Supporting Students With Complex Paediatric Feeding Disorders in a New Zealand Specialist School:

Identifying Barriers and Facilitators to Enable Behaviour Change

Michelle E. Erlam

A thesis submitted in fulfilment of the requirements for the

Master of Science in Speech Science, The University of Auckland, 2024.

Abstract

Background: Complex paediatric feeding disorders (PFDs) are common in children with physical, behavioural, and cognitive needs. This study 1) identifies barriers and facilitators to supporting students with complex PFDs in one specialist school and 2) provides early implementation strategies to change school and health SLTs' behaviour when supporting students with PFD.

Method: During the Observe phase, three data sets were collected: 1) 113 school records, 2) 42 meal observations, and 3) interviews with five teachers, six speech-language therapists (SLTs), and two parents. A Capability Opportunity Motivation and Behaviour (COM-B) analysis was used to identify barriers and facilitators from the data sets to supporting PFDs. In response to the COM-B findings, two implementation cycles were completed, evolving in response to environmental factors and stakeholder involvement. To achieve co-identified behaviour goals, the Behaviour Change Technique Taxonomy (BCTT-v1) was used to identify and implement techniques.

Results: The COM-B analysis established that 34% of students had documented eating and drinking difficulties, and 14% had documented enteral feeding. Inconsistent documentation of management strategies, such as mealtime and enteral feeding plans, occurred, and no standardised assessment procedure was in place. SLTs experienced stress when supporting students with complex PFDs and were concerned about being held liable for students’ health in the school setting. Eating and drinking with acknowledged risk (EDAR) occurred in the specialist school but was not consistently documented or monitored. Families used PFD recommendations flexibly, leading to differences in mealtime management between home and school. School-based SLTs felt professionally isolated, and hospital-based SLTs did not know what support students in specialist schools required. Throughout the implementation cycles, school SLTs were enabled to use various behaviour change techniques to develop their service provision. Gaps in the service provision for school-aged students continue.

Conclusions: SLTs supporting students with complex PFDs in specialist schools need support themselves, often feeling isolated and sometimes fearful. Better collaboration between families, health, and school professionals, alongside more explicit service structures of school-based PFDs, is required to provide students with a holistic, equitable service. Risk is evident in school-aged PFDs, and school SLTs need to better understand the New Zealand legal context to support students and families. Implementation science successfully enabled some behaviour change within a specialist school setting.

Preface

I was the primary researcher in this project, enrolled in a Master of Science at a New Zealand University. I am a New Zealand (NZ) qualified speech-language therapist with training in paediatric dysphagia assessment and intervention as part of my undergraduate degree and three and a half years of work experience before starting this project. Whilst working in specialist and mainstream schools across NZ and the United Kingdom, I supported many families and students with PFDs who required support to make complex feeding decisions. Some of these families engaged in various types of EDAR in educational settings and at home. I found these situations difficult to navigate, often feeling isolated and burdened with the responsibility of the decision. Additionally, I observed SLTs provide varying services, impacted by their experience, confidence and personal beliefs in the absence of school service delivery guidelines. Subsequently, my clinical experience influenced how I engaged with this project and should be noted.

Acknowledgements

This thesis would not have been possible without the trust and support of the host school, the staff and the families who engaged with this project. Thank you for inviting me into your lives and striving for the best outcomes for your students and children. Many SLTs, lawyers and healthcare professionals have supported this project, providing feedback and insight into the barriers we experienced. Your feedback has been invaluable and shaped this project into what it is today.

Thank you to my supervisors, Anna Miles and Bianca Jackson, for your consistent and practical support throughout this project. You validated the issues I experienced in practice and helped me dream of solutions, continually advocating for students who often do not have their own voices. Additionally, I received funding from the School of Psychology, The University of Auckland’s Departmental Research Development Fund (DRDF), which enabled me to complete this project.

No person is an island, and I could not have completed this thesis without support from my inner circle, who provided continual encouragement throughout this process, reminding me to be kind to myself and have a growth mindset. I especially want to thank Petra for your patience, kindness, and practical support in helping me develop my writing style. I will always be thankful for your constant encouragement.

Presentations / Publications

Data from this thesis has been presented at the IALP 32nd World Congress:

Erlam, M., Miles, A., & Jackson, B. (2023, August 21-25). *Barriers and facilitators to supporting children with complex paediatric feeding disorders in a New Zealand specialist school setting.* [Paper presentation]. *International Association of Communication Sciences and Disorders (IALP) 32nd World Congress*, Auckland, New Zealand.

The following peer-reviewed publications are in preparation from this thesis:

Erlam, M., Miles, A., Jackson, B., Moerenburg, M., & Henaghan, M. (in preparation) Ethical and legal considerations when working with children with complex feeding disorders in New Zealand.

Erlam, M., Miles, A., & Jackson, B. (in preparation) Supporting students with complex paediatric feeding disorders in a New Zealand specialist school: Identifying barriers and facilitators to enable behaviour change.

The following open letter to parliament is in preparation from this thesis:

Erlam, M., Miles, A., & Jackson, B. (in preparation) Gaps in supporting students with complex paediatric feeding disorders in a New Zealand specialist school.

Table of Contents

1 INTRODUCTION 1

1.1 Paediatric Feeding Disorder (PFD) 1

1.1.1 PFD: The Medical, Feeding Skills, Nutritional and Psychosocial Domains 2

1.1.2 Who Is Involved in Supporting Children With PFDs 3

1.1.3 Speech-Language Therapy 3

1.2 Person-Centred and Family-Centred Care 4

1.3 Shared Decision-Making 6

1.4 PFD and Ethics 6

1.4.1 Zone of Parental Discretion 8

1.5 Eating and Drinking With Acknowledged Risk (EDAR) 9

1.5.1 Health Considerations for EDAR 10

1.5.2 Legal Considerations for EDAR 12

1.5.3 EDAR Policies and Guidance in Adult Populations 14

1.5.4 EDAR in Paediatric Populations 18

2 SUPPORTING CHILDREN WITH PFDS IN THE SCHOOL SETTING 24

2.1 From Hospital to School-Based Support for Children With PFDs 24

2.2 SLT Support of PFDs in Different Countries 24

2.2.1 United Kingdom 24

2.2.2 United States 25

2.2.3 New Zealand 27

2.3 Collaboration Between Health, School Professionals and Families 32

2.4 Families' Experiences of School Support for Students With PFDs: Barriers 32

2.5 Families' Experiences of School Support for Students With PFDs: Facilitators 33

2.6 School SLT Experiences of Supporting Students With PFDs 34

2.6.1 School SLT Confidence Levels When Supporting Students With PFDs 35

2.7 Suggested Interventions for School SLTs Supporting Students With PFDs 36

2.7.1 Suggested Interventions: Collaborative Consultation 36

2.7.2 Suggested Interventions: Direct Therapeutic Intervention 37

2.7.3 Suggested Interventions: Progressive Disorders or Medically Fragile Students 38

2.7.4 Suggested Interventions: Transition to or From Tube Feeding 38

2.8 School SLT Practices in use 39

2.9 Barriers and Facilitators to School SLTs Supporting PFDs 44

2.10 Recommendations for School SLTs Supporting Students With PFDs 45

2.10.1 Documentation: Policy, Guidelines and Mealtime Plans 45

2.10.2 Coordinated Approach Between Health and School Professionals 46

2.10.3 Engagement Between Staff and Families 46

2.10.4 Educated Staff and Families 46

2.11 Significance of my Research Study 46

2.12 Thesis Outline 47

3 METHOD 48

3.1 Aim 48

3.2 Rationale for the Chosen Methodology 48

3.2.1 Action Research 49

3.2.2 Implementation Science Frameworks 51

3.3 The Current Study 51

3.4 Methods 54

3.4.1 Setting 54

3.5 Observe Phase: Gather Behavioural and Environmental Data 55

3.5.1 Classroom Observations 56

3.5.2 Interviews 57

3.5.3 School Record Documentation Audit 59

3.6 Reflect and Plan Phase: Analysis of Data and Planning for Implementation Cycles 61

3.7 Implementation Cycles 1 and 2 61

4 RESULTS: OBSERVE PHASE - ESTABLISHING THE FACTORS THAT INFLUENCE CHANGE THROUGH CAPABILITY, OPPORTUNITY AND MOTIVATION 63

4.1 Capability: Physical 63

4.1.1 Classroom Staff 63

4.1.2 Students 65

4.2 Capability: Psychological 65

4.2.1 Classroom Staff 65

4.2.2 Families 66

4.2.3 SLTs 67

4.3 Opportunity: Physical 70

4.3.1 School 70

4.3.2 Families 73

4.3.3 SLTs 73

4.4 Opportunity: Social 76

4.4.1 School 77

4.4.2 Families 77

4.4.3 SLTs 78

4.5 Motivation: Reflective 80

4.5.1 Classroom Staff 80

4.5.2 Families 81

4.5.3 SLTs 82

4.6 Automatic Motivation 82

4.6.1 Classroom Staff 82

4.6.2 SLTs 83

5 RESULTS: IMPLEMENTATION CYCLES 1 AND 2 85

5.1.1 Reflect and Plan Phase 85

5.1.2 Accuracy Checking and Data Sharing 85

5.1.3 Intervention Functions and Policy Categories 86

5.1.4 Identification of Behaviour Change Techniques (BCTs) 90

5.1.5 Development of Resources to use in Implementation Cycles 92

5.2 Implementation Cycle 1 92

5.2.1 Meeting With School SLTs to Co-Identify Behaviour Goals 97

5.2.2 Evaluation of the Created Resources 99

5.2.3 Draw Attention to Discrepancies Between Current Practice and Behaviour Goals 102

5.2.4 Introduction of Expectations for Increased Collaboration With Families and Health 103

5.2.5 Discussed Complex PFD Cases With School SLTs and Encouraged Collaboration With Health SLTs 105

5.3 Implementation Cycle 2 106

5.3.1 Health SLTs Complete Training Regarding VFSSs 109

5.3.2 Meeting With SLTs to Evaluate Goals and Review Agreed-Upon Resources 111

5.4 Reflection 116

6 DISCUSSION 117

6.1 Family-Centred Care (FCC) and Shared Decision-Making 117

6.1.1 Risk Tolerances and Informed Decisions to EDAR 117

6.1.2 Collaborative Informed Decision-Making 118

6.1.3 Stepping Into Another Person’s Shoe 120

6.2 Collaboration Between Health, School Professionals and Families 120

6.2.1 Professional and Collegial Isolation 121

6.2.2 Cross-Agency Collaboration 122

6.2.3 Involving Stakeholders 123

6.3 School SLT Experiences of Supporting Students With PFD 124

6.3.1 Fear and Disproportionate Responsibility 124

6.3.2 Change Takes Time 125

6.4 School SLT Practices in use 126

6.4.1 Assessment Practices 126

6.4.2 Inconsistent and Inefficient Documentation 128

6.4.3 Specialist School Service Structure 129

6.4.4 Adapting Information to the Specific Environment 131

6.4.5 Documents Alone do not Change Practice 132

6.5 Limitations 132

7 FUTURE DIRECTIONS AND CONCLUSION 135

7.1 Future Directions 135

7.1.1 Paediatric EDAR Guidelines 135

7.1.2 Advocacy Work for Holistic Care of PFDs 135

7.1.3 Continuing use of Implementation Science Within School Settings 136

7.2 Conclusion 136

8 APPENDIX A 138

9 APPENDIX B 140

10 APPENDIX C 143

11 APPENDIX D 148

12 APPENDIX E 151

13 APPENDIX F 156

14 APPENDIX G 159

15 APPENDIX H 160

16 BIBLIOGRAPHY 163

List of Tables

Table 1: Ethical Principles Discussed in the NZSTA Code of Ethics 7

Table 2: Aspects of Te Whare Tapa Wha and Links to PFDs 9

Table 3: Similarities and Differences Between Adult and Paediatric EDAR 19

Table 4: Life-Limiting Conditions in Children 21

Table 5: Top Five Statements From the Delphi Study 23

Table 6: Distribution of Specialist Schools Across New Zealand 29

Table 7: Risk Rating Table 32

Table 8: Comparison of Common School SLT Practices 40

Table 9: Categories of SLT Practices When Supporting a Student With Oropharyngeal Dysphagia 41

Table 10: Percentage of School SLTs to Complete PFD-Related Tasks 43

Table 11: Features of Participatory Action Research (PAR) and how They Are Suitable for the way the Current Research Was Conducted 50

Table 12: Host Specialist School Therapist Demographics 55

Table 13: Example of Mealtime Observation Data Collection Template 57

Table 14: Interviewee Demographics 59

Table 15: Example of School Record Documentation Audit 60

Table 16: Mealtime Strategies Used by Classroom Staff 64

Table 17: Types of Written PFD Assessments 68

Table 18: Findings From the School Record Documentation Audit 71

Table 19: Differences Between two Local Level Agreement (LLA) Meetings Functioning in Different Geographical Regions..76

Table 20: Breakdown of the Types of Therapy Students Received............................79

Table 21: Consideration of Intervention Functions and Policy Categories Using the APEASE Criteria for This Study 88

Table 22: Behaviour Change Techniques (BCTs) Linked to the Intervention Functions and Policy Categories..91

Table 23: BCTs Utilised in Implementation Cycle 1, Undergoing an Act, Evaluate, Modify Process 94

Table 24: Recommended Behaviours After Initial COM-B Analysis 98

Table 25: Membership and Responsibility of the Advisory Group Members..........100

Table 26: BCTs Utilised in Implementation Cycle 2, Undergoing an Act, Evaluate, Modify Process 107

Table 27: Review of Behaviour Goals and Recommended Behaviours at Evaluation of Implementation Cycle 2..112

Table 28: Review of Resources After Implementation Cycle 1 115

List of Figures

Figure 1: The New Zealand Risk Feeding Guideline Summary Table....................... 16

Figure 2: RCSLT Flowchart for EDAR.. 17

Figure 3: Map of Specialist Schools Across New Zealand 28

Figure 4: Recommended Areas of Practice to Enable School SLTs to Support Students with PFDs.. 45

Figure 5: Overview of Thesis Design 53

Figure 6: Participatory Action Research (PAR) Structure of Act, Evaluate, Modify 54

Figure 7: Overview of Observe Phase 63

Figure 8: SLT Assessments for Students With a Documented Indication of PFDs ... 69

Figure 9 Overview of Implementation Cycles 85

List of Abbreviations

Abbreviation	Long Form
AAC	Alternative and augmentative communication
APA	American Psychological Association
ASHA	American Speech-Language-Hearing Association
BCT(s)	Behaviour change technique(s)
BCTT	Behaviour Change Technique Taxonomy
BCW	Behaviour Change Wheel
BLENNZ	Blind and Low Vision Education Network NZ
CEN(s)	Clinical excellence network(s)
COM-B	Capability, Opportunity, Motivation – factors that influence Behaviour
EDAR	Eating and drinking with acknowledged risk
EHCP	Education, Health and Care Plan
FCC	Family centred care
ID	Intellectual disabilities
IDEA	Individuals With Disabilities Act
IDDSI	International dysphagia diet standardisation initiative
IEP	Individual education plan
LLA	Local level agreement
MoE	Ministry of Education
MoH	Ministry of Health
NBM	Nil by mouth
NHS	National Health Service
NZ	New Zealand
NZSTA	New Zealand Speech-Therapists' Association
ORS	Ongoing Resource Scheme
OT	Occupational therapist
PAR	Participatory action research
PFD(s)	Paediatric feeding disorder(s)
RCSLT	Royal College of Speech and Language Therapists
SEND	Special education needs and disabilities
SLT	Speech-language therapist
UK	United Kingdom

US	United States
VFSS	Videofluoroscopic swallow study
ZPD	Zone of parental discretion

1 Introduction

In the New Zealand specialist school system, speech-language therapists (SLTs) are employed after tertiary-level training to support school-aged children, or students, to access the curriculum by developing their communication skills. SLTs are equally qualified to support students' potential development to eat and drink safely, efficiently, and consistently. This latter function of SLTs is the concern of this thesis. Importantly, although SLTs in specialist schools may be tasked with supporting students’ eating and drinking, it is often contentious and even neglected. A child who is hungry, thirsty, malnourished, frequently unwell with respiratory infections, or anxious around food and drink is not in an ideal or even good enough physiological state for learning (Huffman & Owre, 2008; Power-deFur, 2023).

1.1 Paediatric Feeding Disorder (PFD)

Paediatric feeding disorder (PFD) is a term used to describe the breadth of feeding difficulties that arise from a range of medical, nutritional, feeding skills, and psychosocial factors in children and adolescents (Goday et al., 2019). Historically, multiple terms were used inconsistently to describe the different presentations of children or adolescents with eating, drinking, or swallowing difficulties, as no universally accepted definition existed (Goday et al., 2019; Gosa et al., 2017). For example, a *swallowing* problem or *dysphagia* was used to refer to an anatomical, physiological, or skill-based disorder that impacted an individual’s ability to coordinate a typical swallow. In contrast, difficulty *feeding* indicated behavioural feeding difficulties and disorders, such as avoidant/restrictive food intake disorder (ARFID) (Gosa et al., 2017). Goday et al. (2019) introduced the term PFD to provide a more holistic understanding of how paediatric feeding and swallowing are interconnected, affecting the individual and those around them. Despite this term being adopted worldwide in 2019, much of the literature reviewed in this thesis was published prior to 2019. Subsequently, dysphagia and feeding will sometimes be used in this thesis for literature printed preceding 2019.

As a symptom of many diseases and conditions, paediatric feeding disorders (PFDs) are common and can be disruptive to families. While the exact prevalence of PFDs in children is challenging to calculate, studies suggest that 20-50% of typically developing children and 80% of children with disabilities experience PFD-related difficulties (Benjasuwantep et al., 2013; Lindberg et al., 1991; Pados et al., 2021; Sullivan et al., 2000; Udall, 2007). While these figures are obtained from North American research, it is reasonable to assume that the prevalence of PFDs in New Zealand is similar as such difficulties in children are mostly related to body function and structure rather than environmental factors

(Dodrill & Gosa, 2015). According to the most recent New Zealand Disability survey, there are 941,000 children under 14 in New Zealand, 103,521 of them living with a disability (Statistics New Zealand, 2013). PFD-related difficulties, however, are not recorded in the New Zealand Disability Census. Therefore, if we apply the PFD prevalence data of 80% to children with disabilities, who are the primary focus of this thesis, more than 80,000 (80% of 103,521 = 82,816.8) children in New Zealand will experience a PFD at some point in their childhood.

1.1.1 PFD: The Medical, Feeding Skills, Nutritional and Psychosocial Domains

Eating and drinking are complex processes involving conscious and unconscious control of motor and sensory physiology that are highly tuned for every specific mealtime and feeding context. The PFD diagnosis comprises four interconnected domains that impact multiple aspects of a child's life. The *medical* domain refers to the impaired structure and function of bodily systems, affecting a child's development of *feeding skills* or skills that children require to eat and drink safely and effectively. These feeding skills include the motor and sensory control of structures involved in the process of eating, including oral structures, the aerodigestive tract, hands and postural stability (Goday et al., 2019). For example, a child with cerebral palsy experiences damage to their musculoskeletal and nervous system. They may experience an altered perception of senses, such as hypersensitivity to taste or hyposensitivity to the feeling of food in their mouth and pharynx, which impacts their feeding skills and, consequently, swallow safety (Goday et al., 2019; Taylor et al., 2021).

A child whose bodily systems do not function typically has a reduced capacity to ingest adequate food and fluids, hindering their *nutritional* gains. Children with PFDs are often at a higher risk of malnutrition, dehydration or overnutrition (Goday et al., 2019). Adding complexity to a child's health needs, those who experience difficulties in one domain often experience difficulties in others, subsequently impacting a child's interactions and relationships within a family. For example, children's eating and drinking needs are supported by families, with activities such as food planning, shopping, preparation, and serving, all of which happen within family life.

Many children with PFDs face *psychosocial* challenges as their PFD-related difficulties impact multiple areas of their health and well-being (Goday et al., 2019). Some, for example, demonstrate anxiety, emotional dysregulation, and disordered thinking, thus increasing disruptive behaviours during mealtimes. Sometimes, their behaviours affect interactions with caregivers and the wider family, prolonging mealtime difficulties (Goday et al., 2019). Investigating this phenomenon, Silverman et al. (2021) and Taylor et al. (2021) aimed to measure caregiver stress during these times. Recruiting from an American hospital with caregivers of children aged eighteen months to five years, Silverman et al. (2021) used self-report questionnaires. Taylor et al. (2021), conversely, utilised phone interviews for Australian caregivers of children under 18 with cerebral palsy. Silverman et al.'s (2021) findings concluded that these specific caregivers reported higher levels of stress and altered perceptions of their child as problematic when compared to caregivers with typically developing, same-aged children. Additionally, Taylor et al.'s (2021) caregivers reported concern regarding their children's swallow safety, nutrition, and disinterest in eating meals. Despite different demographics and having access to other services in both studies, most children presented with difficulties in all PFD domains (Silverman et al., 2021; Taylor et al., 2021). Complex PFDs are common regardless of a child's environment, age, and available support.

1.1.2 Who Is Involved in Supporting Children With PFDs

PFDs, and often the medical diagnosis that leads to them, are complex conditions affecting a child's health and family life (Goday et al., 2019). Involving various professionals and collaborating with wider familial networks is considered best practice (Homer, 2016; Jackson et al., 2019; Simione et al., 2020). In New Zealand, SLTs are a key professional group in managing PFDs. The family and child or adolescent may also require input from paediatricians, occupational therapists, physiotherapists, dietitians, nurses, carers, teachers, teacher aides, dentists, oral hygienists, and psychologists, depending on their presentation, needs and setting (Felicetti et al., 2020; Homer, 2008; Homer, 2016; Lefton-Greif & Arvedson, 2008). Each professional uses their expertise to advocate for students to receive holistic care. However, due to the number of practitioners involved, disagreements within the team may arise, adding complexity to the team dynamics and support a child receives (Huffman & Owre, 2008; Jackson et al., 2022; A. Miles et al., 2021).

1.1.3 Speech-Language Therapy

Trained in typical and atypical paediatric feeding development and assessment, speech-language therapists (SLTs) recommend interventions, provide training, and advise on risk management (Jackson et al., 2019). SLTs are legally and ethically able to make recommendations but not mandates to families; ultimately, the caregivers and general practitioners or paediatricians hold the responsibility for the child's care. New Zealand-trained SLTs complete either a four-year undergraduate or two-year postgraduate qualifying degree, including foundational education in anatomy and physiology, as well as training on PFD assessment and intervention. Referring to other services or accessing supervision when required, new graduate SLTs are expected to independently manage non-complex cases (Jackson et al., 2019). In New Zealand, SLTs are typically employed by the Ministry of Health, Ministry of Education, or directly by a school, further discussed in Chapter 2. As school-aged children's PFDs are commonly chronic, they often receive support from multiple agencies and SLTs as they transition into different services.

1.2 Person-Centred and Family-Centred Care

Evolving over time, recent best practice models of service delivery have put professionals in a supporting role (Gillam, 2016; Huffman & Owre, 2008). In the current New Zealand health landscape, person and family-centred care are dominant models. By person-centred care, one recognises that each person is competent in choosing interventions aligning with their values and preferences, empowering individuals to make informed decisions about their care. Clinicians' care is, therefore, guided by one's choices (Forsgren et al., 2022). This model has resulted in improved self-perceptions, reduced stress, increased satisfaction, and quality of life, alongside decreased length of hospital stays and readmission rates (Delaney, 2018; Forsgren et al., 2022; Whitehead et al., 2019). Prevalent in adult-based care, it is often used in nursing (Delaney, 2018) and speech-language therapy practice (Forsgren et al., 2022).

Each country chooses a preferred model of care for clinicians supporting families; some consider person-centred care best suited to this (Royal College of Paediatrics and Child Health, 2021). However, in New Zealand, person-centred care is considered less appropriate when supporting children with reduced capacity, as they are often part of a family unit, each with its own culture and beliefs intertwined with the child's health and well-being (McCarthy & Guerin, 2022). Additionally, caregivers may make decisions for children depending on the child's capacity and understanding, as discussed later in this chapter. For this reason, family-centred care (FCC), which supports the whole family as a unit, is often considered best practice when working with children. A recent systematic review (McCarthy & Guerin, 2022) identified key processes of FCC to be:

- Service operations – service coordination, joint goal setting, working collaboratively, etc.
- Participatory caregiving – forming equal and partnering relationships to facilitate shared decision-making.
- Communicating information and coaching.
- Relational caregiving – being flexible, demonstrating respect, and interpersonal sensitivity.
- Child-focused activities.
- Professional competency and development – clinician upskilling to utilise FCC principles.
- Psychological support – including emotional support and parent counselling as part of the service delivery.
- Support network and community integration – making families aware of existing supports (McCarthy & Guerin, 2022).

While FCC is recognised as best practice, Shields et al. (2012a; 2012b), writing from a nursing perspective, criticised the approach due to the limited evidence surrounding its implementation and efficacy. The authors, however, did not specifically critique FCC in SLT services but evaluated literature relating to hospitalised children. As inpatient hospital care differs from community support, Shield et al.'s (2012a; 2012b) findings have limited generalisations to SLTs working in community or outpatient settings. Conversely, McCarthy and Guerin (2022) completed a recent systematic review evaluating studies that utilised FCC as part of multi-disciplinary team (MDT) services, some of which included SLTs. Most studies employed quasi-experimental designs, with only three (10%) randomised control trials (RCTs) identified. The authors highlighted the paucity of experimental designs evaluating FCC, arguing instead that quasi-experimental ones are best suited to evaluate the complexity of FCC. Additionally, many core principles of FCC make it challenging to assess, such as compromised fidelity to treatment protocols and limited ability to assign participants to control conditions.

Notably, FCC may vary depending on a child's age and environment. Mandak and Light (2018) found that caregivers with young children perceived high levels of FCC from SLTs. On the other hand, caregivers with school-aged children or adolescents perceived lower levels of FCC from SLTs, potentially due to larger clinician caseloads, lack of clinician time, and reduced parent contact compared to early childhood services. The authors, however, did not specify whether children had PFDs, thus limiting the generalisation of these results to SLTs supporting students with PFDs. Families' experiences of FCC within school settings are further discussed in Chapter 2. Gathering perspectives on what mattered most to families with children 2-5 years with PFDs, Simione et al. (2020) found that caregivers valued practices aligning with FCC and strove for outcomes that improved their child's health and quality of life. Families' views may change as their children age; therefore, these findings only relate to those with children from a similar age range. Regardless, the findings demonstrate how health and quality of life are often intertwined for families, influencing the decisions they make.

1.3 Shared Decision-Making

A central component of FCC, shared decision-making involves family and professionals contributing to setting goals and making decisions together. For families to do this, they must be well-informed on possible intervention options and outcomes. Subsequently, better-informed people have more accurate expectations, influencing the types of decisions a family makes (McCarthy & Guerin, 2022; Whitehead et al., 2019). Taylor et al. (2021) found that caregivers often problem-solved to find solutions responsive to their child's behaviours and needs. For this reason, carers preferred professionals who supported them in making feasible and individualised decisions for their families. Worthy of note, however, was that families and professionals did not always agree on a course of action, sometimes creating ethical ramifications for professionals.

1.4 PFD and Ethics

In New Zealand, as in many countries, SLTs and other health professionals must abide by their own Code of Ethics (New Zealand Speech-Language Therapists' Association, 2020). The New Zealand Speech-language Therapists' Association (NZSTA) code stipulates several principles relevant to working with PFDs, shown in Table 1.

Table 1

Ethical Principles Discussed in the NZSTA Code of Ethics (New Zealand Speech-Language Therapists' Association, 2020)

Principle	Example of principles in an area of PFD management
Beneficence and non-maleficence.	SLTs will discuss the options and possible outcomes with a family and child, recommending what will most likely improve or maintain health outcomes (beneficence) while reducing the likelihood of harm the child and family could experience (non-maleficence).
Professional competence.	SLTs will recognise the extent of their PFD knowledge and skills, seeking support from appropriate sources when required.
Promotion and development of the profession.	SLTs will train teams to explain various aspects of PFDs, enabling teams to understand the SLTs' role in supporting PFDs and how the PFD affects the child and family.
Professional integrity.	If families and children make informed decisions against an SLT's PFD recommendations, SLTs will treat the child and family respectfully, upholding their dignity when discussing their case with other professionals.
Fairness.	SLTs will allocate more resources to support families and children with complex PFDs or environments to provide an equitable service. The service may require more liaison with professionals, additional family meetings, provision of information in multiple formats, etc.

These ethical principles quickly become familiar to SLTs working with PFDs, as deciding on the "right" feeding plan for a child is complex. SLTs frequently support families and children to make decisions about oral versus enteral tube feeding, or texture-modified diet versus shared family meals. Families may accept or decline to follow professional recommendations, a legally protected right of health and disability consumers in New Zealand (The Code of Health and Disability Services Consumers' Rights Regulations 1996), further discussed in section 1.5.2.

In Greece, family adherence to SLT recommendations was examined for children aged three to seven years with complex PFDs (Charpentier et al., 2020). Though the authors' use of the word adherence does not align with FCC as it does not infer the use of shared decision-making, the study does provide examples of families who declined to follow professional recommendations. Caregivers adhered to between 56% and 89% of SLT recommendations, except for preparatory strategies, which were adhered to 49% of the time. Families found some strategies were practically challenging to implement, such as the time taken to use sensory warm-up strategies; caregivers found it easier to implement strategies that considered their child's individual difficulties (Charpentier et al., 2020). These results highlight the importance of involving families in shared decision-making to ensure strategies can be tailored to the family's and child's needs.

At times, SLTs may feel that the family's decisions impact their own ability to adhere to their professional, ethical principles, such as *non-maleficence,* where SLTs seek to prevent harm and *beneficence,* where SLTs' professional actions should benefit others (Huffman & Owre, 2008; New Zealand Speech-Language Therapists' Association, 2020). Therefore, it is not uncommon for SLTs to question how they can continue supporting families ethically when the family makes a decision that the SLT considers "risky" and contrary to their own likely more cautious recommendations.

1.4.1 Zone of Parental Discretion

As clinicians have shifted towards FCC and shared decision-making, more space has been created for families to disagree and decline to follow professional recommendations. Askren and Leslie (2019) highlighted that children or families who decline to follow SLT recommendations are frequently labelled non-compliant or non-adherent. Further perpetuating negative biases about the child or family, these terms do not recognise a person's legally protected right to make informed decisions, which is further discussed in section 1.5.2. Gillam (2016), a professor in bioethics with a background in healthcare, created a framework to shape how clinicians approach shared decision-making to address this. The *zone of parental discretion* (ZPD) is a framework allowing caregivers to make decisions that are "good enough" for a child, recognising that a child's care does not have to be optimised. Decisions that are good enough may not align with professional recommendations but would not cause significant harm. An often contentious space, the ZPD will almost always require an element of interpretation. As part of this interpretation, Gillam (2016) advocated that clinicians consider how the child would be affected if the caregivers' decisions were overridden. The ZPD enables professionals to view families more holistically, recognising that while some decisions may be safer for a child's physical health, they can be equally damaging to the family's psychological and spiritual well-being.

Healthcare providers are sometimes criticised for narrowly viewing a person's health as synonymous with physical health, overlooking how culture, preferences, and beliefs affect their well-being (Davis-McFarland, 2008). Durie (1985), a New Zealand expert in indigenous Māori health, created Te Whare Tapa Whā to support individuals to broaden their view of what health encompasses. A health model that visualises four aspects of a person's well-being as four walls of a house, Te Whare Tapa Whā and examples of how PFD may impact this model are outlined in Table 2.

Table 2

Aspects of Te Whare Tapa Whā and Links to PFDs

Aspect/wall	Definition	Example of link to PFD
Spiritual health.	Spiritual awareness includes religious beliefs, practices, and connection to the surrounding environment.	A child's PFD influences their ability to participate in practices important to family culture.
Mental health.	Thoughts, emotions, and their effect on one's body.	Children with PFD may exhibit anxiety, frustration, or apathy around food and drink.
Family health.	How family and friends impact daily life.	PFDs can impact family routines and well-being.
Physical health.	Anatomy and physiology of one's body.	A child's health and their PFD are intrinsically linked.

As seen in Table 2, holistic approaches to healthcare enable clinicians to consider how decisions impact different aspects of a person's life and demonstrate the complexities associated with PFDs.

1.5 Eating and Drinking With Acknowledged Risk (EDAR)

Caregivers or children may make decisions within the ZPD when choosing to eat and drink with acknowledged risk (EDAR), previously called *risk feeding* or *comfort feeding*. EDAR encompasses situations where a child or caregiver decides not to modify food or drink or continues oral intake despite a health professional's assessment that eating and drinking will increase the risk of aspiration, dehydration, and malnutrition (Royal College of Speech and Language Therapists, 2021; Soar et al., 2021; The University of Auckland & Hutt Valley District Health Board, 2016; Whitehead et al., 2019). The term “risk” in EDAR has been controversial, as risk has negative connotations and inappropriately implies that the removal of risk in the form of eating and drinking removes all adverse health outcomes associated with the act of swallowing (Murray et al., 2019; Wallis & Ryan, 2012). Murray et al. (2019) criticised how pervasive the language of risk has become in healthcare to the point where staff disregard a client’s preferences. I will use the term EDAR throughout this thesis to refer to any practices associated with risk feeding or comfort feeding.

It should be noted that risk is poorly defined and quantified in PFD, so although we discuss risk, we do so without clear scientific evidence of what is a sign of risk or how much of it needs to be observed to trigger a more cautious approach (Imdad et al., 2023; A. L. Miller et al., 2024). For example, the term risk may refer to the observation that saliva, food, or fluid from the pharyngeal cavity enters the airway below the vocal folds, otherwise known as aspiration (Rosenbek et al., 1996). Quantifying aspiration is a work in progress, and how much is too much aspiration is unknown. When aspiration occurs, the child may or may not exhibit clinical signs such as coughing and choking. It is generally accepted that children who have a strong, prompt response to aspiration are more likely to clear any aspirated material from the trachea and are, therefore, at less risk than those who have an absent cough response (Dharmarathna et al., 2021; Dodrill & Gosa, 2015; Imdad et al., 2023; A. L. Miller et al., 2024; Rosenbek et al., 1996).

Notably, coughing, choking, and aspiration are all risks associated with eating and drinking and can all occur in someone without a disordered swallow. For this reason, everyone has some degree of risk when swallowing, and it is impossible to create risk-free swallowing conditions. Subsequently, determining risk in children with PFD is far from simple.

1.5.1 Health Considerations for EDAR

EDAR practices are often accompanied by an increased risk of aspiration (Royal College of Speech and Language Therapists, 2021; Soar et al., 2021; The University of Auckland & Hutt Valley District Health Board, 2016; Whitehead et al., 2019). Adverse health outcomes can result from aspiration, including aspiration pneumonia, cobblestoning of the trachea, and bronchiectasis, among others (Imdad et al., 2023; Wallis & Ryan, 2012).

Aspiration pneumonia is a lung infection commonly thought to result from recurrent aspiration, though there is contention about how significant a role aspiration alone plays in developing this. Additionally, some children who aspirate regularly experience no pathological changes or observed effects from the aspiration (Imdad et al., 2023; A. L. Miller et al., 2024; Murray et al., 2019; Wallis & Ryan, 2012). Health outcomes associated with aspiration are multifactorial and are thought to be impacted by the following factors:

- Videofluoroscopic objective measures (e.g., laryngeal penetration vs. tracheal aspiration, pharyngeal constriction ratio, etc.) (Dharmarathna et al., 2021; Imdad et al., 2023).
- Acidity and microbial content of aspirated material.
- Volume of aspirated material.
- Structure of aspirated material (e.g., solid vs. liquid).
- Silent aspiration – absent response to aspiration or an absent cough.
- A child’s co-morbidities.
- A “blunted host response” (e.g., immunocompromised person, prematurity, etc.) (Wallis & Ryan, 2012, p. 138).

Suppose a family or child follow a nil-by-mouth (NBM) diet, where they receive nutrition enterally. In that case, they are still at risk of aspirating on their saliva, potentially harbouring bacteria or other regurgitated material from their stomach (Murray et al., 2019). When a person aspirates on material with a high microbial and acidity content, they are at increased risk of developing adverse health outcomes (Wallis & Ryan, 2012). Therefore, a NBM diet may reduce, but not eliminate, the risk of aspiration or adverse health outcomes.

Recent literature examining the link between videofluoroscopic studies (VFSS) and aspiration risk or health outcomes has been completed with paediatric populations using quasi-experimental, observational designs (Dharmarathna et al., 2021; A. L. Miller et al., 2024) and a systematic review (Imdad et al., 2023). Both study designs reliably analyse data with systematic reviews providing a meta-analysis of the included research (Haynes & Johnson, 2009; Melnyk & Fineout-Overholt, 2023). Additionally, expert opinion pieces have reviewed the literature regarding aspiration, risk, and adverse health outcomes (Wallis & Ryan, 2012). While expert opinion pieces are considered the lowest level of evidence due to the authors' lack of structure, controls, and transparency, they remain valuable in fields with limited literature (Haynes & Johnson, 2009; Melnyk & Fineout-Overholt, 2023), such as paediatric EDAR. Subsequently, the paucity of research compels clinicians to draw from adult-based literature (Murray et al., 2019) but does limit the generalisation of their findings to paediatric populations.

