range of Motion. Range of motion differences were reported in seven children by SLTs. Examples of range of motion differences included bolus position, tongue position and latch differences.

Caregiver 7 described latch differences that required support during bottle feeding, in that she needed to "flick her lips out". Caregiver 1 commented on her child's chewing differences, which resulted in Child 1 chewing food mostly in the front of her mouth, or that the child made "little cheek pockets" of food.

Oral Motor Function Category: Manipulation. SLTs noted manipulation differences in seven children. These differences included children's chewing patterns, such as munching and mashing, or other related jaw movements. They also included tongue movements, such as anterior-posterior movement, poking tongue out, and spitting out food.

Some caregivers voiced manipulation differences. Interestingly, Caregiver 1 explained that her child didn't seem to use her back teeth for chewing. As a result, the family adapted the foods they offered, including softer foods or cutting foods in longer strips to encourage chewing, and adapting the way their child ate. Caregiver 4 shared about Child 4's chewing abilities and progress with dissolvable foods, "She'd suck on them and then once it got soft, she would then spit it out again. She'd always keep it at her gumline. She wouldn't go past her gumline for a good few months."

Oral Motor Function Category: Coordination. SLTs identified coordination differences in five children. Notable features included an elevated suck-to-swallow ratio and observable tongue quivering. In addition, SLTs documented tongue protrusion, hypernasality and eating with an open mouth for some children.

Coordination was less frequently reported by caregivers, with one caregiver who recounted her child's coordination through differences in suck-to-swallow ratio. She described Child 4's breastfeeding as sucking for a few bursts with discoordination, resulting in part of the bolus coming out of the child's mouth after a few sucks: "She [Child 4] would feed, take a couple of swallows, she'd spit another couple of mouthfuls back at me and then go back to a couple of swallows and then spit out."

Oral Motor Function Category: Timing. Three children had timing differences documented by SLTs. This included bolus size ranging between variable size or smaller than expected for oral skills, several swallows per single bolus, and difficulties with continuous drinking.

Interestingly, few caregivers commented on timing. Caregiver 1 recalled her child taking small, single sips:

> . . . [She] would take only little, tiny sips. If it was ever an open cup, it was really tiny, little . . . a little sip and then put it down, a little sip and put it down.

Oral Motor Function Category: Control. Control differences were recorded in the notes of three children by SLTs. Documented control differences were loss of food/drink (bolus to the floor of the child's mouth) and the use of pacing while bottle feeding. No caregivers mentioned control differences.

Oral Motor Function Category: Oral Transit. SLTs noted three children had oral-transit differences. Reports of these differences included increased effort to transfer food/liquid in mouth, holding food/drink in their mouth for extended periods, drinking liquid to 'wash down' solids, and disorganised sucking rhythm while feeding.

Caregivers retold oral-transit differences through the functional impact to mealtimes. For example, Caregiver 2 explained the impact on oral transit for unexpected textures, getting stuck on her child's palate for extended periods, affecting the oral transit of the food and not moving to the next phase of swallowing:

> I think sometimes it's the things [food textures] he struggles with are things that you least expect him to, because they can be soft things [food textures] that just form a ball and just sit stuck up in the palate.

Caregiver 1 (in a previously documented quote in the oral sensory section of this chapter) voiced the impacts of her child's sensory differences (pocketing food and overfilling mouth), that impacted oral transit whereby she spat out foods and had fatigue related to eating:

> Yeah, definitely delays in chewing and the ability to actually move the food, so it would just sit at the front, or she'd make little cheek pockets. She collects things in the sides and then get to the point either that she had too much in her mouth so then she's gagging and spitting it all out, or the fact that I think sometimes she had chewed for so long that she was exhausted and she was like, "I don't know what to do with this now." There were definitely times where there was panic on her face. She's like, "I don't know what to do with

> this. What am I doing?" and then would just be actively spitting it out. I think it definitely got to the point where there's sometimes a little bit of panic. "What am I doing? I actually can't swallow this. I don't know what to do."

Pharyngeal Sensory Processing

Clinical assessment provides important visual evaluation to SLTs on the oral phase whereas the pharyngeal phase requires information from instrumental assessments. Therefore, information available for this sub-domain was commented on for the five children who had VFSS. No other instrumental assessments were recorded.

One caregiver of a child who had a VFSS shared information about Pharyngeal Sensory Processing. Pharyngeal Sensory Processing will be described using categories of response to bolus and residue as follows.

Pharyngeal Sensory Processing Category: Response to Bolus During Pharyngeal Transit. Four of five children who had a VFSS were noted by SLTs to have under or over response to boluses during pharyngeal transit. Information provided by SLTs included pre-swallow pooling and delayed swallow trigger.

One caregiver described her child's sensory response to bolus during pharyngeal transit. Caregiver 1 explained increased pharyngeal awareness of liquids following implementation of thickened liquids for her child. Child 1 was on thickener following a VFSS, which confirmed silent penetration, and indicated no immediate bodily response to airway compromise. This caregiver described that Child 1 started to throat clear and cough once thickener was introduced, and had not done so prior:

> I think she actually became more aware of it when it was thickened [liquids]. I think [she] definitely didn't respond too much [on thin liquids]. She would quite happily drink [thin liquids] and not cough, but then we added the thickener and then she would have some coughing. I think that's just her poor perception [on thin liquids] of what's happening in her body [which] is definitely a contributing factor.

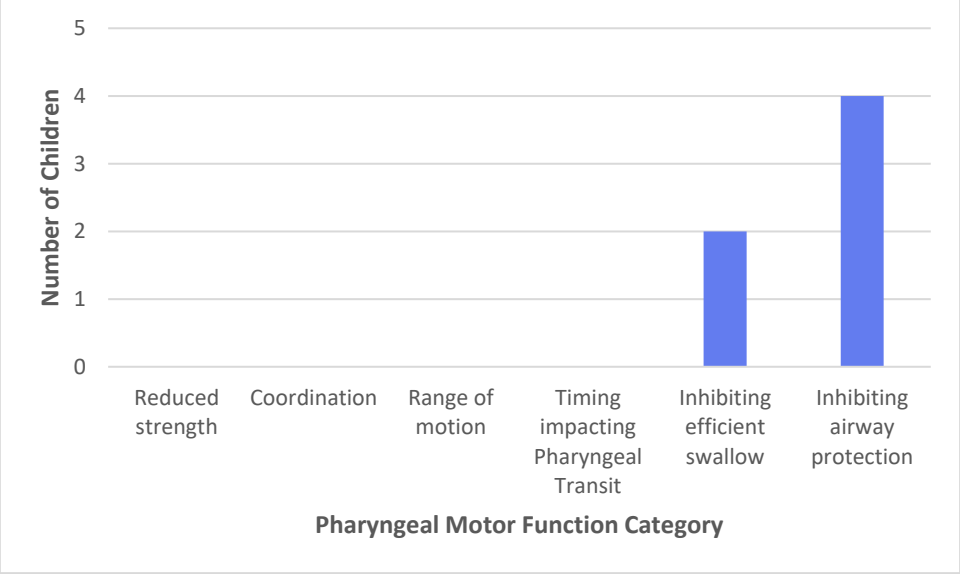
Pharyngeal Sensory Processing Category: Residue Remaining Post-swallow. SLTs noted all five children had pharyngeal residue, ranging in amount between coating to severe, and present in several locations of the pharynx. No caregivers mentioned pharyngeal residue.

Pharyngeal Motor Function

SLT notes on Pharyngeal Motor Function were based on instrumental assessments of the five children who had VFSS documentation. Some categories of Pharyngeal Motor Function were not noted by SLTs (Figure 4). Pharyngeal Motor Function inhibiting efficient swallow and/or airway protection was mentioned by SLTs and caregivers and is discussed further.

Figure 4

Pharyngeal Motor Function Categories Noted by SLTs for the 10 Children



Pharyngeal Motor Function Category: Inhibiting Efficient Swallowing. SLTs documented Pharyngeal Motor Function inhibiting efficient swallowing in two children, which included effortful and audible swallows.

Caregiver 1 commented that her child used a chin tuck when swallowing for airway protection, potentially due to confirmed airway violation confirmed from VFSS:

> It was actually quite interesting because before getting any professional help in she had worked things [management strategies for feeding skill difficulties] out for herself. She had learnt to tuck her chin, which we always saw her doing but we didn't know that's why she did it. She actually really cleverly caught some things [feeding skill difficulty] for herself, which I guess might be why we actually got to that point before we realised there was a problem because she herself had caught on and was safeguarding herself.

Pharyngeal Motor Function Category: Inhibiting Efficient Airway Protection. Four of the five children who had a VFSS were noted to have Pharyngeal Motor Function inhibiting efficient airway protection. SLTs documented decreased airway protection as penetration and aspiration. Delayed coughing in VFSS findings as a result of airway violation was reported for only one child.

Caregiver 3 shared that she could recognise when her child had an aspiration event based on bodily responses, while no other caregivers mentioned information on decreased airway protection:

> . . . you'd know he'd aspirate, you can hear it happen, and then you're like, 'oh shit', (excuse my language), but then you'd be like, 'oh no, this is coming', and then pretty much every time he would end up getting quite sick. . . It was literally seeing that [aspiration event], and it would be within 24-48 hours after we'd seen an aspiration [leading to illness and/or hospital admission].

Feeding Skill Dysfunction

Feeding Skill Dysfunction consists of activity limitations and participation restrictions, defined by the ICF as difficulties doing activities and problems with involvement in life situations an individual may experience respectively (World Health Organization, 2001). In the Feeding Skill Domain, Feeding Skill Dysfunction includes Limitations in Oral Feeding Skills and Restrictions in Mealtime Participation due to Safety Concerns, which are categorised into three main areas of Feeding Skill Dysfunction (Table 3). These categories are unsafe oral

feeding, delayed feeding skills and inefficient oral feeding. As mentioned in the methodology chapter, it is important to note that most of the findings in this section come from the interviews with the caregivers. Information in the SLT notes reported by caregivers was excluded from data collection and therefore SLT representation is limited to their notes on observed signs of difficulty, clinical impairments and instrumental assessments.

Table 3

Feeding Skill Dysfunction Categories and Sub-domains

Feeding Skill Dysfunction (Activities and participation/limitations and restrictions)	
Category	**Sub-domain**
Unsafe Oral Feeding	Restrictions in mealtime participation due to safety concerns: • Adverse mealtime events • Adverse cardiorespiratory events • Aspiration

Delayed Feeding Skills	Limitations in oral feeding skills:
	• Unable to consume age-appropriate liquids and food textures
	  ○ Liquid modification
	  ○ Early texture progression
	  ○ Texture exclusion
	• Unable to use age-appropriate utensils and devices
	• Unable to self-feed at age-appropriate expectation

Inefficient Oral Feeding	Limitations in oral feeding skills: • Insufficient oral intake • Prolonged mealtime duration • Unable to use age-appropriate mealtime seating • Requires more assistance or special strategies relative to other children of same age

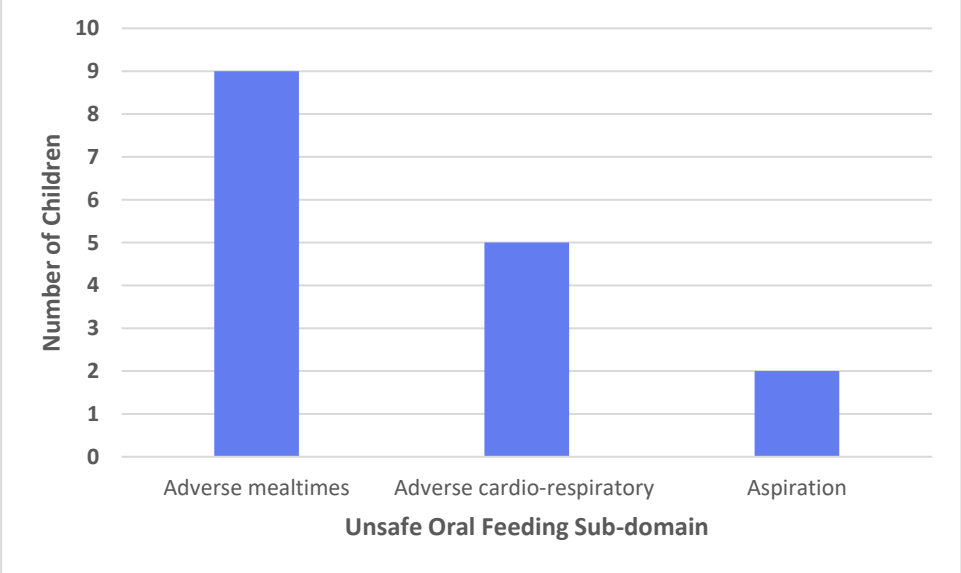
Note. Adapted Paediatric feeding disorder: Consensus definition and conceptual framework, by Goday et al. (2019). https://doi.org/10.1097/mpg.0000000000002188

Unsafe Oral Feeding

Children were noted by SLTs to have restrictions resulting from all three types of unsafe oral feeding (Figure 5). Similarly, caregivers commented on restrictions present for their children in at least one of the sub-domains.

Figure 5

Adverse Events Noted by SLTs for the 10 Children



Adverse Mealtime Events. Nine children were noted to have adverse mealtime events by SLTs. Information provided by SLTs included bodily cues such as eye blinking, watery red eyes, sneezing, hand splaying, hiccups, gagging, coughing and gulping. Additionally, fatigue, vomiting and voice changes, such as 'wet-sounding cough' or 'grunting' or 'gurgly' sounds were documented.

Caregivers shared similar stories of adversities related to mealtimes for their children, including throat clearing, coughing and choking. Caregiver 3 shared the extent of this, often resulting in her needing to stop feeding and reposition her child, ". . . we'd have to literally take him off the breast or off the bottle and turn him over because you could see that he was choking quite a bit, but other times it was just like a cough and spluttering."

Moreover, Caregiver 4 observed her child's reaction while drinking liquids, "lots of spluttering, lots of the panicked eyes, . . . trying to retch almost" and "Definitely scared. Very bulgy eyes, tongue out, bright red face, almost collapsing into a ball in her chair." Some caregivers mentioned choking. Caregiver 9 recounted how this occurred around feeding times and would result in Child 9 having colour changes:

> . . .it was always around feeding times, where he would choke, make this choking sound, and he would change colour. The choking would then cause him to hold his breath and then he would go like a bluey-purple colour.