Additionally, a seminal article by Langmore et al. (1998) used a prospective outcomes study design to determine the most significant predictors of developing pneumonia in an elderly population. Whilst dysphagia was a risk factor, having dysphagia alone did not cause pneumonia unless other risk factors were present. The most significant predictors for developing pneumonia were dependency on others for feeding and oral care and being enterally fed before the pneumonia. Additional studies have been completed to further verify Langmore et al.'s (1998) findings and highlighted a total of 20 potential predictors, seven of which were significant predictors of developing aspiration pneumonia (Ball et al., 2023; Hollaar et al., 2016; Langmore et al., 2002; Lanspa et al., 2015). Ball et al. (2023) used a retrospective cohort service evaluation on more recent client files to identify the most significant predictors of developing aspiration pneumonia, the most significant being recurrent chest infections and current sepsis or delirium, followed by an insensate larynx. These conclusions enable SLTs to identify factors increasing the risk of developing pneumonia and demonstrate the complexity surrounding health outcomes and PFDs. These studies were all completed with adult populations, thereby limiting the generalisation of the results to children or adolescents with PFDs. Yet, these risk factors are often prevalent in children with PFD. As no similar studies have been completed on the paediatric population, SLTs must use the available evidence to inform their practice.

1.5.2 Legal Considerations for EDAR

When families or children make choices with increased risk that differ from "safety-focused" professional recommendations, these decisions are often complex and contentious. Health professionals should be familiar with the legal system in their respective countries and recognise when legal advice is required (Kelly et al., 2018). In New Zealand, The Code of Health and Disability Services Consumers' Rights 1996, referred to as The Code, stipulates the rights of individuals receiving health and disability-related services. The Code 1996 identifies that those receiving health and disability services have a legally protected right to make an informed choice and give informed consent.

Families and children have the right to be fully informed and to fully understand their options and the potential outcomes of their options (The Code of Health and Disability

Services Consumers’ Rights Regulations 1996). The Code 1996 stipulates that everyone should receive information that a *reasonable consumer* would expect to receive. Recognising that reasonable consumers are not an identifiable group, Skegg and Paterson (2015), experts in New Zealand medical law, suggest that professionals provide information in a way that is responsive to the family’s prior knowledge, their concern or interest in a particular option, their occupation, and their health literacy. The Code 1996 defines *informed consent* as agreeing with one of the potential options health professionals discuss with those receiving health and disability services, thus enabling families to make informed decisions to receive services, decline to follow professional recommendations, or withdraw their consent.

Anecdotally, SLTs claim to have very little information to guide their practice when sharing information with families and children with PFDs to enable them to make informed decisions. O’Keeffe et al. (2023), a group of experts interested in swallow perspectives, advocacy, and research (SPARC), advocated for clinicians to use language such as “you might consider” instead of “you must”. SLTs’ use of language may enable families and children to view themselves as active decision-makers instead of passive healthcare recipients. Additionally, SLTs should provide accurate and balanced information about relevant treatment options. For example, the authors suggested clinicians openly discuss the adverse effects of modified diets on a person’s quality of life and the potential safety benefits of modified diets. This is because families and children cannot make fully informed decisions if both points of view are not discussed.

SLTs can also draw from informed consent guidelines published by individual organisations, such as the Ministry of Education (n.d.) and Te Whatu Ora (n.d). These guidelines often include country-specific laws or profession-specific codes of ethics but do not thoroughly review research related to informed consent. Due to the paucity of research in this area, the principles discussed by O’Keeffe et al. (2023) can be applied to clinicians supporting families and children with PFDs, even though the information is specifically related to the use of modified diets for adults.

Another legal consideration when supporting paediatric clients is who makes the decision. The Code 1996 specifies that every individual must be presumed competent to make an informed decision unless there are reasonable grounds to indicate that the individual is not competent. Children with PFDs often require surrogate decision-makers, such as family members, because they may be underage or not capable of making their own decisions given their cognitive skills. In New Zealand, those 16 years old and above can make medical and health-based decisions (The Code of Health and Disability Services Consumers' Rights Regulations 1996; Skegg & Paterson, 2015). Children younger than 16 years, however, can be deemed *Gillick Competent,* meaning they can consent to or refuse consent to medical and health-based treatments (Ministry of Justice, 2004). Whilst there is no single test to receive Gillick Competence, professionals often rely on discussions with the child to determine their ability to understand the health-based decision and its outcomes (Larcher & Hutchinson, 2010).

If a child does not receive Gillick Competence, experts in bioethics and paediatric care still advocate for *immature minors* to be involved in decision-making (Hudson et al., 2019). Defining immature minors as pre-adolescents and incompetent to make their own choices, the authors encouraged the principle of child assent to be followed. By this, they referred to the recommendation of a child's involvement within their decision-making process to the full extent of their capacity. In their eyes, this supports and advocates for the future autonomy of the child in question.

The Code 1996 further endorses the principle of child assent, stipulating that individuals with "diminished competence" have a right to make informed decisions to the extent appropriate to their level of competence. An individual's competence is not constant; each decision requires different levels of understanding, and a person's competence can be influenced by their health, social circumstances, and cognitive development as they age (Leslie., 2017). While the capacity of children and those with intellectual disabilities is evidently complex, they should be supported to communicate in such a way that allows for personal agency (Doell & Clendon, 2018). For some, this may be as simple as reading their body language to determine their preferences. For other children, however, alternative forms of communication may be required, such as visuals, talking mats, and communication systems, amongst others.

1.5.3 EDAR Policies and Guidance in Adult Populations

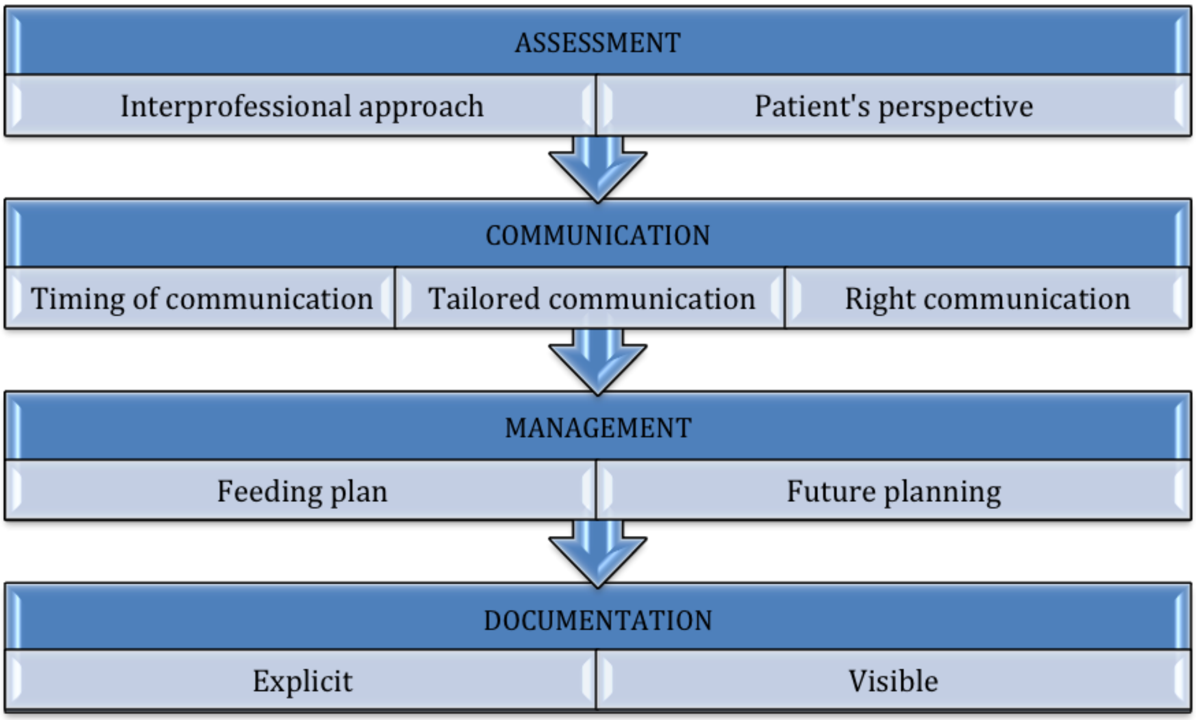
Soar et al. (2021) completed a systematic review identifying 36 articles to determine if EDAR protocols improved client care in community and acute settings, with enhanced health benefits and service provision where a protocol was in place. Primarily focused on adult cohorts, some healthcare outcomes included clients spending fewer days NBM without artificial nutrition, increased documentation of feeding plans, EDAR decisions, and mental capacity assessments. Additionally, Soar et al. (2021) identified factors that influenced the development and successful implementation of EDAR protocols, such as inter-professional communication, communication with patients, and education for clients and families. Though these protocols demonstrated positive outcomes, the amount of EDAR research is small and primarily observational (Haynes & Johnson, 2009; Melnyk & Fineout-Overholt, 2023), and this must be taken into consideration.

The previous factors Soar et al. (2021) alluded to are included in several guidelines and proformas developed by researchers and professionals supporting EDAR in adult populations. In New Zealand, The University of Auckland and Hutt Valley District Health Board (2016) developed risk-feeding guidelines to assist health professionals supporting adults considering EDAR. These were developed by researchers and SLTs who reviewed the literature, interviewed professionals, clients, and their families, completed a clinical documentation audit, and consulted an advisory group. Including evidence-based statements and recommendations, the guidelines below summarise best practice, as seen in Figure 1. The recommendations primarily focus on the active involvement of all team members, person-centred care, explicit documentation of any decisions made, and easy access to documentation for all.

The Royal Hospital for Neuro-Disability (2016) published resources to support the EDAR decision-making process in England. The documentation package included a flowchart to support decision-making, associated legal information, resources to support capacity assessments, and proforma to record decisions. Whilst these were helpful, the resources were limited. Despite being developed by the Speech and Language Therapy and Dietetics department of the Royal Hospital for Neuro-Disability, the authors provided no additional information about how the documents were developed. Unfortunately, this did restrict the robustness of the resources themselves. Furthermore, the documents refer to the English legal system, which confines the generalisation of their use.

Figure 1

The New Zealand Risk Feeding Guideline Summary Table



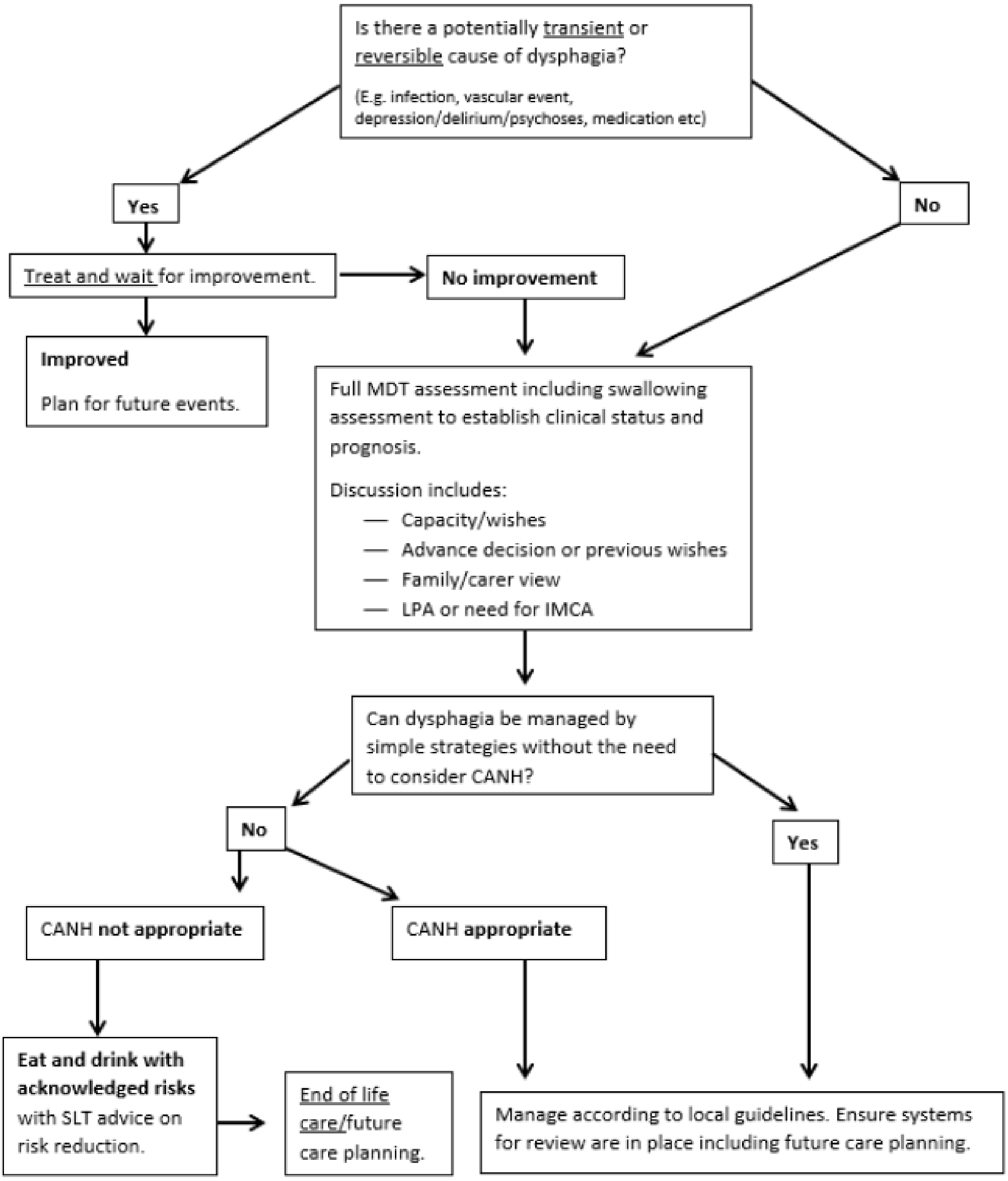
Note. Used with permission from the authors.

More recently, the Royal College of Speech and Language Therapists (RCSLT) (2021) released guidelines developed by a working group that reviewed the literature regarding EDAR. The authors recommended including the following steps during the decision-making process, which is supported by a flowchart as seen in Figure 2:

- Ensure a clinical assessment of swallowing is completed.
- Assess capacity.
- Establish the goal of intervention/care.
- Facilitate communication with the multi-disciplinary team (MDT).
- Set out an advance care plan where appropriate.

Figure 2

The RCSLT Flowchart for EDAR



Note. Used with permission from the authors.

Elsewhere in the world, Speech Pathology Australia similarly published guidelines developed by a working group advising SLTs on how to support adults who EDAR. The authors specify that people who choose to EDAR should not be denied SLT or ongoing treatment for other medical conditions. Instead, they advocated that people who decide to

EDAR should have the right to change their minds at any point, thus ensuring their needs are met (Whitehead et al., 2019).

These organisations and their documentation explored above all recommend that SLTs work collaboratively within multi-disciplinary teams, utilise person-centred care, explicitly document all aspects of intervention, assess a person's capacity, and work within ethical principles. In conjunction, these guidelines recognise that people may choose to EDAR for a range of reasons, such as:

- To participate in social, religious, and cultural practices.
- Individuals utilising enteral feeding and wanting to eat orally for pleasure.
- Difficulty implementing recommendations.
- Preferring to eat specific foods.
- Denial of eating and drinking difficulties.
- Nearing the end of life and wanting to optimise their quality of life (Royal College of Speech and Language Therapists, 2021; The University of Auckland & Hutt Valley District Health Board, 2016; Whitehead et al., 2019).

Once again, it must be noted that the guidelines, resources, and literature above refer to health professionals working with adult populations, thereby limiting their usefulness with paediatric populations. There is, however, a dearth of literature for health professionals supporting children who EDAR. For this reason, adult literature is often adapted to meet the needs of professionals supporting families and children.

1.5.4 EDAR in Paediatric Populations

As mentioned previously, there are similarities and differences between adult and paediatric EDAR, further outlined in Table 3.

Table 3

Similarities and Differences Between Adult and Paediatric EDAR

Similarities	Differences
Limited capacity to make decisions.	Children grow and develop, making their medical and social needs more complex.
Legal and professional requirements for documentation.	Palliative care is often home-based, with families completing much of their cares and procedures.
Considering the quality of life against health deterioration, maintenance or promotion.	
MDT ethical decision making.	Children receive more aggressive end-of-life care compared to adults.
Person-centred approaches.	Family-centred approaches.

Current Practice. Little is known about the practices of SLTs working with children who EDAR. In one study, a practising SLT who frequently supported paediatric EDAR sent questionnaires to RCSLT-registered PFD clinical excellence networks (CENs) in the United Kingdom. Seventy-seven percent of SLTs found determining which children were appropriate for EDAR challenging and described varying confidence levels to support such decisions. When working with families, SLTs did not consistently understand the level of risk associated with EDAR and felt professionally isolated. Additionally, they found it challenging to support parental understanding and compliance with agreed strategies. In response to this, some SLTs discharged children whose families chose to EDAR as they deemed the risk to be too high (Feint & Langeroudi, 2021). While this study was grounded in the realities of community SLT practice with a good grasp on the complexities of this topic, one must acknowledge that these findings were presented to a CEN instead of released in a peer-reviewed journal, reducing their rigour.

Similarly, to investigate New Zealand SLTs' clinical experiences, Jackson et al. (2022) surveyed SLTs supporting school-aged children with complex PFDs, such as EDAR. SLTs provided varying degrees of assessment and management for students with PFD, with 38% of reports being written collaboratively and 63% of reports including risk management. To enable SLTs to support complex feeding decisions, SLTs accessed professional supervision, although this was inconsistent and was not always with a more experienced clinician. In conjunction with this, school staff and MDT members relied on SLTs' eating and drinking assessment, but SLTs were not confident in their prediction of aspiration risk.

While many of these studies described SLT experiences supporting EDAR, little is known about what the practices looked like in community settings. Chadwick (2014) used an exploratory survey to gather information about the practices of dietitians and SLTs when supporting a *tastes* program for people with intellectual disabilities (ID). They describe a form of EDAR where individuals who receive all nutrition enterally eat small amounts of food and fluid, sometimes for pleasure and sometimes to transition from enteral to oral feeding (Chadwick, 2014; Clinical Network for Paediatric Tube Feeding, 2019; Crary & Groher, 2020; Homer, 2016; Jones et al., 2020). Individuals who received tastes typically received 1-9 teaspoons of the food, often a puree or extremely thick fluid (IDDSI level 4). Often targeting a person’s preferences, SLTs and dietitians would offer a variety of foods and fluids, sometimes considering the pH levels of these. Little information, however, was included about the client population who received the tastes, such as their age, who supported them, and in what setting the tastes occurred. Because of this, the literature contains limited descriptions of how others implemented tastes programs and what level of support was provided.

These studies indicate that SLTs across the United Kingdom and New Zealand experience a range of difficulties when supporting families and children who EDAR. In both countries, SLTs struggled to identify risk, which is unsurprising as it is poorly defined and quantified in PFD (Feint & Langeroudi, 2021; Jackson et al., 2022). Some suggested differentiating between *real* and *assumed risks* to facilitate more accurate identification and discussion of risk with families. Real risk encompasses clear and measurable clinical indicators that a child will be seriously harmed, such as identified choking risks, oral feeds that cause a child distress, and repeated aspiration events resulting in life-threatening respiratory conditions. Conversely, assumed risk infers that specific feeding strategies may cause adverse health outcomes, potentially contributing to a shortened life, but definitive evidence of this cannot be provided (Kaizer et al., 2012; Radford et al., 2020).

Recommendations for EDAR. To further this, Radford et al. (2020), experts in PFDs, advocated for clinicians to continue supporting families and children who EDAR, even when they declined to follow SLT recommendations. The authors adapted Chambers and Goldman’s (2018) categories of life-limiting conditions, highlighting four categories of children who receive palliative care to broaden SLTs' perspectives of who may be appropriate for EDAR, seen in Table 4. Category four included children with stable, chronic health conditions causing severe disability, likely limiting the child's lifespan. As many children with complex chronic disabilities (and subsequent PFDs) enrolled in specialist schools fit this category, EDAR may be an appropriate strategy to utilise, further discussed in Chapter 2.

Table 4

Life-Limiting Conditions in Children

Category	Definition	Example conditions
1	Life-threatening conditions for which curative treatment may be feasible but can fail.	Children with cancer when treatment fails, irreversible organ failure, and cardiac anomalies.
2	Life-limiting conditions, where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in everyday activities.	Complex cardiac disease, cystic fibrosis, and Duchenne muscular dystrophy.
3	Life-limiting, progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.	Neurodegenerative conditions (e.g., Batten disease), metabolic conditions (e.g., mucopolysaccharidoses), and neuromuscular conditions.
4	Irreversible but nonprogressive (stable) life-limiting conditions causing severe disability, leading to susceptibility of health complications and likelihood of premature death.	Severe cerebral palsy or multiple disability diagnoses. Complications that may cause death include severe recurrent pneumonias or intractable seizures.

Note. Adapted from (Radford et al., 2020).

Additionally, many children who require dietary modifications or enteral feeds may be good candidates for EDAR. For example, families might have cultural, spiritual, or religious significance associated with food and may gain a sense of spiritual and mental well-being when eating and drinking orally. Furthermore, alternative feeding options may not always be appropriate, and EDAR may be deemed the safest option to maintain nutrition and hydration requirements. SLTs could, therefore, recommend a range of feeding strategies that are responsive to the child’s health. For example, children experiencing stable health may require harm-minimisation strategies when EDAR to reduce any assumed risks. Alternatively, children with deteriorating health may require strategies that prevent choking and create positive experiences of oral feeding. Families then may switch to nurturing tasks (e.g., mouth care, oral tastes) when oral feeding is no longer a positive experience (Radford et al., 2020).

To enable clinicians to better support children who EDAR, Feint and Langeroudi (2021) developed an EDAR care bundle and piloted this with community SLTs working with PFDs in the Evelina London catchment area. The EDAR care bundle included information sheets, flowcharts, and proforma for families and SLTs to complete together to document the EDAR plan. Using a questionnaire, the authors gathered feedback from SLTs who appreciated the “structured and objective” procedure, enabling the team to analyse the risks and benefits of EDAR. The feedback was that they valued having documentation and procedures to guide conversations, ensuring no information was overlooked or forgotten. Feint et al. (2022) then completed a Delphi study to establish a clinical consensus of what components would be helpful in a care bundle for SLTs supporting families and children who EDAR. Thirty-one expert PFD SLTs agreed on the statements in Table 5, enabling SLTs to consider those documents useful in clinical practice.

Table 5

Top Five Statements From the Delphi Study

Top 5 Statements	Mean	Consensus (%)
Documentation of actions taken to minimise risks of EDAR.	1.19	100
Prompt questions to ensure the paediatric client's and/or caregiver's views have been considered.	1.19	100
A section to enable SLT eating and drinking recommendations to be documented and shared with MDT.	1.26	69.8
Capacity assessment prompts to establish the paediatric client's capacity to make an EDAR decision.	1.26	96.8
A written form to enable EDAR recommendations to be communicated to paediatric clients/caregivers.	1.26	90.3

Most of the literature above discusses the management of EDAR from a health perspective, and so little is known about EDAR in educational settings. In New Zealand, SLTs working in a health setting anecdotally receive more in-depth training on assessing and managing PFDs through their workplace. They also can access a higher level of collaboration with other professionals. The exploration of SLT support of PFDs in school settings is the focus of Chapter 2.

2 Supporting Children With PFDs in the School Setting

Whilst PFDs can be a life-long or shorter-term ailment, this thesis focuses on school-aged children in the New Zealand (NZ) specialist education system with chronic conditions. This chapter will discuss the broad framework of management alongside parent and practitioner barriers and facilitators. Perspectives of the stakeholders and the variety of practices internationally provide a background to this implementation study.

2.1 From Hospital to School-Based Support for Children With PFDs

Oral feeding starts at birth and difficulties can be noted immediately, with as many as 42% of infants born preterm having a PFD (Pados et al., 2021). For this reason, many of these children start their journey in a hospital setting, supported by various medical professionals. Supporting families to make informed decisions about their child’s PFD, these professionals provide services based on the family’s health-based decisions. Much of the literature informing health professionals' practice comes from medical teams with access to resources and expertise in a hospital setting (Homer, 2016; Huffman & Owre, 2008; Lefton-Greif & Arvedson, 2008). In New Zealand, once a school-aged child is discharged from the hospital and returns to school, the school SLT primarily supports families with their child’s PFD (Jackson et al., 2019). Delivering services globally in a community-based healthcare model, SLTs support a growing number of children with complex medical conditions who are increasingly stable enough to attend schools. It is for this reason that school SLTs worldwide have experienced heightened responsibility and autonomy (D'Angelo, 2018; Huffman & Owre, 2008; Nottingham & O'Donoghue, 2017; O'Donoghue & Dean-Claytor, 2008). Furthermore, depending on the country, SLTs will have varying practices when supporting students within each school environment.

2.2 SLT Support of PFDs in Different Countries

Each country’s culture, legislation, and protocols influence how professionals support families and their children with PFDs at school, thereby impacting the relevance of research from various countries. The section below describes how SLTs aid students with PFDs in different countries, briefly reviewing legislation where required. Much of the literature discussing school-based PFD support has emerged from the United States (US), a country with different regulations, culture, and funding to New Zealand (NZ). This should be considered when determining how relevant US literature is to a NZ setting.

2.2.1 United Kingdom

In the United Kingdom (UK), most SLTs working in health and school settings are employed by a regional National Health Service (NHS) Trust. This is optional, however, with some SLTs being employed directly by specialist schools or other organisations. Anecdotally and in contrast to New Zealand, British SLTs working in health and school settings find collaboration easier when employed by the same organisation, such as the NHS.

The Special Educational Needs and Disability Code of Practice 2015 stipulated that children with special education needs and disabilities (SEND) must have an Education and Health Care Plan (EHCP). The EHCP includes quantifiable information regarding the level of support a child requires throughout the school day, such as descriptions of teacher aide support and allied health support, including the hours each task requires. A section relating to PFDs is typically included for children requiring that support.

The local government authority reviews each EHCP and makes decisions for the family and person based on what is written within the plan. For example, the local government authority decides on the provision level provided and what school the child is placed in. The SEND code of practice specifies that any decisions should take a person-centred approach. A local mediation process is completed if disputes arise between the local government authority and the family. If unsuccessful, the family or person may take their case to a tribunal to be resolved (Special Educational Needs and Disability Code of Practice: 0 to 25 years 2015). Despite the awareness of PFD, however, there is minimal literature available from the UK about school-based PFD support.

2.2.2 United States

In the United States (US), the Individuals with Disability Education Act (IDEA) stipulates that children have the right to receive a free appropriate public education (FAPE), roughly equating to the same public education available to children without disabilities. To facilitate a FAPE, IDEA lists eligibility criteria, enabling children to receive SLT services in schools (Individuals with Disabilities Education Act, 2004). Whilst IDEA does not include PFD or dysphagia in its eligibility list, it does mention health problems encompassing PFDs (Homer, 2016; Power-deFur, 2009; Power-deFur, 2023). As an increasing number of children with complex PFDs attended schools, the American Speech-Language-Hearing Association (ASHA) advocated for school SLTs to consider PFD as educationally relevant for the following reasons:

1. “Students must be safe while eating in school. This includes providing appropriate personnel, food, and procedures to minimise risks for choking and for aspiration during oral feeding.
2. Students must be adequately nourished and hydrated so that they can attend to and fully access the school curriculum.

3. Students must be healthy (e.g., free from aspiration pneumonia or other illnesses related to malnutrition or dehydration) to maximise their attendance at school.
4. Students must develop skills for eating efficiently during meals and snack times so that they can complete these activities with their peers safely and in a timely manner" (American Speech-Language-Hearing Association, 2007, pp 1-2).

Children with disabilities are required to have an individualised education program (IEP), which includes quantifiable information on the support the child requires. Completed by the team supporting the child, each IEP promotes collaboration between team members (Homer, 2016; Power-deFur, 2009; Power-deFur, 2023; U.S Department of Education, 2004).

Within the US, SLTs are employed to service schools. Some schools employ PFD-trained SLTs to work in a *School-Based Teams* model, where SLTs and other professionals (e.g., OT, PT, nurse, etc.) monitor, assess, and provide intervention for students. School-Based Teams are considered the most effective model of care, but not all schools have access to PFD-trained SLTs. These schools utilise a *System Core Teams* model, where a PFD-trained SLT, OT and nurse travel to different schools across a district to support students with PFD. Ongoing monitoring of students with PFDs is more challenging with a System Core Teams model, however, as the PFD-trained professionals do not regularly see the students and cannot modify any support based on the student's progress (Homer, 2008).

Homer (2008), a US expert in school PFD support, recommended that teams use the following service structure when supporting students with PFDs:

- Student referral to the dysphagia/PFD team.
- Assignment of a dysphagia/PFD case manager.
- Communication with caregivers.
- Screen and clinical evaluation.
- Individual education plan.
- Swallowing and feeding plan and training.
- Individualised health plan and training.
- Referral for instrumental evaluation.
- Implementation of the swallowing and feeding plan.
- Therapeutic treatment.
- Process for transferring and discharging students.

This service structure has since been widely adopted across the US (Homer, 2008; Homer & Carbajal, 2015). However, some components of this service structure are not commonly used in NZ specialist schools, such as “referring students to the PFD team” or “discharging students”. This is because specialist school SLTs in NZ tend to monitor all students with PFD instead of waiting for classroom staff to refer them.

2.2.3 New Zealand

In New Zealand (NZ), the government provides funding through the Ongoing Resource Scheme (ORS) for students from 5 to 21 years of age with the highest level of needs. This funding entitles students to access support from a teacher-aide, specialist teacher, and allied health professionals, such as SLTs, occupational therapists, physiotherapists, and educational psychologists. Those supporting students with ORS funding must collaboratively write IEPs, specifying the additional support the student requires (Ministry of Education, 2011).

Children with ORS funding are given the option to attend either a mainstream or a specialist school. However, only those who attend mainstream schools can access allied health professionals and cultural advisors employed by the Ministry of Education (MoE) (Ministry of Education, 2023c). Children with PFDs in mainstream schools may have two SLTs, one employed by the MoE, who supports students’ access to the curriculum, and one employed by the Ministry of Health (MoH). In mainstream schools, MoH SLTs are responsible for assessing students and creating individualised mealtime and intervention plans. Conversely, MoE SLTs monitor the student’s plan, requesting additional assessment from MoH SLTs when required. An overarching Memorandum of Understanding governs this collaboration between the MoH and MoE alongside a region-specific document called the *Local Level Agreement* (LLA). The LLA enables MoE SLTs to access supervision from MoH SLTs and ongoing collaboration.

Alternatively, students who receive ORS funding can enrol at a day specialist school, from here on referred to as specialist schools. In NZ, there are 27 specialist schools across the country (Ministry of Education, 2024), as displayed in Figure 3. The specialist schools in NZ are highly concentrated in Auckland, as seen in Table 6. No nationwide guidelines, however, stipulate how SLTs should support students with PFDs. In fact, many write their own policies outlining what services they will provide. Despite the lack of nationwide guidelines, specialist schools are in high demand. The number of students enrolled in specialist schools has increased by an average of 162 per year over the past five years, indicating the increasing demand for placements in these schools (Education Counts, 2023). Anecdotally, most specialist schools have waitlists with enrolled students tending to have the most complex needs. Moreover, families occasionally move from the regions to live close to a specialist school so their child can attend one.

Figure 3

Map of Specialist Schools Across New Zealand

Table 6

Distribution of Specialist Schools Across New Zealand

Island	Area	Number of schools
North	Northland	1
	Auckland	10
	Waikato	2
	Coromandel	1
	Bay of Plenty	2
	Hawke’s bay	2
	Manawatu	1
	Wellington	2
South	Nelson	1
	Christchurch	3
	Otago	1
	Southland	1

Students enrolled in specialist schools receive an allocation of funding, which the school uses to employ allied health professionals and cultural advisors. Subsequently, students enrolled in specialist schools do not access support from the MoE staff, and most specialist schools in NZ directly employ their own SLTs. In NZ, no criteria or guidelines stipulate the type or frequency of services specialist school SLTs should provide students. Subsequently, specialist school SLTs independently decide how they support students. Solely responsible for assessing students with PFD, these school SLTs write safe eating plans, provide intervention, and refer for instrumental assessments as required. This is a much broader scope of practice than SLTs employed by the MoE (Ministry of Education, 2024). On the other hand, specialist school SLTs receive less training than MoH SLTs and have less ongoing collaboration with MoH SLTs. This is anecdotal, however, and should be noted as such.

Specialist school SLTs support students to access different aspects of the curriculum, such as literacy, numeracy, language, etc. The NZ curriculum does not explicitly mention eating and drinking, however, it includes a range of skills called key competencies needed for people to maximise their participation in society. One key competency, *participating and contributing,* specifies that students should be supported to “…contribute appropriately as a group member, to make connections with others, and to create opportunities for others in the group.” (Ministry of Education, 2023b, para. 20). Students whose PFD is not supported in school settings may have limited abilities to participate and contribute during the school day, potentially worsening educational outcomes (American Speech-Language-Hearing Association, 2007; Power-deFur, 2023). For example, students who do not receive adequate nutrition are not consistently alert and engaged to participate in their educational context, thereby affecting their attendance. Additionally, students may only be able to participate safely in mealtimes when an SLT has trained staff to minimise choking and aspiration risks.

Furthermore, the NZ government has signed up to the Conventions on the Rights of Persons With Disabilities (2008) and the Rights of the Child (1990). These conventions stipulate that children have a right to access education and healthcare (Convention on the Rights of the Child, 1990) and that people with disabilities have a right to access habilitation, rehabilitation, inclusion in the community, healthcare, adequate nutrition, and education (Convention on the Rights of Persons With Disabilities, 2008). As discussed above, a person’s PFD impacts their:

- Access to education (American Speech-Language-Hearing Association, 2007; Power-deFur, 2023).
- Inclusion in their community at mealtimes and special occasions when food is often the centre of events (Davis-McFarland, 2008).
- Access to adequate nutrition (food and water), which may be affected by the nutritional, feeding skill, medical or psychosocial domain of their PFD (Goday et al., 2019).
- Need for habilitation and rehabilitation, as most people who do not receive treatment for their PFD do not improve (Dumont et al., 2022).

By signing up for these conventions, NZ SLTs are obliged to support children and people with disabilities to access the above rights. As students spend most of their day at school, SLTs are best placed to support PFDs in school settings.

Power-deFur (2023) advocated for US SLTs to support students with PFDs in school-based settings, as US schools have a duty to act *in loco parentis*. A legal principle based on past legal decisions rather than any specific laws, in loco parentis is a common law doctrine. In school settings specifically, the term indicates that teachers and school staff have “delegated powers” to look after a child as a parent would. This term was prevalent in NZ education guidelines in past years and often related to behavioural discipline. NZ legal experts criticised in loco parentis for not considering students' wishes and not aligning with legislation such as The Health and Safety at Work Act 2015 (Hall & Manins, 2001a; Hall & Manins, 2001b). More recent informed consent guidelines, however, stipulate that in loco parentis is no longer considered relevant in the school environment as families must provide informed consent (Ministry of Education, n.d.). Additionally, students accessing a health or disability service, such as those receiving input from a school therapist, have a legally protected right to make informed decisions as specified by The Code 1996 (section 1.5.2). Subsequently, in loco parentis is no longer used within the NZ education system and has been replaced by informed decision-making.

While families and students have legally protected rights to make decisions, schools have legally protected rights to reduce risks for staff and students from a health and safety perspective. The Health and Safety at Work Act 2015 stipulates that schools must provide training, instruction, and supervision necessary to protect staff and students from risks to their health and safety. The Act distinguishes a *hazard*, a person, situation or thing with the potential to cause illness, injury or death, from a *risk*, the likelihood that illness, injury or death may occur when exposed to a hazard. It recommends that people assign a risk rating to hazards and complete actions to reduce the risk of hazards, as seen in Table 7.

As previously discussed in section 1.5, risk is poorly defined and quantified in PFDs, which complicates the use of risk ratings when supporting students with PFDs in school settings. An extreme risk hazard could be students with poor oral motor skills and a tendency to overstuff their mouths when eating IDDSI level 7 foods, potentially resulting in a choking incident causing death or permanent injury. For this reason, The Health and Safety at Work Act 2015 encourages introducing alternate activities to reduce the risk of extreme-level risk hazards. One such high-level risk hazard could be students with pharyngeal-level dysphagia wanting to eat food different from their recommended IDDSI levels. The student may aspirate and develop pneumonia that might require medical treatment. However, much of the associated risk with this case is assumed risk (section 1.5.4), and multiple factors impact the development of aspiration pneumonia and adverse health outcomes (section 1.5.1). The Health and Safety at Work Act 2015, therefore, recommends minimising the risk by introducing *controls* that reduce the risk's consequences or the chance of it occurring. This indicates that schools could legally accommodate high-level risk hazards if controls were introduced, and it was deemed the best solution by the family and student. These students are highly complex and require professionals to work collaboratively to best support them student.

Table 7

Risk Rating Table

Assessed risk level	Risk level description	Actions
Low	If an incident occurs, there is little likelihood of injury.	Undertake with existing mitigations.
Medium	If an incident occurs, there is some chance of injury requiring first aid.	Additional rules or considerations may be needed.
High	If an incident occurs, the injury would likely require medical treatment.	Controls will need to be in place before undertaken.
Extreme	If an incident were to occur, it would be likely that death or permanent injury would result.	Consider alternatives to the activity or additional significant safety measures required.

2.3 Collaboration Between Health, School Professionals and Families

Under the Memorandum of Understanding between the MoE and MoH, school and health SLTs are guided to collaborate to provide services to families. Collaboration is consistently recognised as essential, yet C. K. Miller (2009) aptly described the process as “elusive”. School SLTs are encouraged to routinely collaborate with health teams to gather clinical information, attend instrumental assessments, discuss SLT recommendations, and request support for students’ complex PFDs. In conjunction with this, health teams rely on school SLTs to monitor a child’s PFD, report changes, provide information before instrumental assessments, and implement ongoing therapy (Homer, 2008; Homer & Carbajal, 2015; Lefton-Greif & Arvedson, 2008; C. K. Miller, 2009). School SLTs often rely on families to provide general medical information regarding their child’s PFD. As students with chronic PFDs typically receive input from health teams in their first few years, families spend years learning how to adapt to their child’s PFD and become experts on how to support their child (D'Angelo, 2018). Each team member brings a unique perspective, each relying on the other to provide holistic support for the student.

2.4 Families’ Experiences of School Support for Students With PFDs: Barriers

Few studies have examined families' perspectives and experiences of receiving support for their school-aged child's PFD. One study, however, gathered families' perspectives on the barriers and facilitators to school-based PFD support using interviews (Angell et al., 2008), while another summarised family experiences of PFD-related support from schools (Angell et al., 2009). More recently, A. Miles et al. (2021) used interviews and a documentation audit to determine barriers and facilitators to school-based PFD support, although they did not speak to families directly. The findings from these articles are summarised below.

Findings suggested that families found it challenging to work with therapists who had negative dispositions or attitudes, minimal interest in PFDs, or a limited understanding of PFDs. Lack of communication between school and home was a barrier. Because families adapted students' plans and strategies daily in response to their changing PFD presentations, they found it challenging to communicate this with schools that sought a clear structure and process to follow. When schools wrote PFD plans, families did not consistently understand them or their rationale (Angell et al., 2008; Angell et al., 2009). Subsequently, disagreements occasionally occurred between the family and school about how to support a student's PFD (Angell et al., 2008; Angell et al., 2009; A. Miles et al., 2021). Additionally, sometimes families found it difficult to progress their child's plan before their allotted review time (A. Miles et al., 2021). Despite these, facilitators existed that supported their child at school.

2.5 Families' Experiences of School Support for Students With PFDs: Facilitators

Within these studies, families found it easiest to work with therapists who were willing to learn, expressed genuine concern for students and an openness to other opinions. Therapists who utilised family knowledge and perspectives, with congruence between school and home goals, designed plans that were deemed to be more effective by families (Angell et al., 2008; Angell et al., 2009). Despite valuing IEPs and annual meetings, families recognised they were not enough to facilitate more consistent communication between home and school but appreciated home-school notebooks, phone calls, and regular emails (Angell et al., 2008; Angell et al., 2009; A. Miles et al., 2021).

The authors advocated for school staff to create a safe space where families could openly share opinions, so each person's perspective was heard and a consensus reached. For this reason, families and staff required training on how to best support students with PFDs (Angell et al., 2008; Angell et al., 2009; A. Miles et al., 2021). Preferring training to occur at home, families sought strategies curated to the home environment with therapists who could model the recommended strategies with their children (Angell et al., 2008; Angell et al., 2009). It was clear from this that a supportive, interested, and knowledgeable therapist could facilitate family involvement with the school around PFDs, whilst the opposite was also possible.

However, Angell et al. (2009) did not divulge which articles were included in their synthesis. They did not use a standardised method of literature synthesis, such as a scoping review or systematic review, thereby limiting the article’s validity. Both Angell et al.’s (2008; 2009) articles refer to literature and report results older than 10 years, which also narrows the article's relevance. However, the American Psychological Association (APA) (2020) do not recommend age limits when citing studies, recognising that some articles influence areas of practice for longer than 10 years. Despite these limitations, few studies have been published on this topic, making these articles valuable to understanding families’ perspectives on PFD management in schools.

2.6 School SLT Experiences of Supporting Students With PFDs

Much of the research relating to school-based PFD management has been completed in the United States (US) and conducted around 2007, coinciding with ASHA’s (2007) release of guidelines stating that PFDs were educationally relevant. Research into school-based support for students with PFDs has since tapered off, making most of the articles included in this chapter older than 10 years. As mentioned above, these articles have continued to be valuable to the field despite their age (American Psychological Association, 2020).

As school SLTs in the US saw more students with complex PFDs on their caseloads (Bailey et al., 2008; Huffman & Owre, 2008; Owre, 2006), several authors attempted to understand school SLTs’ experiences and perspectives. Bailey et al. (2008) ran focus groups, and Hutchins et al. (2011) released a survey to gather school SLTs’ perspectives on supporting students with PFDs. School SLTs did not consistently receive training on PFDs in their professional education, and some had little experience supporting this population (Bailey et al., 2008). Most SLTs agreed that supporting PFDs was educationally relevant and part of their role in schools. The majority viewed themselves as responsible for completing additional PFD training to raise their competency levels and knew how or where to access it (Hutchins et al., 2011).

SLTs were fearful about supporting their students’ PFDs and wanted to make mealtimes as safe as possible. School staff did not always comply with dietary modifications recommended by hospital staff, and school SLTs requested support from community-based medical teams (Bailey et al., 2008). Additional support was requested, such as district procedures, protocols and guidelines, school administrative provision, or input from health teams (Bailey et al., 2008; Hutchins et al., 2011). Bailey et al. (2008) suggested that dismissing SLTs' concerns would be detrimental to future service delivery and support of PFDs in schools.

2.6.1 School SLT Confidence Levels When Supporting Students With PFDs

School SLTs experienced varying confidence levels when supporting students with PFDs, and because of this, Hutchins et al. (2011) and O'Donoghue and Dean-Claytor (2008) used surveys to gather this data. It was found that SLTs with previous experience in medical settings, who had supported students with PFDs in school settings, and had PFD-related training had higher confidence levels (Hutchins et al., 2011). Contrastingly, seventy-one percent of SLTs trained after the year 2000 had confidence levels under 50%, and 62-82% of SLTs trained from 1980-2000 had confidence levels of under 50% (O'Donoghue & Dean-Claytor, 2008). These results demonstrate that most SLTs have low confidence levels regardless of when they are trained, indicating that SLTs' confidence levels are influenced by other factors, such as collaboration, guidelines, and experience.

More recently, Felicetti et al. (2020) used a Likert scale survey to determine the *comfort levels* of school SLTs supporting students with PFDs. The phrase "comfort level" has slightly different connotations to "confidence level", as the word comfort denotes more emotion than confidence. However, the two words were considered similar enough to compare results. Sixty-one percent of school SLTs were uncomfortable supporting students with PFDs, with Likert scale ratings of 1 or 2, which aligns with O'Donoghue and Dean-Claytor's findings (2008). SLTs with more experience who had worked in other settings, such as hospitals or schools, were more confident, again aligning with Hutchins et al.'s findings (2011).

Similarly, Neubauer and Singleton (2023) used a Likert scale survey to gather school SLTs' confidence levels for PFD-related roles and responsibilities. After developing a list of 17 roles and responsibilities for school SLTs supporting students with PFDs, the authors asked participants to rate their confidence in each item, seen in Table 9. SLTs selected a mode Likert scale rating of 1 for 59% (10/17) of the listed roles, indicating they were not confident completing most roles, seen in bold font in Table 9. SLTs selected a mode Likert scale rating of 5 for 12% (2/17) of the roles, indicating they were very confident completing a small number of roles. These roles were "recognising signs of choking" and "knowing when to refer to medical professionals". SLTs with more experience who had taken more professional development courses, however, had higher confidence levels, again aligning with the previous studies (Hutchins et al., 2011; O'Donoghue & Dean-Claytor, 2008). These results indicate that US SLTs continue to feel underconfident when supporting students with PFD in schools.

Notably, fifteen percent of SLTs supporting students with PFDs in schools reported high confidence levels despite having minimal coursework or experience related to PFDs (O'Donoghue & Dean-Claytor, 2008). Hutchins et al. (2011) speculated that these SLTs did not fully grasp their lack of knowledge and skills relating to PFDs. SLTs' ability to reflect on their practice, access supervision, collaborative practice, and ongoing professional development will likely impact their confidence levels when supporting students with PFDs. For this reason, SLTs should be aware of the recommended practices for supporting students' PFDs in school settings.

2.7 Suggested Interventions for School SLTs Supporting Students With PFDs

Experts in the field have recommended various practices to guide school SLTs to support students with PFDs (Homer & Carbajal, 2015; Homer, 2016). Separated into four different areas, these practices will be further discussed below:

- collaboration consultation.
- direct therapeutic intervention.
- intervention with students with progressive disorders or medically fragile students.
- transition to or from tube feeding.

2.7.1 Suggested Interventions: Collaborative Consultation

SLTs engage in collaborative consultation when supporting school staff to monitor a student's PFD. Homer (2015; 2016) outlines the following tasks involved in this type of practice:

1. Monitoring the implementation of the swallowing and feeding plan.
2. Sharing information with swallowing and feeding team members (e.g., training).
3. Coordinating swallowing and feeding team members (e.g., collaboration).
4. Using feedback as part of the consultative process (e.g. coaching).
5. Resolving conflicts throughout the process.

For example, once a mealtime plan has been created, school SLTs support classroom staff to follow the strategies and environmental modifications specified. The plan may include food presentation and feeding strategies (e.g., pacing, verbal cues, encouraging dry swallows, food placement in the mouth, etc.), use of feeding equipment, positioning, and diet modifications (e.g., IDDSI levels). School SLTs often train and coach staff on how to follow mealtime plans or increase their PFD-related knowledge (Bailey et al., 2008; Homer, 2016; Mabry-Price, 2015). School SLTs collaborate with external health professionals when required and resolve conflicts, sometimes relying on school senior leadership teams and external health professionals during the resolution process (Homer, 2008; Homer & Carbajal, 2015; Homer, 2016; C. K. Miller, 2009).

The above literature guides SLTs' practice but constitutes *expert opinion pieces,* which are the lowest level of evidence due to their lack of structure, controls and transparency when critically appraising articles (Ingham-Broomfield, 2016). The authors often write from their own experience, demonstrating their use of clinical expertise as part of evidence-based practice (EBP). Clinical expertise is essential in guiding SLTs' practice, particularly when research in the field is sparse (Haynes & Johnson, 2009; Melnyk & Fineout-Overholt, 2023).

2.7.2 Suggested Interventions: Direct Therapeutic Intervention

The second area of practice involves the provision of direct therapeutic interventions (Homer & Carbajal, 2015; Homer, 2016). Few studies review PFD-related direct therapeutic intervention for school-aged students, as many studies include children too young to attend school. Gosa et al. (2017) completed a systematic review of therapeutic interventions for children with PFDs, 86% of whom were between two and seven years of age. Considered the highest level of evidence, systematic reviews analyse the study's quality, enabling SLTs to critically analyse the information and apply it to their caseload (Haynes & Johnson, 2009; Melnyk & Fineout-Overholt, 2023). The authors demarcated direct therapeutic intervention into three categories: oral motor interventions, sensory-based interventions, and behavioural-based interventions.

Oral motor interventions. Oral motor interventions include a range of exercises that move the structures and muscles involved in swallowing to improve muscle strength, tone and coordination. When choosing specific exercises for students based on their current skills and areas of development, SLTs target functional skills, such as chewing, cup drinking, spoon feeding, etc. Oral motor exercises prompt students to move muscles or structures against resistance either by using chewy tubes or food to target skills (e.g., use of transitional foods, placing foods on back molars, etc.). Adults sometimes use equipment such as vibrating toys to stimulate oral structures to enable movement (Gosa et al., 2017; Homer, 2016). In Gosa et al.'s (2017) systematic review, oral motor interventions received a phase one level of evidence rating, the least robust of the five phases. Most of the papers examined oral motor interventions in combination with other interventions. Despite the limited evidence, Homer

(2016) advocated for therapists to continue using oral-motor interventions owing to the strong clinical expertise supporting their usefulness.

Sensory-based interventions. Sensory-based interventions include activities promoting sensory integration, such as brushing, weighted vests, deep pressure to joints, etc. (Gosa et al., 2017). All papers examined sensory-based interventions in combination with others, reducing one's ability to determine the effectiveness of these in isolation. Gosa et al. (2017) rated sensory-based interventions as having a phase one level of evidence. Despite this, sensory-based strategies are still used by SLTs, again owing to the strong clinical expertise supporting their usefulness (Homer, 2016).

Behavioural interventions. Behavioural interventions include protocols utilising the following strategies: positive reinforcement and extinction, stimulus shaping and fading, caregiver involvement and education, systematic desensitisation, and operant conditioning (Gosa et al., 2017). While there were a greater number of experimental and quasi-experimental designs for behavioural interventions with higher quality designs, Gosa et al. (2017) deemed the overall quality of designs to be phase 1.

Overall, the quality of research for direct intervention is low, which impacts SLTs' ability to draw valid conclusions about the efficacy of an intervention for students with PFDs (Gosa et al., 2017). Despite this, Homer (2016) encouraged SLTs to utilise interventions that result in positive changes for students, discontinuing strategies if no progress is measured or observed.

2.7.3 Suggested Interventions: Progressive Disorders or Medically Fragile Students

The third area of practice involves supporting students who are medically fragile or who have progressive disorders, as discussed in Chapter 1. This area of practice heavily relies on effective communication between family members and the medical team supporting the student (Gillam, 2016; C. K. Miller, 2009; Radford et al., 2020).

2.7.4 Suggested Interventions: Transition to or From Tube Feeding

The final area of practice involves transitioning to or from tube feeding, again reliant on effective communication between the family, school team, and the medical team (Clinical Network for Paediatric Tube Feeding, 2019; Jones et al., 2020). When tube weaning, students require multiple forms of direct intervention to develop oral-motor skills, oral-sensory skills and behavioural skills associated with oral eating and drinking (Clinical Network for Paediatric Tube Feeding, 2019; Homer, 2016). A New Zealand study found that health SLTs viewed tube weaning as a priority and advocated for transitioning, which was not the case for non-health SLTs. Once children reached school age, tube feeding was normalised, and tube feeding dependency was less of a concern (Jones et al., 2020). Homer (2016) highlighted that schools do not have total responsibility for transitioning students from tube to oral feeds, but schools can support students throughout the process. For example, schools can introduce small amounts of new food to students. Multiple studies review how closely school SLT practices align with the recommended practices.

2.8 School SLT Practices in use

As discussed above, school SLTs can support students with PFDs in various ways that are responsive to the school setting and students' needs, yet SLT support is often dependent on their level of knowledge. Homer (2008) supported the implementation of school-based PFD support in the Louisiana school district. SLTs "monitored" or "provided consultation" for 65% of students who were nil-by-mouth (11%) or orally fed (54%) and provided "direct therapy" for 35% of students who were nil-by-mouth (4%) or orally fed (31%).

Hutchins et al. (2011) and Owre (2006) used surveys to determine the most common practices of school SLTs supporting PFDs in Vermont (Hutchins et al., 2011), across 41 states and two countries (Owre, 2006). These findings are listed in Table 8. Hutchins et al. (2011) used the same PFD-related practices as Owre (2006) to facilitate a comparison of the results across the two studies. Unfortunately, Owre (2006) did not specify how they analysed their data, and Hutchins et al.'s (2011) data varied too greatly to be compared. For example, Hutchin et al.'s (2011) participants' most frequent practice was 17.3%, and Owre's (2006) participants' most common practice was 42%. No explanation was given for why the percentages differed (Hutchins et al., 2011). Therefore, I have chosen not to compare the percentages between the two studies but the order of practices.

Some practices had similar rankings across the two studies. For example, "evaluation and provision of hands-on therapy" was the most common practice in Owre's (2006) findings and the second most common in Hutchins et al.'s (2011) findings. In both studies, the least common practice was the "implementation of established district-wide dysphagia programs and procedures". The similarities between the two studies demonstrate how SLTs across the country prioritised direct therapy yet consistently found implementing a district-wide dysphagia program challenging to achieve. Other practices had markedly different rankings, such as the "provision of in-service training for school staff", ranking second in Owre's (2006) findings yet seventh in Hutchins et al.'s (2011). These differences demonstrate how factors, such as geography or the passing of time, can influence SLTs' practices.

Table 8

Comparison of Common School SLT Practices

Order of practices	Frequency and percentage of types of PFD management from Hutchins et al. (2011)	Top 10 common SLT practices in PFD management from Owre (2006)
1	Collaboration with other professionals (17.3%).	Evaluation and provision of hands-on therapy (42%).
2	Evaluation and provision of hands-on therapy (15.4%).	Provision of in-service training for school staff (39%).
3	Identifying and referring to medical personnel (15.4%).	Obtaining medical information from the child's physician (37%).
4	Establishing accommodations and precautions only and ensuring follow through as a consult (15.4%).	Identifying and referring to medical personnel (35%).
5	Coordinating with medical SLP and school team to evaluate and plan intervention (13.5%).	Collaborating with other professionals (30%).
6	Obtaining medical information from the child's physician (13.4%).	Managing dysphagia interventions independently (26%).
7	Provision of in-service to school staff regarding dysphagia and safe feeding (7.7%).	Coordinating with medical SLT and school team to assess and plan (26%).
8	Obtaining medical clearance from a physician for dysphagia intervention (7.7%).	Obtaining medical clearance from a physician for dysphagia intervention (25%).
9	Managing dysphagia interventions independently (3.8%).	Establishing accommodations and precautions only and ensuring follow through as a consultant (25%).
10	Implementation of established district-wide dysphagia programs and procedures (1.9%).	Implementation of established district-wide dysphagia programs and procedures (14%).

Felicetti et al. (2020) used a survey that included a case study of a child with oropharyngeal dysphagia to gather data on how participants would support the child's PFD. Each SLT participant wrote a treatment plan, and an overview of these practices is listed in Table 9 and described below. *Direct interventions* were defined as SLTs working directly with the student in therapy sessions, and *accommodations* were defined as SLTs providing indirect support via working with staff, other students, or writing plans.

Table 9

Categories of SLT Practices When Supporting a Student With Oropharyngeal Dysphagia (Felicetti et al., 2020)

Category	**Direct intervention (57.9% (n=77/133))**	**Accommodations (12.8% (n=17/133))**
Example of practices	-Oral motor exercises (54.5%) -Diet considerations (45.5%) (e.g., IDDSI). -Safe swallow techniques (45.5%) (e.g., check for pocketing, food placement, etc.). -Other types of intervention (e.g., specific tools, compensatory strategies, pharyngeal exercises, oral motor stimulation).	-Staff training and education (94.1%). -Emergency planning (42.1%) -Monitoring (e.g., mealtime supervision). -Social accommodations (e.g., including friends in mealtime management). -Location/seating changes.
Category	**Follow protocol set forth by another professional (10.5% (n=14/133))**	**Refuse treatment/refer to outside professionals (21.8% (n=29/133))**
Category	**Unsure (31.6% (n=42/133))**	
Example of practices	-Expressed discomfort about creating a treatment plan and were unsure how to proceed.	

Note. No categories were mutually exclusive.

The practices included under direct intervention align with A. Miles et al.'s (2021) observations of mealtime in a New Zealand specialist school. During mealtimes, class staff utilised the following strategies:

- Dietary modification for PFD (e.g., IDDSI modifications)
- Feeding support (e.g., suction, wiping mouth, hand-over-hand feeding support)
- 1:1 supervision
- Prompts (e.g., to chew, swallow, drink)
- Communication supports (e.g., adult modelling *help* on AAC)
- Specialist mealtime equipment (e.g., sipper cup, non-slip mat)

Strategies to increase swallow safety during mealtimes, diet modifications, and specialist equipment were used in both studies (Felicetti et al., 2020; A. Miles et al., 2021). A. Miles et al. (2021) did not record the use of pharyngeal exercises or oral motor exercises, but this could be because they did not collect data on therapy input outside mealtimes. These findings indicate that similar PFD strategies occur during mealtimes in schools across multiple countries.

Indicating the large number of SLTs who continue to feel uncertain in their ability to support PFDs, over half (63.9%) who completed the case study were "unsure" of what to do, would "follow a protocol set by another professional", or would "refuse treatment/refer to outside professionals" (Felicetti et al., 2020, p. 532). No two participants produced the same treatment plan; only 10.4% of plans provided what the authors termed a fully integrated treatment plan (Felicetti et al., 2020).

Neubauer and Singleton (2023) used a survey to analyse the percentage of school SLTs completing a range of roles and responsibilities, as seen in Table 10. Thirty-three percent of SLTs supporting PFDs "provided feeding and swallowing treatment services", lower than the 57.9% of SLTs who provided direct intervention in the case study (Felicetti et al., 2020, p. 857). However, the case study reflected what SLTs would do with a hypothetical student, while Neubauer and Singleton's survey reflected actual tasks SLTs completed (2023).

Table 10

Percentage of School SLTs to Complete PFD-Related Tasks (Neubauer & Singleton, 2023)

Task	% of total SLTs (N=220)	% of SLTs managing PFD (N=126)
Recognising the signs and symptoms of choking	57.3%	100%
Interpreting history information related to feeding and swallowing	50.9%	88.9%
Recognising the signs and symptoms of aspiration	45.9%	80.1%
Engaging in feeding and swallowing team collaboration with school nurses and staff	44.1%	77.0%
Determining if feeding and swallowing services are educationally relevant	38.2%	66.7%
Assessment of oral motor function for eating	37.2%	65.1%
Making referrals for a medically based swallowing evaluation	34.5%	60.3%
Assisting with safe eating and swallowing (e.g., size of bolus, pacing)	34.1%	59.5%
Training caregivers or school staff on managing feeding and swallowing	32.7%	57.1%
Engaging in feeding and swallowing collaboration with a medical team	26.4%	46.0%
Identifying an abnormal vs. normal swallow	25.0%	43.7%
Providing recommendations for an appropriate diet or modifying a diet	24.1%	42.1%
Interpreting MBSS reports and reports from other professionals	20.9%	36.5%
Providing feeding and swallowing treatment services	19.1%	33.3%
Performing a swallowing and feeding evaluation	17.3%	30.2%
Fostering nutritional status	13.6%	23.8%
Diagnosing a swallowing or feeding disorder	9.5%	16.7%

Note. Only 60% (126/220) of respondents supported PFD cases.

2.9 Barriers and Facilitators to School SLTs Supporting PFDs

School SLT practices do not consistently align with the recommended practices for school SLTs, indicating barriers preventing best practice (Felicetti et al., 2020; Homer, 2016; Hutchins et al., 2011; Neubauer & Singleton, 2023; Owre, 2006). Felicetti et al. (2020) used a survey, and A. Miles et al. (2021) used classroom observations, a documentation audit, and interviews to determine the barriers and facilitators of school SLTs supporting students with PFDs. Felicetti et al. (2020) found that only 40.5% of school SLTs had PFD-related training, and clinicians were not always prepared to support PFDs, instead acting as barriers. SLTs with different comfort levels experienced various barriers. For example, SLTs who were "very comfortable" supporting PFDs lacked time, and SLTs who were "somewhat comfortable" supporting PFDs did not believe PFDs were academically relevant.

School SLTs experienced difficulties with collaboration practices, such as obtaining the appropriate documentation from health teams and collaborating with external medical professionals. At times, SLTs found it challenging to communicate with families and ensure follow-through at home, further complicated by minimal caregiver engagement at school (Felicetti et al., 2020; A. Miles et al., 2021). While language such as "follow-through at home" implies that shared decision-making did not occur, the finding signified some difficulties with the home-school relationship. Additionally, school SLTs did not consistently create mealtime plans in a collaborative manner that involved families and classroom staff who supported the child during mealtimes. They also did not feel confident supporting a conflict resolution process when disagreements occurred between the family and school team (A. Miles et al., 2021).

School staff (e.g., teachers and teacher aides) experienced barriers to supporting students with PFDs, such as new and temporary staff being inconsistently trained to support students with PFDs in classroom settings. Classroom staff felt burdened with the responsibility of monitoring mealtime plans, sometimes experiencing emotional fatigue, stress and feelings of failure when supporting students at these times. Twenty-five percent of students had a formal mealtime plan, while 55% had a documented indication of a PFD. Mealtime plans, however, did not consistently include the same information used during mealtimes (A. Miles et al., 2021).

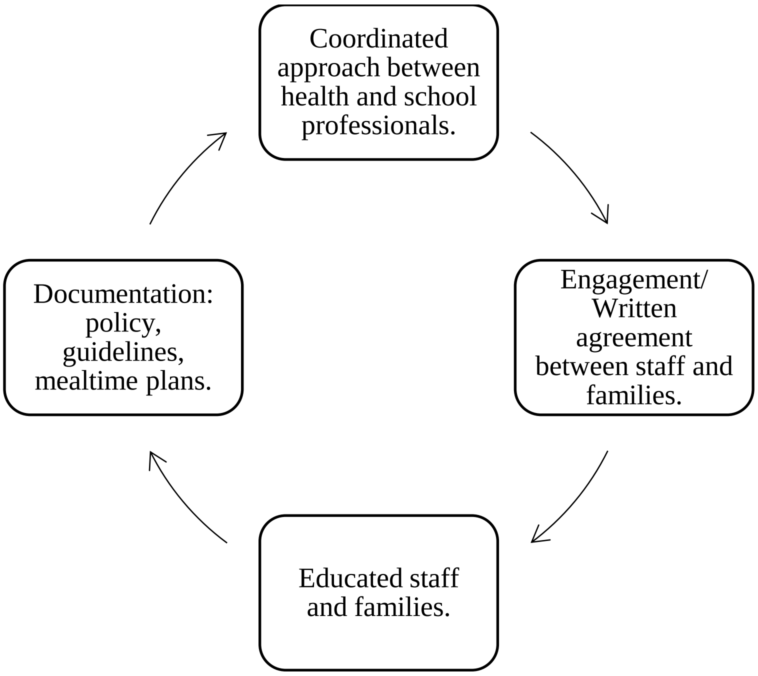
A. Miles et al. (2021) identified a range of facilitators that enabled SLTs to support students with PFDs. While aspects of collaborative practice were challenging, the region's local-level agreement supported collaboration between the health teams and school SLTs. This agreement enabled school SLTs to jointly assess students with health SLTs and receive consultation with complex PFD cases. Families were encouraged to meet with school teams to discuss their child’s PFD at any time, and the student’s mealtime plan was reviewed twice a year. In addition, classroom staff had established routines to support students during mealtimes and were passionate about their jobs. Wanting to make mealtimes enjoyable for all, the school staff knew their students well and gave them their full attention during mealtimes.

2.10 Recommendations for School SLTs Supporting Students With PFDs

Overall, US school SLTs and specialist school SLTs from one New Zealand school experienced a range of barriers to providing a coordinated and consistent service when supporting students with PFDs (Felicetti et al., 2020; Hutchins et al., 2011; A. Miles et al., 2021; Nottingham & O'Donoghue, 2017; O'Donoghue & Dean-Claytor, 2008). A. Miles et al. (2021) recommended various practices to aid school SLTs, as seen in Figure 4.

Figure 4

Recommended Areas of Practice to Enable School SLTs to Support Students With PFDs



2.10.1 *Documentation: Policy, Guidelines and Mealtime Plans*

A. Miles et al. (2021) advocated for guidelines and policies that enable the transfer of documentation between schools, health teams, and families. Recommending that school SLTs create robust mealtime plans that include all the strategies used, the authors suggested that school SLTs use a template to structure these plans. Homer (2008; 2016) provided templates for mealtime plans and guidelines, while others have created policies and guidelines for school SLTs (American Speech-Language-Hearing Association, 2007). These documents, however, have not been adapted to the New Zealand context and are inconsistently adopted in the US. While documentation is essential, it is not enough to change SLTs' practice.

2.10.2 Coordinated Approach Between Health and School Professionals

Collaboration practices are consistently recognised as best practice when supporting students with PFDs (Homer, 2008; A. Miles et al., 2021; C. K. Miller, 2009; Nottingham & O'Donoghue, 2017). In spite of this, recent studies across the US and NZ indicate that collaboration can be difficult (Felicetti et al., 2020; A. Miles et al., 2021). A. Miles et al. (2021) advocated for a "coordinated transparent approach" when supporting students with PFD in school settings. Collaboration is especially important for SLTs who feel less confident when supporting students with PFD.

2.10.3 Engagement Between Staff and Families

Family-centred practice is essential when supporting students with PFD, as discussed in Chapter 1 (Angell et al., 2009; McCarthy & Guerin, 2022; Simione et al., 2020). However, no clear guidelines or structures exist to support the resolution of disagreements between school staff and families (A. Miles et al., 2021). Plans developed collaboratively with families were more effective at home (Angell et al., 2008; Angell et al., 2009), with experts recommending that SLTs be familiar with their legal responsibilities when supporting families and students with PFDs. This subsequently reduces the risk of legal disputes when disagreements occur (Bailey & Lugg, 2009; Kelly et al., 2018).

2.10.4 Educated Staff and Families

School staff were sometimes concerned that families did not fully understand the rationale behind SLT recommendations or the risks to their child's health (A. Miles et al., 2021). To address this, A. Miles et al. (2021) suggested that school SLTs and staff run education sessions and create short educational videos that families could attend or watch (A. Miles et al., 2021). Additionally, a large proportion of school SLTs had low confidence levels when supporting students' PFDs (Felicetti et al., 2020; Hutchins et al., 2011; Neubauer & Singleton, 2023; O'Donoghue & Dean-Claytor, 2008), indicating the need for SLTs to access ongoing professional development and supervision relating to PFDs.

2.11 Significance of my Research Study

My research aims to explore how New Zealand (NZ) SLTs support students with PFDs in specialist schools and investigate how to improve this support. As previously discussed, much of the research relating to PFDs is specific to clinical settings. As medical management improves, more children with complex medical diagnoses enrol in schools which subsequently require support from school-based SLTs (Homer, 2008; Homer & Carbajal, 2015; Huffman & Owre, 2008; Lefton-Greif & Arvedson, 2008; Nottingham & O'Donoghue, 2017). Some authors have created guidelines, books, and articles to enable SLTs to support students with PFDs in schools (American Speech-Language-Hearing Association, 2007; D'Angelo, 2018; Homer, 2008; Homer, 2016). However, these resources originated from the United States (US) and do not consistently apply to NZ settings. SLTs across the US and NZ demonstrated a range of confidence levels, knowledge, and skills when supporting students with PFDs, with SLT provision appearing to depend on the individual SLTs as opposed to policies or guidelines (Bailey et al., 2008; Felicetti et al., 2020; Homer, 2008; Hutchins et al., 2011; Jackson et al., 2022; A. Miles et al., 2021; Neubauer & Singleton, 2023; O'Donoghue & Dean-Claytor, 2008; Owre, 2006). My clinical experience denotes the presence of EDAR practices in school settings, but no study has reviewed the prevalence of this or sought the experiences of school teams and families when practising it.

Much research on school-based PFD support stems from the US, whose legal system differs significantly from NZs. Radford et al. (2020) highlighted how many children with chronic life-limiting conditions are appropriate candidates for EDAR for a variety of reasons. The zone of parental discretion is a tool clinicians can use when supporting families to make complex, informed decisions, such as when choosing to EDAR (Gillam, 2016; Radford et al., 2020). However, A. Miles (2021) found that PFD-related disagreements occurred between schools and families and no guidelines or tools were used to support the resolution of the decision. Conflict resolution must also align with NZ laws, such as The Code of Health and Disability Consumers’ Rights 1996 and The Health and Safety at Work Act 2015. Subsequently, these decisions are complex and poorly understood.

2.12 Thesis Outline

This thesis attempts to address the aforementioned gaps, and the mechanisms used to address these gaps are described in Chapter 3. Chapter 4 describes how SLTs support students with PFDs at one NZ specialist school, outlining the current practices of SLTs, classroom staff and caregivers. Additionally, techniques used to develop school SLT practice are explicitly discussed in Chapter 5. My research findings are summarised, and future research directions are suggested in Chapter 6.

3 Method

3.1 Aim

Based on my background, I approached this project with the following overarching aims:

- Explore how SLTs support students with paediatric feeding disorders at one specialist school.
- Explore what implementation approaches and changes could improve the management of students with paediatric feeding disorders at one specialist school.

Subsequently, the following research questions were asked:

1. What factors influence New Zealand specialist school SLTs' ability to support students with paediatric feeding disorders?
2. What are the perceptions and aspirations of stakeholders (school staff, local health professionals, and family) on the support of students with paediatric feeding disorders at the specialist school?
3. What changes do stakeholders believe are needed to improve the support of students with paediatric feeding disorders at one specialist school?
4. What implementation approaches do stakeholders believe could optimise change in the support of students with paediatric feeding disorders at one specialist school?

3.2 Rationale for the Chosen Methodology

Before embarking on clinical research, one should reflect on the optimal methodology for specific research questions. Researchers will use efficacy studies to determine whether a single intervention makes a measurable difference for a target population. To ensure these differences are due to the intervention alone, researchers design the study to reduce the influence of external factors on the intervention. For example, researchers often rigorously follow experimental procedures and use homogenous participant groups. However, practising clinicians typically have varied caseloads and work in environments where they cannot replicate these study designs, thus reducing the likelihood that the intervention would provide the same measurable change in their workplace (Curran et al., 2012; Douglas et al., 2015).

In contrast, effectiveness studies are designed to examine whether results from an efficacy study can be generalised to real-world settings. Often completed in community settings, these study designs have looser restrictions than would be advocated by an efficacy study, thereby allowing for flexibility in protocol adherence to account for population needs. A shortfall of effectiveness studies is their inability to consider the barriers and facilitators present that affect clinician's uptake of an intervention (Curran et al., 2012; Douglas et al., 2015). For example, clinicians often revert to practices influenced by organisational culture, funding, and ingrained beliefs (Cook, B. & Odom, 2013; Douglas et al., 2015; Nilsen, 2015; Olswang & Prelock, 2015).

In turn, action research and implementation science are alternative designs that utilise quasi-experimental science to explicitly examine the impact external factors have on the uptake of interventions while assessing the effectiveness of strategies that support the implementation of the target intervention (Bradbury, 2015; Cook, B. & Odom, 2013; Nilsen, 2015).

3.2.1 Action Research

Action research is an umbrella term for implementation study designs that place a high level of importance on working with a community of people to better understand a situation and improve practice in the "real world" (Bradbury, 2015; Casey et al., 2018; McNiff & Whitehead, 2011). It attempts to reduce the research-to-practice gap, a widely recognised disparity between evidence-based practice and how clinicians work with clients in their real-world practice. Olswang and Prelock (2015) posited that the gap is influenced by the lengthy process of conventional treatment research, the reliance on scientific journals for dissemination, and SLT scepticism as to whether research results will accurately translate to their setting. Utilising action alongside reflection, theory, and practice in the pursuit of practical solutions, action research attempts to remedy this gap by working "with" a community of people affected by an issue (Bradbury, 2015). Involving the community in research reduces the distance between the practitioner and researcher, in turn minimising any cultural gap that may affect how research can effectively be implemented (Casey et al., 2018).

Participatory action research (PAR) is a subcategory of action research that focuses on engaging individuals affected by the situation as co-researchers in the study. These co-researchers work together to collectively investigate and ask, "Is our work going as we wish? How do we improve it where necessary?" (McNiff & Whitehead, 2011, p. 8). Fundamental in co-designing and implementing the study, the co-researchers often work in a cyclical manner that evaluates and modifies the intervention (Bradbury, 2015; Somerville, 2014). Contrastingly, in more classic experimental designs, recipients of the intervention are involved in the study as participants but have no say in the intervention design and how it is delivered (Somerville, 2014). The salient components of PAR and its suitability for this thesis are outlined in Table 11 (Baldwin, 2012; Bradbury, 2015; McNiff & Whitehead, 2011).

Table 11

Features of Participatory Action Research (PAR) and how They Are Suitable for the way the Current Research Was Conducted

Feature of participatory action research	Rationale for its merit in the research design of this thesis
Included stakeholders throughout the process.	Key stakeholders, or those affected by and involved in the situation (teachers, parents, paediatricians, SLTs), participated in an advisory group and provided regular feedback on the implementation cycles.
Conducted with, not on, participants.	The specialist school SLTs acted as 'co-researchers' by co-designing and implementing resources whilst actively being involved in any behaviour change techniques utilised in the study.
Transformative, not informative.	The study attempted to show people how the world could be by transforming specialist school SLTs' beliefs, perceptions, and practices instead of just informing the researchers about current practices and beliefs (Baldwin, 2012).
Conducted in cycles.	Cycles were used to gain insights from stakeholders to change any resources and the implementation plan.
Empowered participants by building their power, knowledge, skills and agency.	A primary focus of the study was to empower the specialist school to better collaborate with external agencies, recognise treatment pathways for their students, and work with families to support a student's PFD.
Acknowledged that perfect neutrality and objectivity do not exist.	The study sought to understand the experiences, perspectives, priorities, and concerns of all parties, using these to shape the implementation stage of the design.
Challenged traditional hierarchies and power dynamics.	The study sought to break down power dynamics between parents, specialist school staff, and health-based SLTs to enable increased collaboration and improved processes.