Caregivers shared stories of adverse events, such as coughing and gagging, which escalated or resulted in negative consequences, such as vomiting. For example, Caregiver 9 explained: ". . . tears falling from his right eye when feeding. He would sound like he was choking, like a choking sound, and then would cough, splutter, vomit." Caregivers 3 and 7 reported their infants fell asleep while feeding, indicating fatigue related to feeding.

Adverse Cardiorespiratory Events. SLTs noted five children to have adverse cardio-respiratory events. This included increased respiration (work of breathing), rattly breathing and laboured breathing. Furthermore, information that children sounded chesty during/after meals and colour changes related to mealtimes were reported by SLTs.

Caregivers shared information within the context of adverse mealtime events. This was frequently observed by caregivers through changes in colour and breathing during mealtimes. Caregiver 8 described the effects of such adversities during a mealtime:

> We would feed him, and he would go bright red, and we'd have to sit him up, we'd have to tap his back until he either vomited, or he'd gasp and gasp and gasp, and we'd watch his eyes water, and then he'd be okay.

Aspiration. Two children were noted by SLTs to have aspiration from VFSS documentation. One caregiver commented on aspiration. As mentioned, previously in Pharyngeal Motor Function area of Inhibiting Efficient Airway Protection (pg. 63), Caregiver 3

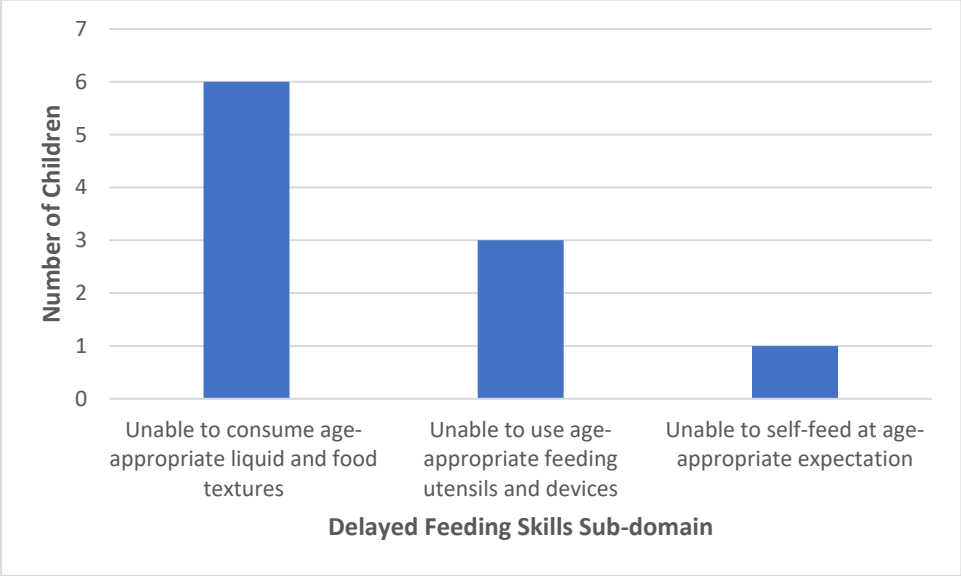
shared that she heard aspiration events as they occurred, and, within 24 to 48 hours, her child would become unwell and/or be admitted into hospital.

Delayed Feeding Skills

Delayed feeding skills include inability to consume liquids and food textures, use of feeding utensils and devices, and inability to self-feed, all at age-appropriate expectations within the Limitations in Oral Feeding Skills sub-domain. SLTs documented limitations to feeding skill among children in all areas (Figure 6). Additionally, caregivers mention delays in feeding skills and the functional impact.

Figure 6

Delayed Feeding Skills Sub-Domains Noted by SLTs for the 10 Children



Unable to Consume Age-Appropriate Liquid and Food Textures. SLTs noted six children had differences in their ability to consume age-appropriate liquids and food textures. Texture tolerance, such as managing only smooth puree past expected age range, and disengaging with soft meats by throwing them off the plate were documented. In addition, information recorded by SLTs including the use of thickened liquids and non-oral supplementation.

Caregivers reported greater differences in their children's ability to consume age-appropriate liquids and food textures in various ways, such as requiring thickened liquids, progressing through textures earlier than expected, excluding certain textures, avoiding certain events, variability and the child's preference for safe foods. In this quote, Caregiver 8 recounts how her child could only manage one texture at a time due to delayed feeding skills:

> The other thing we had to do was only have one item of food at a time. He couldn't handle having a bowl of puree and crackers and go between [during the meal]. That was too much for him to figure out. So, he would do just puree, and once that was finished and if he was not croaky, then if he was still wanting food we'd offer him some crackers or something, different texture, but he would eventually croak.

Liquid Modification. Two caregivers shared information about use of thickened liquids. Caregiver 3 shared the positive effect of thickener for her child:

> It just fit well, perfectly, and he worked it out within himself quite quickly . . . he could be in more comfortable positions. I didn't feel like I was having to hold his head up so much and stop him from choking. There wasn't as much spluttering.

Caregiver 1 shared a story of her child not being able to drink a juice box while away from home due to not having thickener available at that time. Caregiver 3 recounted the need to limit the volumes of thin liquid, as her child progressed off thickened liquid and back onto thin liquids, ". . . we started doing water with a straw, cup with a straw. We started with quite a small amount, 20 ml over the day, and he really loved it. He thought he was a real big boy."

The inability to consume age-appropriate liquids was retold by some caregivers to cause unexpected difficulties, such as ingesting water while at the splash pad (Caregiver 1), and information described by Caregiver 3 about her child who showed frequent interest in drinking what he couldn't have:

> Because we didn't let him have water because water's the thinnest thing, that's all he wanted, because he couldn't have it and he knew that, and he would try anything to have water, including if it rained he would try and suck the water from outside off the deck, just everything, or if the kids left a drink around, we'd have to be so vigilant. . . he became very aware around the water thing, that he wasn't having water, very early. Particularly the way he would be in the bath, look at me out the corner of his eye and then try and drink it. . . but he just wanted to know what all the fuss was about. . .

Early Texture Progression. Caregivers provided insight about their children progressing through textured foods earlier than the age-appropriate stage due to the small volumes consumed, decreased interest or difficulties with skill appropriate food textures. Caregiver 3 shared her experience of earlier texture progression due to difficulties her child had with thinner purees. As a result, Caregiver 3 added texture to purees earlier than for her other children so, ". . . he [child 3] could just move it around in his mouth and feel it and stuff . . ."

Caregiver 4 voiced progressing through textures quicker, as her child was not interested in smooth textured foods, "That's [smooth textured foods] not what she would put in her mouth. It would always be for her skill set, those danger foods that she would want in her mouth." Caregiver 4 later explained that Child 4 preferred foods being, ". . . quite big chunky and solid foods. If she needed to and she got panicked or scared, she could stop it going down her throat [as opposed to smoother textured foods] . . ."

Texture Exclusion. Caregivers reported challenges with age-appropriate food textures, adapting drinks/foods at events for their child. Caregiver 1 described her child wanting a juice box, in order to be similar to her peers:

> "I want to be independent", and "I want to be a big girl", so there's definitely the impact of like, "Hey, you can't drink the juice box at the birthday party like everyone else. You can have it, but we need to empty it into a drink bottle, or we need to cut the top open and put your thickener in so you can have it." Those kind of things interfere of wanting to be like everybody else.

Caregiver 4 described her child going on “food strike” after she was unwell or admitted to hospital, whereby she refused all food textures except for dissolvable textures. Caregiver 4 would “slowly introduce” refused textures after “about a week”. Caregiver 2 explained how her child struggled to eat lollies that require chewing: “Halloween’s quite a tricky one because there’s lots of things he can’t eat, but we get him to trade the lollies with his brothers and then we buy special things that he can have [eat].” While Caregiver 3 explained how some food textures change in mouth, for example, from solid to liquid forms and how not all smooth purees have the same thickness, and that these would cause difficulties for her child:

> Ice blocks were always a big one [difficult texture for child to eat]. Everyone had ice blocks. It might look solid but it’s not going to stay solid [melts to a liquid form]. That was always one. Even yoghurt, sometimes that was too thin, and people would assume, oh yes, he’s little, he can have yoghurt. Like no, he can’t always have yoghurt.

Unable to Use Age-Appropriate Feeding Utensils and Devices. SLTs documented three children who had differences in ability to use age-appropriate feeding utensils and devices. These differences included prolonged use of a teat bottle as a primary form of obtaining nutrition, use of slower flow drinking vessels and decreased tolerance of a spoon when fed.

Caregivers described differences in the use of age-appropriate feeding utensils and devices. This included explanations, such as use of specific slower-flow drinking vessels, using hands to eat in place of a spoon (Caregiver 7), and refusal to drink milk through a bottle but accepting it with cereal (Caregiver 10).

Unable to Self-Feed at Age-Appropriate Expectations. One SLT noted one child having differences in ability to self-feed at age-appropriate expectations. Caregiver 8

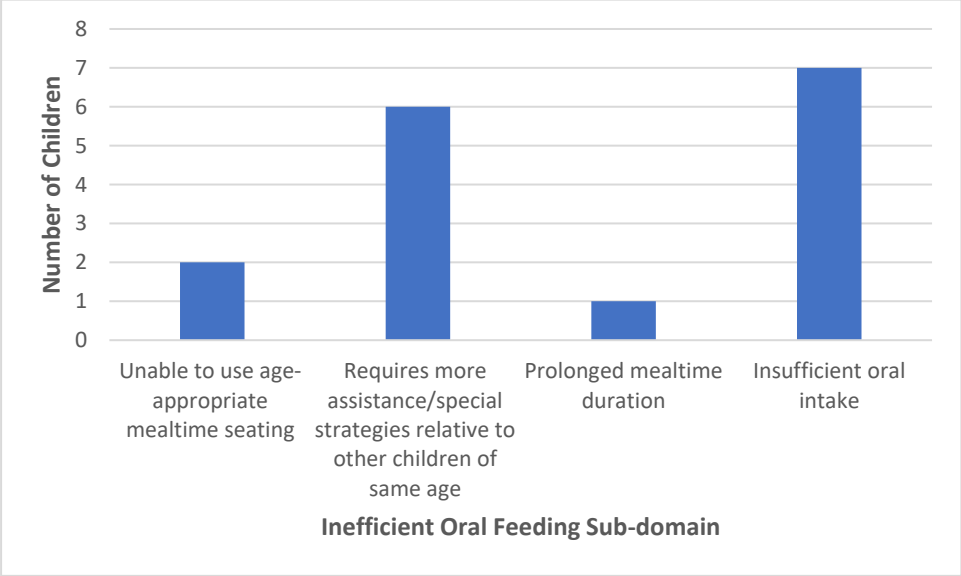
mentioned differences in her child's ability to self-feed, whereby he, ". . . couldn't hold a spoon or anything [self-feeding actions] himself."

Inefficient Oral Feeding

Inefficient oral feeding may be observed through insufficient oral and prolonged mealtimes of more than 30-minute duration, unable to use age-appropriate mealtime seating and requiring more assistance than other children of a similar age. SLTs noted inefficient oral feeding within several sub-domains (Figure 7). Caregivers provided detailed information on how inefficient oral feeding presented in everyday life.

Figure 7

Inefficient Oral Feeding Sub-domains Noted by SLTs for the 10 Children



Insufficient Oral Intake. Seven children were noted by SLTs to have insufficient oral intake, requiring supplemental nutrition. This was defined in SLT notes by use of non-oral feeding methods, such as nasogastric tube (NGT) or gastrostomy tube (GT) feeds or top-ups, which occurred directly after oral feeds or at night, while the child was asleep, or over several hours.

Similarly, insufficient oral intake mentioned by caregivers included use of the non-oral feeding, such as NGT or GT feeds for weight gain. Additionally, caregivers reported insufficient oral intake when their child was unwell. While Caregiver 8 described the slow process with small amounts being tolerated orally, “We knew we couldn’t do it [feeding] fast . . . you had to do a baby size spoon, but still only a quarter [smooth puree] on the baby spoon. It was really small amounts [on the spoon].” Equally, Caregiver 3 described Child 3 only eating small volumes of food at mealtime: “He’s very much more of a snacker and eats small amounts. He never sits down and eats a very large amount of food at all.” Furthermore, Caregiver 1 shared how different her child’s eating was when compared to other children, “[Child 1] licked a bit of cheese and ate the icing off something and all the other kids are still eating”.

Caregivers referred to consumption of age-appropriate foods by talking about their child being cautious with unfamiliar foods, taking “tiny, little bites” (Caregiver 2), and having a limited variety of foods with a preference for particular foods, “he wouldn’t pick up other foods. He wouldn’t attempt anything else. He just wanted the same thing. He was very good at eating. We [Child 8] ate the same thing three times a day. . .” (Caregiver 8), and, “. . . not the whole grains or any of those other things, it was just Weetbix and fruit and yoghurt” (Caregiver 2). Caregiver 1 mentioned difficulties her child had with consuming age-appropriate foods. While in public spaces, the caregiver would modify foods, yet Child 1 requested a familiar liquid afterwards:

> . . . we need to take some yoghurts with us, and we need to take some food [when going out]. We can’t go to a restaurant and order something and know whether she’s going to be able to eat it or not. We try and give her those experiences and we cut things up very small and all those things [strategies], but it’s almost guaranteed that we’ll get home and then we’ll have to give her a bottle with some protein powder or something in it because she will have licked a noodle and thrown a carrot at someone.

Prolonged Mealtime Duration. One child was noted to have prolonged mealtime duration by a SLT. Caregiver 4 retold that Child 4 was "on and off [the breast] all the time" for up to "40 minutes to an hour", which resulted in daily activities taking longer due to the child's frequent feeding and extended mealtimes.

Unable to Use Age-Appropriate Mealtime Seating. Two children had differences in using age-appropriate mealtime seating, according to SLTs. One of the children required a specialised seating system, while the other child needed movement while eating (as opposed to being seated).

Caregivers shared information on use of supportive mealtime seating, including a specialised seating system for eating (Caregiver 8), and the impact of supportive seating positioning:

> . . . once we seated her in the correct position, because before we had kind of just like, "You can sit on the floor, picnic style", and those kind of things, so once we had found that that wasn't the best way for her to do it [and adapted her seating during mealtimes], that back arching changed a little bit [after seating adaptation]. (Caregiver 1)

Requires More Assistance or Special Strategies Relative to Other Children of Same Age. Six children were noted by SLTs to require more assistance/special strategies relative to similarly aged children. SLT notes included eating at select mealtimes and skipping others, snacking throughout the day, and higher-calorie foods given to manage mealtime variations. SLTs noted that babies required support to relatch onto the teat and with postural stability.

Caregivers shared information about several special strategies required for their children. This included higher-calorie fortification, such as using cream or high-fat foods (Caregiver 2) due to fewer mealtimes tolerated by their children. Caregiver 7 retold using additional mealtimes, whereby her child had a meal first, followed by something else to eat when the rest of the family ate their meal. Caregivers shared the need for decreased

distractions/low stimulation environments, including quiet places (Caregiver 7). The importance of limiting distraction was emphasised by two caregivers, as their children required more attention and focus to eat:

> I think she actively has to think about eating. A lot of us, we could sit here and have this conversation and be eating and talking at the same time. She does not have the ability to do that. It's either eating or talking. She can't do more than one thing. And I think she actively has to think "where am I putting this food? How am I eating it?" I think there's definitely a lot of thought and full attention that goes into her being able to eat effectively. (Caregiver 1)

> . . . they were talking at the table or if they were laughing, he's like, "Mum, you almost made me choke." So I think it requires him to be still and focused to eat because if I was trying to do something else he'd end up coughing and he says things get stuck. (Caregiver 2)

Other strategies retold by caregivers included slower flow rate, and encouraging smaller sips for liquids. Specific utensils, eating food only off a certain colour plate (Caregiver 10) and the child utilising self-initiated chin tuck, which her caregiver thought she was doing as a way of protecting her own airway (Caregiver 1).

Summary

The information provided by SLTs and caregivers highlighted the complexities and relatedness between sub-domains of the Feeding Skill Domain for children. Information was provided for 10 children through SLT notes. Five children had information from instrumental assessments available, giving SLTs information on the pharyngeal phase swallowing and airway violation. Nine caregivers were interviewed and provided information on their children's feeding skills. Using the Feeding Skill Domain, SLT notes and caregiver interviews demonstrated Feeding Skill Impairment and Feeding Skill Dysfunction, meeting criteria for a PFD diagnosis. The next chapter discusses the main findings of PFD diagnosis, complexity, prominent feeding skills and participation in daily life alongside previous literature.

Chapter Five: Discussion

Introduction

This chapter critically explores the main findings of this study within the context of existing literature. The chapter concludes by highlighting the broader theoretical and clinical implications of these findings.

Paediatric Feeding Disorder Diagnosis

This mixed-methods study explored the feeding skills of children within a CDS through SLT and caregiver perspectives. Using the Feeding Skill Domain of the PFD Framework to define these children's feeding skills provided a universally recognised way to understand their oral skills. To date, research examining the Feeding Skill Domain has been limited (Estrem et al., 2022). Therefore, the study addressed a research gap in the Feeding Skill Domain in younger children with disability and within the Aotearoa New Zealand context. The findings suggest the PFD Framework is useful and applicable within a CDS setting.

This study extended current knowledge by integrating caregiver and clinical perspectives, using the Feeding Skill Impairment and Feeding Skill Dysfunction sub-domains of the PFD Framework. Caregivers provided contextual dimension to SLT perspectives, which validated the importance of a comprehensive understanding of children's feeding skills. The children's Feeding Skill Impairment and Feeding Skill Dysfunction were strongly represented. Furthermore, oral sensory differences, oral motor differences and feeding skill delay/inefficiency were most prevalent amongst the children. The children's feeding difficulties impacted their activities and participation.

All children met the criteria for a PFD diagnosis in the Feeding Skill Domain. In contrast, in Galai et al.'s (2022) study, 32% of the sample met PFD criteria predominantly

within the Feeding Skill Domain. Based on these children being at risk or with DD, this study's findings are consistent with previous data, indicating feeding difficulties in up to 90% of children with developmental delays (Manikam & Perman, 2000; O'Regan Kleinert, 2017; Rohil et al., 2025). Moreover, in the United States, PFD is diagnosed in approximately one in five children with other health conditions (Kovacic et al., 2021).

Eight of the 10 children in this study had difficulties present for more than three months, as evidenced by the SLT initial and final notes, which shaped the timeline for discussion with caregivers. Therefore, they would have been diagnosed with chronic PFD, according to Goday et al. (2019), though it is likely all the children had chronic PFD based on the waiting duration of onset symptoms, referral, waitlist and review timeframes. This is an important consideration for timeliness of specific PFD support, as early eating difficulties may lead to other feeding disorders in later life (Pergeline et al., 2025).

Multi-dimensional and Complex

In this study, all children presented with several complex, individual and inter-related difficulties across the Feeding Skill Impairment sub-domains and Feeding Skill Dysfunction categories simultaneously from both perspectives. These children's feeding difficulties impacted their body function and participation. It highlights the uniqueness and multi-dimensional nature of PFD (Goday et al., 2019; Milano et al., 2019; Muldoon et al., 2022).

The literature indicates that one domain of the Framework may impact another (Pergeline et al., 2025). For instance, existing literature reports cross-over from the Feeding Skill Domain and Medical Domain into the Nutritional Domain for children (Drayton et al., 2023). In a recent study by Morris et al. (2026), children who had Feeding Skill Domain differences, had difficulties related to their feeding that fell within the other PFD domains as well. This study analysed data for the Feeding Skill Domain. However, reading through the

clinical notes and transcripts, there was clear information related to the other domains. Therefore, although not analysed in this study, there may have been cross-over between domains.

The complexities of feeding skill presentation in a single domain and studies indicating cross-over to other domains supports a multidimensional viewpoint on feeding difficulties. Additionally, it supports the ICF-based conceptualisation of feeding difficulties. The way feeding difficulty presents, may vary greatly among children with DD, as the DD diagnosis may result from a broad range of aetiologies (O'Regan Kleinert, 2017). The children in this study had varied Feeding Skill Impairment and Feeding Skill Dysfunction differences. These may contribute to each child's unique presentation as the synthesis of difficulties results in varied outcomes, creating an individualised PFD presentation. Within the service and profession, there should be recognition about the unique presentation and therefore potential for professionals needing to spend increased time supporting a family through tailored, individualised PFD management as recommended by prior research (Goday et al., 2019; Kerzner et al., 2015).

Prominent Feeding Skill Differences

Recognition of feeding skills is important, since such differences have been found to limit children's food variety, volume and increased mealtime durations (Taylor & Taylor, 2021). Moreover, delays in acquiring oral feeding skills may impact their development and feeding behaviour (Manikam & Perman, 2000). In the small percentage of children who met PFD criteria in Galai et al. (2022), the Feeding Skill Domain was the predominant contributing domain. Later research by Galai et al. (2024), indicated a higher number of children under 12 months of age meeting criteria for PFD in the Feeding Skill Domain. In this study, the PFD diagnosis in the Feeding Skill Domain reflects the nature of the study and

participant group. Areas within the Feeding Skill sub-domains that were prominent are discussed in this section.

Oral Sensory Function Differences

Both SLTs and caregivers provided several reports of oral sensory differences in the children which impacted mealtimes. Reports of children's response to taste, temperature and texture resulted in children displaying fear, choosing specific branded foods, refusal, avoidance, awareness of subtle taste/texture variations, decreased oral sensation and overfilling their mouths. This resulted in caregiver reports of adaptations to mealtimes such as separate food preparation, offering exact temperature/tastes preferences, modifying environments and monitoring children's feeding safety.

These findings are similar to those of Morris et al. (2026) whereby all children in their study exhibited sensory over- or under responsivity. RCR were used to gather data and the majority of the children were under 9 years of age. Additionally, the children had neurodevelopmental disorders as the most prevalent comorbidity, such as learning difficulties and/or DD and ASD most prevalent. Wright et al. (2007) found that mothers participating in a baby study in the United Kingdom reported that their toddlers avoided certain food textures, particularly 'slimy' foods. Furthermore, Marshall et al. (2016) studied two groups of children with feeding difficulties aged between 2 and 6 years. This study provided insight into children who had oral hypersensitivity, who consumed more processed fruits and vegetables (mean difference 3.3 foods), exhibited a significantly greater frequency of difficult mealtime behaviours (mean difference 5.8 behaviours) and consumed fewer overall foods (mean difference 3.6 foods).

Therefore, the finding that oral sensory difficulties were highly reported in this study from both perspectives as well as identified in prior literature, indicates the importance of

assessing and understanding children's Oral Sensory Function and the impact on mealtime behaviour. Understanding children's sensory profiles and the dynamic multi-sensory properties of food and drink, are important for clinicians to educate caregivers on.

Oral Motor Function Differences

All children in this study presented with oral motor differences from both perspectives. This is reassuring, as past literature highlighted that these difficulties are often undiagnosed or missed (Drayton et al., 2023; Morris et al., 2026). In this study, SLTs identified discreet differences in the children's Oral Motor Function, which caregivers contextualised within everyday settings. SLTs reported differences in strength, range of motion and manipulation. Caregivers reported differences in the children's mealtime behaviours through: mealtime fatigue, negative reactions, chewing styles and anterior spillage. Oral motor difficulties reported included adaptations such as offering smaller amounts of liquid/food, offering softer/cut up foods, and spitting out foods. Furthermore, findings of this study indicated that children developed compensatory behaviours, including head position changes, avoiding difficult foods (by selecting preferred/safe foods), controlling volumes ingested and chewing styles.

Marshall et al. (2016) researched Oral Motor Function differences and found that two thirds of the groups of children studied (one group with ASD and the other with a non-medically complex history) presented with mild to moderate oral motor difficulties. Oral motor difficulties were defined through assessment of a child consuming three textures to observe their abilities: eating puree from a spoon, drinking from an open cup/bottle and chewing food. Severity ratings included: exclusive chewing difficulties classed as mild, and additional difficulties, with spoon and/or cup drinking difficulties classed as moderate

difficulty. Marshall et al. (2016) found children with greater oral motor difficulties consumed more calories daily and more processed fruits and vegetables.

Additionally, using clinical intake summaries for children referred to behaviour-analytic feeding intervention in Australia and Aotearoa New Zealand, Taylor and Taylor (2021) found skill development consequences associated with their feeding difficulties, including oral motor differences. These included prolonged chewing, nibbling, overstuffing of mouth, difficulties with tongue lateralisation and difficulties with lip closure. Morris et al. (2026) found over half of the group of children studied presented with oral motor differences and the caregivers reported differences such as delayed texture progression, chewing difficulties, food pocketing, and spitting out food.

Existing literature indicates that greater oral motor difficulties resulted in increased daily calories and more processed foods. Moreover, there is research showing that children with PFD may have micronutrient deficiencies despite maintaining adequate growth (Drayton et al., 2023), and are at risk of inadequacies in multiple nutrient groups (Brown et al., 2025). Oral motor differences in this study indicated how prominent these differences were. Furthermore, they provided insight into children's avoidance of difficult foods, chewing styles, food avoidance, spitting out foods and preferences for modified textures and volumes which may explain connection between Feeding Skill and Nutritional domains. Children may adapt based on their feeding skill difficulties, by selecting foods that are easier to chew and manipulate, avoiding more challenging foods, which, over time, may reduce the variety and nutrient-dense foods they eat.

Mathisen et al. (1989) highlighted the importance of assessing Oral Motor Function, which is an area that SLTs have a critical role in assessing and educating caregivers. Therefore, with all children presenting with oral motor differences in this study, and previous

studies with similar findings, further reinforces the need for thorough oral motor assessments by an SLT, and their valuable role in PFD management as part of an interdisciplinary team (Goday et al., 2019).

Feeding Skill Dysfunction

Differences in feeding skills result in unsafe oral feeding, delayed feeding skills and inefficient oral feeding (Goday et al., 2019). In this study, all children presented with Feeding Skill Dysfunction. Both SLTs and caregivers noted signs of unsafe oral feeding, such as gagging, choking and coughing. These responses are consistent with Taylor and Taylor (2021), who found gagging and coughing in RCR, as well as Morris et al. (2026), who also found gagging reported by caregivers in health records. Noticing these signs of feeding difficulty may be due to the overt presentation. These events can be scary for children and caregivers to experience, particularly if occurring several times a day. It is important that children with unsafe oral feeding have timely access to PFD support.

Delayed feeding skills and inefficient oral feeding were reported in this study, with the daily impacts of these differences understood by caregivers, who described these through limitations and restrictions of the children's feeding skills. Caregivers reported their children experiencing: fatigue, distress, decreased participation, required mealtime adaptations, modification/exclusions of specific foods and liquids, non-oral supplementation and increased mealtime supervision. Additionally in this study, the SLTs indicated children having Limitations in Oral Feeding Skills, such as consumption of liquids and food textures, requiring more assistance than other children of a similar age and insufficient oral intake.

Previous research found feeding difficulties functionally impacted daily life, from caregiver reports of food refusal, prolonged mealtime, decreased volume intake, food texture avoidance and distinct food preferences (Estrem et al., 2016). Taylor and Taylor

(2021) found children's feeding skill difficulties prohibited consumption of food. Research has also demonstrated caregiver insight of children's feeding difficulties, requiring adaptation and the impact of children's food choices on their social development (Muldoon et al., 2022). Muldoon et al. (2021) highlighted the need for SLT-specific research on the functional impact of feeding skill differences as previous research has focused on aetiologies, including sensory-motor difficulties. This study provided insight into the functional differences for children from two perspectives. Furthermore, the functional impact appeared to be captured well using the PFD Framework.

Participation in Daily Life

Participation is an important consideration, since the ICF emphasises the individual's participation and social inclusion when diagnosed with a disability, such as PFD. Children with disability have differences in participation (Akin et al., 2021). A Statistics New Zealand (2014) survey indicated children with disability were less likely to participate in social activities. Additionally, children with disability did not have regular activities, including playing with other children or going to a playground (Akin et al., 2021).