3.2.2 Implementation Science Frameworks

Many *implementation science frameworks* exist to guide researchers as they plan and execute a study. One such framework, the *Behaviour Change Wheel* (BCW), is designed to provide an in-depth understanding of aspects that affect implementation (Nilsen, 2015). The BCW analyses the capabilities (C), opportunities (O), and motivations (M) within an environment to determine how they impact a behaviour (B), often referred to as a COM-B analysis. Once these components are understood, researchers can adapt interventions to be responsive to the facilitators and barriers within an environment. Additionally, the BCW includes the *Behaviour Change Technique Taxonomy* (BCTT), a systematic list of behaviour change techniques (BCTs) outlining different strategies that enhance the implementation of interventions. These BCTs fall under intervention functions and policy categories, discussed in Chapter 5 (Mitchie et al., 2014).

The BCW was developed through a systematic search of electronic databases and consultation with implementation science experts to identify frameworks of behaviour change interventions. These were evaluated using three criteria: comprehensiveness, coherence, and a clear link to an overarching behaviour model (Michie et al., 2011). From this, experts identified and grouped behaviour change techniques from published classification systems, resulting in 93 BCTs clustered into 16 groups (Mitchie et al., 2013).

3.3 The Current Study

A mixed-methods participatory-social justice design was deemed the best overarching approach for this thesis. This design combines mixed-methods research with the active participation of stakeholders who collectively work towards improving the lives of the marginalised, aligning with social justice theoretical frameworks (Creswell & Plano Clark, 2018). Both action research and implementation science were utilised in this study design, as their mutual aim is to involve stakeholders in the change of community practices and reduce the research-to-practice gap. As both have shared aims, using them in combination enables one to create change in a systematic manner (Casey et al., 2018). PAR was the action research framework chosen for this study for the reasons discussed in Table 11 (Bradbury, 2015; Creswell & Plano Clark, 2018). The BCW was the implementation science framework chosen for this thesis because it provided a comprehensive framework to analyse factors that affected behaviour whilst offering structure to the implementation phase of the study (Mitchie et al., 2014). Additionally, the BCW was selected to compare this study with another that used the COM-B framework to analyse SLT support of PFDs in a New Zealand specialist school (A. Miles et al., 2021). The mixture of PAR and implementation science designs is visualised in Figure 5. The following section will provide a brief overview of the different stages in the study, followed by a more in-depth description of the thesis methods.

In the *Observe* phase, observational qualitative and quantitative data relating to the research questions was gathered. I subsequently analysed the qualitative and quantitative data simultaneously using the COM-B analysis to reveal the factors that impacted the practices of families, SLTs, and classroom staff. The BCW manual was followed to increase the accuracy of the data analysis (Mitchie et al., 2014). During the *Reflect and Plan* phase, target behaviours and BCTs were identified per the BCW manual (Mitchie et al., 2014), alongside developing resources for the specialist school SLTs, as discussed in Chapter 5. Two *implementation cycles* were completed, including a PAR cycle of act, evaluate, modify, as visualised in Figure 6 and discussed further below. I initially planned to gather *participatory evaluation* to better understand the behaviour change and whether it was maintained. However, this study stage has not yet been completed as it is outside the scope and timeframes of this master’s thesis.

Figure 5

Overview of Thesis Design

Completed a literature review and identified research questions.

***Preparatory* phase (*approx. 6 months*)**

Recruited host school and built trust with community members.

***Observe* phase (*approx. 3 months*)**

- Gathered qualitative and quantitative observational data simultaneously
- Analysed using COM-B analysis

***Reflect and Plan* phase (*approx. 3 months*)**

- Followed BCW manual to identify BCTs (behaviour change techniques)
- Created draft resources

Implementation Cycle 1 (approx. 3 months) – utilised a participatory action research cycle:

- Act
- Evaluate
- Modify

Implementation Cycle 2 (approx. 3 months) – utilised a participatory action research cycle:

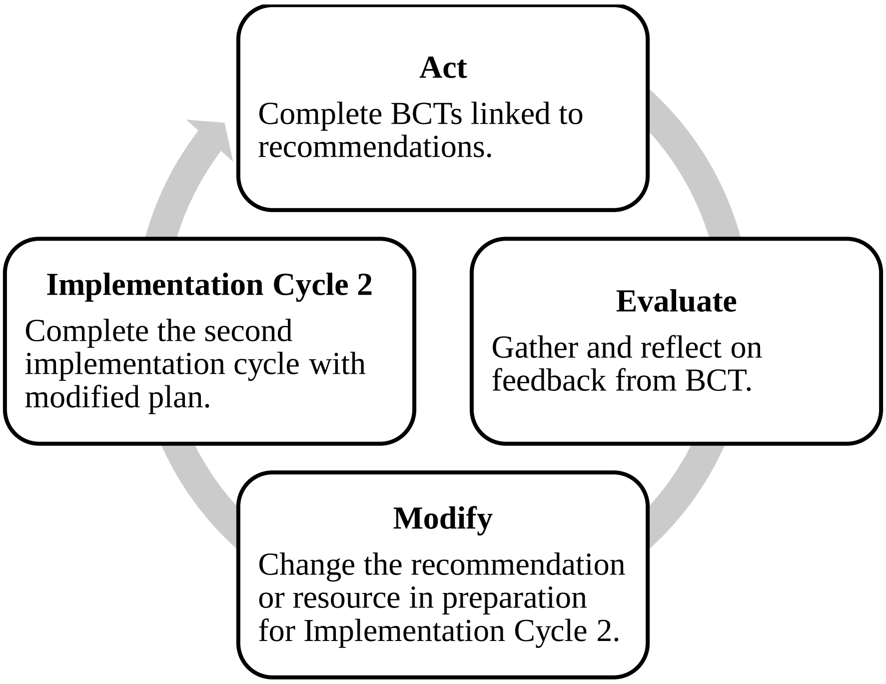
- Act
- Evaluate
- Modify

***Participatory Evaluation* phase** – not within the scope of this thesis.

Make recommendations for future change.

Figure 6

Participatory Action Research (PAS) Structure of Act, Evaluate, Modify



3.4 Methods

Ethical approval was obtained from The University of Auckland Human Participants Ethics Committee (UAHPEC #20224). Approval was granted on 11/04/2022 for a period of three years.

3.4.1 Setting

One host specialist school was chosen for this study. To meet the inclusion criteria, the school needed to be located in Auckland and employ at least one SLT. Additionally, the school must have permitted me to gather the following types of information:

- Interviews with school staff and caregivers.
- Observations of classrooms during a mealtime (e.g., lunch or morning tea).
- An audit of school records related to PFD management.

I approached four specialist schools via email based on the school's location and my knowledge of the students enrolled. The first school expressed interest in the study but declined to participate after learning more about it. The second and third schools that were approached did not have the capacity to be involved. The fourth school agreed to participate after learning more about the study. I had no prior professional connection to the school.

The host specialist school was located in a high socio-economic area with a previous decile rating of 9/10, indicating households had high incomes, low crowding and educated caregivers (Ministry of Education, 2023a). The school serviced 113 students and contained

16 classes at a base school and multiple satellite schools. Each classroom contained a range of four to eight students, one teacher, and two to three teacher aides. Staffing levels depended on the number and complexity of students in each classroom. Students aged five to 21 were enrolled in the specialist school, and all required Ongoing Resourcing Scheme (ORS) funding to attend. This funding is given to students with the highest ongoing levels of need (Ministry of Education, 2011), as discussed in Chapter 2. The school employed two full-time SLTs, two occupational therapists (OTs), one physiotherapist, 25 teachers, 49 teacher-aids, and one principal. The demographics of the school therapists are seen in Table 12.

Table 12

Host Specialist School Therapist Demographics

Role	Years of experience	Country of professional study
School SLT 03	<1 (new graduate)	New Zealand
School SLT 04	6	New Zealand
OT 01	10+	South Africa
OT 02	10+	United Kingdom
PT 01	10+	United Kingdom

3.5 Observe Phase: Gather Behavioural and Environmental Data

Before entering the school, I wrote a short introduction about myself and a summary of the research, which was sent to all staff. To build relationships with school employees, I began by spending a full week at the school. I sat in the staff room for one school day and greeted everyone I encountered. Additionally, the school SLTs identified nine classrooms for which they provided PFD support, in which I planned to complete the mealtime observations. To better acquaint myself with these classrooms, I shadowed the school SLTs as they visited each one. During these visits, I introduced myself and observed the class before requesting to gather any other data. This process, known as prolonged engagement, enabled me to build trust and rapport with participants to gather rich, detailed responses. Collecting comprehensive data increased the credibility and, subsequently, the trustworthiness of my data (Cope, 2014; Korstjens & Moser, 2018).

Data should be gathered in a way that increases its trustworthiness and credibility. Credibility is the measure of how confident one is that their findings are truthful and is a criterion of trustworthiness (which measures whether the findings can be trusted) (Cope, 2014; Korstjens & Moser, 2018). The credibility of my findings was increased by using methodological triangulation and data triangulation. Methodological triangulation is the process of gathering qualitative (interviews, observations) and quantitative (school record audit) data, whilst data triangulation requires one to gather three different types of datasets. Both types of triangulation aim to provide a more nuanced understanding of the situation to increase the credibility and overall trustworthiness of my findings.

3.5.1 Classroom Observations

After meeting classroom staff, I arranged a time to collect mealtime observation data at either morning tea or lunch. My observations were recorded on a printed template (see Table 13 for an examplar). The Observation Template was created based on salient information in the literature review. During these observations, I documented each student's food and drink alongside any strategies and support staff used. Each student's mealtime observation was later compared to the information on students' mealtime plans in their school records to explore discrepancies. Quantitative data from the observation was tallied to allow group-level interpretation (number of students on modified diets, number of students requiring feeding assistance). Qualitative data was coded using *descriptive coding*, summarising each piece of data into a short phrase (M. B. Miles et al., 2018; Saldaña, 2021). For example, the data describing the "mealtime strategies used by classroom staff" was condensed into the code "classroom staff strategies".

Table 13

Example of Mealtime Observation Data Collection Template

Criteria	Student 1
Students that require additional food preparation (e.g., food is presented in an alternative way to the standard adult form).	Yes, the staff heated the food and checked for correct IDDSI consistency.
Students who require assistance from another person when eating. Describe.	Yes, 1:1 supervision from staff, backward chaining for spoon feeding, provided deep pressure sensory input throughout the meal, verbal prompt to swallow, check mouth for residue, place medication in food, model on high tech AAC.
The materials used by children with complex feeding issues.	Bendable spoon, suction bowl, classroom chair and table, high-tech AAC.
The food textures eaten by students (IDDSI levels and any variations)	IDDSI level 4 (food).
Students who have supplemental or alternative tube feedings.	Yes, mic-key button for fluids only. Previous transition from tube feeds to oral food.
Information included on a student's mealtime plan.	Positioning: Ensure 90/90/90 seating position. IDDSI level 4 (food). Feeding techniques: backward chaining for spoon feeding, verbal prompt to swallow, check mouth for residue. AAC: Model words like *more*, *eat*, and *finished* on the student's high-tech device.
Additional strategies used by classroom staff to support students during mealtimes.	Wash dishes, bibs, and flannels at the end of the meal, clean up spilled food, provide bibs for each student, and utilise general whole-class behaviour management strategies.

3.5.2 Interviews

All teachers were invited to participate in an interview via email invitation. Teachers who had pre-existing relationships with their students' caregivers were asked to inform these caregivers of the interview invitation. To gain a broader perspective, I contacted the local health SLTs and two SLTs who had previously worked at the host school. Of those who expressed interest, I directly contacted them to schedule an interview and provide a participant information sheet (PIS) alongside a consent form (CF). The demographics of the interviewees are seen in Table 14.

Interviews were completed at the school in a quiet and private room where possible. Some interviewees requested to meet in public places, such as quiet cafes, which I agreed to. Before each interview, I thoroughly explained the PIS and CF and left space for interviewees to ask questions before signing the forms. I confirmed that the interviewees consented to be audio recorded, reassuring them that I could stop the recording at any time. All agreed to be recorded, and no one requested to stop the recording during the interview. A semi-structured interview format was used, the schedule of which can be found in Appendix 1. I typically started by asking the interviewees about their experiences supporting children with PFDs. This enabled me to understand their feelings and attitudes about the topic before proceeding with the interview. Additionally, interviewees were asked about their experiences supporting children when differences between home and school PFD support occurred and when PFD-related disagreements arose. Each audio recording was transcribed verbatim.

Transcripts were segmented into meaning units consisting of phrases and sentences corresponding to codes. Descriptive coding was used, summarising each meaning unit into a short phrase (M. B. Miles et al., 2018; Saldaña, 2021). For example, the meaning unit “we have a standardised way of operating in a hospital, why can’t we have a standardised way of operating in a school?” was condensed into the code “standardised school protocol”. Each meaning unit was highlighted in the Microsoft Word transcript and allocated a colour based on what COM-B unit I thought the code would fit into.

Table 14

Interviewee Demographics

Role	Years of experience	Place of work
Teacher 01	5	Host school
Teacher 02	10+	Host school
Teacher 03	10+	Host school
Teacher 04	10+	Host school
Teacher 05	10+	Host school
Caregiver 01	N/A	N/A
Caregiver 02	N/A	N/A
School SLT 01	2	Separate specialist school
Health SLT 02	10+	Acute inpatient hospital
School SLT 03	<1	Host school
School SLT 04	6	Host school
School SLT 05	10+	Separate specialist school
Health SLT 06	4	Outpatient and community

3.5.3 School Record Documentation Audit

All student records were kept in an online filing system. I extracted each student's data from the filing system and input the de-identified information into an Excel spreadsheet, as seen in Table 15. The data sheet was created based on salient research found in the literature review. Demographic information such as age, ethnicity, and sex were collected alongside information relating to each student's PFD. I collected information about where feeding was mentioned in the students' records, whether they had recorded instrumental assessments or a feeding plan, and how often these were revised. Data was tallied to allow group-level interpretation, such as the number of feeding plans and instrumental assessments.

Table 15

Example of School Record Documentation Audit

Age	Sex	Diagnosis	Ethnicity	Mealtime plan	Pastoral notes	Signed 2022 IEP	Paediatrician report	Neurologist report	Psychologist report	School therapy program plan	Health SLT report	VFSS report	Dietitian report	Health OT report	Health PT report	School MDT notes	Student medical plan	SLT class resources	Social worker report	BLENNZ report	Positive behaviour plan	PFD assessment	Videos of eating/drinking
5;8	F	Cerebral Palsy - spastic	Tongan	1 - 2021	1	1	2	1	0	1	0	1	1	1	2	1	1	1	0	1	0	Unstructured mealtime observation	1

Enterally fed	Diet	Eating difficulty	Drinking difficulty	Indication of direct therapy	Additional notes	Documented indication of PFD - from therapy program plan
Mic-key for fluids	IDDSI 6 for food supervised	Delayed oral motor skills	Pharyngeal dysphagia	No	Tastes program run in class	Student has a modified diet of minced-moist. They would benefit from a clear mealtime plan.

Note. BLENNZ is an acronym for Blind and Low Vision Education Network New Zealand

3.6 Reflect and Plan Phase: Analysis of Data and Planning for Implementation Cycles

As previously mentioned, quantitative data was tallied to allow group-level interpretation, and descriptive coding was used with the qualitative data (M. B. Miles et al., 2018; Saldaña, 2021). Once all the salient data had been extracted, a second coding cycle occurred where the data was grouped into higher-level categories (M. B. Miles et al., 2018). I grouped the qualitative and quantitative data into the pre-assigned COM-B framework, which included the following codes:

- Capability
  - Physical
  - Psychological
- Opportunity
  - Physical
  - Social
- Motivation
  - Reflective
  - Automatic (Mitchie et al., 2014).

This analysis enabled me to define the situation and identify what factors influenced the behaviour of those involved. I shared these results with the school staff, and we collaboratively identified target behaviours, behaviour change techniques (BCTs), and resources, as described in Chapter 5.

A range of professionals and family members were asked to be involved in an advisory group via email to provide feedback on resources or BCTs during the implementation cycles. The membership in the advisory group included a family law professor, consultant paediatrician, inpatient health SLT, community health SLT, caregiver of a student with PFD, and two specialist school SLTs. These roles were deemed necessary in the advisory group as each may be involved in complex feeding decisions. Some members were chosen because they had been involved with previous PFD projects, and others were recommended to me by experts in the field; however, most were involved in the first phase of data collection and showed ongoing interest in the project. The advisory group's membership and responsibilities are further discussed in Chapter 5.

3.7 Implementation Cycles 1 and 2

During each implementation cycle, we fulfilled the *act* component by completing the BCTs that the school therapists and I co-planned. The co-researchers, myself, and the advisory group then e*valuated* the BCTs. Based on the feedback, the BCTs or resources were *modified* for use in the second implementation cycle. This act, evaluate, modify cycle, as seen in Figure 6, was based on PAR and ensured the appropriateness of all BCTs and resources with the purpose of transforming practice (Baldwin, 2012; Bradbury, 2015).

4 Results: Observe Phase - Establishing the Factors That Influence Change Through Capability, Opportunity and Motivation

In this phase, observational data was collected (Figure 7) to answer the first research aim: to explore how SLTs support students with paediatric feeding disorders at one specialist school. Mealtime observations were completed for 42 of the 51 students; nine children were absent due to illness across the nine classrooms identified by the specialist school SLTs. Additionally, I conducted 13 interviews and a school record documentation audit for 113 students (including those attending off-site satellite classrooms). Data is presented using the COM-B framework.

Figure 7

Overview of Observe Phase

***Observe* phase (approx. 3 months)**

- Gathered qualitative and quantitative data simultaneously
- Analysed using COM-B framework

4.1 Capability: Physical

Physical skill, strength or stamina (Mitchie et al., 2014, p. 63).

4.1.1 Classroom Staff

During mealtimes, classroom staff demonstrated a wide range of skills or strategies in supporting students with PFDs, enabling them to eat safely, have adequate nutritional intake, and develop feeding skills. These strategies are listed in Table 16. Some teachers reported that all classroom staff knew how to ensure adequate support for each student when staff were absent or on breaks:

> *I had a big thing about, you know, I didn't want to have students in my room, as a teacher, who couldn't come in if a teacher aide was away because no one knew how to do this or that.* (Teacher 01)

Table 16

Mealtime Strategies Used by Classroom Staff

Strategy	Number of students the strategy was used with during observations
Pacing (e.g., handing students small portions of food at once).	11/42
Prompt students to prepare for meals (e.g., wash hands, get lunchbox out).	26/42
Behaviour management (e.g., prevent students from stealing others' food).	27/42
Staff prepare food (e.g., heat it and modify it to the appropriate IDDSI level).	23/42
Physical placement of body (e.g., placement of student’s hands on wheelchair arm).	8/42
Feeding strategies (e.g., placing food inside the mouth, holding the cup up to the student's lips).	16/42
Use of AAC.	12/42
Verbal and physical prompts during the meal (e.g., verbal prompt to swallow, physical prompt under elbow).	23/42
Sensory regulation strategies.	5/42
Backward chaining (e.g., loading a spoon and putting it in students' hands).	4/42
Read student’s body cues to pace meal.	15/42
1:1 supervision.	11/42
Adaptive cutlery.	22/42

Conversely, there were instances where only one teacher in a class felt skilled enough to run a PFD-related program. For example, in one classroom, only one teacher was trained to run a tastes program for students who were nil-by-mouth (NBM). This information was not documented anywhere for other team members to access. At the end of the Observe phase, the teacher went on maternity leave, and no other staff were shown how to run the program. Subsequently, it was discontinued while she was on leave:

> *So that's been a bit of a learning curve getting more comfortable with that [program]. It's still something I won't get my teacher aides to do. And there's, thinking of one student in particular, I've been given permission by the parents to give them tastes, but I wouldn't ask their normal support person, people or my carers, or anyone else to do it. It's literally just, I know, I personally have permission to do it.* (Teacher 03)

Moreover, some students would only accept support from one or two staff members at mealtimes:

> *Students might decide no, you're not feeding me today. Which makes sense. I mean, we've had students where you're literally just taking food and glove bite-sized pieces and putting it directly in their mouth. So, if a student doesn't know you or just doesn't feel like sitting with you today, they're not gonna eat from you.* (Teacher 03)

4.1.2 Students

Health SLT 02, who worked in an acute setting, reported frequently seeing students admitted to the hospital after experiencing stable health in the community. These students sometimes took more risks when eating and drinking, which shocked the acute health SLTs. They recognised that families and students with stable health were more likely to take risks when eating and drinking in community settings. Conversely, students' nutrition, swallow safety, and swallow efficiency needed to be optimised in an acute hospital setting when their health was unstable:

> *My colleagues and I, we walk out of those rooms and just go, what the hell have we just seen? And I feel like you [community SLTs] just, you just let so much more go probably not, not in an unsafe way. But I think when you have, when you're in an acute setting, you're very much like, 'everything has to be optimised', and if it's not, you've got a really good medical team behind you to back you up. And actually, there's, there's some really suboptimal but adequate feeding that goes on in the community.* (Health SLT 02)

4.2 Capability: Psychological

Knowledge or psychological skills, strength or stamina to engage in the necessary mental processes (Mitchie et al., 2014, p. 63).

4.2.1 Classroom Staff

Classroom staff valued understanding "why" they were asked to use specific strategies with students or why certain students were fed differently. When staff increased their understanding of PFDs, they felt more confident and were more likely to remember what strategies to use, sharing the information with other staff:

> *The most helpful thing has been the speech-language therapists coming in and saying this is why we're doing it this way to the whole team… Because we don't know it, so we don't necessarily think of it… It just means that people remember it more. And then when these teacher aides are passing it on to new teacher aides, and it goes into the file they know well, this is why, so it sticks a lot better. Everyone's willing to take it a lot more seriously when they know why that's happening.* (Teacher 03)

Some classroom staff did not know when they should request school or health SLT input to assess students' PFDs, review safe eating plans, or provide classroom support. For example, two of the classroom teachers in the school utilised EDAR practices during tastes programs they completed with their students. Both teachers received consent from parents and input from previous SLTs, but the current school SLTs were unaware of the programs. No school staff could explain why the programs had been implemented, demonstrating a limited understanding of the strategies they were using. One teacher ran dysphagia training for her classroom staff without consulting with an SLT:

> *I kind of forget that SLTs do feeding, like, I know that sounds really, like, you know, clueless… like I always think like core boards and social communication, and you know, that kind of thing. AAC, like, but it's [PFDs] not like, the first thing that comes to mind.* (Teacher 01)

4.2.2 Families

Families were often responsible for sharing information regarding their child's PFD with staff. For example, Teacher 03 described instances when caregivers showed staff how to feed their child or suction a student's secretions during school when staff found it challenging. Another parent wrote a three-page document describing how to feed their child different consistencies and provide medication. Classroom staff often asked families for information such as past reports or the contact details of the student's dietitian or paediatrician. Caregiver 02 visited the school multiple times to show staff what consistency was easiest for their child to eat and how to feed their child:

> *Previously, I used to go to school as well… [I have] been to school once or twice and showed them how to make that consistency... So, [I] ask them, okay, you can feed him like this. I showed them how to feed XX (student) as well previously.* (Caregiver 02)

Caregivers described wanting to be active participants in health decisions and valued receiving information from health teams to inform decision-making. For example, when Caregiver 02 attended her child's video fluoroscopic swallow study (VFSS), the health professionals used the VFSS images to describe her child's swallow physiology. These images enabled her to make an informed decision about which consistencies her child ate. Caregiver 01 received information about her child's recurrent chest infections and enteral feeding options, enabling her to make an informed decision about the introduction of enteral feeding for her child:

> *I mean, we always kind of rely on the experts to, you know, to give us the information. And so that we can make an informed decision. I don't think that we ever felt like we got told that this is what you have to do… I'd definitely say that we would be active participants to provide them with all the information that we need to make an informed decision.* (Caregiver 01)

Despite being active participants in decision-making, both caregivers exhibited knowledge gaps about their child's PFD. For example, Caregiver 01 was unsure if her son would always require an enteral feeding tube and how she could support his feeding skill progression. Caregiver 02 was unsure how to reduce her son's oral aversion and if he would tolerate different textures in the future. Both caregivers approached professionals for support and tried various strategies at home to support their long-term goals.

> *We didn't think that he would have it [mic-key button] for as long as what he has, to be completely honest… I didn't know that it would go on that long. Yeah. It is what it is.* (Caregiver 01)

Some caregivers used strategies or practices that were unsafe for their child and outside the zone of parental discretion (ZPD). For example, Teacher 03 observed a caregiver placing food in their child's mouth when the child was dysregulated and unable to swallow safely. Caregiver 02 fed her child while they were asleep in an attempt to increase the volume of food they ate. She no longer continued this practice but appeared unaware of how dangerous it was for her child:

> *Previously, to be honest, when he was like one or two years… he was not able to sit on his own and everything. So, we need to make him sit on a couch and then feed him in between, and even we have given him food while sleeping. Like, like giving, he's lying down. And we tried to give him liquid, and he used to swallow it.* (Caregiver 02)

4.2.3 SLTs

Specialist school SLTs had varying assessment practices. School SLT 01 aimed to review her students' safe eating plans yearly but was unsure whether she should complete any additional assessment. Safe eating plans outlined strategies that enabled students to eat safely during mealtimes. Many school SLTs were unsure if their assessments, plans, and programs aligned with best practice, but they attempted to complete a range of assessments, as seen in

Table 17. Under half of the students with a documented indication of PFD had a written assessment in their file, as seen in Figure 8. These assessments, however, did not appear to be consistently used with students at the specialist school. SLTs felt less confident when they had less assessment data to inform their interventions:

> *Because we do review their mealtime plans every year…So, do we have to do it, you know, are we doing that right? Are we, are we assessing them? You know, we just kind of go, okay, they're doing well. Is there anything, any changes? No changes. All right. Mealtime [is] then updated… But is that, I don't know whether we're doing it right.* (School SLT 04).

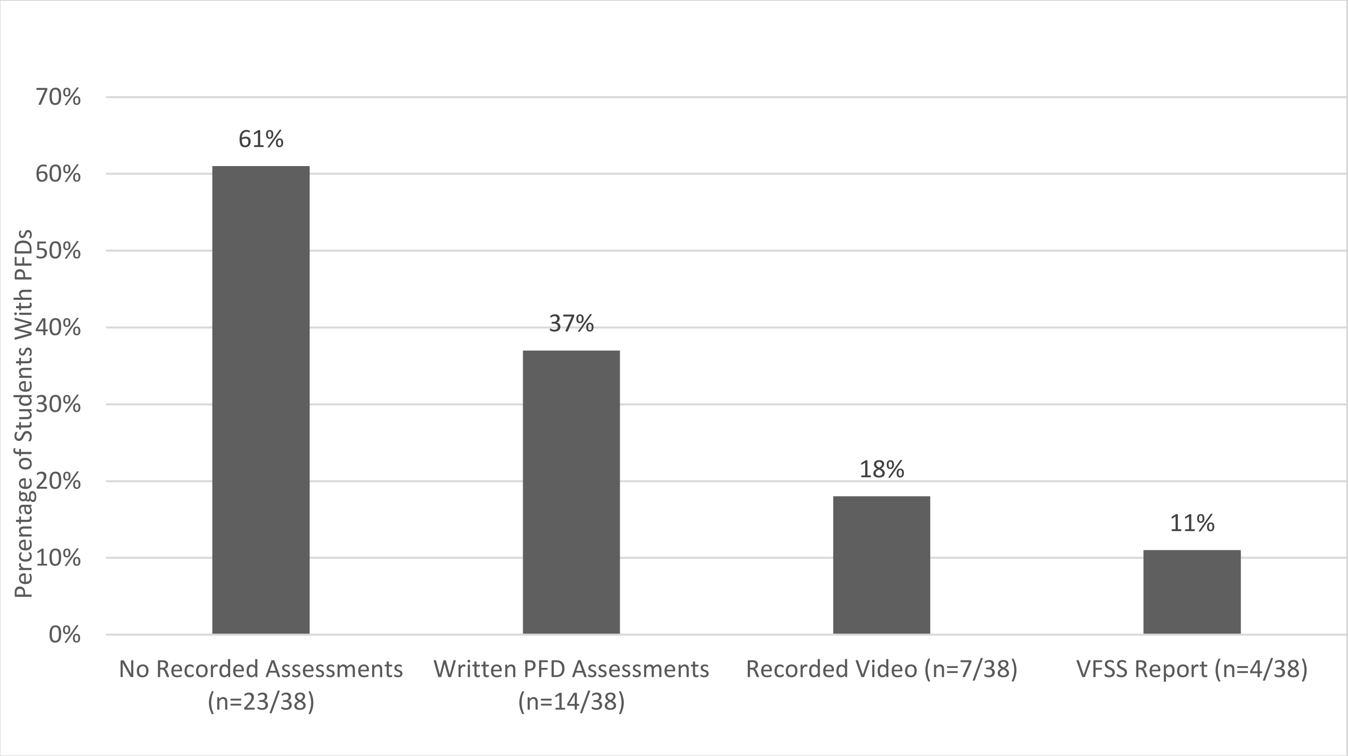
Table 17

Types of Written PFD Assessments

Unstructured mealtime observations
Parent report of +/- concerns
Teacher report of +/- concerns
Documentation of previous SLT input
Standardised checklists
Evaluation of readiness for transition from tube feeding to oral feeding
Structured mealtime observation (IDDSI compliance, swallow safety and function)

Figure 8

SLT Assessments for Students With a Documented Indication of PFDs



Specialist school SLTs did not fully understand how they could liaise with health teams and the responsibilities of each health professional. For example, New Zealand paediatricians oversee children’s overall health and, subsequently, are responsible for tasks like requesting a VFSS, which involves risks such as radiation exposure. Both health SLTs were relieved to collaborate with paediatricians and share the responsibility of supporting students’ wellbeing. Conversely, some specialist school SLTs found it frustrating to liaise with paediatricians to request a VFSS:

> *I would definitely change the fact that if you're working in education, you can't refer for a video fluoroscopy yourself. That's been a large barrier in terms of, it takes a lot of time to get a referral in and then and then you wait. So, if you could get in sooner, you might have better outcomes.* (School SLT 03)

School SLTs often adapted resources and programs to support students’ PFDs in a specialist school setting. For example, SLT 03 adapted her knowledge of the SOS principles to provide in-class support for students with a restricted diet. SLT 05 adapted Talking Mats resources to support a student to partake in a decision about EDAR:

> *And I think it was the experience of the talking mats and asking him the very specific questions about, I think I divided the three sections under; this is challenging for me, this is not too bad, and this is, you know, fine. I could manage this, and I took photographs of food consistencies or name locations or contexts, and all that sort of thing. And the way that he divided out those different options told me that his assessment of his difficulties matched my assessment of his difficulties. But we also looked at potential solutions. And again, his thinking around what might work, what might not work, different from what I would have recommended but, but was sensible, sensible options. Yeah. So, for me, that gave me the information that I shouldn't be making decisions for him. Yeah, but with him.* (School SLT 05)

4.3 Opportunity: Physical

The physical opportunities included opportunities afforded by the environment involving time, resources, locations, cues, and physical 'affordance' (Mitchie et al., 2014, p. 63).

4.3.1 School

The school had many documentation processes that enabled staff to support students with complex PFDs. For example, all students had an online "pastoral notes" system, enabling staff to document notable information regarding students' wellbeing, which senior management then reviewed. Teachers were required to contact families daily through a home school notebook, phone call, email, seesaw (an online, interactive learning platform), or a face-to-face meeting. As seen in Table 18, most families had IEP meetings to discuss their goals and plans for the year. Caregiver 01 stated, "I haven't really talked to anyone in a while about that [VFSS review]. I just mentioned it to XX (teacher) when we had our IEP meeting the other day." All students had a school therapy program plan outlining previous therapy and the planned therapy input for the coming year.

Table 18

Findings From the School Record Documentation Audit

Documentation	Finding	Percentage
IEP	Number of students with IEPs	97% (n=110/113)
Documented indication of PFD	Number of students with a documented indication of PFD	34% (n=38/113)
	Number of total students with safe eating plan	11.5% (n=13/113)
	Number of plans updated in 2022	4.4% (n=5/113)
Safe eating plan for students with PFDs (n=38/113)	Number of students with PFD who have a safe eating plan	34% (n=13/38)
	Number of plans updated in 2022	13% (n=5/38)
Enteral feeding	Number of students with a documented indication of enteral feeding	14% (n=16/113)
	Number of total students with an enteral feeding plan	5% (n=6/113)
Behaviour	Number of students with positive behaviour plan	28% (n=32/113)
	Psychologist report/meeting minutes	14% (n=16/113)
	Strengthening families	10% (n=11/113)
	Family group conference	1% (n=1/113)

Elements of PFD support were not consistently documented, as seen in Table 18. Thirty-four percent (n=38/113) of all students had a documented indication of PFD, yet 34% (n=13/38) of students with a documented indication of PFD had a safe eating plan. Thirteen percent (n=5/38) of these students with safe eating plans had been reviewed in 2022, the year the data was collected. Each safe eating plan was comprehensive, showing sufficient detail to allow someone to feed the student safely:

> *And I always was astounded because the meal plans that I get sent from special school therapists when they come, they are so detailed and…it looks like a legally binding document to me. And I know it's not, but it's the, that really long and really specific and I just don't think I'd be able to do that. They're so amazing*. (Health SLT 02)

The specialist school had a dysphagia policy in place, outlining the responsibilities of each team member. The policy briefly discussed how school staff should proceed when disagreements occurred between the family and school team regarding a student's PFD. When the senior leadership team mediated disagreements in practice, classroom staff felt supported, however, senior leadership teams often referred to SLTs' judgements and external perspectives were rarely sought. School SLT 05 stated,"…the shame for me is that it was left as a speech therapy issue…if a child was being abused, it would become a bigger issue, but because it was dysphagia, it just stayed as a speech therapy issue". The School Dysphagia Policy (2020) did not stipulate when school SLTs should refer to external professionals and who would support families at home with their child's PFD:

> *Leadership team: Work with the team members and whānau or within the team to find a resolution if there are disagreements. If parents/carers do not give informed consent regarding an eating/drinking programme, this should be recorded in the student's file and the team informed. The school team will be responsible for the safe management of the student's eating and drinking within school. Parents will be responsible for management of eating/drinking at home.* (p. 3)

Classroom staff had the appropriate resources to support students with PFDs. For example, each class had equipment to support each student's needs, such as bibs, cloths, showers, blenders, adaptive cutlery/crockery, washing machines, and microwaves. Some teachers intentionally arranged staff timetables so experienced staff were rostered on with newer staff, allowing newer staff to learn from more experienced staff:

> *We have everything there [in the class]; we have facecloths it's easy for us to manage. We have a shower if we need… if this one has to have pureed, we have a blender, you know we have everything. We can heat the food and everything so it's not stressful in that way at all… I guess our environment is suited for feeding different meals.* (Teacher 05)

School staff were often reliant on in-house training to upskill in different areas. A range of verbal and visual strategies supported school staff in learning information and skills related to PFDs. Staff felt supported when SLTs verbally explained strategies and provided written documents visible in the classroom containing pictures and no longer than one page. Staff requested that SLTs provide regular whole-school training on PFDs, coach new staff during mealtimes, and attend class meetings to discuss the team's needs:

> *It was more just getting my head around, like, what each person needed help with and, like, what they could do independently. So yeah, I felt like that was helpful, like*

> *having someone explain to me where the kids were at. So, I do think it would be really helpful to have that, like, on paper or visually… I do think that for new staff coming in, it wouldn't be amiss if there was like a bit more comprehensive training… maybe, like, some more formalised training just for staff in general around feeding.* (Teacher 01)

4.3.2 Families

Caregivers valued the communication practices of the school and the health services they engaged with. Caregiver 02 appreciated receiving regular updates about her child’s activities and well-being from school, describing them as “very responsive”. Caregiver 01 felt supported when she could easily contact health professionals, emphasising how it was important for her to get the right support from the right professionals at the right time:

> *I think it's definitely the communication side of it, like having someone that you can contact when something goes wrong, or you're not sure about something, or you just need to talk something through. I think that for us was a big deal, like having… the SLT and the, you know, the dietitian and… you sort of had everyone's contact. And if she wasn't there, you could contact someone else. So, there was always someone that could help you if you got stuck.* (Caregiver 01)

Caregivers valued the school's PFD-related support, particularly when classroom staff completed an activity or program that parents could not do at home. For example, both caregivers acknowledged how the school provided food-related experiences, such as cooking and food exploration, that they were unable to provide at home due to restraints such as time and resources:

> *And even at school, I think sometimes they allow him to do a messy play, to play with his food, and he can touch his food and everything. I don't do that, to be honest now. Yeah, because it's like all the mess, and I have a carpet, so it's difficult to clean. So, I don't allow him to do that full messy play at home.* (Caregiver 02)

4.3.3 SLTs

Specialist school SLTs and health SLTs had different structures and supports in place. For example, both school and health SLTs had guidelines written by their respective employers. The health-based guidelines included in-depth information about assessment and management. In contrast, the School Dysphagia Policy (2020, p.1) briefly described tasks such as, “assess the student’s swallowing ability in conjunction with the OT and PT as needed”. Health-based SLTs had a clear service structure and an overall goal of increasing oral feeding skills in children. Health SLTs were unsure if specialist school SLTs worked towards improving oral feeding skills, and school SLTs did not change a student's mealtime plan if things were "running smoothly". School SLT 01 questioned why, "We have a standardised way of operating in a hospital; why can't we have a standardised way of operating in a school?". The school's senior leadership teams often based their decisions on school SLTs' recommendations, whereas health SLTs often looked to paediatricians and clinical leads for advice and expertise:

> *I think there's a little bit of uncertainty about the process and, like, how often to do a video [VFSS] or, like, when a plan might change… I think what we [health SLTs] do is we do a video fluoroscopy, and we come up with these recommendations, but our goal is to get them oral feeling a little bit more. So, we're actively doing like therapy and treatment, intervention, to kind of like support. And then we do another video to see if there's been any progression and, like, update the recommendations, so yeah, there's a bit of a lack, I think, of that [in specialist schools].* (Health SLT 06)

School SLTs 03 and 04 did not feel confident creating safe eating plans or programs to support students in progressing their oral feeding skills. Both SLTs expressed their desire to have SLTs who completed the VFSS write the student's safe eating plan. However, Health SLT 02, who completed VFSSs, reported it would be inappropriate for her to write safe eating plans because she did not know the school setting, family wishes, or background, which would impact the plan. Health SLT 06 described school SLTs' hesitation to change PFD-related plans:

> *I know that when I've spoken to other special schools SLTs, they haven't wanted to [change the plan]; they'll be unsure about the referral process to XX (hospital) to do a video fluoroscopy to change things. They're not quite sure how often they should be doing it. There's a few SLTs that definitely ask the questions, and then, as a result, I think maybe things happen from there. Yeah. But yeah, I think there's a little bit of uncertainty about the process and like how often to do a video or like when a plan might change.* (Health SLT 06)

Specialist school SLTs found accessing professional development relating to school-specific PFD strategies difficult. School SLT 01 described her professional training as "great" but felt it primarily taught how to support children between the ages of one to three years, which did not include specialist school students. Specialist school SLTs did not attend any PFD-related training as part of their induction to the school. School SLT 04 attended PFD special interest groups (SIGs) but did not consistently find the information useful to specialist school settings. Specialist school-related SIGs rarely included discussions relating to PFDs.

Health SLT 06 suggested that specialist school SLTs shadow and observe community health SLTs to gain greater knowledge of assessing and supporting PFDs. Additionally, SLT 06 thought health SLTs should observe school PFD programs, assessments, and mealtimes to better understand the school environment and provide feedback if required. Health SLTs wanted to support specialist school SLTs but were unsure what support they required. All school SLTs were supervised, but school SLT 01 wanted PFD-specific supervision.

> *It's like the most complex dysphagia is almost what you're managing, not from a physiology perspective necessarily, but from a parental, whānau safety, school. Like the complexities of it all in terms of liability and safety and parent understanding and stuff is, it's almost harder for them, but they don't necessarily have a lot of emphasis put on it for training or competence, or upskilling, or maintaining of competence. And so, I think that's the vibe I get sometimes from the special school therapists is that they're just like, 'I don't even know what you want me to do'. And then I'm like handing over these kinds of variable recommendations, knowing probably what I would want to do if it was me managing them, but also knowing that that's not my role in the puzzle.* (Health SLT 02)

Specialist school SLTs demonstrated varying collaborative practices with paediatricians and allied health professionals. Some school SLTs routinely gathered documentation and proactively collaborated with medical teams. For example, School SLT 01 contacted the local dietitian yearly to collect updated enteral feeding plans and contacted the community nurse when students needed enteral feeding equipment, or staff required enteral feeding training. In comparison, School SLTs 03 and 04 had no contact information for their local health SLTs or dietitians. Not all enterally fed students had enteral feeding plans, as seen in Table 18. Overall, 75% of specialist school SLTs (n=3/4) felt isolated when supporting students with PFDs. Conversely, health SLTs developed incidental relationships with paediatricians and other allied health professionals by working in close proximity to one another, increasing their collaborative practices:

> *And they [special school SLTs] don't know how to find the name of the paediatrician, and the paediatrician doesn't even cc' this therapist into their reports because they don't even know their name and, like, so removed from us that level of kind of support…I always feel so grateful to have medical teams at the drop of a hat, you know. I can't even imagine how isolating it must be to be in a special school and not even know what doctor to call when you're concerned… the IT systems don't support you to do that [share documentation across organisations], you know, like, you can*

> *come up with a really nice passport or something. But how that gets stored on each person's information system is different to the next one, is really tricky.* (Health SLT 02)

Local-level agreements (LLA) existed between health services and other organisations, such as specialist schools, the Ministry of Education, and early intervention services. The agreement enabled SLTs in non-health-related organisations to consult with health SLTs and for some school-aged students to receive episodic care for PFDs from health SLTs. Each LLA provided different levels of collaboration and support, which varied depending on the geographical region. Table 19 outlines the differences between two LLA meetings in different regions.

> *But the thing about the LLA [meeting] is, it is so discombobulated, so many therapists don't turn up to it. It's PT and OT and SLT, so having a feeding discussion, it doesn't always happen. And when it does happen, it's not everyone's cup of tea either. It's not the way everyone's working; nobody comes to any kind of agreement on it. And you're just back at square one… The local level agreement [meeting] is the right place to do it, but it just needs to be speech-language therapists sitting down, having a discussion, saying this is why you refer. And maybe even just coming in every now and again and seeing what we are doing at school.* (School SLT 01)

Table 19

Differences Between two Local-Level Agreement (LLA) Meetings Functioning in Different Geographical Regions

LLA meeting 1	LLA meeting 2
Met once a term.	Had not met for the past two years due to COVID and staffing levels.
SLT specific.	Included all allied health professionals.
Discussions included updates on hospital staffing, case discussions, and professional development.	No identified structure to meeting.

4.4 Opportunity: Social

Opportunity afforded by interpersonal influences, social cues, and cultural norms that influence the way we think about things (e.g., words and concepts that make up our language) (Mitchie et al., 2014, p. 63).

4.4.1 School

Communication between the specialist school and external organisations was evident. For example, 16% of students (n=18/113) had reports from Blind and Low Vision Education Network NZ (BLENNZ), 13% (n=15/113) had reports from hospital occupational therapists, and 11% (n=12/113) had reports from hospital physiotherapists. Many reports included comments that indicated ongoing communication between the specialist school and external organisations. As seen in Table 18, 28% (n=32/113) of students had a positive behaviour plan, a similar number to those with a documented indication of PFDs. Students with behavioural difficulties had access to more external supports and agencies, such as psychologists, family group conferences, and Strengthening Families meetings. Students with documented indications of PFD had less paperwork from external agencies (Table 17), indicating that school SLTs accessed fewer external supports for students with PFDs compared to students with behavioural difficulties.

Classroom staff feared being held liable, or legally responsible, for the consequences of feeding a student a particular way. For example, Teacher 04 did not want to feed a student the food she ate at home (IDDSI level 7 - regular) because the student had underdeveloped oral motor skills, and the teacher did not want to be held liable if the student choked at school. Teacher 05 declined to feed a student as quickly as his family fed him at home because she was concerned the fast pace would cause overstuffing and increase the student’s risk of aspiration:

> *We've had other issues with parents where it seems like it's a battle between, ‘I'm the parent, this is what I want for my child. Why are you not doing that? Because you're taking care of my child, you should be doing what I want, right?’ And getting them to understand that, well, yes, you're the parent. So, you can do that. We're not the parent. So, if something were to go wrong while we were doing it, we would be held liable. So, we're not willing to take that risk.* (Teacher 03)

4.4.2 Families

Caregivers were more flexible with dysphagia recommendations at home, meaning students were fed differently at home compared to school. For example, one student gained all nutrition through her mic-key button at school but was fed an IDDSI level 7 diet at home. Caregivers 01 and 02 both fed their children different IDDSI levels at home than they had at school. Classroom staff often told families that SLT recommendations needed to be followed at school to meet health and safety requirements, but they did not have to follow them at home.

> *I think handpicking things and using it more as a guide rather than a 'this is what you have to do' kind of thing because you do know your child. You know, someone spends, you know, couple of hours a week with him, but, you know, you kind of get to know what, what they like, what they can do…* (Caregiver 01)

While families sometimes fed their children differently at home, caregivers did not expect classroom staff to consistently use the same strategies or food they used at home. Caregiver 02 acknowledged that her child would only let her feed him certain foods and in certain ways. She did not expect the classroom staff to do everything that she did. Caregiver 01 did not want classroom staff to feel uncomfortable when feeding her child, so she did not expect them to do exactly what she was doing at home:

> *I kind of just took it [SLT recommendations] as that's fair enough. That's their call, I mean, they [classroom staff], you know, I need to make sure that they feel comfortable. And if they don't feel comfortable feeding him, you know…then I guess that's, you know, that's fair. It is what it is. We started, [we] didn't change what we did at home. We just were more conscious of what we send into school now rather than, you know, sending stuff that could potentially be a problem… And they may not feel comfortable doing that. Yeah, and I don't want to make anyone feel like you know, that this [family strategies] is, this is too much of a risk... We work together, I guess.* (Caregiver 01)

Caregivers' relationships with health professionals and classroom staff were an important part of the service they received. Caregiver 01 stated, "It was more personal kind of relationship that you sort of built with the people. Yeah, that was, you know, looking after him. I think that was a big help. In making things easier."

4.4.3 SLTs

School SLTs inconsistently provided therapy for students with PFDs, which appeared to be influenced by the students' environment and the therapist. Thirty-seven percent (n=14/38) of students with a documented indication of PFD received some form of direct therapy, as seen in Table 19. Fifty-seven percent (n=8/14) of this therapy was oral desensitisation for selective eaters, and 43% (n=6/14) was some form of oral motor therapy. Direct therapy for selective eaters was delivered as a class-wide program and only for classes where all students experienced selective eating difficulties. Only school SLT 03 offered direct therapy for students with selective eating difficulties, despite both school SLTs having classes where direct therapy was appropriate. Students with oral motor difficulties had therapy programs incorporated into their safe eating plans that were to be carried out by classroom staff when appropriate resources and time were available. One program recommended that a student use a chewy tube and transitional foods to develop chewing skills. Most programs recommended that students eat an IDDSI level above their recommended diet under close supervision. Few programs explained their purpose or goal, and SLTs did not regularly monitor the programs beyond a yearly review of the safe eating plan. Students without a safe eating plan with a documented indication of PFD did not receive direct therapy.

Table 20

Breakdown of the Types of Therapy Students Received

Types of therapy	Purpose	Percentage of students with documented PFD
‘Fun with food’ class-wide program.	Oral sensory desensitisation for selective eaters.	21% (n=8/38)
Individualised oral motor program.	-Develop chewing and oral motor skills. -Unknown.	16% (n=6/38)

School SLT 05 was the only SLT that supported a student to EDAR within a school setting. Classroom staff utilised EDAR practices with the student before the specialist school SLT became involved. The SLT completed an assessment involving the family, school team, and respite service, but no external health professionals (e.g., paediatrician, health SLT). The SLT adapted a Talking Mat ™ to discuss possible options with the student and support him to make an informed decision to EDAR. The student agreed to not EDAR if his weight was of concern or if no skilled staff were present to support him.

> *So they [classroom staff] kind of knew about the IDDSI levels and what was safe. And when I went into the class, what they tend to do is say, XX (SLT) don't look… sit over here, face this way. We'll give him the lunch then you can face back again. So, they have the training to know that this actually wasn't the recommended way of doing things, but they weren't following the recommended way for, for those other reasons that were actually you know, the more I learnt, very legitimate.* (School SLT 05)

SLTs sometimes knew when families used EDAR practices at home but did not routinely inform health care providers (e.g., paediatricians, health SLTs) or provide follow-up support. Subsequently, these families received no advice on how to EDAR in the safest way possible:

> *So then I had to have that conversation with mum and say, 'Look, if you want to feed him, we don't, we can't do that at school because it's, it's a safety issue for him and his staff aren't feeling comfortable'. And then Mum said, 'That's fine. I will just send you know, the recommended textures. But I'm just going to try with him on the weekend'. And I said, 'That's your decision'. Yeah. So, she was quiet; she was okay with that conversation.* (School SLT 04)

Relationships between school SLTs, classroom staff, and families were sometimes strained when the team discussed complex feeding decisions. For example, one mother disengaged with school SLT 01 after the SLT decided that her child could not eat orally at school as she deemed it to be unsafe. The SLT made this decision against the mother's wishes for her child to eat orally at school.

> *[The teacher was] not on board with eating orally. She had an extremely complex classroom. I do not hold any grudge for her not wanting to engage with me on this at all. It was a strain on my relationship with the teacher. She just, it was just one step too far… And so, I said [to mum], 'Look, if you want to continue to risk feed at home, that is your prerogative. At school, she'll remain nil by mouth'. And mum did not engage with me again after that.* (School SLT 01)

4.5 Motivation: Reflective

Reflective processes involving plans (self-conscious intentions) and evaluations (beliefs about what is good and bad) (Mitchie et al., 2014, p. 63).

4.5.1 Classroom Staff

Classroom staff considered supporting students during mealtimes as part of their job description, regardless of whether they supported students with enteral feeds, diet modifications, or enabled them to self-feed. Some classrooms created a culture where feeding was viewed as manageable, with feasible solutions to any problems that arose. Teacher 01 felt this classroom culture created a stress-free environment for her to learn in:

> *I didn't feel like it was super tricky or anything like that, or that it was like out of my job description…it was never… approached me as something of like, oh, this [supporting students during mealtimes] is like a big scary thing that's really hard… I was just kind of shown how to do it. And then you just kind of get on with it… when I*

> *first started doing mic-key stuff that people were kind of like, you can just breathe like, you know, it's, it's not a medical procedure".* (Teacher 01)

Classroom staff were also often motivated to learn more about PFDs to best support their students. Some teachers completed self-directed learning related to their student's needs and asked how they could support students' feeding safety or progression. For example, Teacher 04 independently sought information about introducing food to students who were nil-by-mouth, and Teacher 01 independently read information about mic-key buttons:

> *And I think just like, for people's kind of like, empowerment… when it comes to, like, knowing why they're doing something, that would be beneficial… even if they were given, like, information to take home about mic-keys or whatever. I vividly remember when I was a BT [beginning teacher], before I got my first class in special ed, googling, 'What is a mic-key button?' Yeah. And, like, reading and stuff like that, but yeah, like, you know, you never, you never know when, like, when you're just placed in a class.* (Teacher 01)

4.5.2 Families

Both caregivers wanted to develop their child's oral feeding skills and for their child to participate in family routines as much as possible. Caregiver 02 sought private therapy when in another country to support their child's oral desensitisation. Caregiver 01 gave her child fluids using an oral syringe at home because she wanted him to drink fluids eventually and knew that he needed to practice drinking small amounts. Caregivers 01 and 02 requested SLT support at home to better understand how to support their child's oral skill progression.

> *I know I shouldn't probably give them water out of the syringe because it's going to get them used to doing that. But well, at least he's practising drinking fluids.* (Caregiver 01)

Caregivers trusted classroom staff more than staff in other organisations, such as respite staff. Both caregivers believed that the classroom staff provided a high level of support for their child, and they had no concerns about the child's safety at school.

> *So, we don't send him to respite. And we don't like to send a respite, that we are here, and he goes away. So, definitely, we are not going to send him to respite at all…Yes, they're doing a really great job, but not [just] with XX (student), with all the students. So, I don't have to worry when he's at school.* (Caregiver 02)

Some families had negative experiences with health procedures and professionals, which reduced their engagement with health services. For example, one family and student had a negative VFSS experience and refused to get a repeat VFSS to determine if the student’s physiology had changed. The school SLT repeatedly discussed how to make the VFSS more positive and comfortable for the student, but the family refused.

> *I mean, I just think, like, if I had known, like, okay, she's gonna go to the XX (hospital) clinic, it's a different videofluoroscopy place than the first one she went to. We can meet the therapist beforehand; we could have, you know, they could have looked different. But the family were just so against it.* (School SLT 01)

4.5.3 SLTs

Specialist school SLTs found it challenging to create safe eating plans that balanced family goals and enabled students to eat safely. For example, School SLT 04 supported a student with IDDSI level 4 recommendations from a past VFSS report, but the family wanted the student to eat an IDDSI level 7 diet. The school SLT struggled to balance SLT recommendations from the VFSS report and family wishes when creating a safe eating plan for the student. Student wellbeing was often at the centre of decisions being made:

> *She wasn't safe across all textures. And trying to navigate that and knowing that the parents really wanted her to eat orally and with her hands, and she had so many motor difficulties. And not being, not saying no because you never want to, like, not have a child or family reach their dream.* (School SLT 01)

Specialist school SLTs felt highly stressed when navigating complex feeding decisions, not always knowing where to turn to for support. School SLT 01 reflected on the long-lasting impact of a stressful case, stating, “…that was just challenging…and upon reflection, she is a student who's going to stick with me for probably the rest of my career on how you can not get it right”.

> *... it was, it was fear because, you know, this child has been nil by mouth for years… I felt I didn't have enough clinical support around me to kind of be very confident with my approach. So, I kind of borrowed ideas, you know, by speaking to the, you know, the senior SLTs there ... But the initial thing was, ‘Oh, where do I start? How do I start? Who do I speak to? Am I doing the right thing?’... Does he have to go for another VFSS even, which mum wasn't really open to that idea, either… a lot of questions, but where do you go for the answers?... I was quite; I was a bit scared, actually.* (School SLT 04)

4.6 Automatic Motivation

Automatic processes involving emotional reactions, desires (wants and needs), impulses, inhibitions, drive states, and reflex responses (Mitchie et al., 2014, p. 63).

4.6.1 Classroom Staff

Classroom staff took more measured risks when they had increased knowledge. For example, teacher 03 had received training from a previous SLT on implementing *tastes* programs. As she became more confident running this program, she used a wider variety of food and differentiated how she presented food to each student, constantly gaining the student's consent. For one student, she placed puree on their lips, which they licked off. For another student, she placed a spoon with small amounts of puree on the student's bottom lip, allowing them to close their lips over the spoon and remove the puree.

> *So, when I first started, I definitely wouldn't have been nearly as confident as I am now. [I] kept things simple and play it safe. Whereas, as I've learned more about what the actual risks are, it's allowed me to go okay, well, if that's the risk, I can actually do this in this area safely.* (Teacher 03)

Each person who encountered EDAR expressed different comfort levels about the level of risk families and students were taking or wanted to take. People's comfort levels appeared to be based on a range of factors, such as a person's familiarity with the student, their knowledge of PFDs, the responsibility they carried for the student's well-being, and their motivations. For example, caregivers who supported their child for many years knew their child's cues and were more willing to utilise EDAR practices than classroom staff. School SLTs who felt isolated and held responsibility for the EDAR decision were less willing to support EDAR practices than experienced SLTs working in a supportive team. School SLT 04 explained, "I feel I'm not confident enough with my knowledge…and experience to kind of go okay … let's try this [EDAR] and let's see what happens. I don't have the confidence to be able to do that".

> *Yeah. So, if we give him, like, those little, what do you call them, like, little chicken things, he'll pick them up, and he puts them in his mouth. You have to watch him though because he'll keep going. Yeah, he does tend to not realise that he needs to chew first and then eat more. But we do try and encourage him to do that himself. Pick things up because… he can kind of do that now... we do supervise them obviously quite closely. But yeah, we don't tend to just limit him to, you know, mash and the texture or things, which tends to be more of the things that he's having at schools… I think, for school, it's a safety thing rather than anything else.* (Caregiver 01)

4.6.2 SLTs

Specialist school SLTs described a divide between education and health, indicating that both had differing priorities. For example, School SLT 03 independently prioritised PFD assessment without expectations from the school and recognised that it wasn't a priority in education. School SLT 04 waited until parents asked about the development of their child's oral feeding skills before suggesting any strategies or writing a therapy plan. Subsequently, each individual SLT provided different levels of support for students with PFD depending on how they individually prioritised PFD assessment and management. This led to differences in service provision within a specialist school and likely across specialist schools.

> *I mean, you feel like, you know, to do your job, it's to tell them about the videofluoroscopy, right? So, you'll always do that. But then it's, like, if you didn't do that, would the parent seek the videofluoroscopy…like not necessarily. Like, in education, it's not really a priority. So, you have to make it your own priority, knowing your scope of practice. Like knowing your responsibilities, but it's something that could be missed.* (School SLT 03)

5 Results: Implementation Cycles 1 and 2

This chapter will provide a narrative review of the Reflect and Plan phase and the two implementation cycles (Figure 9).

Figure 9

Overview of Implementation Cycles

***Reflect and Plan* phase (*approx. 3 months*)**

- Followed BCW manual to identify BCTs (behaviour change techniques)
- Created draft resources

Implementation Cycle 1 (approx. 3 months) – utilised a participatory action research cycle:

- Act
- Evaluate
- Modify

Implementation Cycle 2 (approx. 3 months) – utilised a participatory action research cycle:

- Act
- Evaluate
- Modify

5.1.1 Reflect and Plan Phase

The Reflect and Plan phase was necessary to i) confirm the accuracy of the interpretation of the qualitative and quantitative observational data gathered from the Observe phase and ii), with the support of the stakeholders, devise the initial implementation plan.

5.1.2 Accuracy Checking and Data Sharing

I met with school SLTs 03 and 04 at the end of the Observe phase to discuss the data gathered after completing an initial analysis. The school SLTs requested to review the data without external SLTs, school staff, or families present as the data reviewed their practices. I presented the data in a document, splitting the information into barriers and facilitators, as seen in Appendix 3. To confirm that I had accurately interpreted data from their interviews, the school SLTs *member checked* my initial findings. This increased the trustworthiness of the interview analysis, ensuring the summaries extrapolated from the data were accurate and reliable (Birt et al., 2016).

Example

The school SLTs confirmed that points such as, “thorough dysphagia assessments make SLTs feel ‘safe’ when managing PFD” and, “SLTs feel under-skilled to enable students to progress with oral feeding skills (e.g., texture progression)” were accurate interpretations of their experiences and feelings.

The school SLTs and I reviewed information that was unfamiliar to them, such as the documentation audit and findings from the mealtime observations. Reviewing the data with the school SLTs enabled me to determine what was new information to them, gather their emotional responses, consider possible approaches to moving forward, and identify what mattered most to them.

Example

SLTs 03 and 04 were unaware of how inconsistently their assessment and support of students’ PFDs was documented, as discussed in Chapter 4. They were particularly surprised that tastes programs were occurring without their knowledge. Their reflexive response was to discuss how teachers should stop the tastes programs without speaking to families, determining their purpose, evaluating the programs, or asking teachers what training they had received. SLT 04 stated that the School Dysphagia Policy disallowed EDAR from occurring in the school environment, which was not the case (School Dysphagia Policy, 2020). SLTs 03 and 04 had never supported a family or school team to utilise tastes for oral skill development or comfort, did not understand what components should be included, and did not understand that tastes are not always synonymous with EDAR practices. Their response to this information demonstrated the level of anxiety and fear they experienced regarding tastes and potential EDAR practices. Due to their anxiety and fear, I decided to support them to better understand the topic rather than create resources to support the implementation of tastes programs, as they appeared unreceptive to the idea of introducing tastes.

5.1.3 Intervention Functions and Policy Categories

During this meeting, the school SLTs and I discussed which *intervention functions* and *policy categories* were appropriate for this study, seen in Table 20. As specified in the manual, the intervention functions and policy categories are part of the Behaviour Change Wheel (BCW) procedure. Intervention functions are broad categories of interventions that can result in behaviour change, and policy categories are types of decisions that enable people to complete an intervention (Mitchie et al., 2014). Intervention functions and policy categories are designed to be used in conjunction to support the implementation process. The APEASE criteria are a set of measures a clinician can use to identify which intervention functions and policy categories are appropriate in specific contexts, as seen below (Mitchie et al., 2014):

- **Affordability** – does the intervention cost fall within the accepted budget?
- **Practicability** – can the intervention be delivered as designed to the target population on the scale intended?
- **Effectiveness and Cost-effectiveness** – will the intervention have an adequate effect size related to real-world objectives? Will the effects have a proportionate cost?
- **Acceptability** – how will the intervention be judged and engaged with by relevant stakeholders?
- **Spillover effects/safety** – will the intervention have unintended positive or negative effects?
- **Equity** – will the intervention reduce the disparities in health, well-being or standards of living?

I discussed each intervention function and policy category with SLT 03 and 04 using the APEASE criteria to determine their relevance to the project and school setting, seen in Table 21. Initially, the school SLTs wanted to incorporate the intervention function of "Restrictions" to limit the use of tastes in the school environment. However, they recognised that using restrictions would not be received well by school staff and acknowledged that other forms of intervention functions or policy categories may be better received.

Table 21

Consideration of Intervention Functions and Policy Categories Using the APEASE Criteria for This Study

Intervention function	Does the mode of delivery meet the APEASE criteria?	**Policy categories**	Does the mode of delivery meet the APEASE criteria?
Restrictions (Using formal social rules to set boundaries for a behaviour)	No – not acceptable to wider school staff, may limit equity of service provision.	**Guidelines** (Creating and disseminating guidelines)	Yes – to guide processes around school procedures and paediatric EDAR procedures.
Education (Informing or explaining things to increase knowledge related to a behaviour)	Yes – school SLTs to receive information about VFSS procedures, collaboration with health professionals, and EDAR.	**Environmental/ social planning** (Using a formal planning process to create and implement changes to the physical or social environment)	Yes – to increase collaboration between health and school SLTs.
Persuasion (Using words and images to get people to feel like or dislike for something related to a behaviour)	Yes – school SLTs to receive information from health SLTs to increase the credibility of information.	**Communication/ Marketing** (Using communication channels including electronic, print, and broadcast media to deliver messaging)	Yes – to create resources for school SLTs to refer to and use.

Incentivisation (Applying rewards for a behaviour)	No – not acceptable or affordable for school SLTs.	**Legislation** (Developing and enacting laws)	No – not practical for the scope of this study.
Coercion (Applying costs or punishment to a behaviour)	No – not acceptable or effective for school SLTs, potential to limit spillover effect.	**Service provision** (Providing a service or resources)	No – not acceptable for the design of this study.
Training (Using demonstration, feedback and practice to improve physical or psychological skills related to a behaviour)	Yes – school SLTs to receive training to increase psychological skills related to VFSS procedures, EDAR, and collaboration with health.	**Regulation** (Creating and implementing regulations short of legislation)	No – not practical for the scope of this study.
Enablement (Providing physical or social support, or material, or financial resources making it possible or easier to enact a behaviour)	Yes – to enable school SLTs to feel more supported when managing complex PFDs in a school setting.	**Fiscal measures** (Implementing financial rules, including taxation)	No – not affordable, cost-effective or acceptable to school SLTs.
Modelling (Provide examples for people to imitate, learn from, or aspire to)	Yes – to provide examples of how school SLTs can collaborate with health and support students with PFD in schools.	**Environmental restructuring** (Shaping the physical or social world inhabited by the person to make a behaviour easier or harder)	Yes – to encourage increased frequency and quality of collaboration between health and education.

During the meeting, the school SLTs and I planned what resources and actions would be helpful to enable them to support students with complex PFDs. We collaboratively created the following list of resources and implementation plan:

- Eating and Drinking with Acknowledged Risk (EDAR) Management Plan.
- EDAR at Home – a form for parents to sign if EDAR strategies were used at home.
- School PFD Management Flowchart.
- EDAR Risk Minimisation and Information.
- Inter-Agency Document Transfer.
- VFSS Booking Process for Specialist School Students.
- Paediatric EDAR Guidelines.
- Oral Texture Progression Strategies.
- What to Consider for a Tastes Program.
- Assessment Components for Specialist School Students.
- Family and Student Views of Complex PFD Decisions.

5.1.4 Identification of Behaviour Change Techniques (BCTs)

After choosing the intervention functions and policy categories, I then reviewed the list of behaviour change techniques (BCTs) connected to the Behaviour Change Wheel (BCW), called the Behaviour Change Technique Taxonomy (v1) (BCTTv1). BCTs are a group of observable, replicable, and irreducible actions designed to change behaviour as part of an intervention (Mitchie et al., 2013). Using BCTs increases a study's transparency and replicability, subsequently increasing its internal validity (Creswell & Plano Clark, 2018). While developing the implementation plan with the school SLTs, I identified which BCTs matched the intervention functions and policy categories, as seen in Table 21. This task was completed without the school SLTs' input because the BCTTv1 has 93 items, and I deemed this too laborious for the school SLTs to review.

In the BCCT(v1), each BCT is organised under a numbered category (Mitchie et al., 2013; Mitchie et al., 2014). For example, the BCT Goal Setting (Behaviour) is organised under category one, Goals and Planning. The BCTs I identified during the Reflect and Plan phase are outlined in Table 22 and are structured under their numbered category, as specified in the BCTTv1.

Table 22

Behaviour Change Techniques (BCTs) Linked to the Intervention Functions and Policy Categories

-Intervention functions -Policy categories	Behaviour change techniques (BCTs) utilised during Implementation Cycles 1 and 2	Details of actions taken
1. Goals and Planning		
-Enablement -Environmental/ social planning	**Goal Setting (Behaviour) –** set or agree on a goal defined in terms of the behaviour to be achieved.	-Meeting with school SLTs to co-identify behaviour goals.
-Incentivisation -Environmental/ social planning	**Discrepancy Between Current Behaviour and Goal –** Draw attention to discrepancies between a person's current behaviour (in terms of the form, frequency, duration, or intensity of that behaviour) and the person's previously set behavioural goals or action plans (goes beyond self-monitoring of behaviour).	-Draw attention to discrepancies between the school SLT's current practice and behaviour goals (e.g., collaboration with health for complex PFDs, documentation of students' PFD, etc.).
3. Social Support		
-Environmental restructuring **-Education** -Environmental/ social planning	**Social Support (Practical)** – Advise on, arrange, or provide **practical** help (e.g., from friends, relatives, colleagues, 'buddies', or staff) for performance of the behaviour.	-Discuss complex PFD cases with school SLTs and encourage collaboration with health SLTs.
6. Comparison of Behaviour		
-Education **-Modelling** -Environmental/ social planning	**Demonstration of the Behaviour -** Provide an observable sample of the performance of the behaviour, directly in person or indirectly, e.g., via film or pictures, for the person to	-Model completion of flowchart and use of resources for all students. -Model collaboration with health SLTs (e.g., asking questions, initiating

	aspire to or imitate (includes ‘modelling’).	collaboration with health, etc.).
8. Comparison of Outcomes		
-Persuasion -Environmental/ social planning	**Credible Source -** Present verbal or visual communication from a credible source in favour of or against the behaviour.	-Health SLTs complete training re: VFSS.
12. Antecedents		
-Education **-Enablement** -Guidelines -Communication/ marketing	**Adding Objects to the Environment** - Add objects to the environment to facilitate behaviour performance.	-Provide agreed-upon resources for school SLTs.
-Environmental restructuring **-Enablement** -Environmental/ social planning	**Restructuring the Social Environment** - Change, or advise to change, the social environment to facilitate performance of the wanted behaviour or create barriers to the unwanted behaviour (other than prompts/cues, rewards, and punishments).	-Introducing expectations for increased collaboration with families and health.

5.1.5 Development of Resources to use in Implementation Cycles

After the meeting with the specialist school SLTs, I developed the resources listed in section 5.1.3 over three months. Some of the resources were developed from already existing resources, such as textbooks (Crary & Groher, 2020; Homer, 2016) and existing school documentation. Other resources were developed in consultation with health SLTs. The Paediatric EDAR Guidelines had already been adapted from an existing adult risk feeding guideline (The University of Auckland & Hutt Valley District Health Board, 2016), which was edited to include considerations for school therapists.

5.2 Implementation Cycle 1

Each implementation cycle had a participatory action research (PAR) structure of act, evaluate, modify, as seen in Figure 6, seen in Chapter 3.

The BCTs utilised in Implementation Cycle 1 are outlined in Table 23 and expanded below in chronological order. All BCTs underwent the PAR cycle seen in Figure 6. Given the environmental restrictions, the PAR cycle was necessary to gather stakeholders' input on whether the BCTs, resources, or behaviour goals were appropriate for the setting and feasible to implement. One aim of PAR and implementation science is to reduce the practice-knowledge gap, making stakeholder involvement crucial in the development and implementation of the study (Bradbury, 2015; Nilsen, 2015).

Table 23

BCTs Utilised in Implementation Cycle 1, Undergoing an Act, Evaluate, Modify Process

Act – Implement BCTs linked to behaviour goals		Evaluate	Modify
Actions taken during *Implementation Cycle 1*	Associated behaviour change technique (BCT)		
	1. Goals and Planning		
-Meeting with school SLTs to co-identify behaviour goals.	**Goal Setting (Behaviour) –** set or agree on a goal defined in terms of the behaviour to be achieved.	-School SLTs analysed the barriers to achieving their behaviour goals.	-We modified the behaviour goals and looked to remedy the barriers. I stopped working on the following documents: EDAR Risk Minimisation and Information, EDAR Management Plan, and What to Consider for a Tastes Program.
-Draw attention to discrepancies between the school SLT's current practice and behaviour goals (e.g., collaboration with health for complex PFDs, documentation of students' PFD, etc.).	**Discrepancy Between Current Behaviour and Goal –** Draw attention to discrepancies between a person's current behaviour (in terms of the form, frequency, duration, or intensity of that behaviour) and the person's previously set outcome	-School SLTs evaluated their practice and identified barriers to achieving their behaviour goals.	-School SLTs looked to reduce discrepancy (e.g., increased documentation of students with mealtime plans, increased collaboration with health, etc.).

	goals, behavioural goals, or action plans (goes beyond self-monitoring of behaviour).		
	3. Social Support		
-Discuss complex PFD cases with school SLTs and encourage collaboration with health SLTs.	**Social Support (Practical)** – Advise on, arrange, or provide **practical** help (e.g., from friends, relatives, colleagues, 'buddies', or staff) for performance of the behaviour.	-I continually encouraged school SLTs to collaborate with health SLTs.	-School SLTs reduced the frequency of contacting me for case discussion and increased their collaboration with health SLTs.
	6. Comparison of Behaviour		
-Model completion of flowchart and use of resources for all students. -Model collaboration with health SLTs (e.g., asking questions, initiating collaboration with health, etc.).	**Demonstration of the Behaviour** - Provide an observable sample of the performance of the behaviour, directly in person or indirectly, e.g., via film or pictures, for the person to aspire to or imitate (includes 'modelling').	-I modelled how to use the resources for the school SLT (e.g., completed a PFD needs-based flowchart for all students, used inter-agency documentation transfer form, etc.). I modelled collaboration with health SLTs.	-School SLTs saw how they could use the resources to support their students and asked for the resources. School SLTs saw how they could collaborate with health SLTs.
	12. Antecedents		

-Evaluation of the created resources.	**Adding Objects to the Environment** - Add objects to the environment to facilitate performance of the behaviour.	-Advisory team to provide feedback on the resources.	Accepted track changes and modified the resources based on written or verbal feedback. Continued advocating for home-school collaboration. Actively pursued facilitating relationship building between the specialist school SLTs and health SLTs. Arrange VFSS training with specialist school SIG.
-Introduction of expectations for increased collaboration with families and health.	**Restructuring the Social Environment** - Change, or advise to change, the social environment to facilitate performance of the wanted behaviour or create barriers to the unwanted behaviour (other than prompts/cues, rewards, and punishments).	-Facilitated a meeting between the local health SLTs and specialist school SLTs. Gathered feedback on collaboration between health professionals (e.g., SLTs, paediatricians, etc.) and the local specialist school.	Discontinued working on the following documents: Oral Texture Progression Strategies, Assessment Components for Specialist School Students, and EDAR at Home. Started creating a Suggested Induction Framework to address the lack of internal processes guiding cross-organisation collaboration and overall professional development in PFD.

5.2.1 Meeting With School SLTs to Co-Identify Behaviour Goals

I met with SLTs 03 and 04 to discuss the behaviour goals outlined in Table 24 and agreed on what behaviours would best enable the school SLTs to support students with complex PFDs, as per the Goal Setting (Behaviour) BCT. The list of behaviour goals was developed to improve the support students with PFD received in a specialist school setting. The school SLTs and I decided to focus only on the bolded behaviours in Table 24 during Implementation Cycles 1 and 2, as some behaviour goals were long-term and were not feasible to complete during the two implementation cycles. During our discussion, the school SLTs evaluated the behaviour goals by highlighting barriers to achieving them.