Muldoon et al. (2022) found a commonality among caregivers of the significant difficulty they faced in feeding their children, such as requiring the use of adaptive strategies to promote participation. In previous literature, caregivers described their children's feeding difficulty as having ups and downs, and changing overtime, therefore, these could be viewed as a journey (Estrem et al., 2016). Furthermore, there is literature on caregiver accounts of the impact of feeding difficulties, such as reports of family life organised around mealtimes (Estrem et al., 2018), challenges in daily living activities (Simione et al., 2020), reduced participation (Simione et al., 2020; Tan et al., 2022), caregiver burden (Muldoon et al., 2022) and community inclusion (Taylor & Taylor, 2021).

In this study, differences in participation for children with feeding difficulties were present. Differences included children who required mealtime modifications, altered routines, food/drink modification, caregiver vigilance, modified inclusion in activities and comparison with peers. Examples caregivers provided included the child being restricted from drinking thin liquids, being unable to eat ice blocks despite interest at social gatherings, and requiring specific lollies in social celebrations.

Understanding potential restrictions to participation due to feeding difficulties and other potential disability diagnoses, indicates the need for clinicians to prioritise children's access and participation in mealtime/social gatherings involving food/drink. Additionally, insight into these encourages clinicians to provide practical support and problem solving.

Feeding difficulties impact other areas of development (Clawson et al., 2007; Taylor & Taylor, 2021) and cognitive function (Silverman et al., 2021), subsequently impacting participation. Children receiving service from CDS already have pre-existing DD. Rohil et al. (2025) described such children as being in a cycle, wherein the disability impacts their feeding, eating and/or drinking, in turn, affecting their growth, brain development and cognitive function, further impacting their disability. Therefore, there may be a compounding effect of both feeding difficulties and other developmental areas, which may lead to further influence on both the feeding difficulties presented over time and other developmental areas; further affecting the child's participation in daily activities.

Summary

The PFD Framework was useful to map the children's feeding skills and disability within a CDS. Differences in Oral Sensory Function, Oral Motor Function and Feeding Skill Dysfunction were highly reported by SLTs and caregivers. The caregivers' perspectives were beneficial, as they provided detail on the impact of feeding differences on children's

mealtime participation. Each child presented with unique feeding skill differences that were complex and multi-dimensional. For this study, use of the PFD Framework provided broader understanding of feeding difficulties as a disability impacting on a child's function and participation. Findings showed similarities to the limited literature, and indicated the feeding skill differences and their impact on everyday life. The final chapter concludes the thesis by discussing the purpose, rationale and quality of research, limitations, and implications for future research and clinical practice.

Chapter Six: Conclusion

Introduction

This chapter concludes the study by revisiting the purpose and rationale, while outlining the quality of research and limitations of the research methodology. It then explores the implications of findings for future research and clinical practice. The chapter closes with final thoughts, including reflections on the study and its contribution to the field.

Purpose and Rationale

The purpose of this study was to integrate the Feeding Skill Domain findings of children from SLT and caregiver perspectives, determining the most prevalent sub-domains. A review of existing literature indicated the recent development of the PFD Framework and limited research within the Feeding Skill Domain. SLTs play a key role in supporting children with feeding difficulties while caregivers provide valuable insight into the daily impacts.

To understand the feeding skills of children under 3 years of age within the CDS, the researcher completed RCR of SLT clinical notes, as well as interviews with caregivers. For the RCR, information from clinical notes and instrumental assessments (if applicable) were used to create each child's RCR schedule, which was based off the Feeding Skill sub-domains. They were compiled to provide collective data from SLTs. Thereafter, interviews were coded and mapped onto the Feeding Skill Impairment sub-domains or, when broader, onto the Feeding Skill Dysfunction categories. Lastly, data from both these sources were integrated through methodological triangulation whereby the SLT information was enriched by caregiver perspectives to describe the children's feeding skills.

Quality of Research

This section outlines the strategies the researcher used to enhance the trustworthiness of this mixed-methods research, with a specific focus on the study's

transferability, dependability and confirmability (Mills, 2014). Optimising trustworthiness measures enhances the quality of research and therefore helps to ensure the research makes a useful contribution to the body of literature (Ahmed, 2024).

Transferability

Detailed information about the participants and setting provided for a study, gives other researchers the ability to identify with the research context and increases transferability (Mills, 2014; Pitney et al., 2024). Another aspect that supports transferability to other contexts is thick description of data-collection procedures (Ahmed, 2024). This study explored the feeding skills of children within a specific age range in a CDS in Aotearoa New Zealand; therefore the children studied were clearly defined. The researcher provided key demographic information to allow for comparison to other contexts, and outlined the role of the SLT within the specified CDS. The data collection procedures for both phases of this study were documented in detail.

Dependability

Dependability encompasses the logical, traceable and consistent use of data collection and analysis methods (Ahmed, 2024; Pitney et al., 2024). These areas are often achieved through methodological documentation and audit trails (Ahmed, 2024). This study used an established framework and dual data sources to enhance dependability. Additionally, the research process was thoroughly documented using detailed data-collection schedules and processes. The data collection schedules were reviewed by an external SLT and the researcher's supervisors, with a pilot completed for both phases prior to finalising them. The researcher's supervisor audited the data collected for one participant in the RCR phase.

Confirmability

Confirmability is strengthened through triangulation and reflexivity to provide neutrality during data collection (Mills, 2014). Methodological triangulation may enhance confirmability through obtaining data from multiple sources (Pitney et al., 2024). Furthermore, confirmability may be enhanced through peer debriefing, which involves seeking feedback to support the researcher's interpretations and minimise personal biases (Ahmed, 2024). Confirmability may be strengthened through use of member checking, which involves participant review to ensure accurate representation of their viewpoints and experiences, to confirm findings (Ahmed, 2024; Pitney et al., 2024).

The researcher acknowledged reflexivity through awareness of her own biases as an individual, SLT and CDS staff member, and reflected throughout the project on the potential impact on data collection and analysis. In this study, the use of two perspectives supported a rich understanding of the children's feeding skills, which reflected the researcher's worldview. The constructivist paradigm relies on the participants' views to interpret meanings while the pragmatic paradigm inquires through multiple approaches (Creswell & Creswell, 2023; Creswell, 2018b). The integration of data through methodological triangulation enhanced the trustworthiness of this study. Peer debriefing occurred through ongoing discussion with the researcher's supervisors throughout the process. Moreover, member checking occurred, by providing the caregivers with their transcripts for review prior to data analysis. The researcher ensured that the data collected reflected the direct information taken from the SLT notes, and the information shared by the caregivers in their interviews through verbatim quotations. Verbatim quotations support detailed descriptions to enhance interpretations developed by the researcher (Creswell, 2018a). Additionally, the researcher remained methodical in her data collection approach through the relevant

procedures and with use of a pre-existing framework. During data analysis and integration of data, the researcher referred to data previously coded, and she took enquiries for consensus to one of her supervisors for validation and minimisation of biases.

Limitations

Despite the researcher's best efforts to optimise the trustworthiness of the research, there were limitations to this study. Limitations relating to the recruitment process, the retrospective nature of the research design, and the use of an established framework are discussed in this section.

The recruitment process was a limitation of this study. Recruitment via email may have limited the audience and number of caregivers reached. Potential participants may have viewed email as an inanimate form of recruitment to build trust and receive information. Given that the study targeted a population within a healthcare setting, there are historic conceptions around Western medical settings and colonisation, which may further decrease the likelihood of participation for potential participants receiving the request via email. Furthermore, email may not have been the best form of communication or appropriate for populations who may not use email or have access to the internet.

When considering the participants of the study, the caregivers who volunteered may have had a special interest in the research area, and a prior working relationship with the researcher, contributing to their willingness to participate. The caregivers who participated may have had more capacity than those who did not volunteer to take part in an interview, which may be another limitation to this study.

Another methodological limitation was the retrospective nature of the study. Worster and Haines (2004) highlight that reviewing retrospective notes may result in missing information leading to a non-response bias of results. The SLT notes reflected a moment in

time, had variation in how children's feeding skills were documented, and were not specifically written for this study. Recall bias from caregivers was another potential limitation, as caregivers were required to recall past experiences. Moreover, caregivers' memory accuracy may have been impacted due to the stressful, highly emotional and prolonged nature of feeding difficulties.

Use of the Feeding Skill Domain provided an existing structured framework to understand one domain of PFD, within the study population. As five of the children had instrumental assessments, there was an under-representation of Pharyngeal Sensory and Pharyngeal Motor Function. SLTs may have documented the most pertinent clinical assessment findings in their notes. Additionally, SLT notes stating caregiver reports were excluded from the RCR data collection to maintain SLT-only perspective for that phase. These reasons may explain why SLT information seemed focused on oral phase difficulties and safety of oral feeding.

During data analysis, there was information provided by SLTs and caregivers that could be placed within several sections of the Feeding Skill sub-domains, particularly in relation to Feeding Skill Dysfunction. Through supervisor discussion, the information was placed within the area that felt most applicable. To prevent making deductions, the limitations and restrictions sub-domains were later expanded to Feeding Skill Dysfunction, which better reflected the data that had been provided. Moreover, information obtained about the children's feeding skills did not consider severity and duration of their feeding skill difficulties, including how frequently they occurred. Information was taken from timepoints in SLT notes and discussing children within a selected timeframe, which provided a limited representation of each child's feeding journey.

Implications for Future Research

This section discusses the implications for future research. The areas for future research include gathering a wider range of perspectives and conducting more research in Aotearoa New Zealand for specific groups of children and variables contributing to PFD. Finally, research over longer timeframes, at critical feeding development periods, as well as research across several PFD domains and feeding difficulties from a PFD lens included in national surveys could be considered.

Wider Range of Perspectives

This study represented the perspectives of nine mothers and four CDS SLTs. Although invitations were sent out to all listed caregivers in this study, no secondary caregivers responded. Yap et al. (2026) highlighted the importance of gathering a wider range of perspectives, including from fathers. Future research should aim to focus on other perspectives and endeavour to increase inclusion of other caregiver perspectives during participant recruitment.

Research in Aotearoa New Zealand

This study focused on children aged 1 month to 3 years and a specific healthcare community-based service in one area of the Wellington region. The findings may not be generalised to other age ranges, settings and the overall population. Additional PFD research would be beneficial from a variety of regions and services to provide a broader representation of PFD within Aotearoa New Zealand. Moreover, research within the Feeding Skill Domain as well as the other three domains would be beneficial. Research in the Feeding Skill Domain may be categorised for a variety of textures including liquid, puree, solids and multiple textures, as Delaney, Flatt, et al. (2025b) suggest, feeding skill analysis requires consideration of the associated textures for each skill. The Developmental Texture

Framework (DTF) provides standardised definitions of textures based on food properties, to improve understanding of the stages of texture progression and how it interacts with oral motor skill development. The DTF could be applied to the PFD to identify feeding delay or dysfunction and support earlier monitoring and diagnosis (Delaney, Staskiewicz, et al., 2025).

Influencing Variables

This study specifically obtained information on children meeting criteria/at risk of a disability, and included their diagnosed health conditions, which ranged from gastrointestinal, neurological, prematurity, respiratory and muscle-tone related diagnosis. Six of the children were male. Most of the children were Pākehā with two children identified to have Māori ethnicity and one with Fijian Indian ethnicity. Five children lived in areas with medium deprivation and one child in an area of high deprivation. (Kovacic et al., 2021) found in their study assessing the prevalence of PFD, that PFD was more frequent and increased in children with chronic health conditions, as well as more frequent in males. According to Estrem et al. (2022), studies focusing on PFD and variables including sex, ethnicity, socio-economic status and specific populations would be beneficial due to the lack of research including those variables. While this study provided information on these variables, there were gaps in who was represented in the study, and studies documenting PFD in broader cohorts of children are required.

Some suburbs in the Hutt Valley have high NZDep scores. Higher deprivation is associated with a range of negative health, education and social outcomes (Environmental Health Intelligence New Zealand, n.d.; Ministry of Health, 2025b). Recording measures of deprivation as a variable such as NZDep, may be beneficial in future research. The Ministry of Social Development reported that housing-related health outcomes prevalent in the first 9 months of a child's life (such as mould, dampness, cold, overcrowded homes), were

strongly associated with adverse health outcomes among the children, even when the housing improved (Riggs et al., 2021).

The Hutt Valley has a significantly higher rate (1.27 rate ratio) of potentially avoidable hospitalisations (PAH) than the national rate (1.00 rate ratio) for children aged 0 to 14 years, with hospitalisation rates increasing with greater deprivation (Adams et al., 2022). Additionally, the highest rate of PAH is for children aged 0 to 4 years (Adams et al., 2022). In the Hutt Valley, the top three causes of PAH are a result of respiratory conditions (over one third of the total), dental conditions and gastrointestinal disease (Adams et al., 2022). These three conditions may be part of PFD for some children. Therefore, future research could explore feeding for the children with PAH, particularly those aged 0 to 4 years, to study some of critical feeding developmental stages and the top three PAH conditions. PFD research focused on variables such as sex, ethnicity, socio-economic status, NZDep and PAH may support recognition and understanding of the compounding external factors and intergenerational experiences within the PFD context.

In this study, the unique presentation of each child's feeding skills showed significant barriers and adaptations required to support their difficulties. However, caregivers' stress was not investigated, despite such stress contributing to the caregiver-child dyad, and child and parent quality of life (Estrem et al., 2022). Estrem et al. (2018) reported that caregivers described how children's feeding needs often dominated family life, and represented one of the caregivers' most challenging daily experiences. Additional research illustrated the impact of PFD on the caregiver, including the stress on themselves, time spent off work for appointments, finances and other relationships (Bakula et al., 2023; Estrem et al., 2022; Simione et al., 2020). Corney et al. (2024) found caregivers of children with PFD in Aotearoa New Zealand experience financial strain and impacted relationships. Providing caregivers

with psychoeducational information of PFD may support their understanding while awaiting specialised services. Additional to variables for children previously mentioned, the impact on caregivers, the wider family, the community and the healthcare and disability services should be explored, when considering the functional implications through the ICF lens, whereby PFD interacts with the external environment.