Example

When discussing the behaviour goal, “If families EDAR at home, SLTs should ensure they still receive support if required”, SLTs 03 and 04 repeatedly asked, “Where does the specialist school SLTs’ responsibility end?”. They asked this question to highlight their belief that they weren’t responsible for what or how students were fed at home. They were unsure if they were allowed to complete home visits as part of their role. In a follow-up email, the specialist school principal clarified this by stating, “Our SLTs should only be practising from school; we don’t provide in-home support. It could be that they are providing guidance for parents, but that should be done from school.”.

When discussing the behaviour goal, “Any EDAR happening in the school should have some health-based consultation”, the school SLTs stated that the School Dysphagia Policy disallowed EDAR to occur in the school setting, which was not the case (School Dysphagia Policy, 2020). As the school SLTs continued to display anxiety and fear around EDAR in school settings, I decided not to challenge their understanding of the policy. The school SLTs requested that a health SLT provide a school-wide training on tastes programs to convince staff to discontinue using them. Instead, I suggested that tastes were often client-specific, and they would benefit from health SLT input when supporting these students. For them to discuss specific clients and gain support from more experienced SLTs, I proposed to arrange a meeting between the school SLTs and a local health SLT. They consented to this.

Based on the feedback from the evaluation of the BCTs, I modified the Goal Setting (Behaviour) BCT:

- Modified the behaviour goals and attempted to reduce barriers.

- Discontinued working on the following documents: EDAR Risk Minimisation and Information, EDAR Management Plan, and What to Consider for a Tastes Program, as the specialist school SLTs indicated they would not support these practices.
- Arranged a meeting between school SLTs and local health SLTs to support collaboration for complex students.

Table 24

Recommended Behaviours After Initial COM-B Analysis

Documentation
-SLTs consistently document class PFD-related programs or plans to increase transparency and transfer knowledge. **-Documentation is particularly important for complex PFD cases, such as when EDAR occurs.** **-Specialist school SLTs should seek key documentation from health services when it is unavailable.**
Special school service structure
-SLTs should provide regular school-wide PFD training for school staff. **-School SLTs would benefit from information on assessment components/forms.** **-Schools should have a clear service structure to streamline therapy input and ensure students receive equitable services.** -SLTs in special schools should know what resources their LLA enables them to access (e.g., regular meetings, trainings, collaboration with health SLTs).
Collaborative, informed decision making
-SLTs should provide a balanced discussion of risks and benefits of treatment options. -Families have legally protected rights to make decisions within the ZPD, which includes declining a service or not following professional recommendations.
Cross agency collaboration
-If families EDAR at home, SLTs should ensure they still receive support if required. **-Any EDAR happening in the school should have some health-based consultation.** **-Complex PFDs should be supported by cross-agency, inter-disciplinary teams to provide a holistic service.** **-When school SLTs are unsure about what is ‘safe’ for a student, they should liaise with health SLTs.**

5.2.2 Evaluation of the Created Resources

After setting goals with the specialist school SLTs, I sought feedback on the resources I had developed as part of the Adding Objects to the Environment BCT. As described in my method, an advisory group was created to provide feedback and advice on resources created as part of this study. The responsibilities of each member in the advisory group are outlined in Table 25. Each member was approached because they had experience supporting families and children to make complex PFD decisions, each bringing different perspectives to the decision-making process. Some members had previous involvement with PFD projects, others were recommended to me by experts in the field, and some were involved in data collection and showed interest in the project. Approaching each advisory group member via email, I asked them to provide feedback on resources I had developed for this study. Initially, all members were asked to provide feedback using track changes in Microsoft Word or written feedback via email. However, I recognised that school SLTs and caregivers were less likely to provide written feedback due to time pressures. Therefore, I offered to have meetings with the caregiver and school SLTs so they could provide verbal feedback on the documents. I then marked this feedback using track changes. The caregivers and school SLTs accepted the offer to provide verbal instead of written feedback.

Table 25

Membership and Responsibility of the Advisory Group Members

Membership	Responsibilities	Communication mode
Family law professor	-Provide feedback on resources from a legal perspective. -Advise SLT on laws relating to complex feeding decisions.	-Email -Track changes
Paediatrician	-Provide feedback on resources from a medical perspective.	-Email -Track changes
Inpatient health SLT	-Provide feedback on resources from an acute PFD perspective.	-Email -Track changes
Community health SLT	-Provide feedback on resources from a chronic PFD perspective.	-Email -Track changes
Caregiver of student at host school	-Provide feedback on resources from a family-centred perspective.	-In-person meeting
2 x Specialist school SLTs	-Provide feedback on resources from an education perspective. -Advise SLT on school culture and needs.	-In-person meeting

I sent the documents to the paediatrician, lawyer, and health SLTs to evaluate them as part of the PAR cycle. Only SLTs received documents that contained SLT-specific information, such as the School PFD Management Flowchart. All members reviewed the documents using track changes in Microsoft Word or provided feedback via email. As a result of this evaluation, one health SLT offered to provide some training for the specialist school SLTs on VFSS referrals and procedures when reviewing the VFSS Booking Process for Specialist School Students document. I suggested this training occur at a specialist school special interest group (SIG). I then met with the specialist school SLTs to receive verbal feedback on the resources. They reviewed the structure and content of each document, giving feedback, which was documented using track changes and comments in Microsoft Word.

Example

School SLT 03 stated, “These [documents] are great because then everything is written down on paper and not just in our heads”. This comment highlighted the lack of written structure available for school SLTs when supporting students with PFDs.

In the School PFD Management Flowchart, one suggestion was for specialist school SLTs to inform paediatricians if students and families used EDAR strategies at home. However, the specialist school SLTs did not want to inform paediatricians what caregivers were doing at home, as they did not know the unintended consequences of passing on the information. For example, they did not know if the paediatrician would ask the family to stop EDAR and were concerned that passing on this information would damage their relationship with families.

I then met with the caregiver who agreed to be part of the advisory group. We reviewed the resources over a Teams meeting, and I documented her feedback using track changes and comments in Microsoft Word. This caregiver exhibited high levels of health literacy and had positive experiences with the health system, which impacted the type of feedback she provided on the resources. An attempt was made to recruit another caregiver with a lower level of health literacy whom I interviewed as part of my data collection, however, she declined to participate due to family complications.

Example

The caregiver wanted the school teams to be more aware of how students ate and drank at home, as she thought this may influence how the school teams supported the students. Wanting therapists to provide information on foods she could try at home to develop her child’s oral feeding skills, this caregiver requested to collaborate with school SLTs to create a Safe Eating Plan for her child. I asked if she would want the school SLTs to share her EDAR practices with the paediatrician. She had already told her paediatrician she utilised EDAR practices and was comfortable sharing the information as she did not view it as “wrong”.

Based on the feedback from the evaluation of the BCTs, I modified the Adding Objects to the Environment BCT:

- Accepted track changes and modified the resources based on any written or verbal feedback.
- Continued advocating for home-school collaboration.
- Actively pursued facilitating relationship building between the specialist school SLTs and health SLTs.
- Arranged VFSS training with specialist school SIG.

5.2.3 Draw Attention to Discrepancies Between Current Practice and Behaviour Goals

During the first implementation phase, I highlighted the school SLTs' "discrepancies between current [their] behaviour and goal", a BCT.

Example

One of the school SLTs' goals was to, "...consistently document class PFD-related programs/plans to increase transparency and transfer knowledge". At the beginning of the year, SLTs 03 and 04 independently evaluated their practices and recognised that a large proportion of students did not have up-to-date mealtime plans. They sent me an email asking, "…would you be willing to share the draft decision-making flowchart (i.e., for no plan vs. safe eating (oral motor skill/safety) vs. mealtime plan (behaviour)) that you've created? We are interested in looking at it again and trying it out with some of our students' reviews." I sent them the document and offered to go through the student roll and identify which students needed support, which the school SLTs agreed to. I gathered a list of students, organised by class, and specified the level of support each student may require. I sent them the document via email, completing the Demonstration of the Behaviour BCT. They then used the document to compare what support students were currently receiving and what support they could access.

Another Discrepancy Between Current Behaviour and Goal was the school SLTs' lack of collaboration with external organisations and their goal, "Complex PFDs should be supported by cross-agency, inter-disciplinary teams to provide a holistic service".

Example

SLT 03 called me to evaluate her practice when discussing a student who had a written tastes program completed by classroom staff. This program, however, was not detected by the documentation audit due to being kept in a physical file in the student's class. The program was several years old and contained no indication of health-based consultation and no information of its purpose. I suggested the school SLT contact her local health SLT to gather more information about the student. In response, the school SLT requested the Inter-Agency Document Transfer document, containing contact details of the health SLT and local health service.

When I utilised the BCTs Discrepancies Between Current Behaviour and Goal and Demonstration of the Behaviour, I observed the school SLTs' evaluate their practice and make the following modifications:

- School SLTs attempt to better understand their students' feeding history and the purpose of programs written by previous school SLTs.
- School SLTs asked for documents to change their behaviour to align with their behaviour goals.

5.2.4 Introduction of Expectations for Increased Collaboration With Families and Health

Another BCT utilised in this phase was Restructuring the Social Environment, where an emphasis was placed on collaboration between health SLTs, paediatricians, and specialist school SLTs. While this increased collaboration was a behaviour goal, SLTs 03 and 04 did not actively or consistently collaborate with health SLTs until prompted by myself, despite having access to their contact details. I hypothesised that they may find it intimidating to initiate collaboration with health SLTs, as they had never met or formed a relationship with them. I arranged a meeting between SLTs 03 and 04, two local health SLTs, and myself to foster relationship-building and evaluate the social environment.

Example

Each SLT introduced themselves and discussed commonalities between them such as families, pets, and how long they had been working in their respective jobs. The health SLTs confirmed that specialist school SLTs could access support from them when they had reached their capacity of knowing how to support particular students as specified by each local level agreement (LLA). SLT 03 and 04 discussed their lack of internal processes to guide collaboration with health services.

The health and school SLTs discussed when tastes might be introduced into a school setting and suggested collaborative practices for when students chose to EDAR.

Example

One health SLT suggested that tastes could be introduced when students were beginning the process of tube weaning. SLT 04 reported that the School Dysphagia Policy disallowed tastes from occurring in the school unless it had been approved by the child's paediatrician. This statement differed from her previous stance that EDAR was not permitted in the school, but neither statement was included in the School Dysphagia Policy (School Dysphagia Policy, 2020). This change indicated that her attitude towards tastes was slowly evolving. Both health SLTs encouraged the school SLTs to inform paediatricians when students EDAR at home, aligning with adult risk feeding guidelines (The University of Auckland & Hutt Valley District Health Board, 2016).

Throughout the discussion, I utilised the BCT Demonstration of the Behaviour by demonstrating how easy and acceptable it was to ask the health SLTs questions.

Example

I asked the health SLTs questions about students who were enterally fed for nutritional purposes and how they would support families who chose to EDAR at home. I utilised this BCT to show SLTs 03 and 04 how non-judgemental the health SLTs were when answering questions, in the hopes they would feel more comfortable to approach the health SLTs to ask questions.

A follow-up discussion with the health SLTs highlighted the need for specialist school SLTs to access continuing professional development to increase their knowledge and skills.

We discussed several free online trainings that specialist school SLTs could access, which I decided to collate into a Suggested Induction Framework document. This framework included questions that prompted SLTs to understand the parameters of their service delivery, such as, “Does the school allow school therapists to work in the home setting?” and, “When families enrolled their children in school, what permissions did families give for school staff to liaise with external professionals?”. During this discussion, the health SLTs reflected on how they needed to be more present in specialist school settings to enable increased collaboration between school and health SLTs. This reflection indicated that the health SLTs understood how vital relationship building was.

Based on the feedback from the evaluation of the BCTs, I modified the Restructuring the Social Environment and Demonstration of the Behaviour BCTs:

- Discontinued working on the following documents: Oral Texture Progression Strategies, Assessment Components for Specialist School Students, and EDAR at Home.
- Started creating a Suggested Induction Framework for Specialist School SLTs to address the lack of internal processes guiding cross-organisation collaboration and overall professional development in PFD.

5.2.5 Discussed Complex PFD Cases With School SLTs and Encouraged Collaboration With Health SLTs

I utilised the BCT Social Support (Practical) throughout Implementation Cycle 1, providing practical help to increase school SLTs’ collaboration with health SLTs.

Example

The school SLTs often rang me or emailed me to discuss students with complex feeding difficulties, asking for my opinion. The students frequently had VFSS reports that were 3-8 years old, while utilising plans put in place by another SLT. The family and school team often disagreed about how to best support the students. In these discussions I would ask prompting questions such as, “Why do you think the parent wants that?” or make reflective comments such as, “That’s old assessment data to be working from”. These discussions consistently ended with me suggesting the school SLT contact a health SLT for advice, which the school SLTs did not independently do. Over time, the school SLTs contacted me less frequently and mentioned how they had emailed their local health SLT for advice, instrumental assessment data, or previous medical information they did not have access to. This behaviour indicated that over time, the school SLTs increased their collaboration with health SLTs when unsure about how to support students with complex PFDs.

When I utilised the BCT Social Support (Practical), I observed the school SLTs’ evaluate their practice and make the following modifications:

- Reduced reliance on me for social support and increased collaboration with their local health SLTs.

5.3 Implementation Cycle 2

After modifications had been made to the BCTs, Implementation Cycle 2 commenced. The BCTs utilised in this phase are outlined in Table 26. All BCTs underwent an act, evaluate, modify PAR cycle. Given the environmental restrictions, the PAR cycle was necessary to gather stakeholders' input on whether the BCTs, resources, or behaviour goals were appropriate for the setting and feasible to implement. These BCTs are further expanded on below in chronological order.

Table 26

BCTs Utilised in Implementation Cycle 2, Undergoing an Act, Evaluate, Modify Process

Act – Implement BCTs linked to behaviour goals		Evaluate	Modify
Actions taken during Implementation Cycle 2	Associated behaviour change technique (BCT)		
	1. Goals and Planning		
-Meeting with school SLTs to evaluate goals.	**Goal Setting (Behaviour) –** set or agree on a goal defined in terms of the behaviour to be achieved.	-School SLTs evaluated the goals and actions from Implementation Cycle 1.	-School SLTs and I evaluated and modified the behaviour goals.
	8. Comparison of Outcomes		
-Health SLTs complete training re: VFSS.	**Credible Source** - Present verbal or visual communication from a credible source in favour of or against the behaviour.	-School SLTs evaluated their access to supervision and how complex feeding decisions were managed within a specialist school setting.	-School SLTs requested that health SLTs complete a yearly training for the specialist school SIG and access to PFD-specific supervision. I arranged a meeting with one health SLT, one specialist school SLT, and the NZSTA PFD advisor to discuss specialist PFD supports at a wider level.

	12. Antecedents		
-Meeting with SLTs to review agreed-upon resources.	**Adding Objects to the Environment** - Add objects to the environment to facilitate behaviour performance.		-School SLTs asked me to continue editing the EDAR Risk Minimisation and Information document. We agreed to replace the EDAR Management Plan with Recommendations When Supporting Complex Feeding Difficulties.

5.3.1 Health SLTs Complete Training Regarding VFSSs

I utilised the BCT, Credible Source, by arranging for health SLTs to provide in-person training for the nationwide specialist school special interest group (SIG). Community SLTs who did not have regular health SLT input also attended this SIG, such as SLTs working for organisations that housed adults with intellectual disabilities. As several inappropriate referrals were made, the health SLTs offered to discuss VFSS procedures and when to refer for a VFSS. Subsequently, the health SLTs wanted to encourage specialist school SLTs to contact them when unsure about the appropriateness of a VFSS referral. Prior to the training, the specialist school SLTs sent through a list of questions, some relating to VFSS and others relating to EDAR management. Below is a list of some of the questions relating to EDAR:

> *If a student is NBM/NPO and is fed enterally, but the family is doing tastes for pleasure. That would be considered risk feeding, right, and we wouldn't engage with that at school. Do some schools take this risk, how is it managed?*
>
> *If a student has oral phase dysphagia and is eating a modified 'safe' texture at school, e.g., minced moist/smooth puree/anything else other than Level 7 IDDSI, etc., is this risk feeding or not?*
>
> *With students who can manage a regular diet, however, post-seizure activity, things become unsafe; how is this risk managed?*
>
> *Risk feeding at school - where do we stand when it's our clinical assessment that a student is unsafe to be fed, but we are asked to give advice on what is the safest way "anyway" to feed the student? We are asked to write a mealtime plan/give TAs instructions.*
>
> *How do we balance what the family wants with keeping the student safe and protecting our school staff, and what are our options when we can't reach an agreement?*

The health SLTs set aside time to address these questions at the end of their presentation. During this time, several key points were raised.

Example

Three specialist schools across New Zealand reported they had been threatened with legal action from families when school teams had refused to feed students a particular way at school. The health SLTs recommended that medical teams should be involved in cases like this, which had not occurred. Emphasising that specialist schools should not be dealing with these cases in isolation, the health SLTs referred to the adult risk feeding guidelines (The University of Auckland & Hutt Valley District Health Board, 2016). Notably, only one of the schools appeared to be aware of the current adult risk-feeding guidelines. Before this meeting, the health SLTs were unaware that any schools were being threatened with legal action regarding complex feeding management in school settings.

The specialist school SLTs did not have access to regular dysphagia-specific supervision, as their supervisors were often specialist school SLTs who often had similar levels of knowledge to them. They could contact their local health SLT for support but did not have regular meetings where they could bring complex PFD cases for discussion with a highly experienced PFD SLT. In contrast, SLTs employed by the Ministry of Education, who worked with less complex PFD cases, had regular PFD supervision with a highly experienced PFD SLT. The specialist school SLTs agreed to raise the lack of PFD-specific supervision with the New Zealand Speech-Therapists' Association (NZSTA).

Specialist school SLTs highlighted how few schools had PFD policies or guidelines to direct their practice in school. One school revised their policy to provide guidance for when disagreements occurred between school and home and offered to share its policy with other special school SLTs, increasing inter-school collaboration.

The SLTs involved in the meeting evaluated their current support and requested that the health SLTs provide yearly training for the specialist school SIG to foster relationship building and support them to stay up to date with current practice. The SLTs also deemed it necessary to speak to the NZSTA PFD advisor to see if a list of PFD supervisors could be arranged for SLTs requiring PFD-specific supervision.

Based on the information provided by the Credible Source BCT, the school SLTs evaluated their environment, and I completed the following modifications:

- Arranged a meeting with one health SLT, one specialist school SLT, myself, and the NZSTA PFD advisor to identify and fill PFD needs.

- Health SLTs to complete a yearly training for the specialist school SIG.
- Increased collaboration amongst specialist school SLTs regarding PFD policies.

5.3.2 Meeting With SLTs to Evaluate Goals and Review Agreed-Upon Resources

I then met with the specialist school SLTs to review the two BCTs, Goal Setting (Behaviour) and Adding Objects to the Environment. We first reviewed the goals I had evaluated and modified during the previous cycle, as seen in Table 23. The bolded behaviours indicate the behaviour goals identified by the school SLTs, and the unbolded behaviours are long-term recommendations not targeted as part of this study. Italicised behaviours in Table 26 indicate where a behaviour modification occurred and was discussed with the school SLTs. The changes to these goals are described below Table 27.

Table 27

Review of Behaviour Goals and Recommended Behaviours at Evaluation of Implementation Cycle 2

Behaviour goals from Implementation Cycle 1	Modified behaviour goals
Documentation	
-SLTs consistently document class PFD-related programs or plans to increase transparency and transfer knowledge. **-Documentation is particularly important for complex PFD cases, such as when EDAR occurs.** **-Special school SLTs should seek key documentation from health services when it is unavailable.**	No changes made.
Special school service structure	
-SLTs should provide regular school-wide PFD training for school staff. **-School SLTs would benefit from information on assessment components/forms.** **-Schools should have a clear service structure to streamline therapy input and ensure students receive equitable services.** -SLTs in special schools should know what resources their LLA enables them to access (e.g., regular meetings, trainings, collaboration with health SLTs).	***-Schools should provide induction programs for SLTs and teachers, which should include:*** -PFD training for non-therapists. ***-Access to online PFD assessment/management modules for SLTs.*** **-Schools should have a clear service structure to streamline therapy input and ensure students receive equitable services.** -SLTs in special schools should know what resources their LLA enables them to access (e.g., regular meetings, trainings, collaboration with health SLTs).

	-Special schools should clearly indicate whether school SLTs can provide therapy input at home if required. If not, school SLTs should know how to refer to health services.
Collaborative, informed decision making	
-SLTs should provide a balanced discussion of risks and benefits of treatment options. -Families have legally protected rights to make decisions within the ZPD, which includes declining a service or not following professional recommendations.	No changes made.
Cross agency collaboration	
-If families EDAR at home, SLTs should ensure they still receive support if required. **-Any EDAR happening in the school should have some health-based consultation.** **-Complex PFDs should be supported by cross-agency, inter-disciplinary teams to provide a holistic service.** **-When school SLTs are unsure about what is ‘safe’ for a student, they should liaise with health SLTs.**	***-When families engage in EDAR at home, school SLTs should gain consent to inform the paediatrician who holds responsibility for EDAR plans.*** ***-If families EDAR at home, school SLTs should ensure they still receive support if required, which may involve referring to health SLTs.*** **-No changes made to the last three goals.**

Based on the evaluation of the school SLTs' behaviour goals, the school SLTs and I completed a modification of the Goal Setting (Behaviour) BCT:

- Schools should provide induction programs for SLTs and teachers, which should include access to online PFD assessment/management modules for SLTs.
- When families engage in EDAR at home, SLTs should gain consent to inform the paediatrician who holds responsibility for the student's overall well-being.
- If families EDAR at home, SLTs should ensure they can access support if required, which may involve referring to health SLTs.

To conclude the study, the school SLTs and I evaluated the resources we had agreed on as part of the Reflect and Plan phase and subsequently modified them. All changes to these documents are outlined in Table 28, while those occurring in Implementation Cycle 2 are described in further detail below.

When evaluating the EDAR Management Plan, the school SLTs and I agreed that their current "safe eating plan" encompassed the various recommended areas one should include when writing an EDAR plan (The University of Auckland & Hutt Valley District Health Board, 2016). While EDAR is complex, we agreed that a feeding decision could be complex without the use of EDAR practices and that "complex feeding decision" was a more appropriate term for their school setting. The school SLTs suggested that I write a list of considerations for complex feeding decisions, as they did not consistently remember to include all components the adult EDAR guidelines recommended, which I agreed to.

When evaluating the EDAR at Home form, the school SLTs agreed it would be sufficient to email the paediatrician to let them know when EDAR occurred for a particular student and document this in their notes. I modified the School PFD Management Flowchart based on feedback from Implementation Cycle 1 and showed this to the school SLTs. The school SLTs reported that the flowchart referred to documents and information they were unaware of, such as the Evaluation of Readiness for Transition From Tube Feeding to Oral Feeding. They hypothesised that the document would immediately give them access to additional information that would enable them to support their students.

Due to feedback from Implementation Cycle 1, I discontinued working on the EDAR Risk Minimisation and Information resource. In response, the school SLTs requested that I finalise the resource so they could provide it to families who chose to EDAR at home. I subsequently requested that a health SLT review this document before it was finalised.

Table 28

Review of Resources After Implementation Cycle 1

Resources agreed upon during the Reflect and Plan phase	Modification and outcome of the resources post Implementation Cycle 1
Eating and Drinking with Acknowledged Risk (EDAR) Management Plan.	Converted into a List of Considerations for Complex Feeding Decisions in Specialist Schools, seen in Appendix 4.
EDAR at Home resource.	Discontinued, school SLTs agreed it would be sufficient to email the paediatrician.
School PFD Management Flowchart.	Modified and re-reviewed by health SLT, seen in Appendix 5.
EDAR Risk Minimisation and Information resource.	Discontinued, school SLTs requested it be re-instated, seen in Appendix 6.
Inter-Agency Document Transfer.	Completed during Implementation Cycle 1. This document has not been included as an appendix as it details confidential information.
VFSS Booking Process for Specialist School Students.	Completed during Implementation Cycle 1, seen in Appendix 7.
Paediatric EDAR Guidelines.	Work in progress.
-Oral Texture Progression Strategies. -Assessment Components for Specialist School Students.	Condensed into Suggested Induction Framework for Specialist School SLTs, which includes links to free online modules containing relevant information, seen in Appendix 8.
What to Consider for a Tastes Program resource.	Discontinued.
Family and Student Views of Complex PFD Decisions resource.	More time was needed to create or adapt this resource.

Based on the feedback from the evaluation phase, the school SLTs and I completed a modification phase to the PAR cycle, making changes to the Adding Objects to the Environment BCT, as seen in Table 28.

5.4 Reflection

By using the BCTs attached to the Behaviour Change Wheel (BCW), the school SLTs, health SLTs, and I were able to move through two implementation cycles in approximately six months. Major dilemmas and discrepancies between policy and practice were identified, and some immediate solutions were successfully implemented. The school and health SLTs identified dilemmas and solutions during the implementation cycles that I had not recognised. The solutions that created the most change were relationship building between health and education SLTs and strengthening SLTs' collaborative practice. These practices are often recommended, but few studies analyse how to achieve this. The work to support these SLTs remains and is ongoing but has not been documented in this thesis. These solutions are part of what is required to close the research-to-practice gap.

6 Discussion

In this MSc research project, I explored how SLTs supported students with paediatric feeding disorders at one specialist school and considered what implementation approaches and changes could improve the support for these students. Four research questions were asked, and this chapter will discuss the themes from each and draw conclusions.

1. What factors influence New Zealand specialist school SLTs' ability to support students with paediatric feeding disorders?
2. What are the perceptions and aspirations of stakeholders (school staff, local health professionals, and family) on the support of students with paediatric feeding disorders at the specialist school?
3. What changes do stakeholders believe are needed to improve the support of students with paediatric feeding disorders at one specialist school?
4. What implementation approaches do stakeholders believe could optimise change in the support of students with paediatric feeding disorders at one specialist school?

6.1 Family-Centred Care (FCC) and Shared Decision-Making

Shared decision-making is a central component of family-centred care (FCC) and, subsequently, a recommended practice for SLTs supporting families (Mandak & Light, 2018; McCarthy & Guerin, 2022; Simione et al., 2020). This research identified factors and stakeholders' perceptions that affected how specialist school SLTs supported students with PFDs (section 6.1.1). Furthermore, stakeholders identified changes to improve the support specialist school students received (section 6.1.2) and explored implementation approaches (6.1.3).

6.1.1 Risk Tolerances and Informed Decisions to EDAR

Families with students who had stable health and lived in the community appeared to have higher PFD-related risk tolerances and, therefore, took more PFD-related risks. Heath SLTs, for example, saw riskier eating and drinking practices from some students who had unexpectedly been admitted to the hospital. Deeming these riskier practices to be reasonable for students when their health was stable, health SLTs recognised how they added complexity to overall PFD management (section 4.1.2). Knowing the risks involved, some families used EDAR practices with their school-aged child at home to develop feeding skills or ensure inclusion in family activities. These findings align with D'Angelo (2018), who highlighted that families who have received evaluation, treatment, and discharge from a medical team often adapted PFD-related strategies to use in community settings. As families cared most about PFD outcomes relating to their child's health and quality of life (Simione et al., 2020), those with stable health often prioritised outcomes relating to a child's quality of life. Subsequently, these families developed expertise in how to best support their child's PFD across a range of settings, considering their child's overall health.

Families viewed professional recommendations as a "guide", often choosing to follow some strategies whilst discarding others. Strategies were easiest to follow when they aligned with family needs. Consequently, families valued working collaboratively with clinicians who enabled them to make informed decisions (section 4.2.2). This has been seen in previous literature where caregivers inconsistently followed professional recommendations, finding strategies that were considered feasible easiest to follow (Charpentier et al., 2020). Additional research indicated that families preferred SLTs willing to learn from them, who utilised family knowledge to create programs and worked towards shared goals (Angell et al., 2008; Angell et al., 2009; McCarthy & Guerin, 2022; Simione et al., 2020).

For students with PFDs, families consented for classroom staff to use EDAR strategies in school settings. School SLTs were not consistently aware when EDAR occurred, and health professionals were rarely involved. These complexities highlighted the need for additional SLT input and monitoring (section 4.2.1). However, these findings demonstrate family and staff willingness to use riskier practices in school settings, particularly for students with stable yet life-limiting conditions (Table 4) (Radford et al., 2020). Whilst school SLTs were not consistently aware of EDAR, this provides new evidence of families' wishes for it to be undertaken in school settings, classroom staff's willingness to cater to this, and how the two can work together to make informed decisions. It is worth mentioning, however, that the implementation of EDAR practices in the school did not consistently follow best-practice guidelines, indicating the need for more formalised policies and procedures to be developed (Langeroudi et al., 2022; Royal College of Speech and Language Therapists, 2021; The University of Auckland & Hutt Valley District Health Board, 2016; Whitehead et al., 2019).

6.1.2 Collaborative Informed Decision-Making

For this reason, families wanted to work with SLTs to create plans that captured the right balance between risk and safety at school. Caregiver 01 wanted staff to ask more about how she was feeding her child at home, as she thought it would prompt staff to try new strategies or IDDSI levels at school. However, neither caregiver expected classroom staff to feed their children in ways that made them feel uncomfortable, exhibiting flexible expectations of PFD management at school. These findings demonstrate how families wanted to work in a family-centred model of practice but did not always experience it, aligning with previous research where caregivers experienced higher levels of family-centred care for young children as opposed to school-aged children (Mandak & Light, 2018). A decline in family-centred care in school settings may be influenced by their multi-faceted dynamics that are not observed in other settings. For example, school staff regularly navigate teacher beliefs, senior leadership teams that answer to external boards, academic expectations, and classroom routines (Cook, B. & Odom, 2013; Cook, C. et al., 2019). Subsequently, SLTs may find the inclusion of family-centred care, specifically collaborative, informed decision-making with families, more difficult in school environments due to the added complexities.

In turn, SLTs found it challenging to balance family goals and what they felt was safe for the student. Apart from mandated IEP meetings, no guidelines existed to enable SLTs' collaborative practice with families. When they could not reach an agreement with families, school SLTs were unsure what level of risk could or should be taken in schools and how to support students. In response to this, several New Zealand families took legal action against schools because they did not follow family wishes, which included riskier practices during students' mealtimes. School SLTs wanted guidelines specifying what constituted appropriate risk in a school setting and how to support families and school teams to make complex feeding decisions (section 5.3.1). When supporting families to make complex feeding decisions, Radford et al. (2020) recommended that SLTs use the zone of parental discretion (ZPD), requiring SLTs to distinguish between assumed risk and real risk (section 1.5.4) (Kaizer et al., 2012; Radford et al., 2020). Demarcating real risk from assumed risk may enable school SLTs to support families to make informed decisions about how students can eat and drink at school, a legally protected right as per The Code of Health and Disability Services Consumers' Rights 1996 (section 1.5.2). This may also enable classroom staff to better understand the risks, so they are more able to adjust their strategies depending on the child's presentation.

Conversely, Jackson et al. (2021) found that New Zealand SLTs, 30% of whom worked in specialist schools, were not confident when predicting the aspiration risk of school-aged children they supported. If SLTs are not confident in predicting aspiration risk, they are unlikely to feel confident distinguishing between real risk and assumed risk, which impacts their ability to use the ZPD (Gillam, 2016; Radford et al., 2020). If unable to use the ZPD, school SLTs are unlikely to feel comfortable supporting families to make informed decisions in a school setting and may revert to strategies that maximise swallow safety without considering familial input.

6.1.3 Stepping Into Another Person's Shoe

To enable collaborative practice between caregivers and school teams, families wanted school teams to better understand how PFDs impacted their lives. Caregiver 01, who was involved in the implementation cycles, suggested that school SLTs ask her more about what strategies she used at home in the hopes that they may broaden how they fed her son. An additional benefit to better understanding what she did at home would be realising the motivations and goals behind her behaviours, allowing SLTs to gain a more holistic view of her child's wellbeing. This finding aligns with indigenous health models, such as Te Whare Tapa Whā (Table 2), illustrating how PFDs can significantly impact a person's familial, spiritual, mental, and physical well-being (Davis-McFarland, 2008; Durie, 1985). Additionally, the ZPD encourages clinicians to think about the harm caused to families if their wishes are overridden (Gillam, 2016; Radford et al., 2020). Stepping into a person's shoes in attempts to view health holistically allows clinicians to see where one's priorities lie, supporting them as opposed to one's own agenda.

6.2 Collaboration Between Health, School Professionals and Families

Collaborative practices have many benefits, such as enabling SLTs to draw on a range of professional and familial knowledge as well as sharing responsibilities amongst team members. For this reason, collaboration is encouraged for school SLTs (Homer, 2008; Homer, 2016) and those supporting EDAR in adult populations (Royal College of Speech and Language Therapists, 2021; The University of Auckland & Hutt Valley District Health Board, 2016; Whitehead et al., 2019). Factors, stakeholders' perceptions, and aspirations that affected how specialist school SLTs supported students with PFD were identified (section

6.2.1). Subsequently, stakeholders explored changes to improve the support specialist school students received (section 6.2.2) and implementation approaches (section 6.2.3).

6.2.1 Professional and Collegial Isolation

School SLTs often supported families and students without any input from health SLTs or paediatricians. Due to this, collaboration between health and school SLTs was infrequent unless a student required a VFSS. One specialist school SLT had never contacted their local health SLT or paediatrician while employed at the school and did not know how to access support. Another school SLT recognised that complex PFD decisions should, "become a wider issue starting with management" but did not explicitly state the need for health input when supporting complex PFDs. In contrast, health SLTs were grateful to work alongside a range of professionals including paediatricians who were responsible for the child's overall health. While the Memorandum of Understanding enabled collaboration between school and health professionals, those working in health were only funded to work with children up till three years of age, limiting how they supported students in specialist schools. Overall, specialist school SLTs were isolated when supporting students with PFDs, likely impacted by government policies and system structures. These findings align with previous results, where school SLTs demonstrated inconsistent collaboration with health professionals, 77% collaborating with school nurses and 46% collaborating with medical teams (Neubauer & Singleton, 2023). Older studies similarly found collaboration between school SLTs, classroom staff, and medical teams was inconsistent when evaluating and planning intervention (Hutchins et al., 2011; Owre, 2006). These findings suggest that cross-agency and cross-discipline collaboration are inconsistent in multiple countries, particularly for SLTs supporting PFDs in schools.

Similarly, classroom staff were not consistently aware of their knowledge gaps and did not always recognise when to ask for SLT support. For example, Teacher 01 stated, "I kind of forget that SLTs do feeding". Because teachers did not ask for support, SLTs were unable to monitor student progress and provide training for staff when required. Staff with more knowledge took more calculated risks, but these risks were not consistently documented or monitored by SLTs (section 4.6.1). These findings align with previous research where some SLTs had high confidence levels that were unfounded due to their limited training and experience, indicating a decreased grasp of their lack of knowledge and skills (Bailey et al., 2008; Hutchins et al., 2011). In light of this, SLT collaboration with school staff and adequate training are essential components in ensuring a shared understanding and safe practice occurs within schools (Homer, 2008; Homer & Carbajal, 2015; Homer, 2016).

6.2.2 Cross-Agency Collaboration

Collaboration amongst health professionals is widely recognised as a cornerstone of supporting PFDs in schools (Homer, 2008; Homer & Carbajal, 2015; Homer, 2016; Lefton-Greif & Arvedson, 2007) and EDAR management (Royal College of Speech and Language Therapists, 2021; Soar et al., 2021; The University of Auckland & Hutt Valley District Health Board, 2016; Whitehead et al., 2019). Yet cross-agency collaboration was not consistently observed in this study, as previously discussed. School SLTs' collaborative practices varied across New Zealand (NZ) and depended on the therapists employed in the region and the regional Memorandum of Understanding. To combat this, specialist school SLTs requested PFD-specific supervision from specialised clinicians as they were often supervised by other school SLTs. This has been seen in previous literature, where New Zealand SLTs supporting PFDs did not consistently trust their supervisor's judgement as they sometimes received supervision from therapists less knowledgeable than themselves (Jackson et al., 2019). Additionally, New Zealand specialist school SLTs requested more regular training from health SLTs to upskill and maintain connections. Similarly, many school SLTs in the United States viewed themselves as responsible for building their competencies and skills in PFDs (Hutchins et al., 2011) and felt more confident when completing more professional development and being more experienced (Hutchins et al., 2011; Neubauer & Singleton, 2023; O'Donoghue & Dean-Claytor, 2008). While professional development can take many forms, collaboration is one activity that increases a clinician's confidence and skills and is typically recommended for those less confident (Felicetti et al., 2020; Neubauer & Singleton, 2023).