Eating Patterns and Resources

In this study, both perspectives provided information on the children's Oral Sensory Function and Oral Motor Function. These impacted mealtimes, resulting in children's food refusal/avoidance, negative reactions to mealtimes, eating fatigue, decreased oral intake and brand-specific choices of foods eaten. As discussed in the previous chapter, children with Feeding Skill differences are more likely to eat processed foods (Marshall et al., 2016) and have micronutrient deficiencies (Drayton et al., 2023). The New Zealand Health Survey (Ministry of Health, 2025a) found that there was a decline in children aged 2 to 14 years meeting vegetable intake guidelines from 8.6 to 5.8%. Future research may explore children's eating behaviours and patterns of children with PFD in comparison to those without. Furthermore, future research exploring the financial and family resources required to support children with PFD needing adaptations, such as texture modification (easier-to-chew foods and thickener) and specialised drinking vessels/cutlery may be beneficial.

Study Timeframe

This study provided understanding of children's feeding skills within a specific timeframe. The children's ages ranged from 1 to 50 months at initial SLT note and 5 to 53 months at last recorded SLT note. In contrast, Galai et al. (2024) investigated characteristics of PFD based on age of PFD presentation. Findings suggested that the pattern of PFD

differed according to the age of presentation, with feeding skill development being the predominant concern among children under 1 year of age (Galai et al., 2024).

Prospective studies may consider exploring children's feeding skills over a longer period of their development in natural settings with structured procedures (Delaney, Flatt, et al., 2025a). Alternatively, future studies may explore children's feeding skills at specific time points, since feeding practices evolve across developmental stages (Pook et al., 2026). Suggested time points could be at three stages; under 1 year of age, over 1 year of age and over 6 years of age. These broad time points would capture the critical feeding developmental stages including early feeding skill development, the progression through textured foods and, lastly, the refinement and increased efficacy of oral skills (Delaney, Staskiewicz, et al., 2025; Estrem et al., 2022; Galai et al., 2024).

Multiple Domains

This study documented SLT and mother's perspectives on the Feeding Skill Domain, which provided valuable insight into the children's PFD. The study was focused specifically on that one domain. This is despite information crossing over into other domains and the researcher's clinical experience of this. Therefore, an area for future research would be through interdisciplinary collaboration between health professionals and a variety of caregivers to explore children's feeding difficulties across all four domains of the PFD Framework. Interdisciplinary mixed methodology studies are needed for PFD and to improve clinical practice, including studies focusing on understanding attitudes, exploring predictors, developing tools and evaluating interventions (Thompson & Wanqing, 2020).

Paediatric Feeding Disorder as a Disability

In this study, all children met criteria for a diagnosis of PFD within the Feeding Skill Domain, and they were receiving input from CDS SLTs. They had a range of health conditions

that would put them at risk, or with associated DD. In Aotearoa New Zealand, the prevalence of dysphagia is projected to increase significantly in the aging population, and the associated healthcare burden has been highlighted (Gunby et al., 2025). Similar studies highlighting the impact of PFD are yet to be completed. Feeding difficulties are not reported on in the New Zealand Disability Survey (Corney et al., 2024). Furthermore, there are few, inconsistently funded PFD services and no services that are specific to Māori, or that follow a Kaupapa Māori approach (Corney et al., 2024).

Including feeding difficulties within the New Zealand Disability Survey using the PFD Framework, may yield information about feeding difficulties for Aotearoa New Zealand. This may support recognition of feeding difficulties as a disability by Whaikaha – Ministry of Disabled People, with implications on future PFD funding. Additionally, the progressive lens of disability being a difference in ability requiring community modification, may encourage mana-enhancing Māori language and frameworks to reframe differences in feeding skills similar to efforts placed into other areas of disability.

Speech-Language Therapist Capacity and Training

Children presented with a range of mealtime challenges in this study. These children received feeding support from a specialised service. The frequency of their Feeding Skill Domain challenges was not studied, nor was their level of difficulty prior to receiving support from the CDS SLTs. Duncan et al. (2024) estimated a small, constant annual increase in the number of paediatric dysphagia cases. A large group of caregivers were invited to participate in the study, and their children were supported by 2.0 full-time equivalent SLTs who are supporting the whole Hutt Valley area. Therefore, training of SLTs in tertiary institutions to support children with PFD and more research on PFD within the Feeding Skill

Domain may, in turn, support funding and awareness about the need and complex input required.

Implications for Clinical Practice

This section outlines the implications for clinical practice by synthesizing the study's findings with practice suggestions for SLTs including adopting use of the PFD Framework, prioritising caregivers in PFD management, and highlighting the importance of interdisciplinary collaboration and access to instrumental assessments.

Framework Usefulness

A scoping review by Delaney, Flatt, et al. (2025b) found a lack of consistency for measuring feeding skills in a thorough and universal way. The findings of this study were structured well by categorising and integrating the data using the Feeding Skill Domain of the PFD Framework. Moreover, use of the Feeding Skill Domain captured the multidimensionality and complexity of the children's feeding skills, making the framework clinically applicable. Through caregiver reports, this study provided information on the impact of feeding skill differences on mealtimes, which supported the ICF basis of the Framework. Therefore, the findings suggest that the PFD Framework was a standardised and useful way for categorising feeding skills while considering the functional impact of feeding difficulties for this group of children within a CDS.

The ICF viewpoint describes an individual's function, as opposed to their disability (World Health Organization, 2018), and the PFD Framework focuses on the functional impact of feeding difficulties (Goday et al., 2019). In this study, caregivers provided information about inclusion, independence, safety, participation, reducing distress and managing mealtimes. Moreover, the reports by SLTs and caregivers on children's Feeding Skill Dysfunction highlight the importance of support for children with PFD and their families to

extend beyond swallowing safety and nutritional intake. This emphasises the importance of prioritising the functional impact of feeding skills and family-centred care when supporting families.

SLTs may utilise the Feeding Skill Domain as part of the thorough assessment of a child's feeding. The Framework provides a standardised form of management for children with PFD, by incorporating PFD terminology in reports, notes and caregiver education. This may encourage other clinicians supporting children with PFD to do similar by utilising the PFD domains for assessment and incorporating PFD terminology. The use of common PFD vocabulary may help healthcare professionals and families to achieve mutual understanding and engage in collaborative management, reframing historic unilateral definitions of feeding difficulties (Goday et al., 2019; Pergeline et al., 2025).

In previous research, Milano et al. (2019) highlighted a functional approach to identifying and supporting feeding difficulties prior to a referral to specialised feeding services. The sequential approach ensured feeding difficulties were systematically identified and managed appropriately (Milano et al., 2019). The approach supported management of milder PFD while identifying children with more severe PFD (or PFD across domains). Moreover, Erlam et al. (2025) linked aspects of Te Whare Tapa Whā to examples of PFD for children with chronic PFD to outline principles for supporting children with eating and drinking with acknowledged risk in Aotearoa New Zealand. The use of innovative programmes and approaches such as these will support PFD awareness and knowledge. In clinical practice, programmes about oral feeding skills such as texture progression, bite-size exposure and oral motor benchmarks (Jones, 2025) are required and may support increased awareness for referrers, health professionals and caregivers. Moreover, these could

encourage collaboration and knowledge of the PFD framework between different services and healthcare service-levels.

Caregiver Inclusion

The use of mixed methods was valuable in understanding these children's oral feeding skills in this study. Caregivers contextualised SLT notes through examples of mealtimes, participation impacts, and feeding behaviours in a range of contexts. These caregiver perspectives were essential in understanding children's feeding skill differences. The caregivers were aware of their children's feeding difficulties, and provided large amounts of detail on the behavioural and participation-based manifestations and safety considerations. Caregivers are central to the feeding environment (Estrem et al., 2016; Estrem et al., 2018) and may be the first to identify their child's feeding difficulties (Estrem et al., 2016).

Caregivers are pivotal in shaping mealtime environments (Estrem et al., 2016) and develop adaptive expertise (Muldoon et al., 2022). Despite under-representation of caregiver perspective in the literature (Estrem et al., 2018), they should remain at the forefront of the decision-making process and part of management of children with PFD. Additionally, caregivers provide important contextual insight into understanding a child's unique PFD profile. Health professionals should prioritise caregiver inclusion in the management of a child's PFD and support the caregivers' knowledge of PFD.

Interdisciplinary Collaboration

This study provided two different perspectives to the children's feeding skills, giving insight into the Feeding Skill Impairment and Feeding Skill Dysfunction. This meant that PFD was viewed within the Feeding Skill Domain by a researcher with SLT expertise, describing only a part of the children's PFD presentation. In a service such as CDS, healthcare

professionals may be working in a multidisciplinary way to support children with PFD. In Aotearoa New Zealand, many children with PFD receive support from other community based SLTs, including specialist schools (Jackson et al., 2019). Ideally, there should be integration of professional expertise of PFD working together as part of an interdisciplinary team. Goday et al. (2019) and Milano et al. (2019) acknowledged that support from an interdisciplinary team across all four domains of the PFD Framework may not be possible but remains the best standard of care in supporting children with PFD.

In some community-based services supporting children with PFD, an interdisciplinary team approach may be limited. Furthermore, there is a gap in specialities, such as psychologists specialising in PFD supporting the Psychosocial Domain. Health professionals should continue to practice in a multi- and interdisciplinary way with emphasis on collaboration with the rest of the team. In the interim, professionals could utilise the PFD Framework and a severity rating of PFD. This use of shared, consistent terminology to describe a child's PFD may be beneficial in providing access to services and triaging appropriately (Dodrill, 2021).

Instrumental Assessments

In this study, the Pharyngeal Sensory Processing and Pharyngeal Motor Function sub-domains were only recorded for those children who had instrumental assessments. Of the five children who had VFSS, only one child was reported to exhibit an overt sign of decreased airway protection (delayed coughing) during the instrumental assessment, yet three other children had inefficient airway protection confirmed by VFSS. Similarly, Weir et al. (2011) found that overt signs of airway violation were not present in children, indicating that the absence of overt signs cannot rule out aspiration. Moreover, limited availability of instrumental assessments may lead to under-recognition of pharyngeal phase-based feeding

difficulties. Access to instrumental assessments is critical for determining aspiration events (Manikam & Perman, 2000). SLTs determine the suitability and usefulness of instrumental assessments. Instrumental assessments are an important part of SLT management of children PFD for Pharyngeal Sensory Processing and Pharyngeal Motor Function sub-domains, since overt signs of decreased airway protection may not be present. Therefore, SLTs require access to training and facilities to complete the necessary instrumental assessments as required. Furthermore, instrumental assessment reports could be standardised to include PFD specific terminology including the Pharyngeal Sensory Processing and Pharyngeal Motor Function sub-domains.

Final Thoughts

This study explored feeding skills of children between 1 month to 3 years of age with disability in a CDS from Aotearoa New Zealand. The use of the PFD Framework was an effective way to understand the children's feeding skills. All children within the study met criteria for PFD within the Feeding Skill Domain. Caregiver perspectives provided rich information to enhance the SLT clinical notes. The unique presentation of each child's Feeding Skill Domain highlights the importance of collaboration between professionals, the family, and the wider community in supporting children with PFD.

SLT utilisation of the Framework may promote use of a common global language to define the Feeding Skill Domain and increase awareness of PFD, which may encourage colleagues to do the same. PFD is an emerging diagnosis in Aotearoa New Zealand and is not yet recognised as a funded disability. There is research globally indicating the complexity and widespread impact of PFD, and this study contributes to local research.

With greater advocacy and growing research about PFD in Aotearoa New Zealand, there is hope for movement to recognising PFD as a disability, acknowledging the impacts on

families and SLT services, and, in turn, progressing service delivery and training of professionals supporting these children.

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Appendices

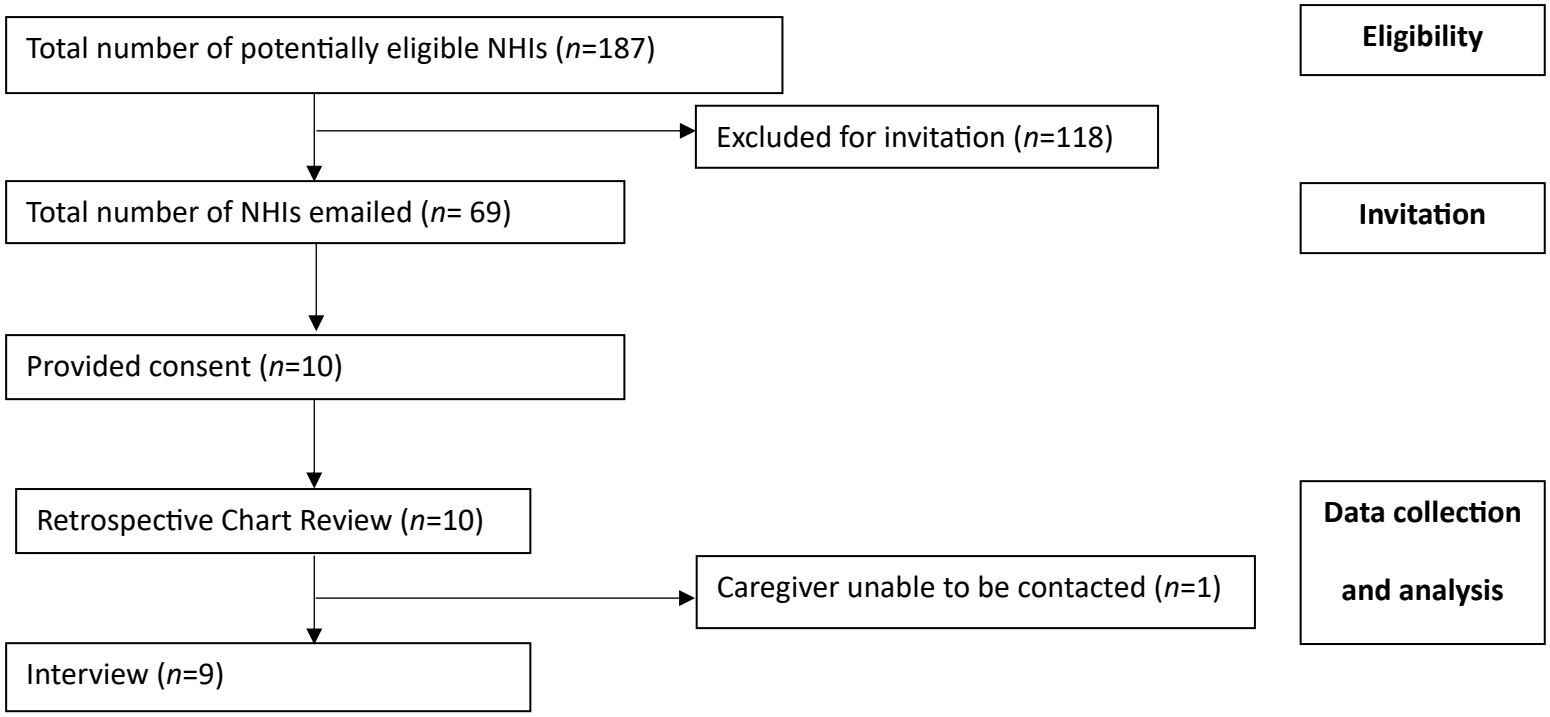
Appendix A: Supplementary Table Three

Examples of Feeding Skill Impairments and Dysfunction associated with Pediatric Feeding Disorder
(Goday et al., 2019)

Impairment (Body functions and impairments*)	**Dysfunction** (Activities and participation/limitations and restrictions*)
Oral sensory functioning • Under- or over-response to sensory aspects of liquids and food textures inhibiting acceptance and/or tolerance **Oral motor function** • Reduced strength, coordination, range of motion, timing inhibiting oral movements required for acceptance, control, manipulation and/or oral transit of liquids and food textures **Pharyngeal sensory processing and/or motor function** • Under- or over-response to bolus during pharyngeal transit or residue remaining post-swallow • Reduced strength, coordination, range of motion, timing impacting pharyngeal transit of liquids and food textures • Inhibiting efficient swallowing and/or airway protection	**Limitation in oral feeding skills** • Unable to consume age-appropriate liquid and food textures • Unable to use age-appropriate feeding utensils and devices • Unable to self-feed at age-appropriate expectations • Unable to use age-appropriate mealtime seating • Requires more assistance or requires special strategies relative to other children of same age • Prolonged mealtime duration • Insufficient oral intake **Restrictions in mealtime participation due to safety concerns:** • Adverse mealtime events (e.g. coughing, choking, gagging, vomiting, discomfort, stress, fatigue, refusal) • Adverse cardio-respiratory events (e.g. apnea, bradycardia, increased work of breathing) • Aspiration

Legend: *International Classification of Functioning, Disability, and Health (ICF) terminology

Appendix B: Participant Flow Chat



Appendix C: Caregiver Email Invite



Invite email to Caregivers

Tēnā koutou katoa/Greetings to you all,

RE: Participation in a master's study exploring children's feeding skills

You are invited to participate in a research study, **Factors affecting feeding skills of children in a Child Development Service.** It is a retrospective study for a master's study at Massey University. The focus of the study is to identify and explore factors affecting feeding skills of Tamariki within the Child Development Service (CDS). We are looking for 10 families for this study, if interest to participate is more than this, we will randomly select 10.
The attached information sheet and video (see link: https://youtu.be/7Z5eulgBc0k) provides more detail of the study. Your choice to participate or not, does not affect any services received at Hutt Hospital.

Participating involves consent for Heidi to access and obtain information from your child's speech-language therapy (SLT) notes from CDS. This provides SLT perspectives on children's feeding skills.
Additionally, participating could involve semi-structured interview with Heidi to discuss your child's feeding. This provides Caregiver perspectives on their child's feeding skills.
Participation in interviews can be arranged in early 2025 based on your availability.
You can choose to consent to *both* (access to SLT notes and interview), *access to SLT notes only* or *none* of the study. If you choose to participate, please contact Heidi, and sign the consent form attached.

A follow up email reminder of this invitation will be resent in five days. If you have any questions about the study and/or your participation, contact Heidi or her supervisors: Heidi.Meyer.1@uni.massey.ac.nz, S.Clendon@massey.ac.nz, E.Jones@massey.ac.nz

Ngā mihi,
Child Development Service Research

Follow up email to potential participants

Kia Ora,
This is a reminder of the invitation to participate in the study per email sent below. If you did not receive the email and are interested in participating, please contact Heidi Meyer Heidi.Meyer.1@uni.massey.ac.nz
If you received the email and do not wish to participate, please ignore this email.

Thanks in advance.

Appendix D: Caregiver Information Sheet

D1 Information

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis

Caregiver information sheet

Tena koutou katoa/Greetings to you all,

Ko Heidi Meyer tōku ingoa/my name is Heidi Meyer. I am a currently undertaking a study as part of my Master of Speech and Language Therapy degree at Massey University's Institute of Education. You may know me as a speech-language therapist (SLT) from Hutt Hospital. Choosing to participate or not will not affect any services you receive from the hospital. **The focus of the study is to identify and explore factors affecting children's feeding skills in a child development service.** My supervisors are Dr Sally Clendon and Mrs Emily Jones.

The study has two phases that require your consent to:

- Access your child's electronic Speech and Language therapy (SLT) notes.
- An interview with you about your child's feeding.

What is this research about?
This research focuses on Tamariki/children within the Child Development Service (CDS) and the factors affecting their feeding skills. Feeding in young children is complex and difficulties affect a large group of the population receiving services from CDS. There is limited information about this group of children within the New Zealand context. Massey University Human Ethics Committee (OM1 24/19) and Te Whatu Ora Capital, Coast and Hutt Ethics Committee have granted me permission to do this research.

Why am I being asked to take part?
Your child has been seen previously by CDS, Hutt Hospital and has met the following selection criteria of the study:

- Your child received services for their feeding from Speech-language therapists between January 2021 and December 2024.
- Your child met the Disability Support Services criteria for CDS input.

What benefits will the research bring?
Findings of the study will be compiled and written into a report. This will add new information to further develop knowledge on children's feeding skills. If you decide to participate in the interview, you will be compensated for your time with a koha (grocery voucher).

What will I be asked to do?
You are asked to consider either option 1 or 2 explained below however are NOT required to agree to either:

1. A. Consent to the researcher accessing SLT notes of your child. The researcher will be the only person accessing the SLT notes using a data collection schedule to gain specific information.
   B. An Interview with the researcher. The interview will be informal, semi-structured and take approximately 60 minutes. Interviews are audio-recorded for transcription. The researcher or a professional transcriber (who has signed a confidentiality agreement) will transcribe recordings.

OR

2. Consent to the researcher accessing SLT notes of your child. The researcher will be the only person accessing the SLT notes using a data collection schedule to gain specific information.

What risks are involved?
The researcher will have access to identifying information from your child's SLT notes. She shall deidentify data collected, meaning no data can be linked back to your child. The researcher reviews SLT notes in a private space and will collect data in a timely way. Upon completion of data collection, the researcher has no further access to SLT notes.

Participants may feel discomfort discussing previous experiences of their child's feeding difficulties, particularly during interviews. The following shall be offered for participants consenting to review of SLT notes or both parts of participation:

- You have the choice to answer or not, stop the interview at any stage and take breaks.
- A support person can be present.
- You choose the location, time, and day of interview.
- The researcher will summarise the interview at the end.
- Details on free/low-cost counselling service and organisations are provided.
- You can review and edit your transcript for up to two weeks (14 days) from time received.

What will happen to the data?
Information you provide will be used alongside information obtained from SLT notes. The data will provide quantitative (through SLT notes) and qualitative (through caregiver interviews) information. No identifying details of individuals will be used in the study. The researcher may share de-identified information with supporting cultural advisors. De-identified findings may be used in presentations and publications arising from the research.

All data is retained for five years upon completion of final thesis report.
Identifiable and de-identifiable data will be safely stored as follows:

- Soft copy data is stored on the researcher's password electronic storage account (Massey OneDrive), which is password protected.
- Hard copy consent forms will be scanned and digitally stored on researcher's password protected Massey One Drive.

If you have any concerns about the process of gathering data, Dr Sally Clendon (S.Clendon@massey.ac.nz) and Mrs Emily Jones (E.Jones@massey.ac.nz).

What rights do I have?
You are under no obligation to consent.
For consent to access SLT notes, you have the right to:

- Ask questions about the study at any time during participation.
- Withdraw from the study up to two weeks (14 days) after consent has been given.
- A summary of the study findings when it is concluded.

For caregiver interviews, you have the right to:

- Bring a support person to the interview.
- Decline to answer any questions.
- Ask questions about the study at any time during participation.
- Provide clarification on the understanding that your name will not be used.

- Ask for the recording device to be turned off at any time during the interview.
- Review and edit the transcript from the interview.
- Withdraw from the study up to two weeks (14 days) after transcript has been sent to you.
- A summary of the study findings when it is concluded.

You may choose to take part in option #1 (consent for SLT notes review & interview) or #2 (consent for SLT notes review only) or none of the study at all. If you agree to take part in the research study, please complete the attached consent form and return it to via email to Heidi.Meyer.1@uni.massey.ac.nz or in person collection can be arranged.

Please contact any of us if you have any questions about the study. Contact details are as follows:

Student Researcher	**Supervisor 1**	**Supervisor 2**
Miss Heidi Meyer Student Speech and Language Therapy Institute of Education Massey University Heidi.Meyer.1@uni.massey.ac.nz	Dr Sally Clendon PhD, Associate Professor Speech and Language Therapy Institute of Education Massey University +64 9 414 0800 S.Clendon@massey.ac.nz	Mrs Emily Jones Senior Professional Clinician Speech and Language Therapy Institute of Education Massey University +64 9 213 6532 E.Jones@massey.ac.nz

This study has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/19. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, humanethics1@massey.ac.nz

Thank you for considering this request. This information sheet is yours to keep.

Ngā mihi,



Heidi Meyer
Student ID: 24003884
Heidi.Meyer.1@uni.massey.ac.nz

D2 Access to Support Handout

Access to support handout

Support groups (feeding specific):

Online, American: https://www.feedingmatters.org/family-support-resources/

Online, Australian: https://childfeeding.org/resources/

Online/in person, Wellington: https://parent2parent.org.nz/locations/wellington/

Counselling and support:

Online, New Zealand: https://www.familyworkscentral.org.nz/counselling/

Online, New Zealand: https://www.kererutherapy.com/

Hutt valley: https://www.takirimai.org.nz/Services

Hutt valley: https://www.pacifichealthhutt.co.nz/

Hutt valley: https://www.huttvalleydhb.org.nz/your-health-services/mental-health/

Hutt valley: https://www.vibe.org.nz/mental-health-services

Hutt valley: https://www.tepaepae.co.nz/our-services

Appendix E: Caregiver Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis

Participant consent form

I have read and I understand the Information Sheet provided. I have had the details of the study explained to me and any questions I have asked, have been answered to my satisfaction. I understand that I may ask questions at any time during the study. I have been given sufficient time to consider whether to participate in this study. I understand participation is *voluntary* and that *I may withdraw* from the study up to 14 days after consent is given.

You can choose to decline participation. If you do not wish to participate in the study, please disregard this document.

IF willing to participate, please **tick the appropriate boxes**

Consent to access the Speech-language therapy notes:

☐ **I consent** to the access and review of my child's electronic Speech and Language therapy notes from the Child Development Service, Hutt Hospital under the conditions set out in the Information Sheet.

Consent to Caregiver interview:

☐ I **DO NOT** consent to an interview to discuss my child's feeding skills under the conditions set out in the Information Sheet.

☐ **I consent** to an interview to discuss my child's feeding skills under the conditions set out in the Information Sheet.

I **agree/do not agree** to the interview being audio recorded. (circle one)

I **want/do not want** to have my transcript of recording returned to me. (circle one)

Declaration by Participant:

I, _____ [PRINT FULL NAME] hereby

consent to take part in this study per above indicated choices.

Signature: _____ Date: _____

Heidi Meyer Student ID: 24003884 MSLT candidate

Appendix F: Retrospective Chart Review Data Collection Schedule

RCR data collection template

Adapted from demographics tool by Jones (2025) & Feeding Skill sub-domains by Goday et al. (2019)

Participant #:
Date coded: Date updated:
Comments/limitations during review:

CHILD CHARACTERISTICS:					
Sex:					
Ethnicities: (mark X)	Māori	Pacific Islander	Asian	NZ European	Other
Catchment area:					
Diagnosed health conditions/Primary diagnosis:					
Age at time of referral:					
Age seen by SLT:					
Age discharged from SLT:					
Duration of input:					
PRIMARY CONTACT:	Mother	Father	Grandparent	Other	
Te Whatu Ora/ Professionals involved (mark X)	Paediatrician	Dietician	CDS	Audiology	Other
FEEDING SKILL/SLT INFORMATION:					
Initial assessment (closest entry after January 2021) **Primary mode of feeding at initial assessment:** **Date:** **Age:**					
Consistency (if several)					

Body function:		
Oral sensory (OS)		
Oral motor (OM)		
Pharyngeal sensory (PS)		
Pharyngeal motor (PM)		
Activity & participation in daily life: (limitations & restrictions)		
Discharge/final assessment (closest entry before December 2024) **Primary mode of feeding at final assessment:** **Date:** **Age:**		
Consistency (if several)		Solids:
Body function:		
Oral sensory (OS)		
Oral motor (OM)		
Pharyngeal sensory (PS)		
Pharyngeal motor (PM)		

Activity & participation in daily life: (limitations & restrictions)		
Instrumental assessment: VFSS/FEES **Date:**		**Age (chronological/adjusted):**
Consistency (if several)		
Body function:		
Oral Sensory (OS)		
Oral motor (OM)		
Pharyngeal sensory (PS)		
Pharyngeal motor (PM)		
Activity & participation in daily life: (limitations & restrictions)		

Green – CG report/discussion (from SLT notes)
Purple – SLT ax initial
Dark red – SLT ax final
Orange – VFSS
Blue – FEES

Appendix G: Retrospective Chart Review Procedure

Before reviewing notes:

- Researcher ensures consent form was signed.
- Consent form uploaded to Massey One Drive.
- Researcher sets up private workspace.
- Data collection schedule is reviewed by supervisors and external SLT.

While reviewing notes:

- Researcher opens Concerto/Single Clinical Portal (medical software) and enters NHI into search tab. Medical information sorted by Service (Child Development Service).
- Researcher allocates participant number.