A divide between health SLTs and education SLTs was apparent, with SLT 03 stating that supporting PFDs was “not really a priority” in education settings. Subsequently, school SLTs were not permitted to provide in-home support for students with PFDs. These SLTs did not consider what support families may need for their child, often believing they were not responsible for families' decisions or actions. While families could make their own informed decisions, this belief left some without any support when they required it. Both caregivers in this study used EDAR strategies and wanted more SLT support in the home environment. The divide between health and education has been seen in previous literature, where some school SLTs in the United States did not believe supporting PFDs was academically relevant and, subsequently, a part of their role (Felicetti et al., 2020; Hutchins et al., 2011; Neubauer & Singleton, 2023). A ramification to school SLTs not providing in-home support on the premise that it's not one's job is the occurrence of a service gap. Additionally, school SLTs rarely discussed this service gap with health services, resulting in *dead zones*, where no SLTs monitored family need and families had no way of accessing support. Subsequently, students without access to home-based SLT services may be fed differently at home compared to school and unknowingly to families, not receive adequate nutrition. These students may come to school tired and unable to fully participate in classroom activities. For this reason, school SLTs and health SLTs need to collaborate to ensure students receive a holistic service and can participate fully in their daily lives.

6.2.3 Involving Stakeholders

Involvement of stakeholders, or those affected by and involved in the situation, was essential when designing resources and implementation cycles to ensure the project was responsive to the environmental needs and culture. SLTs 03 and 04 were stakeholders that acted as co-researchers by co-identifying behaviour goals, resources, and an action plan. Changes were made to the behaviour goals, resources, and action plan throughout the cycles based on their input. For example, SLTs 03, 04, and I discontinued editing some resources and re-wrote some behaviour goals after learning that school SLTs were not permitted to provide SLT support at home. If I completed the research without input from stakeholders, I would have unknowingly created resources and implemented plans that did not account for the school's service delivery parameters. While I believe families should receive SLT input at home, any resources and plans encouraging school SLTs to provide in home care would be unlikely to result in behaviour change.

These findings align with participatory action research methodology, specifying the importance of stakeholder collaboration to increase the usefulness of resources and plans to the environment (Bradbury, 2015; McNiff & Whitehead, 2011; Somerville, 2014). Furthermore, involving school SLTs as co-researchers challenged the traditional hierarchy commonly observed between researchers and participants, where participants have no influence on the study design. In this study, the school SLTs' ideas and opinions were highly valued and significantly changed the study design, encouraging them to be solutions-focused while taking ownership of the study outcomes (Bradbury, 2015; Casey et al., 2018; McNiff &

Whitehead, 2011). Subsequently, collaboration is not only essential when supporting students with PFDs but also between primary researchers and key stakeholders, likely increasing behaviour change.

6.3 School SLT Experiences of Supporting Students With PFD

Over time, students with more complex PFDs entered the school system as their health was better managed in community settings. School SLTs, therefore, have been exposed to heightened responsibility and autonomy when supporting these students (D'Angelo, 2018; Huffman & Owre, 2008; Nottingham & O'Donoghue, 2017). This research identified factors alongside stakeholders' perceptions and aspirations, affecting how specialist school SLTs supported students with PFD (section 6.3.1). Additionally, implementation approaches were used and are discussed (section 6.3.2).

6.3.1 Fear and Disproportionate Responsibility

School SLTs described how fear permeated their experiences when supporting complex PFDs, particularly when feeling isolated. In the current climate, most school SLTs did not aspire to support EDAR in school settings, even when it aligned with family wishes. SLTs' fear was often linked to their belief that PFD-related support should maximise safety, as evident by their use of the term safe eating plan when terms such as, "swallowing and feeding plan" are more common (Homer, 2016). However, swallowing always includes some form of risk and whilst student PFD-related safety is paramount, it is impossible to safeguard students entirely from risk. Additionally, some therapy involves risk, such as transitioning students from tube to oral feeding (Clinical Network for Paediatric Tube Feeding, 2019) and interventions for students who are medically fragile (Radford et al., 2020). Both are deemed necessary for student's pleasure, oral desensitisation, oral motor development, and overall well-being. Whilst school SLTs felt safer when students' safety was maximised, The Health and Safety at Work Act 2015, which guides employers on how to keep people safe in school environments, tolerates some level of risk in a workplace (Table 7). The Act recommends that controls be introduced to reduce the impact of high-risk hazards, the wording of this indicating that schools may legally accommodate some PFD-related risks if risk minimisation strategies are documented, put in place, and consented to.

Additionally, SLTs felt isolated when supporting school-based PFDs (section 4.3.3). School SLTs may have perceived more fear when isolated as the responsibility of students'

PFD fell solely in their care. Conversely, health SLTs described working closely with paediatricians who held the overall responsibility for a student's wellbeing. These two contrasting accounts demonstrate the different levels of support health and school SLTs experience. These findings align with research describing school SLTs' desire to make dysphagia management as safe as possible to mitigate their fears and feelings of isolation (Bailey et al., 2008).

Subsequently, school staff were often afraid of being held legally responsible or liable for students' eating and drinking and, ultimately, their health when at school. At times, staff fed students differently from how they were being fed at home to reduce the risk of aspiration or choking. Staff sometimes claimed an almost protective role over students when families fed their children in ways the staff did not agree with. Relationships between school staff and families were damaged when staff overrode families' wishes about how to feed a student (section 4.4.3). These findings indicate that staff held the mindset of in loco parentis, where they have 'delegated powers' to look after a child like a parent would while at school (Hall & Manins, 2001a; Hall & Manins, 2001b). The Ministry of Education (n.d.) highlighted that in loco parentis is no longer considered relevant, instead recommending that professionals gain informed consent from families. Additionally, informed consent and decision-making is a legally protected right, even when families choose not to follow professional recommendations (The Code of Health and Disability Services Consumers' Rights 1996; Skegg & Paterson, 2015). Our findings indicate that school SLTs and staff fear of PFD-related liability, combined with an in loco parentis mindset, impacted their ability to apply informed consent and shared decision-making to their practice.

Our findings also suggest that SLTs interviewed as part of this project do not have a good understanding of the various laws operating in their community. As much of the school-based PFD literature comes from the United States, the laws and court cases described in these articles do not reflect New Zealand's culture or legal system. To reduce the risk of legal disputes between families and schools, experts have recommended understanding the local laws that impact health and disability services (Bailey & Lugg, 2009; Kelly et al., 2018). Any policies or guidelines developed should enable SLTs to navigate conflicts between families and school staff using family centred principles, whilst outlining relevant laws to inform any shared decision-making.

6.3.2 Change Takes Time

Time was essential in the behaviour change process when challenging beliefs that underlay a person's behaviour. This was seen during the two implementation cycles, spanning approximately six months of time. For example, after hearing that tastes programs were occurring in the school, school SLTs 03 and 04 wanted to halt all programs without seeing them, inaccurately reporting that the School Dysphagia Policy (2020) forbade EDAR. Over the course of the implementation cycles, the school SLTs lessened citing the policy and started discussing complex students with health SLTs. For example, school SLTs 03 and 04 discussed students who were in the initial stages of tube weaning or students who used EDAR strategies at home with health SLTs. These findings demonstrated how time was a necessary component of the implementation cycles to allow for SLT to change their beliefs and subsequent behaviours.

These findings align with participatory action research methodology, utilising cycles that allow time for researchers and co-researchers to build their knowledge, beliefs, and perspectives of how things could be (Bradbury, 2015). Baldwin (2012) described this as *transformative*, meaning that knowledge acquired during the cycles transforms the co-researchers' practices. For this reason, sufficient time should always be integrated into study designs to allow for the authentic transformation of practice.

6.4 School SLT Practices in use

School SLTs employ a wide range of practices when supporting students with PFDs in the United States (Felicetti et al., 2020; Hutchins et al., 2011; Neubauer & Singleton, 2023; Owre, 2006) and in New Zealand (Jackson et al., 2022; A. Miles et al., 2021). Factors alongside stakeholders' perceptions and aspirations that affected how specialist school SLTs supported students with PFD were identified (sections 6.4.1-6.4.2). Subsequently, stakeholders identified changes that would improve the support specialist school students received (sections 6.4.3-6.4.4) and implementation approaches are discussed (sections 6.4.5-6.4.6).

6.4.1 Assessment Practices

School SLTs' practice was impacted by unmethodical and inconsistent assessments of PFDs. Whilst school SLTs used a range of PFD assessments to gather information, they were not systematically or regularly used with students. PFDs affect multiple areas of a child's life, from their nutritional intake to their relationship with family members. Consequently, a thorough and holistic assessment of a child's PFD is necessary to ensure families receive appropriate support to reduce poor nutrition, health, and quality of life outcomes (Arvedson, 2008; Goday et al., 2019; Simione et al., 2023). Experts in the field recommend that assessment be interdisciplinary and include the following components:

- Examination of oral anatomy, oral reflexes, oral sensory processing, oral motor skills, swallowing skills, airway protection, and physiological stability.
- Trials of modified foods and fluids, feeding equipment, and feeding strategies when necessary.
- Observation of the child's environment, behaviour, and interactions between the child and caregivers and staff during meals (Arvedson, 2008; Crary & Groher, 2020; Homer, 2016).

However, 61% of students with a documented indication of PFD had no written assessment in their file (Figure 8). No students received an assessment that included all the above components, impacting SLTs' ability to sufficiently inform how they support students and families. School SLTs felt underconfident when assessing students, with SLT 01 perceiving that her current assessment practices may impact the quality of her recommendations and support for her students (section 4.2.3). Additionally, no written documentation indicated how frequently SLTs should re-assess students and what the re-assessment should include. Regular assessment for school-aged students is necessary, therefore, as their skills, anatomy, and physiology changes as they grow (Arvedson, 2008; Crary & Groher, 2020; Homer, 2016).

Our findings align with Neubauer & Singleton's (2023) results, where only 65.1% of school SLTs supporting PFDs assessed oral motor function and 30.2% performed a swallowing and feeding evaluation. This data suggests that school SLTs across multiple countries are not adequately assessing their students, impacting their ability to determine possible outcomes, such as risk. As discussed in Chapter 1, risk is a poorly defined and quantified term in PFDs, and experts recommend that clinicians discuss the difference between real risks and assumed risks (Kaizer et al., 2012; Radford et al., 2020). If therapists are not regularly assessing students in a holistic manner, they are less likely to convey information that accurately represents the real risks and assumed risks impacting a student's PFD and recommend a range of approaches that are responsive to these types of risks.

6.4.2 Inconsistent and Inefficient Documentation

School SLTs' ability to support students with PFDs was impacted by their documentation practices. To support consistent PFD practices, school staff completed many pieces of documentation and practices, such as IEPs, pastoral notes, daily family contact, and school therapy programs. Conversely, under half (34%) of students with documented indications of PFD had safe eating plans, and only 13% of these plans had been updated in 2022. Additionally, some staff used PFD-related programs, such as tastes, that were not documented anywhere, reducing SLT awareness and monitoring of students' needs and well-being. Inconsistent documentation and individual staff training rather than whole staff training impacted program consistency and student progress (section 4.3.1). This inconsistency was seen in a previous New Zealand-based study, where 46% (n=13/28) of students with a documented indication of PFDs had a written mealtime plan, and individual teachers implemented skilled feeding regimes at mealtimes that were not followed when that teacher was absent (A. Miles et al., 2021). The corroboration of these results denotes inconsistent PFD-related documentation in specialist schools to be prevalent across New Zealand, suggesting limited nationwide guidelines and structures to support practice. Experts in school PFD management suggest nationwide guidelines and protocols may ensure students receive what they require (Homer, 2008; Homer & Carbajal, 2015; Homer, 2016).

While EDAR practices in schools have been discussed, the documentation of EDAR specifically affected the support students received. School SLTs did not consistently document when families used these strategies at home, reducing cross-agency and cross-discipline knowledge of its occurrence. Subsequently, paediatricians, the specialist responsible for overseeing a child's overall health (The University of Auckland & Hutt Valley District Health Board, 2016), were not informed of EDAR practices that may have impacted their health (section 4.4.3). These findings provide new evidence to suggest that EDAR is not adequately documented when students are in community settings, such as specialist schools and at home. Adult EDAR guidelines, often used in the absence of paediatric ones, recommend documenting any decision made and sharing the documentation with relevant professionals (Royal College of Speech and Language Therapists, 2021; The University of Auckland & Hutt Valley District Health Board, 2016; Whitehead et al., 2019). Additionally, studies on paediatric EDAR specify that documentation should explicitly record actions taken to minimise risks alongside SLT eating and drinking recommendations (Table

5) (Feint & Langeroudi, 2021; Feint et al., 2022). These findings demonstrate how current practices within one NZ specialist school do not follow recommended best practice for EDAR, impacting the services a family receives.

The school SLTs were unaware of how inconsistent their PFD-related documentation was and how this affected their practice. When presented with this data, they were shocked and wanted to make instant changes to their practice, working towards the behaviour goals of, "increasing documentation of class PFD-related programs/plans to increase transparency and transfer knowledge". While school SLTs were initially reluctant to document EDAR and inform other professionals about its occurrence, they aspired to better collaborate, document, and monitor students. Though much of the research relating to school PFD support discusses what practices SLTs complete or don't complete, these findings provide new evidence to demonstrate how SLTs strive to provide the best support for their students. Sometimes, school SLTs found it difficult to keep track of the many students on their caseloads and identify what input each requires.

6.4.3 Specialist School Service Structure

School SLTs described an unclear service structure within schools that impacted their ability to assess students and provide therapy. SLT 01 desired for all specialist schools to operate in the same way as each other, indicating that clear service structures were not being used across New Zealand specialist schools. Contrastingly, health SLT had clear service structures in place relating to assessment and therapy provision with the goal of ongoing oral feeding. To remedy this, the school SLTs and I co-created a PFD management flowchart (Appendix 4) to prompt the school SLTs to provide appropriate support for students based on their presentations. School SLTs found this flowchart useful, with SLT 03 stating, "These [documents] are great because then everything is written down on paper and not just in our heads". These findings demonstrate how guidelines can support SLTs, aligning with previous literature which recommends for schools to have guidelines and protocols in place within schools but also across a district (Homer, 2008; Homer & Carbajal, 2015; Homer, 2016). Homer's (2008; 2016) guidelines suggest that students access SLT support on a referral basis, whereas referral and discharge of students does not occur in most New Zealand specialist schools. This is because SLTs are expected to monitor all students within a specialist school (A. Miles et al., 2021). Subsequently, additional protocols are required for New Zealand specialist schools, outlining a service structure that all SLTs work towards instead of relying on what an individual SLT thinks is appropriate.

In addition to this, school SLTs primarily supported their students by assessing PFDs, referring for VFSSs and creating safe eating plans. Homer (2016) outlines the following four areas of practices school SLTs can use to support their students with PFD (section 2.7):

- Collaborative consultation
- Direct therapeutic intervention
- Intervention with students with progressive disorders or medically fragile students
- Transition to or from tube feeding

School SLTs primarily supported school staff to monitor a student's PFD, otherwise known as collaborative consultation (Homer & Carbajal, 2015; Homer, 2016). School SLTs occasionally provided some direct intervention, but the provision of therapy depended on the therapist, the student's classroom, and whether they had a safe eating plan (section 4.4.3). There was no evidence of transition to or from tube weaning, despite having students on their caseload who were appropriate for this type of support. School SLTs followed guidelines from health professionals when supporting students who were medically fragile but did not initiate communication with medical teams about EDAR for pleasure when families had consented for it to be completed by the school team. Not knowing how to support school SLTs, health SLTs recognised that students' safe eating plans often stayed the same while they attended specialist schools.

These findings have been seen in previous research completed in the United States, where not all SLTs provide direct therapy for their students (Hutchins et al., 2011; Neubauer & Singleton, 2023; Owre, 2006). Thirty-three percent of school SLTs provided direct therapy for students (Neubauer & Singleton, 2023), corresponding with older research where SLT provided direct therapy for 35% of students (Homer, 2008). Additionally, over half (53.4%) of SLTs completing a case-study for a child with oropharyngeal dysphagia were unsure what to do, would follow a protocol set by another professional or would refuse treatment and refer to outside professionals (Felicetti et al., 2020). These results indicate that the provision of therapy may be based on individual SLTs as opposed to student need, a concerning finding as most children with PFDs who do not receive treatment do not naturally improve as they age (Dumont et al., 2022). Significantly, the Convention on the Rights of Persons With

Disabilities (2008) stipulates that people with disabilities have the right to habilitation, rehabilitation, and to gain maximum independence and participation in all aspects of life. Students are unable to gain independence or fully participate in life if they are not provided direct therapy to habilitate their PFD, which is unlikely to naturally improve as they age.

6.4.4 Adapting Information to the Specific Environment

Prior to this study, school SLTs had access to books, journal articles, school guidelines, adult EDAR guidelines, expert advisors, free online training, and undergraduate training that discussed how to best support students with PFD. School SLTs sometimes found these resources difficult to use as many targeted children aged one to three, did not mention school-aged children, or were not relevant to the New Zealand context. These findings demonstrate that school SLTs struggle to use resources that do not consider their environment or caseload. In contrast, SLTs requested access to resources that were immediately relevant to their caseload, discussing how the resource could be used to support students. SLTs engaged more with adapted resources, showing a preference for resources to fit alongside their current practices (section 5.3.2).

These findings align with previous literature where SLTs' practice did not change after attending conferences or workshops, reading peer-reviewed journal articles, or accessing guidelines, thereby creating a research-to-practice gap. In response to this gap, implementation science aims to target behaviour change in "real-world" environments (Cook, B. & Odom, 2013; Douglas et al., 2015; Nilsen, 2015; Olswang & Prelock, 2015). The Behaviour Change Wheel (BCW), the implementation science design used in this study, attempts to understand factors that influence aspects of implementation (Mitchie et al., 2014). By understanding the capabilities, opportunities and motivations, I was able to adapt resources to the school's individual environment, student population, and staff. Specifically, the factors that had the biggest influence on the SLTs and school practices were the physical and social opportunities. These included:

- School and health SLTs had different structures and supports available to them, sometimes leaving school SLTs to feel professionally isolated (physical opportunity).
- School staff did not want to be held liable for students' health (social opportunity).
- Some families fed their children differently at home than at school but didn't expect school staff to use all the strategies they did at home (social opportunity), etc.

Consequently, I attempted to address these factors in the implementation cycles to enable school SLTs to meet their behaviour goals, considering their specific environmental factors. This study provided new evidence of how implementation science in structured research caused change to occur in the complex environment of a specialist school.

6.4.5 Documents Alone do not Change Practice

A common way to disseminate information is the creation and use of written information or documents, yet we know that documents alone don't change a clinician's behaviour (Cook, B. & Odom, 2013; Douglas et al., 2015; Nilsen, 2015; Olswang & Prelock, 2015). Creating change in schools is often difficult due to the busy school environment, often containing complex dynamics that differ from other organisations (Douglas et al., 2015; Hagermoser Sanetti & Collier-Meek, 2019). In this thesis, the behaviour change techniques (BCTs) causing the most significant change increased collaboration and relationship building between SLTs working in different settings and organisations. This is not surprising as people-centred work is often reliant on collaboration and one's ability to develop relationships (Hagermoser Sanetti & Collier-Meek, 2019). For example, the co-researchers and I used the BCT Restructuring the Environment to build relationships between health and school SLTs, highlighting areas of practice that required additional input. The BCT Credible Source was used when health SLTs provided training for specialist school SLTs, where specialist school SLTs asked EDAR-related questions and accentuated nationwide system gaps.

The use of BCTs provided new evidence of the plethora of strategies SLTs can use alongside written documentation to generate change in a complex environment for a complex topic that had not occurred before. While the BCTs were orchestrated by the co-researchers and myself in a formal research capacity, the use of BCTs are inside the remit of a practicing SLT. Therefore, this project demonstrated the plethora of BCTs SLTs could use to bring about change in schools when clinicians consider the factors impacting the environment, as seen in the COM-B (Mitchie et al., 2014).

6.5 Limitations

A significant limitation to the analysis of the implementation cycles was my inability to collect follow up data to determine the extent of school SLTs' behaviour change and the maintenance of this change. Whilst I was able to gather observational data from the implementation cycles, this data could not be directly compared to the data gathered in the Observe phase. We initially planned to gather follow-up data in the Participatory Evaluation phase, however, the co-researchers were amid a belief and practice change when we came to collect the data. Due to this, we were not confident that follow-up data would accurately depict the change that was occurring. As this project had to be completed over two years part time as per the Master of Science regulations, we deemed the Participatory Evaluation phase to be outside the timeline and scope of this master’s thesis.

My restricted interaction with families was an additional limitation in this study. Few families engaged with me while I was recruiting, possibly due to their busy lives, negative experiences with the topic, or my lack of relationship with them. Families best interacted with me when teachers contacted them personally to discuss the study with them. However, this approach put a large toll and responsibility on teachers, and not all teachers were willing to individually contact families. Of the families interviewed, only one agreed to be part of the advisory group. Both caregivers who agreed to be interviewed had relatively good levels of health literacy and positive experiences with health teams. Families with negative experiences of the health system and lower health literacy may have provided a different perspective than the families I engaged with.

While school SLTs 03 and 04 member checked my analysis of the data which increased its trustworthiness (Birt et al., 2016), member checking my analysis of the data with other interviewees was not completed. School SLTs 03 and 04 did not want other members of staff to see an overall analysis of the data, as much of it pertained to their own practice. As member checking was completed at the end of 2022, other SLTs and teachers were less available to meet due to end of year pressures. There was also limited time to member check in 2023 due to the initiation of implementation cycles. Overall, additional member checking would have increased the trustworthiness of my data analysis.

To enable school SLTs to act as co-researchers, I did not provide a thorough explanation of the COM-B framework, BCTs, or implementation science. Given the success of the BCTs in creating behaviour change, school SLTs would benefit from a better understanding of implementation science, empowering them to use it in their day-to-day practice. Additionally, other behaviour change taxonomies exist that have been adapted to school settings to consider the unique environment of schools (Hagermoser Sanetti & Collier-Meek, 2019). Subsequently, school SLTs would have benefited from being involved in the decision-making process about which implementation science framework to use, fostering a better understanding of which framework could be integrated into their work.

7 Future Directions and Conclusion

7.1 Future Directions

EDAR continues to be a contentious topic within PFDs, yet it occurs in schools and at home for school-aged children with teachers and families who want support from SLTs.

7.1.1 Paediatric EDAR Guidelines

As discussed in Chapter 1, EDAR guidelines are available for those supporting adults, what is missing is paediatric guidelines. Paediatric EDAR occurs in school settings, but there are no guidelines that encompass the school context, containing complex legal considerations (The Code of Health and Disability Services Consumers' Rights Regulations 1996; Health and Safety at Work Act 2015). Future paediatric EDAR guidelines should acknowledge these laws and outline how they may impact support that students receive within school settings.

Disagreements between school staff and families are common within school settings, and decisions relating to complex PFDs are often supported by senior leadership teams and school therapists. Comparatively, decisions relating to complex behavioural needs are often supported by external professionals and agencies. Future paediatric EDAR guidelines should encourage school teams to collaborate with health professionals, such as paediatricians who hold the final responsibility for feeding decisions, and health SLTs who typically have greater knowledge in this area.

Children's capacity and their ability to contribute to a decision is a complex yet important component relating to paediatric EDAR. Future paediatric guidelines should specify how children can contribute to decisions that they may not have capacity to independently make. Guidelines should discuss Gillick Competence (Larcher & Hutchinson, 2010) and The Code's 1996 endorsement of child assent where those with diminished competence are involved in decision-making process to the full extent of their capacity (The Code of Health and Disability Services Consumers' Rights Regulations 1996; Hudson et al., 2019).

As discussed in section 6.4.5, guidelines alone do not result in behaviour change and should be implemented alongside other strategies to ensure the research to practice gap is further closed.

7.1.2 Advocacy Work for Holistic Care of PFDs

A significant gap in service was identified throughout this thesis, referred to as a "dead zone", where some specialist school SLTs were not permitted to provide in home support for students with PFDs. SLTs employed by the Ministry of Health are not funded to work with school aged children, occasionally providing some consultation for families under the Memorandum of Understanding and Local Level Agreements (section 2.2.3). For this reason, school aged children attending specialist schools did not consistently access therapy at home, where care and strategy use sometimes differed from what was being provided in school settings. As this thesis ended, my supervisors and I wrote a letter to ministers in the Ministry of Health, Ministry of Education, and Ministry for Disabled Peoples to highlight this dead zone and advocate for students with PFDs to receive a more holistic type of care. This is an ongoing piece of advocacy work that will require support beyond the scope of this thesis.

7.1.3 Continuing use of Implementation Science Within School Settings

This project has shown how BCTs can generate behaviour change for those working in school settings. Subsequently, future studies should consider using implementation science frameworks to reduce the research to practice gap. A range of implementation frameworks exist, each with a different purpose and structure (Nilsen, 2015). Those looking to use implementation science within schools should consider their end goal before choosing a framework, contemplating which structure best suits the complex dynamics present in schools. Whilst implementation science can be used by researchers, it is feasible for school therapists to use it outside of a formal research context to change their day-to-day practice. School SLTs may find this supports them to implement best practice within classrooms and could be considered one of the tools in their toolbox when supporting anyone to change their behaviour.

7.2 Conclusion

Based on the qualitative and quantitative data gathered throughout this study, specialist school SLTs lacked access to structures and policies to guide their support of students with complex PFDs, who were more likely to choose higher-risk feeding practices in community settings. School SLTs' assessment, cross-agency collaboration, and documentation were inconsistent, leading to disproportionate responsibility for students' PFDs and recurrent feelings of fear. School SLTs described the divide between health and education priorities, stating PFD support was not a priority in Education. Significant service gaps were present, such as providing in-home support for school-aged children, guidelines for students who EDAR, and provision of therapy. School SLTs recognised these gaps and wanted to provide better support, but were restricted by workplace guidelines, culture, and a lack of service structure. Families wanted school SLTs to create plans that encompassed their goals and preferences while wanting more support at home.

School and health SLTs worked towards creating a more structured service provision for the host school SLTs, which included a service pathway for students and families wanting to EDAR. However, the SLTs were unable to provide a service in dead zones where service provision was restricted from both health and education, such as supporting school-aged students at home. Some practice change was produced from the implementation cycles and was enhanced by involving stakeholders, adapting information to the local environment, and increasing collaboration, all of which took time. These practice changes were influential for the one school, but overall change is still needed to best support school-aged students with PFDs.

8 Appendix A

Semi-Structured Interview Schedule for SLTs, School Staff, DHB Staff and Caregivers

Some children have eating and drinking difficulties that are pretty straightforward and well-managed, but we are going to talk about children with eating and drinking difficulties that are complicated or problematic. You don't need to mention any names of anybody, but if you do I will remove them from the transcript.

1. Tell us about your experience working with children and their family where complex feeding decisions have been made.
2. Have you encountered any tricky situations regarding a child's eating/drinking?
   Follow up:
   - What happened?
   - How did people manage this? Tell us about the process taken.
   - Could you tell me how you were involved in this?
3. How well do you think the children's eating/drinking difficulties are managed at school/ at home?
4. Who is in charge of the eating and drinking plan? Is this plan different at home compared with school/hospital? Why is it different?

If the person is working directly with children with eating and drinking difficulties…

1. What sort of special attention related to eating/drinking do children in your care have? (Special attention relating to food modifications, personal aid during eating/drinking, staff meetings)
2. Think of a time when complex-feeding decisions have been managed well. What happened?
3. And if there is a time when it wasn't managed well, what happened?
4. Do eating and drinking difficulties have impact on the classroom environment? What about the home environment?
5. Is there anything about the way that eating and drinking difficulties are managed that you would change, keep or add?

   Follow up:
   - to change: what do you think might improve this management?
   - to keep: why do you think this has generated a positive impact?

6. What else would help you to support the children with complex feeding issues?
7. Do you have anything else you want to mention?

9 Appendix B

Summary Table of COM-B Analysis

	COM-B component	Summary of findings
Capability	Physical capability	Classroom Staff
		-Staff were skilled in supporting support students with PFDs, but PFD-related skills were not consistently shared between staff in a classroom.
		Students
		-Students in community settings with stable health took risks when eating and drinking.
	Psychological capability	Classroom staff
		- Staff felt empowered by knowledge. Some staff lacked PFD-related knowledge which impacted how they supported students and when they asked for help.
		Families
		-Families regularly shared information and skills with classroom staff but also displayed gaps in their PFD-related knowledge. -Families valued being active participants when making informed decisions.
		SLTs
		-School SLTs adapted resources and programs to support their students with PFDs. -School SLTs had inconsistent assessment and collaboration practices, which impacted their PFD management.
Opportunity	Physical opportunity	School
		-The school had many documentation processes that enabled staff to support students with PFDs, but elements of PFD support were not consistently documented, and no policy specified how to support students with complex PFDs. -Classroom staff had sufficient resources to support PFDs and were reliant on in-house training to upskill.

		Families
		-Families valued the communication practices and support provided by health professionals and school staff.
		SLTs
		-School and health SLTs had different structures and supports available to them and school SLTs often felt professionally isolated. -SLTs described a lack of available training and sometimes felt underconfident when supporting students with PFDs. -LLAs enabled collaboration between health and external organisations, but collaborative practices varied across geographical regions.
	Social opportunity	School
		-Staff didn't want to be held liable (legally responsible) for students' health. -Staff communicated with external agencies but did not regularly communicate with health-based SLTs.
		Families
		-Some families fed their children differently at home than at school but didn't expect school staff to use all the strategies they did at home. -Relationships between professionals and families were an important part of the service.
		SLTs
		-SLTs inconsistently provided therapy to students with PFD. -Only one school SLT supported a student to EDAR in a school setting and at home. SLTs did not routinely inform or collaborate with health services when EDAR occurred. -SLTs sometimes made decisions that strained the relationships between families and school staff.
Motivation	Reflective motivation	Classroom staff
		-Staff were motivated to learn about and support students' PFDs.
		Families

		-Families didn't want to limit their child's eating and drinking progression and exhibited a high level of trust in classroom staff. -Some families had negative experiences with health services, reducing their desire to re-engage with them.
		SLTs
		- School SLTs found it difficult to balance family goals and what they felt was "safe" for the student, often describing high levels of stress.
	Automatic motivation	Classroom staff
		-Staff with more knowledge took more calculated risks. -Each person had different comfort levels relating to risk, which were impacted by a range of factors such as familiarity with the student, PFD knowledge, and responsibility for student wellbeing.
		SLTs
		- School SLTs described differing priorities between "health" and "education".

10 Appendix C

Initial Results Sharing With School

Findings - Facilitators	Potential resources	School SLT input
School staff felt knowledge empowered them to understand the "why" behind strategies.	Regular, school-wide, staff dysphagia training.	
Thorough dysphagia assessments made SLTs feel safe when managing PFD.	VFSS referral procedure and list of contacts for advice.	
Parents wanted to contribute to the strategies used with their child at school, which did not mean that parents wanted the school to be doing everything they do at home.	Document to structure conversations regarding risk feeding and record plans made in collaboration with family.	
Good communication between therapists and senior management team enabled both parties to feel supported (e.g., pastoral notes).		
School-wide programs were in place (e.g., pastoral notes, behaviour plans, therapy program plan, etc.), indicating school-wide implementation with other strategies is successful.		
Two-way communication exhibited between the school and other organisations (e.g., 16% of students had BLENNZ reports, 13% had DHB OT reports, 11% had DHB PT reports).		

Staff were enabled to support PFDs when SLTs used the following strategies: verbal explanations, written documents that are visible in the classroom, regular whole-school training on dysphagia, SLTs coaching new staff during mealtimes, nurse completing enteral feeding training, and plans that are 1-page in length.	
SLTs suggested it would be useful to have: DHB SLTs observe school feeding programs, assessments and mealtimes, PFD-specific supervision, and health SLT or school SLTs review video sessions or assessments.	List of suggestions and recommendations to support special schools.
Class culture around feeding was deemed manageable with practical solutions, not “this big scary thing that’s really hard” and to “just breathe”.	
Teachers felt that supporting students’ eating and drinking was part of their job description.	
Parents did not want to limit their children’s food and eating progression.	
Parents did not want school staff to feel uncomfortable feeding their children.	
Some parents used the feeding advice that was given to them as guidance and modified it to fit their child.	
SLTs were open about how difficult complex feeding can be.	
Parents trusted school staff to look after their children and did not trust other organisations to the same degree (e.g., respite care).	
Findings - Barriers	

Some skills were held by 1 class member and not documented anywhere (e.g., tastes program).	Document outlining different strategies one can use in a tastes program.	Disclaimer about oral hygiene. What are the factors you need to consider before starting a tastes program.
Some teachers did not know when they needed SLT input (e.g., teacher completing tastes program without informing SLTs).		
Lack of knowledge about how to contact DHB contacts and unclear pathways or guidelines around engaging with hospital SLTs.	List of current DHB contacts, guidelines for local DHB contact.	
34% of total students had a documented indication of eating and drinking difficulty. 11.5% of total students had a mealtime plan (34% of students with PFD) and 4.4% of total students (13% of students with PFD) had been reviewed in 2022. **This aligns with previous NZ research.**	Specify who requires a feeding plan and how frequently they need to be reviewed.	
37% of students with PFD has a written assessment, mostly based around mealtime observations.	Possible components of dysphagia assessments.	What to do if VFSS is not appropriate or consented to.

5% of students had dietitian reports when 14% of students had documented evidence of being enterally fed.	Form for inter-agency documentation transfer.	
No structures in place to enable students who are cognitively able to be involved in decisions regarding complex eating and drinking.	Resources to ensure paediatric client's and caregiver's views have been considered. ? Capacity assessment ? Talking mats	
Dysphagia policy in place, no guidance about how to resolve conflicts or manage complex feeding decisions.		
School staff do not want to be held liable for students' risk or "putting staff at risk".	Resource of possible actions to minimise risks when risk feeding occurs.	
Parents are more "flexible" with dysphagia recommendations at home, leading to differences in mealtime management between home and school.		
Lack of multi/inter/transdisciplinary work, feeding left up to SLTs.		
SLT uncertainty around how to support students with long term enteral feeding.		
SLTs felt under skilled to enable students to progress with oral feeding skills (e.g., texture progression).	Progression chart and strategies. Link to online PD courses.	What is considered risk feeding? (e.g., is bite melt for

		texture progression considered risk feeding?).
Parents have sometimes developed strategies that are not safe for students (e.g., force feeding, feeding while asleep).	Information package on risk feeding.	

11 Appendix D

List of Considerations for Complex Feeding Decisions in Specialist Schools

This document is designed to prompt specialist school SLTs when supporting families and students who are making complex feeding decisions. Additional, more in-depth resources are listed on page two of this document.

Familial Involvement

Families often make decisions within the zone of parental discretion (ZPD), an area where decisions can be *good enough* for a student but may not be perceived as *medically optimal* by the medical team (Gillam, 2016). Families have a legally protected right to choose how to feed their child at home within the ZPD, even when their practices go against professional recommendations (The Code of Health and Disability Services Consumers' Rights Regulations 1996; Skegg & Paterson, 2015). Families who make decisions in this zone may still require SLT support at home.

Gather information on how the **family are feeding their child at home.** Consider the following points:

- What are the whānau's long-term goals for the student?
- Which of the following reasons impact the family's decision to feed their child:
    - Cultural beliefs.
    - Pleasure.
    - Oral skill development.
    - Social aspects of eating and drinking.
- Do the family want or require additional support at home for:
    - Oral skill development.
    - Strategies to minimise risk.
    - Oral health.
- Can the school provide support at home or do the family need input from a community health SLT?

Gather information on how the **family want their child fed at school.** Consider the following points:

- Are there components of the family's wishes that can be incorporated into school routine?
- Do you need health SLT input on how to classify different types of risk?
    - High risk vs. low risk, assumed risk vs. real risk.

- What do classroom staff, such as the teacher and teacher aides, feel comfortable doing at school? How are they currently feeding the student?
- How confident do school SLTs feel to train staff to use potential strategies? Do school SLTs need support from a health SLT?

Discuss who Should be Involved

- Paediatrician – they are responsible for a student's overall health and should be notified if any form of risk feeding/EDAR is occurring, as this could impact students' health.
- Health SLT – if the school SLT requires additional support.
- Classroom staff.
- Occupational Therapists and Physiotherapists.
- Senior management team – if therapists require support to manage conflict resolution.

Information to Include in the Written Plan

The feeding plan for school.	What the whānau choose to do at home.
Why the decision was made.	Who was involved in the decision.
Family members to sign a section stating they understand the risks and benefits of the plan.	

(Feint & Langeroudi, 2021; The University of Auckland & Hutt Valley District Health Board, 2016).

Strategies to Minimise Risk.

Oral hygiene advice.	Mobility (if applicable).	Texture modification.
Feeding techniques.	Positioning.	Fatigue management.
Respiratory strategies (e.g., supported coughing techniques).		