Using data collection schedule:

- Researcher accesses and records demographic information.
- Use of Starship age calculator as needed: https://starship.org.nz/health-professionals/calculators/corrected-age-calculator/
- Researcher uses information entered by CDS SLT in service forum – usually with the following labels: 'SLT assessment report', 'community progress notes', 'outpatient progress notes', 'SLT clinic letter', 'SLT discharge letter', 'VFSS report', 'FEES report'.

After reviewing notes:

- Researcher scans and uploads soft copies of data stores in Massey One Drive.
- Researcher codes data.
- Researcher brings any questions/consensus to subject matter supervisor.
- Two completed schedules are peer reviewed by supervisor.

Appendix H: Retrospective Chart Review Codes

ORAL SENSORY

Taste:

- Preference for sweet foods

Texture:

- Avoids/separates lumps
- Food separated (vs mixed consistency) – deconstructed
- Sensitivity to wet textures
- Preference for hard/crispy textures

Temperature

Other sensory:

- Tongue poked out mouth after each swallow
- Overfills mouth
- Pocketed whole foods
- Decreased/inconsistent mouth opening to spoon
- Occasionally spit and chew some textures despite adequate oral motor skills reported

ORAL MOTOR

Reduced strength:

- Decreased bilabial seal resulting in occasional anterior spillage
- Anterior spillage left side
- Small bites
- Difficulty biting
- Oral residue
- Some/reduced lip closure
- Weak suck
- Loss of suction/clicking noise

Coordination:

- Tongue quiver
- Hypernasal sounding
- Ate with mouth open
- Stored food on tongue
- Variable suck:swallow ratio
- Increased sucks per swallow (over three sucks) “self-pacing, initially five then one suck per swallow”
- Teat drawn inwards (tongue quiver)
- Poking out tongue (with first solids)

Range of motion:

- Bolus anteriorly
- Some lateralisation

- Tongue bunched anteriorly
- Limited range of tongue wave motions
- Shallow latch – open mouth + sides of tongue seem
- Lip curled in (latch) “minor assistance uncurling lip to latch”

Timing inhibiting oral movements required for acceptance:
- No continuous drinking
- Several swallows per bolus
- Small bolus size
- Ranging bolus size

Control:
- Incohesive bolus resulting in loss to floor of mouth
- “Scraped puree on upper and lower teeth”
- Use of rested pacing

Manipulation:
- Reduced chewing (uses hands to squash food)/variable chewing
- Munching/vertical chewing
- Limited tongue/jaw movement during chewing
- Mashing movements
- Chews and spits out
- Spat out
- Anterior-posterior tongue movements
- Puree pushed out of mouth
- Occasional anterior loss of lumpy pieces (for mashed consistency)

Oral transit:
- Holding in mouth
- Held bolus in mouth for longer periods (piecemeal deglutition)
- Drank water to wash down food
- Disorganised sucking rhythm
- Sucking on puree (vs skilled transiting)
- Effortful oral transit (laboured and increased duration of oral transit)

PHARYNGEAL SENSORY

Under/over responsive:
- Preswallow pooling
- Delayed swallow trigger

Residue:
- Coating-severe residue in valleculae, pyriform, posterior pharyngeal wall

PHARYNGEAL MOTOR

Reduced strength

Coordination

Range of motion

Timing impacting pharyngeal transit

Inhibiting efficient swallow:
- Effortful swallow
- Audible/noisy swallow

Inhibiting efficient airway protection:
- Penetration
- Aspiration

LIMITATIONS

Unable to consume age-appropriate liquid and food textures:
- Use of thickened liquids
- Doesn't tolerate solids other than smooth puree (at 8 months of age)
- Not engaging with soft meats (meatballs) at 18 months of age – throws off plate before eating rest of food
- Liquids via NGT

Unable to use age-appropriate feeding utensils and devices:
- Prolonged drinking from baby bottle (2 years 4 months of age using teat bottle only)
- Not tolerating spoon
- Slower flow teat

Unable to self-feed at age-appropriate expectations

Unable to use age-appropriate mealtime seating:
- Use of specialised seating system
- Eating while moving around

Requires more assistance or requires special strategies relative to other children of same age:
- Eats some meals (not all) e.g. “eats breakfast, morning tea and dinner”
- Given high calorie foods (to manage shorter mealtimes and snacking)
- Delatches requiring support to re-latch
- Disorganised/fidgety body movements
- Grazes

Prolonged mealtime duration

Insufficient oral intake:
- Mixed feeding (non-oral and oral), ‘variable feeding’
- Night time feeds (top-ups for lack thereof during the day)
- Overnight NGT

RESTRICTIONS

Adverse mealtime events:
(choking, vomiting, discomfort, stress, refusal)

- Coughing
- Gagging
- Fatigue
- Eye blinking
- Wet-sounding cough
- Watery, red eyes
- Gulping
- Sneezing
- Vomiting
- Croaky, grunting, gurgly
- Hand splaying
- Hiccups

Adverse cardio-respiratory events:
(e.g. apnoea, bradycardia)

- Increased work of breathing
- Rattly
- Exhaled sigh after each swallow
- Laboured breathing
- Increased respiration rate
- Chesty noise
- Colour changes

Aspiration

Appendix I: Interview Procedure

Arranging interview:

- Researcher ensures consent form was signed.
- Consent form uploaded to Massey One Drive.
- Researcher contacts caregivers to arrange a day/time/place for the interview.
- Researcher reminds the caregiver the day before the interview and ensures accessibility. Reschedules if request/alters interview to improve accessibility.

Prior to interview:

- Researcher receives relevant training on conducting interviews.
- Interview schedule reviewed by supervisors & external SLT.
- Researcher ensures recording device is working.
- Researcher obtains and prepares Koha voucher and thank you envelope.
- Professional transcriber contacted. Transcriber signed disclaimer document.

On day of interview:

- Researcher confirms consent form signed.
- Researcher sets up interview space if hosting (not at interviewee home), if not hosting, researcher acquaints self to location (if interviewee home/public space).
- Researcher communicates to supervisor of whereabouts (location) and duration intended.
- Items to take:
    - Water/warm drink
    - Tissues
    - Hand sanitiser
    - Counselling resource handout
    - Recording device
    - Interview prompts
    - Pen
    - Oral/pharyngeal visual
    - PFD supplementary table
    - Koha voucher in envelope

After the interview:

- Researcher updates supervisor on completion of interview.
- Researcher emails interviewee to thank them for their time.
- Researcher sends transcript to transcriber for typing.
- Once typed, researcher sends transcript to interviewee.

Appendix J: Interview Schedule

J1 Introduction and Scene Setting

Mihi/Introduction

- Greet the participant and engage in conversation about their day/week.
- Affirm gratitude for their participation and time in engaging with my research.
- Ask if the participant would like to do a karakia (if applicable) or start in a specific way.

Whakawhanaungatanga/establish connection

- Introduce self – my background, where I am from, my family, emigration to NZ, student, my interest resulting in study.
- Invite participant to share about themself – where they are from, cultural identity, their family.

Kaupapa/interaction purpose

Provide information on Feeding Skill Domain:

- Acknowledging complexity
- Briefly explaining PFD (table)
- Explaining parts of Feeding Skill Domain (visual)
- Focus of study

"Feeding (otherwise known as eating/drinking) is a complex area with many factors impacting causes and outcomes on everyday life. The purpose of this interview is to gain your perspectives on your child's feeding skill within the paediatric feeding difficulties (PFD) framework. The domain looks at two areas of feeding; mouth (oral cavity) and throat (pharyngeal space) phases of swallow and secondly, the impact of difficulties with these on activities/participation. Our focus will be on your child's eating/drinking skills."

Participant rights:

- Reiterate rights of participant and information sheet

"We will take up to 60 minutes. You can choose not to answer questions. At any time, you can request a break/pause and/or you can ask to stop recording. The information you share will be used as part of a master's study. Your child's and your name will not be used. Information you provide will be kept confidential and stored safely. At the end of the interview a koha voucher will be provided. You may know me from my role at CDS, what you say will not impact services your child receives/will receive through CDS. Do you have any questions before we start?"

Re-establish participant consent

Begin recording

Warm up

- Direct to child's age time point and focus on Feeding Skill Domain

"We know your child received support from CDS from ages of XX to XX (within study timeframe). Let's go back to that time. I will ask some general and potentially also some specific questions related to the stages of eating/drinking they were at during that time.

Picture of oral and pharyngeal cavity
Visual timeline of starting to end point including child's ages

J2 Content Questions

"Let's talk specifically within the oral/pharyngeal section for your child's eating and drinking."

Body function	Liquids (feeding/drinking)	Solids (eating)
Overarching question 1: <u>What were your child's oral feeding skills like at the time?</u>	Breast and/or bottle (0 to 12months) Bottle, sippy cup, open cup, spout bottle (12+ months)	Start with solids (4 to 6+ months) Foods requiring chewing and current eating (12+ months)
<u>Probe:</u> When thinking of oral phase, we think of the job the parts of the mouth play, this includes the way they feel: tastes, awareness, smells (sensory) and the muscles working together (motor) *Oral sensory (OS)* *Oral motor (OM)*	*OS:* Was there need for changes to taste/smell/look? For example, only accepting a specific temperature bottle. *OM:* Were there differences in the mouth phase such as sucking and latching differences?	*OS:* Was there need for taste/smell/look changes? For example, refusing certain types of food, wanting to use a specific bowl. *OM:* Were there differences in the mouth for example opening mouth to spoon, chewing, food in mouth after swallowing? Smaller than expected bolus size or bite size for age.
<u>Probe:</u> Thinking about your child's swallow. Did they experience any effort/discomfort? Did they need multiple swallows? Did anything stay behind after swallowing (sensory) and the muscles working together (motor) *Pharyngeal sensory (PS)* *Pharyngeal motor (PM)*	(if not answered above in oral) PS: Any physiological signs of difficulty? For example, coughing, throat clearing. PM: Was it difficult for them to swallow? For example, incoordination, delayed swallow, or decreased strength.	(if not answered above in oral) PS: ⬅ PM: Were there throat motor differences? For example, incoordination, delayed swallow, or decreased strength.

- Reinforce/emphasis content shared by participant

"Now let's talk about eating and drinking at the time in daily life."

Activity and participation in daily life	Liquids (feeding/drinking)	Solids (eating)
Overarching question 2: Were there limitations to your child or your family's participation in daily life because of your child's these difficulties? Probe: As a result of eating/drinking difficulties: • Were there activities that your child/the family could not do/ had barriers to doing? • Were there challenges with mealtimes? • Did you adapt mealtimes? • Was the time spent eating/drinking within expected range? • Were they eating/drinking enough?	Could they consume age-appropriate liquids? (alternatively, could ask about modifications would imply not age-appropriate?) Could they use cups and drink bottles based on their age?	Could they consume age-appropriate foods? Did food have to be cut into smaller pieces, only certain textures could be broken down? Could they feed themself when they got to the age of doing so? Could they use cutlery based on their age?
Overarching question 3: Were there restrictions/negative events due to eating/drinking related safety difficulties? Probe: Examples of these include choking, gagging, vomiting, discomfort, and refusal of meals.	Any signs of aspiration like coughing, watery eyes, colour changes, breathing harder/faster, chest illness?	⬅

Final question:

- Reiterate useful/insightful information provided.
- Is there anything about your child's eating and drinking at that time that you would like to add that we haven't discussed?

End recording

Poroporoaki/closing:

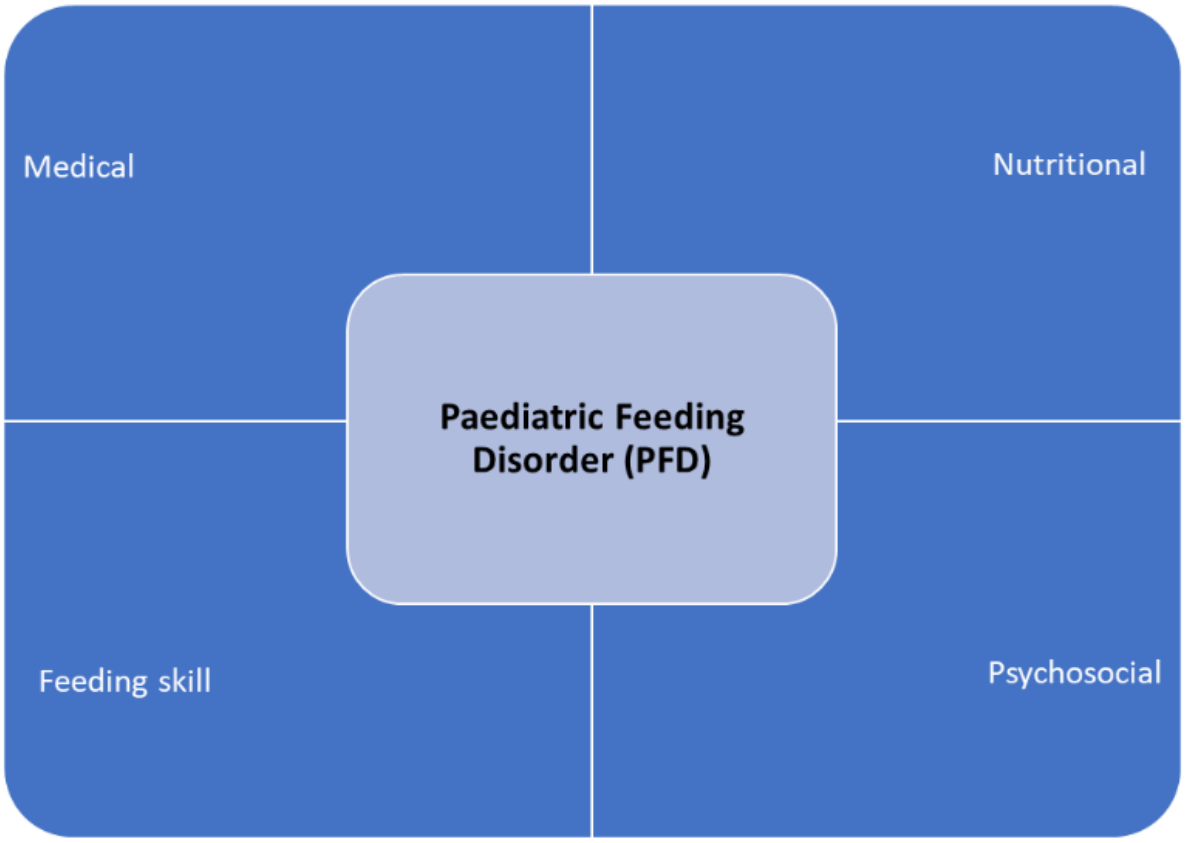
- Thank participant for sharing their experience and acknowledge complexity – *provide list of counselling services if applicable*
- Provide information on how the transcript of the interview will be shared for review, and that researcher and supervisors are available to answer questions about the study.
- Ask participant if they want a copy of study findings once completed (circle one) Yes No
- *Provide koha*
- Initiate closing karakia or goodbyes (as applicable)

J3 Access to Support Handout

Support groups (feeding specific):
Online, international: https://www.feedingmatters.org/family-support-resources/
Online/in person, Wellington: https://parent2parent.org.nz/locations/wellington/
Tube Feeding NZ, Facebook group: https://www.facebook.com/groups/177124695794208/

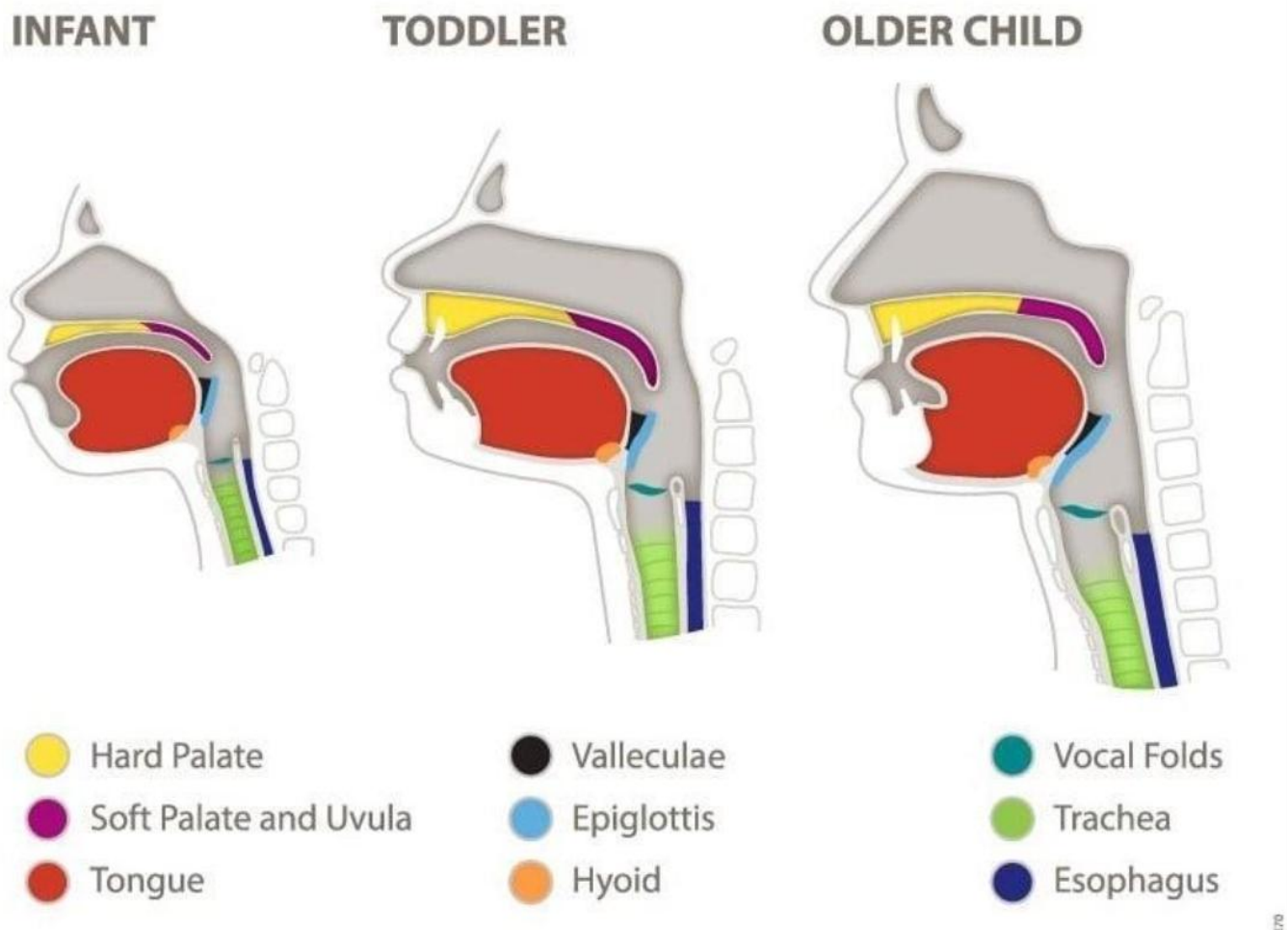
Counselling and support:
Online, New Zealand: https://www.familyworkscentral.org.nz/counselling/
Online, New Zealand: https://www.kererutherapy.com/
Hutt valley: https://www.takirimai.org.nz/Services
Hutt valley: https://www.pacifichealthhutt.co.nz/
Hutt valley: https://www.huttvalleydhb.org.nz/your-health-services/mental-health/
Hutt valley: https://www.vibe.org.nz/mental-health-services
Hutt valley: https://www.tepaepae.co.nz/our-services

J4 Paediatric Feeding Disorder Visual



Pediatric feeding disorder: Consensus definition and conceptual framework, by Goday et al., 2019. *https://doi.org/10.1097/mpg.0000000000002188*

J5 Lateral View Oral and Pharyngeal Phase Visual



Adaptation from Arvedson, J.C., & Lefton-Greif, M.A. (1998). Pediatric videofluoroscopic swallow studies: A professional manual with caregiver guidelines. Copyrighted and used with permission by American Speech-Language-Hearing Association (n.d). Pediatric feeding and swallowing [Practice portal]. https://www.asha.org/practice-portal/clinical-topics/pediatric-feeding-and-swallowing/?srsltid=AfmBOoo54ENmf0XYKU0BZeeWNIJiz23rPjJ7C41Xrgkf7W7ejlQYxmGq#collapse_5.

J6 Examples of Feeding Skill Sub-domains

Body function	**Liquids** Breast and/or bottle (0 to 12 months) Bottle, sippy cup, open cup, spout bottle (12+ months)	**Solids** Start with solids (4 to 6+ months)
Oral sensory:	• Any liquid pocketing/pooling • Refuses certain material of spout cup • Unaware of liquid loss or food in mouth • Prefers certain temperature of liquid • Any over or under reactions to taste/temp of fluids	• Prefers bland foods or spicy foods • Brand-specific preferences • Gags on food despite adequate skills • Unaware of food loss or food in mouth • Prefers certain temperature of food • Any over or under reactions to taste/temp of fluids
Oral motor:	• Loss of food from mouth despite attempts to contain • Slow sucking/weak sucking- loose lip seal on nipple/teat • Needed to give chin/cheek support	• Smaller than expected bolus size or bite size for age • Bolus scatter, oral residue unable to clear • Inaccurate chewing motions, inability to bite through foods, inadequate breakdown of foods • Gagging with foods when unable to move back in mouth or breakdown • Lack of advancement of diet for an entire texture category • Child needed to push food in with fingers to move food into mouth
Pharyngeal sensory:	• Any eye tearing, colour change in face/on around lips, concentrating, staring spells, coughing, throat clearing, heavy breathing, voice changes, gulping • Residue post swallow	
Pharyngeal motor:	• Needed to take breaks with feeding/eating/drinking • Needed a slow flow teat	

Appendix K: Signed Transcriber Confidentiality Agreements

K1 Transcriber One



Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis

Transcriber confidentiality agreement

I [redacted] **(PRINT FULL NAME)** agree to transcribe the recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature: CJMcVie Date: 27 March 2025

K2 Transcriber Two



Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis

Transcriber confidentiality agreement

I [redacted] agree to transcribe the recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature: V Jones Date: 27th March 2025

Appendix L: Health and Disability Ethics Committee Exemption

Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis. is out of scope

donotreply@infonetica.net <donotreply@infonetica.net>
Sat 27/04/2024 10:32 AM

To:Heidi Meyer <Heidi.Meyer.1@uni.massey.ac.nz>

27 April 2024

Miss Heidi Meyer

[redacted]
Lower Hutt
5010
New Zealand

Tēnā koe Heidi

This is an automated message to inform you that, based on your answers in the HDEC screening form, your study Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis. is out of scope and does not require HDEC approval. This does not mean the project does not require ethics review, only that it is out of scope for HDEC review. This scope is described in section three of the Standard Operating Procedures for Health and Disability Ethics Committees.

Please note, your locality may have additional ethical review policies, please check with your locality. **If your study involves a Te Whatu Ora locality, you must contact the locality research office before you begin. If your study involves a university or polytechnic, you must contact its institutional ethics committee before you begin.**

If you consider that our advice on your project being out of scope is incorrect please contact us as soon as possible giving reasons for this.

This letter does not constitute ethical approval or endorsement for the activity described in your application, but may be used as evidence that HDEC review is not required for it.

This form was generated by:

Miss Heidi Meyer

The out of scope determination was made due to the following answers received:

S1 - value	S2. Human Gamete - value	Screen.Study Type - value	Screen.ActiveParticipants - value	Screen.VulnerableParticipants - value
Yes	No	Observational Study	Relatives or caregivers of consumers of health or disability support services	None of the above

Screen.Identified Disclosure - value	Screen.Identified HealthInfo - value	Screen.Consent HealthInfo - value	Screen.Useof Tissue - value	Screen.TissueUseWithout Consent - value
No, identifiers will be attached and the data will be deidentified by the research team	Yes	No, participants have not consented to this	No	

Screen.TissueConsent - value	Screen.TissueExemption - value	Screen.TissueFUR - value	Screen.Features. FullPathway - value	Screen.ClassI Device - value
			None of the above	No

Screen.MastersExempt - value	Screen.Guthrie - value	Screen.Disclaimer - value
Yes	No	Yes

Appendix M: Massey University Human Ethics Application Approval Letter

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

18/09/2024

Dear: Heidi Meyer

Re: Ethics Application - OM1 24/19 - Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis.

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Ohu Matatika 1 at their meeting held on **Tuesday, 9 April 2024**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely



Professor Tracy Riley,
Acting Chair, Research Ethics Chair's Committee

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

Appendix N: Interim Research Advisory Group – Māori Approval Letter

Te Whatu Ora – Capital, Coast and Hutt Valley

INTERIM RESEARCH ADVISORY GROUP – MĀORI (IRAG-M)

14 October 2024

Heidi Meyer
[redacted]

RE: IRAG-M #1134 – Factors affecting feeding skills of children in a Child Development Service. A retrospective analysis.

Tēnā koe Heidi

Thank you for your consideration of ethical issues for whānau Māori. We appreciate that your research aims to contribute to better health outcomes for children. We note that there may be Māori participants in your study and we have provided advice accordingly.

We note your comment that "Strategies for recruitment of Māori were not the focus of the study, and therefore not accounted for." However, research that is conducted without Māori participation may result in findings that are less relevant to Māori and therefore Māori benefit less than non-Māori. Therefore, we urge you to develop strategies and processes to maximise the recruitment and retention of Māori participants in your research. Such strategies could mitigate any potential risk of "re-traumatisation, need for autonomy in the interview process, and generational health inequities" as identified by your kaitiaki Māori.

You state that "This study has not developed patient information and consent forms that are appropriate for Māori." This may be just a wording issue – but PICFs should be appropriate for Māori, whether Māori are the focus of the study or not.

Although you state that no protocols have been made for tikanga Māori, the advice from the kaitiaki Māori does relate to tikanga Māori – supporting autonomy by allowing participants to choose the interview location they prefer, providing koha to participants, taking care not to retraumatise participants. Allowing time for whakawhanaungatanga at the beginning of interviews, and karakia if the participant wishes could be other ways you could incorporate tikanga Maori.

We encourage you to provide contact details for Māori cultural support services on the information sheet, rather than waiting for participants to request it. This is common practice for most health research and may help to raise awareness of such services among Māori whānau.

RAG-M Application Form

We encourage you to consider ways in which the research could support health literacy of participants, while not impacting the findings. For example, is there any information you could provide participants at the end of their interviews that may be helpful for managing feeding? Or contact details for relevant therapy services? Along with the koha, these approaches can help to balance the relationship between participant and researcher and reduce the extractive nature of research (while understanding that the research is being done to improve services and outcomes in the longer term).

We appreciate the professional development you have completed and we encourage you to attend a Research Tikanga workshop facilitated by Te Whatu Ora at Wellington Hospital. This may assist you for future I-RAGM applications.

☑ Your application has been endorsed.

All the best for this research.

Ngā mihi nui,

Interim Research Advisory Group – Māori (IRAG-M)

Appendix O: Locality Approval

From: Research [CCDHB] [redacted]
Sent: Monday, 11 November 2024 10:31 AM
To: Research [CCDHB] [redacted]; Heidi Meyer [redacted]; Heidi.Meyer.1@uni.massey.ac.nz
Subject: Official Notification: Locality Approval Granted: Feeding skill abilities of disabled children inNewZealand: Hutt Hospital

Locality approval ID: 2024-CCHV-304

11-11-2024

Re: Feeding skill abilities of disabled children inNewZealand

Kia ora/Dear Heidi Meyer,

Hutt Hospital

This email acknowledges that the Research Office of Te Whatu Ora - Health New Zealand Capital, Coast and Hutt Valley has received and reviewed a request to conduct a research project and it was **approved** for this research to be conducted in our district.

The approval is provision of annual review and notification to the Research Office of any major protocol amendments, SUSARs as relevant to participants and provision of the final report for the project.

When the researcher receives approval for his/her research project from the Capital, Coast and Hutt Valley District Research Office, they agree to provide HDEC (as applicable) view only access for the approved research project.

If you have any concerns or need additional information, please contact the Research Office at Res-Research@ccdhb.org.nz.

Ngā mihi/Yours sincerely,

Raulle Sol Cruz

Research Manager

Centre of Clinical Excellence | Capital, Coast and Hutt Valley

TeWhatuOra.govt.nz

Capital, Coast | Private Bag 7902, Newtown, Wellington 6242 | 04 385 5999 Hutt Valley | Private Bag 31907, Lower Hutt 5010 | 04 566 6999