(The University of Auckland & Hutt Valley District Health Board, 2016)

Additional resources

Adult Risk Feeding Guidelines

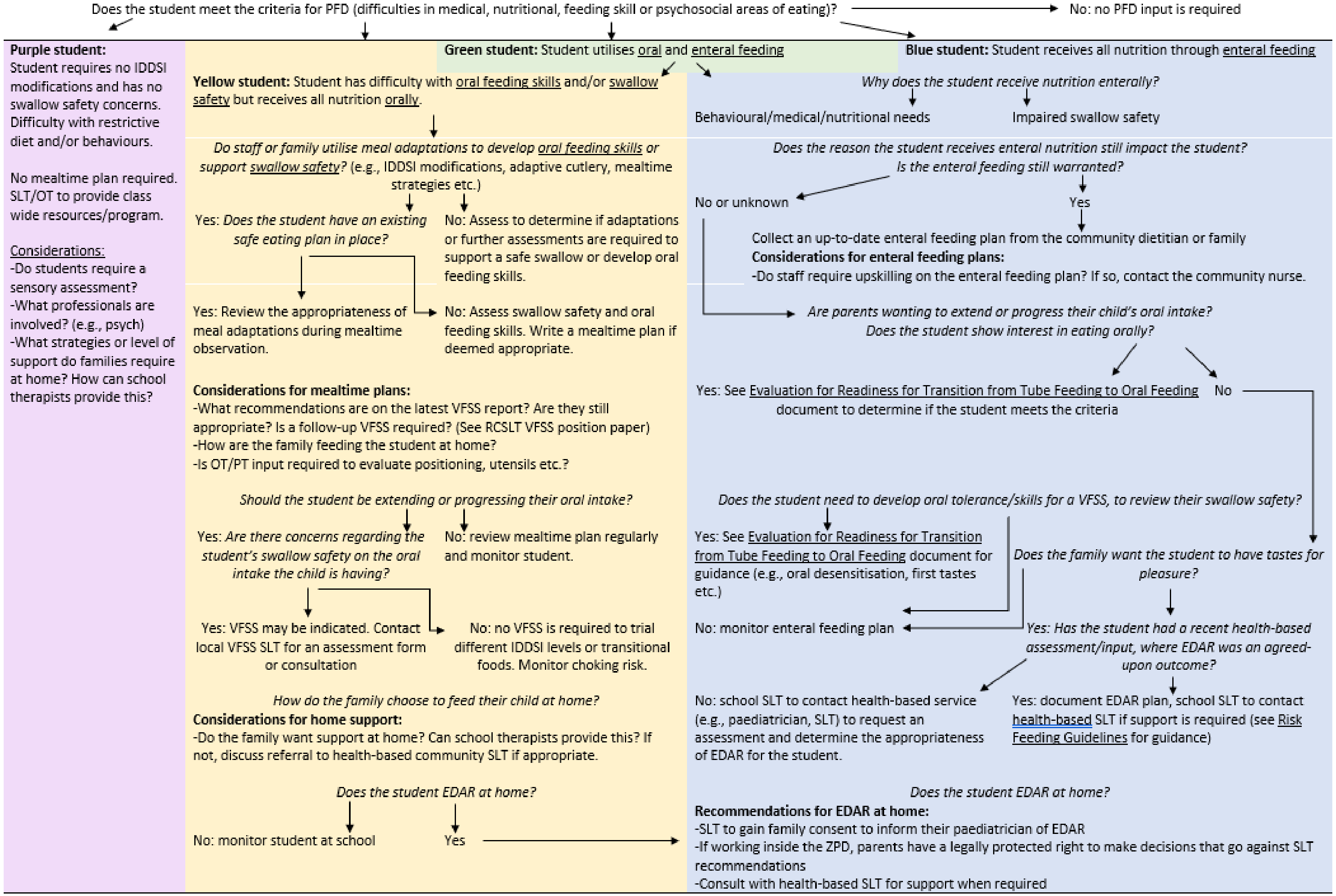
Paediatric Tube Feeding information for Speech Language Therapists: https://starship.org.nz/guidelines/paediatric-tube-feeding-information-for-speech-language-therapists/

Evaluation of readiness for transition from tube feeding to oral feeding: https://starship.org.nz/guidelines/evaluation-of-readiness-for-transition-from-tube-feeding-to-oral-feeding/

Note: All specialist school SLTs can access support from their local health SLT or XX (hospital) under their local level agreement. To gather local health SLT details, contact your local hospital.

12 Appendix E

PFD Management Flowchart



Does the student meet the criteria for PFD (difficulties in medical, nutritional, feeding skill or psychosocial areas of eating)?

No: no PFD input is required

Purple student:
Student requires no IDDSI modifications and has no swallow safety concerns. Difficulty with restrictive diet and/or behaviours.

No mealtime plan required. SLT/OT to provide class wide resources/program.

Considerations:
-Do students require a sensory assessment?
-What professionals are involved? (e.g., psych)
-What strategies or level of support do families require at home? How can school therapists provide this?

Yellow student: Student has difficulty with oral feeding skills and/or swallow safety but receives all nutrition orally.

Do staff or family utilise meal adaptations to develop oral feeding skills or support swallow safety? (e.g., IDDSI modifications, adaptive cutlery, mealtime strategies etc.)

Yes: *Does the student have an existing safe eating plan in place?*

No: Assess to determine if adaptations or further assessments are required to support a safe swallow or develop oral feeding skills.

Yes: Review the appropriateness of meal adaptations during mealtime observation.

No: Assess swallow safety and oral feeding skills. Write a mealtime plan if deemed appropriate.

Considerations for mealtime plans:
-What recommendations are on the latest VFSS report? Are they still appropriate? Is a follow-up VFSS required? (See RCSLT VFSS position paper)
-How are the family feeding the student at home?
-Is OT/PT input required to evaluate positioning, utensils etc.?

Should the student be extending or progressing their oral intake?

Yes: *Are there concerns regarding the student's swallow safety on the oral intake the child is having?*

No: review mealtime plan regularly and monitor student.

Yes: VFSS may be indicated. Contact local VFSS SLT for an assessment form or consultation

No: no VFSS is required to trial different IDDSI levels or transitional foods. Monitor choking risk.

How do the family choose to feed their child at home?

Considerations for home support:
-Do the family want support at home? Can school therapists provide this? If not, discuss referral to health-based community SLT if appropriate.

Does the student EDAR at home?

No: monitor student at school

Yes

Green student: Student utilises oral and enteral feeding

Blue student: Student receives all nutrition through enteral feeding

Why does the student receive nutrition enterally?

Behavioural/medical/nutritional needs

Impaired swallow safety

Does the reason the student receives enteral nutrition still impact the student? Is the enteral feeding still warranted?

No or unknown

Yes

Collect an up-to-date enteral feeding plan from the community dietitian or family
Considerations for enteral feeding plans:
-Do staff require upskilling on the enteral feeding plan? If so, contact the community nurse.

Are parents wanting to extend or progress their child's oral intake? Does the student show interest in eating orally?

Yes: See Evaluation for Readiness for Transition from Tube Feeding to Oral Feeding document to determine if the student meets the criteria

No

Does the student need to develop oral tolerance/skills for a VFSS, to review their swallow safety?

Yes: See Evaluation for Readiness for Transition from Tube Feeding to Oral Feeding document for guidance (e.g., oral desensitisation, first tastes etc.)

Does the family want the student to have tastes for pleasure?

No: monitor enteral feeding plan

Yes: Has the student had a recent health-based assessment/input, where EDAR was an agreed-upon outcome?

No: school SLT to contact health-based service (e.g., paediatrician, SLT) to request an assessment and determine the appropriateness of EDAR for the student.

Yes: document EDAR plan, school SLT to contact health-based SLT if support is required (see Risk Feeding Guidelines for guidance)

Does the student EDAR at home?

Recommendations for EDAR at home:
-SLT to gain family consent to inform their paediatrician of EDAR
-If working inside the ZPD, parents have a legally protected right to make decisions that go against SLT recommendations
-Consult with health-based SLT for support when required

Definitions

Paediatric feeding disorder (PFD): "…impaired oral intake that is not age-appropriate and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction" (Goday et al., 2019, p. 124).

Domain	Definition	Examples
Medical factors	Impaired structure/function of the GI, cardiorespiratory, and neurological systems are frequently associated with dysphagia.	See Supplementary Table 1: http://links.lww.com/MPG/B507
Nutritional factors	Restricted quality, quantity, and/or variety of beverages and foods consumed, placing them at risk of malnutrition, overnutrition, micronutrient deficiency or toxicity, and dehydration.	See Supplementary Table 2: http://links.lww.com/MPG/B507
Feeding skills factors	*Oral sensory functioning* – inhibits/limits acceptance and tolerance of liquids and food textures expected for age. *Oral motor functioning* – limits bolus control, manipulation, and/or transit of liquids and solids	*Oral sensory functioning* – associated with specific characteristics of liquids and food textures such as the flavour, temperature, bolus size, viscosity, texture, or appearance. *Oral motor functioning* - characterized by inefficient intake, messy eating, poor control of liquids and foods, slow or ineffective bolus formation and propulsion, gagging during bolus formation, and post swallowing residue.

	Pharyngeal sensation – inhibits airway protection and efficient swallowing. *Pharyngeal motor functioning* – inhibits pharyngeal movements to be fully functional, a child's feeding skills must be safe, age appropriate, and efficient.	*Pharyngeal sensation* – often associated with poorly timed and coordinated swallowing during pharyngeal transit, poor awareness of bolus location, presence of pharyngeal residue post-swallow, and silent aspiration. *Pharyngeal motor functioning* – evidenced by reduction in strength and coordination of pharyngeal constrictors, velar and laryngeal elevation, and vocal fold closure.
Psychosocial factors	*Developmental factors* – delays of motor skills, language, socialization, and cognition. *Mental and behavioural health problems* – in the child/caregiver dyad. *Social influences* – caregiver-child interactions and cultural expectations within a mealtime context. *Environmental factors* – a distracting feeding environment.	*Developmental factors* – often result in a mismatch between the feeding abilities of the child and the feeding expectations of adult caregivers who are responsible for feeding the child. *Mental and behavioural health problems* – In a child, dysregulated temperament, mood disorders, anxiety, or disordered thinking. In a caregiver, stress and/or other mental health factors. *Social influences* – Caregivers may misinterpret a child's hunger and satiety cues or have different cultural beliefs about feeding and nutrition than others. *Environmental factors* – use of television, other electronic devices or resorting to feeding only when a child is asleep.

(Goday et al., 2019).

Swallow Safety: The ability to transfer the bolus from the mouth to the stomach without consistent penetration or aspiration into the lower airways. In a typical swallow, part of the bolus occasionally enters the person's airway. However, their reflexes (e.g., cough reflex) can effectively expel parts of the bolus from the airway (Crary & Groher, 2020; Dodrill & Gosa, 2015; Pizzorni et al., 2019).

Eating and Drinking with Acknowledged Risk (EDAR): One of several terms used to describe when a person decides not to modify food or drink or continues oral intake, despite a health professional's assessment that oral intake of food or drink will increase their risk of aspiration, dehydration, choking and malnutrition (Radford et al., 2020; Soar et al., 2021; The University of Auckland & Hutt Valley District Health Board, 2016).

Health-Based Assessment: May include assessments or consultations with health-based professionals, such as an SLT, paediatrician, consultant or dietitian. Paediatricians should always be made aware of these assessments or consultations. SLT assessment is typically accessed under the regional LLA and may differ from region to region.

Zone of Parental Discretion (ZPD): "Ethically protected space where parents may legitimately make decisions for their children, even if the decisions are sub-optimal for those children (i.e. not absolutely the best for them). The ethically acceptable zone for parents' decisions about young children is broader than the single point at the top of the scale where the child's absolute best interests lie (if that point could ever be determined) and extends down to the cut-off line, or threshold, where the child will be harmed if the parents' decision is followed. In this space, 'good enough' parental decisions should be tolerated, until the point where they would cause harm to the child" (Gillam, 2016, p. 2).

Resources:

Videofluoroscopic evaluation of oropharyngeal swallowing function (VFS): The role of speech and language therapists RCSLT Position Paper (pp.1-5): https://rcslt.org/wp-content/uploads/media/Project/RCSLT/videofluoroscopic-position-paper.pdf

Paediatric Tube Feeding information for Speech Language Therapists: https://starship.org.nz/guidelines/paediatric-tube-feeding-information-for-speech-language-therapists/

- Includes: strategies for oral desensitisation, facilitating first tastes, IDDSI, encouraging oral motor development, transitioning between IDDSI levels, equipment for oral sensory motor development, strategies to facilitate normal oral motor patterns

Evaluation of Readiness for Transition from Tube Feeding to Oral Feeding document: https://media.starship.org.nz/evaluation-of-readiness/Evaluation_of_Readiness_Tool.pdf

The University of Auckland Adult Risk Feeding Guidelines document: https://flexiblelearning.auckland.ac.nz/speech-science-dysphagia-education-hub/6/files/riskfeedingguideline_post-endorsement.pdf

13 Appendix F

EDAR Risk Minimisation and Information

Eating or drinking with acknowledged risk (EDAR) or *risk feeding* is the decision to not to modify food or drink or continue oral intake, despite a health professional's assessment that oral intake of food or drink will increase their risk of aspiration, dehydration, choking and malnutrition (Radford et al., 2020; Soar et al., 2021). Aspiration is where some or all the food/drink taken orally enters the airway, which can travel to the lungs if not cleared by a cough. Choking can occur when food enters the airway and becomes stuck, interfering with a person's ability to breathe (Crary & Groher, 2020).

Possible outcomes from aspiration in paediatrics

Lung collapse	Choking	Bronchiectasis (chronic suppurative infection)
Recurrent pneumonia	Chronic cough	No changes

Factors that likely influence changes in lung health post aspiration

pH (e.g., water vs. reflux)	Microbial content, influenced by oral hygiene	Frequency of events (e.g., single, large aspiration event vs. multiple, small, silent aspiration events)
Fluid volume	Solid contents	
Individual resistance or immunity	Co-existing condition	

(Wallis & Ryan, 2012)

People assume that the severity of a person's dysphagia predicts whether they will develop aspiration pneumonia (Wallis & Ryan, 2012). However, research has shown that dysphagia and aspiration alone is not enough to predict whether people develop aspiration pneumonia (Langmore et al., 1998; Ortega et al., 2015). Health status, swallow safety and oral health are 3 important factors that influence whether a person develops pneumonia from aspiration. These 3 factors have been coined the 3 pillars of aspiration (Ashford, 2023; Ortega et al., 2015).

3 Pillars of Aspiration

1	2	3
Impaired health status (e.g., immunity and body conditioning.	Impaired airway protection (e.g., aspiration).	Impaired oral environment (e.g., oral bacteria).

Note. Adapted from Ashford (2023).

Oral Health:

Oral health is a term used to describe the health of a person’s teeth, gums, and oral mucosa, or skin inside the mouth such as lips and cheeks. Children and adolescents with developmental disabilities are more likely to have poor oral hygiene and those who are enterally fed, or gain their nutrition from a gastrostomy tube, have a significantly increased risk of poor oral hygiene.

Good oral hygiene is important for comfort, and to ensure that bacteria or food/drink residue do not build up in the mouth which can be carried to the lungs, increasing the risk of chest infections (Norwood Jr et al., 2013).

Reasons why People Might Eat or Drink with Acknowledged Risk (EDAR):

- Whānau belief about disability and feeding, which may be impacted by their culture.
- Reported improvement in a child or adolescent’s desire to eat (e.g., opening his mouth for the spoon) and/or their oral skills (e.g., starting to chew).
- Continued practice in oral feeding, although this is only beneficial if feeding is a safe and positive experience for the child or adolescent.
- Increased participation in social events when peers, staff or family members are eating and drinking. Specific celebrations or events may be particularly important for whānau or school teams.
- Eating and drinking orally brings joy, pleasure or satisfaction to the child/adolescent, increasing their quality of life.

Factors to Minimise the Risk of Aspiration When Eating or Drinking With Acknowledged Risk (EDAR):

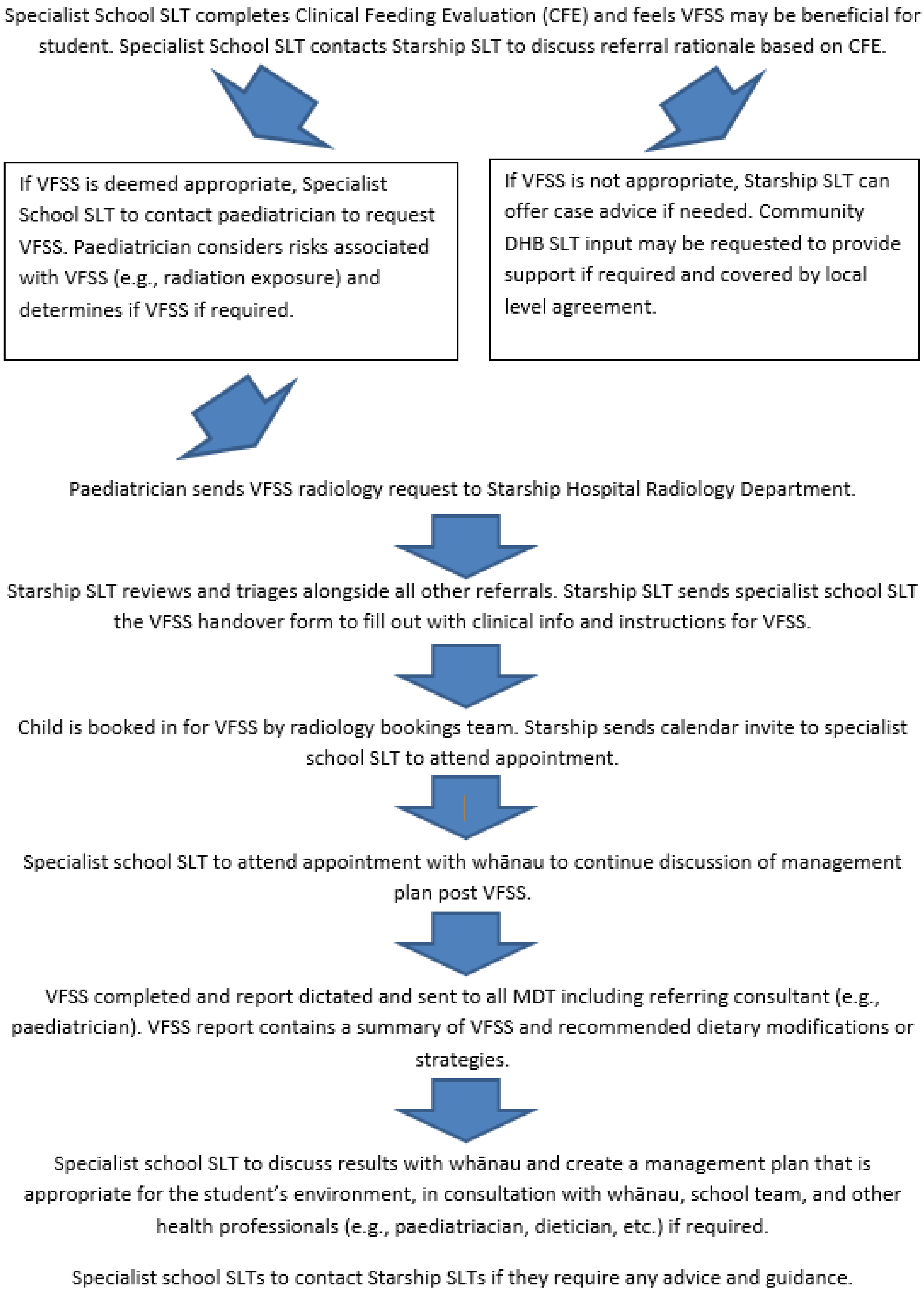
Interest	Posture	Breathing	State
Mouth open, looking intently at you and the food, interested in eating = Ideal for feeding	Sitting still, upright with maximal trunk/head support in their seating system = Ideal for feeding.	Well rested, breathing normally with a clear sounding breath and a steady rate = Ideal for Feeding.	Calm and alert = Ideal for feeding.
Not opening mouth, distracted, neutral about eating = Not ideal, be enthusiastic, **WAIT** until they show interest.	Sitting still, upright with trunk/head support not in their seating system = Not ideal, **put in seating system.**	-Tired -Breathing sounds slightly wet or rattly -Breathing is fast or heavy = Not safe, **rest and re-evaluate.**	Not fully calm or fully alert = Not ideal, **WAIT** until alert.
Turning head away from food, resistant, uninterested in eating = Not safe or enjoyable, **STOP FEEDING.**	Laying down or reclined with minimal trunk/head support = Not safe, **STOP FEEDING.**	-Breathing sounds very wet, noisy, rattly -Breathing is fast or heavy = Not safe, **STOP FEEDING.**	Upset, tired, or resistant = Not safe or enjoyable, **STOP FEEDING.**

Note. Adapted with permission from an unpublished Starship Community resource.

14 Appendix G

Outpatient Videofluoroscopy (VFSS) Booking Process for Specialist School Students

Note: This flowchart is applicable for students aged 5-18



Specialist School SLT completes Clinical Feeding Evaluation (CFE) and feels VFSS may be beneficial for student. Specialist School SLT contacts Starship SLT to discuss referral rationale based on CFE.

If VFSS is deemed appropriate, Specialist School SLT to contact paediatrician to request VFSS. Paediatrician considers risks associated with VFSS (e.g., radiation exposure) and determines if VFSS if required.

If VFSS is not appropriate, Starship SLT can offer case advice if needed. Community DHB SLT input may be requested to provide support if required and covered by local level agreement.

Paediatrician sends VFSS radiology request to Starship Hospital Radiology Department.

Starship SLT reviews and triages alongside all other referrals. Starship SLT sends specialist school SLT the VFSS handover form to fill out with clinical info and instructions for VFSS.

Child is booked in for VFSS by radiology bookings team. Starship sends calendar invite to specialist school SLT to attend appointment.

Specialist school SLT to attend appointment with whānau to continue discussion of management plan post VFSS.

VFSS completed and report dictated and sent to all MDT including referring consultant (e.g., paediatrician). VFSS report contains a summary of VFSS and recommended dietary modifications or strategies.

Specialist school SLT to discuss results with whānau and create a management plan that is appropriate for the student's environment, in consultation with whānau, school team, and other health professionals (e.g., paediatriacian, dietician, etc.) if required.

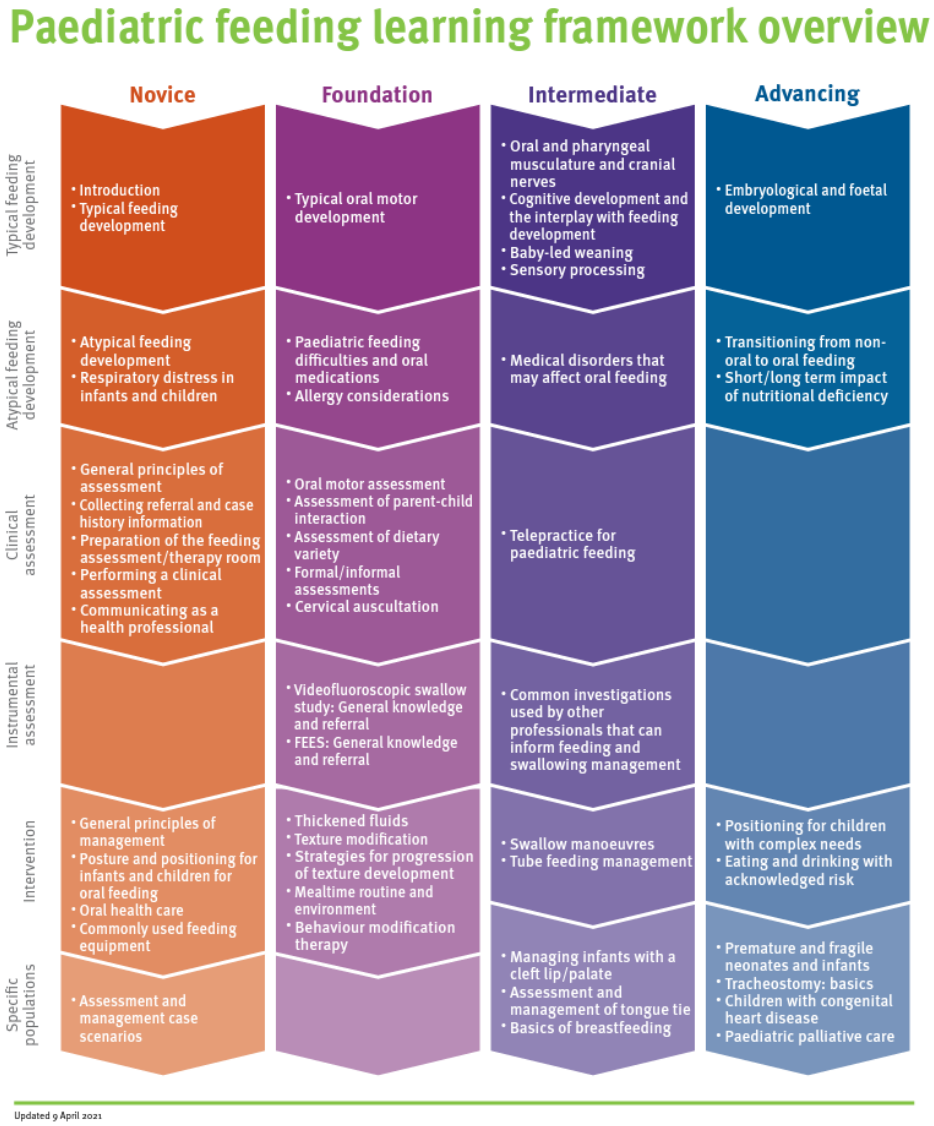
Specialist school SLTs to contact Starship SLTs if they require any advice and guidance.

15 Appendix H

Suggested Induction Framework for New Zealand specialist schools

Online PFD-related professional development resources for SLTs:

- GoodFellow EDS difficulties level one, accessed via: https://www.goodfellowunit.org/group/113
    - useful resource for new graduates or SLTs new to specialist schools.
- The University of Auckland Children's eating, drinking, and swallowing resource page, accessed via: https://flexiblelearning.auckland.ac.nz/speech-science-dysphagia-education-hub/2.html
- Queensland Health Paediatric feeding learning framework, accessed via: https://ilearn.health.qld.gov.au/d2l/login
    - Below is a visual structure of the different online trainings available through Queensland Health, some of which are free.



Paediatric feeding learning framework overview

	Novice	Foundation	Intermediate	Advancing
Typical feeding development	• Introduction • Typical feeding development	• Typical oral motor development	• Oral and pharyngeal musculature and cranial nerves • Cognitive development and the interplay with feeding development • Baby-led weaning • Sensory processing	• Embryological and foetal development
Atypical feeding development	• Atypical feeding development • Respiratory distress in infants and children	• Paediatric feeding difficulties and oral medications • Allergy considerations	• Medical disorders that may affect oral feeding	• Transitioning from non-oral to oral feeding • Short/long term impact of nutritional deficiency
Clinical assessment	• General principles of assessment • Collecting referral and case history information • Preparation of the feeding assessment/therapy room • Performing a clinical assessment • Communicating as a health professional	• Oral motor assessment • Assessment of parent-child interaction • Assessment of dietary variety • Formal/informal assessments • Cervical auscultation	• Telepractice for paediatric feeding	
Instrumental assessment		• Videofluoroscopic swallow study: General knowledge and referral • FEES: General knowledge and referral	• Common investigations used by other professionals that can inform feeding and swallowing management	
Intervention	• General principles of management • Posture and positioning for infants and children for oral feeding • Oral health care • Commonly used feeding equipment	• Thickened fluids • Texture modification • Strategies for progression of texture development • Mealtime routine and environment • Behaviour modification therapy	• Swallow manoeuvres • Tube feeding management	• Positioning for children with complex needs • Eating and drinking with acknowledged risk
Specific populations	• Assessment and management case scenarios		• Managing infants with a cleft lip/palate • Assessment and management of tongue tie • Basics of breastfeeding	• Premature and fragile neonates and infants • Tracheostomy: basics • Children with congenital heart disease • Paediatric palliative care

Updated 9 April 2021

- Paediatric Tube Feeding information for Speech Language Therapists: https://starship.org.nz/guidelines/paediatric-tube-feeding-information-for-speech-language-therapists/
    - Includes: strategies for oral desensitisation, facilitating first tastes, IDDSI, encouraging oral motor development, transitioning between IDDSI levels, equipment for oral sensory motor development, strategies to facilitate normal oral motor patterns, etc.
- Evaluation of Readiness for Transition from Tube Feeding to Oral Feeding document: https://media.starship.org.nz/evaluation-of-readiness/Evaluation_of_Readiness_Tool.pdf
- Strategies for Increasing Oral Nutritional Intake: https://media.starship.org.nz/strategies-for-increasing-oral-nutritional-intake/Strategies_for_increasing_oral_nutritional_intake.pdf
- Strategies to Optimise Feed Tolerance: https://media.starship.org.nz/food-tolerance-strategies/food_tolerance_strategies.pdf
- Videofluoroscopic evaluation of oropharyngeal swallowing function (VFS): The role of speech and language therapists RCSLT Position Paper 2013: https://rcslt.org/wp-content/uploads/media/Project/RCSLT/videofluoroscopic-position-paper.pdf
- Risk Feeding Guideline: https://flexiblelearning.auckland.ac.nz/speech-science-dysphagia-education-hub/6/files/riskfeedingguideline_post-endorsement.pdf
- To receive regular emails about PFD from NZ SLTs across the coutry, email nzpaeddysphagia@googlegroups.com and ask to be added to the group.

School-specific information for SLTs to discuss with their senior management team:

- When families enrolled their children in school, what permissions did families give for school staff to liaise with external professionals?
    - When do school staff have to inform families of liaison with external professionals?
    - When do school staff have to gather consent for liaison with external professionals?
- Does the school allow school therapists to work in the home setting?
    - Can school therapists complete home visits or do families need to come into school to receive input?
    - Can school therapists run training for families?
- What’s the LLA between the local health services and special school?

  - Does the LLA have any regular meetings?
  - Who is the local health-based community SLT?
- What professional supervision is available?
  - How regularly can school SLTs receive supervision?
  - Who can school SLTs approach if they require urgent supervision?
- Where do I access VFSS if needed?
  - Who is the contact person?
  - What is the referral process?

16 Bibliography

American Psychological Association. (2020). *Publication manual of the American Psychological Association: The official guide to APA style* (7th ed.). American Psychological Association.

American Speech-Language-Hearing Association. (2007). *Guidelines for speech-language pathologists providing swallowing and feeding services in schools*. American Speech-Language-Hearing Association. https://doi.org/0.1044/policy.GL2007-00276

Angell, M. E., Bailey, R. L., Nicholson, J. K., & Stoner, J. B. (2009). Family involvement in school-based dysphagia management. *Physical Disabilities: Education and Related Services*, *28*(1), 6-24.

Angell, M. E., Bailey, R. L., & Stoner, J. B. (2008). Family perceptions of facilitators and inhibitors of effective school-based dysphagia management. *Language, Speech, and Hearing Services in Schools*, *39*(2), 214-226. https://doi.org/10.1044/0161-1461(2008/021)

Arvedson, J. C. (2008). Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental Disabilities Research Reviews*, *14*(2), 118-127. https://doi.org/10.1002/ddrr.17

Ashford, J. R. (2023, Nov 1). *The three pillars of bacteria aspiration pneumonia*. SA Swallowing Services. https://www.sasspllc.com/three-pillars-of-pneumonia

Askren, A., & Leslie, P. (2019). Complexity of clinical decision making: Consent, capacity, and ethics. *Seminars in Speech and Language*, *40*(3), 162-169. https://doi.org/10.1055/s-0039-1688838

Bailey, R. L., & Lugg, E. T. (2009). Avoiding disputes in school-based management of students with dysphagia: Five key strategies. *Perspectives on Swallowing and Swallowing Disorders, 18*(3), 97-102. https://doi.org/10.1044/sasd18.3.97

Bailey, R. L., Stoner, J. B., Angell, M. E., & Fetzer, A. (2008). School-based speech-language pathologists' perspectives on dysphagia management in the schools. *Language, Speech, and Hearing Services in Schools, 39*(4), 441-450. https://doi.org/10.1044/0161-1461(2008/07-0041)

Baldwin, M. (2012). Participatory action research. In M. Gray, J. Midgley & S. A. Webb (Eds.), *The SAGE handbook of social work* (pp. 467-481). Sage. https://doi.org/10.4135/9781446247648

Ball, L., Meteyard, L., & Powell, R. J. (2023). Predictors of aspiration pneumonia: Developing a new matrix for speech and language therapists. *European Archives of Oto-Rhino-Laryngology, 280*, 5101-5114. https://doi.org/10.1007/s00405-023-08153-z

Benjasuwantep, B., Chaithirayanon, S., & Eiamudomkan, M. (2013). Feeding problems in healthy young children: Prevalence, related factors and feeding practices. *Pediatric Reports, 5*(2), Article 10. https://doi.org/10.4081/pr.2013.e10

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research, 26*(13), 1802-1811. https://doi.org/10.1177/1049732316654870

Bradbury, H. (2015). *The SAGE handbook of action research* (3rd ed.). Sage. https://doi.org/10.4135/9781473921290

Casey, M., O' Leary, D., & Coghlan, D. (2018). Unpacking action research and implementation science: Implications for nursing. *Journal of Advanced Nursing, 74*(5), 1051-1058. https://doi.org/10.1111/jan.13494

Chadwick, D. D. (2014). Balancing safety and enjoyment. Current practice when recommending tastes for people with intellectual disabilities who are non-orally fed. *Appetite, 81*, 152-161. https://doi.org/10.1016/j.appet.2014.06.016

Chambers, L. (2018). *A guide to the development of children's palliative care services* (4th ed.). Together for Short Lives. https://www.togetherforshortlives.org.uk/resource/a-guide-to-childrens-palliative-care/

Charpentier, A., Morgan, S., & Harding, C. (2020). A service evaluation of parent adherence with dysphagia management therapy guidelines: Reports from family carers supporting children with complex needs in Greece. *Disability and Rehabilitation, 42*(3), 426-433. https://doi.org/10.1080/09638288.2018.1499048

Clinical Network for Paediatric Tube Feeding. (2019, June 24). *Evaluation of readiness for transition from tube feeding to oral feeding.* Starship. https://starship.org.nz/guidelines/evaluation-of-readiness-for-transition-from-tube-feeding-to-oral-feeding/

The Code of Health and Disability Services Consumers' Rights Regulations 1996, (N.Z.). https://www.legislation.govt.nz/regulation/public/1996/0078/latest/DLM209080.html

Convention on the Rights of the Child, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child

Convention on the Rights of Persons With Disabilities, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008) https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

Cook, B. G., & Odom, S. L. (2013). Evidence-based practices and implementation science in special education. *Exceptional Children*, *79*(2), 135-144. https://doi.org/10.1177/001440291307900201

Cook, C. R., Lyon, A. R., Locke, J., Waltz, T., & Powell, B. J. (2019). Adapting a compilation of implementation strategies to advance school-based implementation research and practice. *Prevention Science, 20*, 914-935. https://doi.org/10.1007/s11121-019-01017-1

Cope, D. G. (2014). Methods and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum*, *41*(1), 89-91. https://doi.org/10.1188/14.ONF.89-91

Crary, M. A., & Groher, M. E. (2020). *Dysphagia: Clinical management in adults and children* (3rd ed.). Mosby. https://doi.org/10.1016/C2017-0-00992-8

Creswell, J. W., & Plano Clark, V. L. (2018). *Designing and conducting mixed methods research* (3rd ed.). Sage.

Curran, G. M., Bauer, M., Mittman, B., Pyne, J. M., & Stetler, C. (2012). Effectiveness-implementation hybrid designs: Combining elements of clinical effectiveness and implementation research to enhance public health impact. *Medical Care*, *50*(3), 217-226. https://doi.org/10.1097/MLR.0b013e3182408812

D'Angelo, E. C. (2018). Dysphagia and feeding for speech-language pathologists in the schools: A team approach. *Perspectives of the ASHA Special Interest Groups, 3*(16), 27-37. https://doi.org/10.1044/persp3.SIG16.27

Davis-McFarland, E. (2008). Family and cultural issues in a school swallowing and feeding program. *Language, Speech, and Hearing Services in Schools, 39*(2), 199-213. https://doi.org/10.1044/0161-1461(2008/020)

Delaney, L. J. (2018). Patient-centred care as an approach to improving health care in Australia. *Collegian: The Australian Journal of Nursing Practice, Scholarship, and Research, 25*(1), 119-123. https://doi.org/10.1016/j.colegn.2017.02.005

Special Educational Needs and Disability Code of Practice: 0 to 25 years 2015, (U.K.). https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

Dharmarathna, I., Miles, A., & Allen, J. (2021). Predicting penetration–aspiration through quantitative swallow measures of children: A videofluoroscopic study. *European Archives of Oto-Rhino-Laryngology, 278*, 1907-1916. https://doi.org/10.1007/s00405-021-06629-4

Dodrill, P., & Gosa, M. M. (2015). Pediatric dysphagia: Physiology, assessment, and management. *Annals of Nutrition and Metabolism, 66*(5), 24-31. https://doi.org/10.1159/000381372

Doell, E., & Clendon, S. (2018). Upholding the human right of children in New Zealand experiencing communication difficulties to voice their needs and dreams. *International*

Journal of Speech-Language Pathology, 20(1), 152-156. https://doi.org/10.1080/17549507.2018.1392611

Douglas, N. F., Campbell, W. N., & Hinckley, J. J. (2015). Implementation science: Buzzword or game changer? *Journal of Speech, Language, and Hearing Research, 58*(6), S1827-S1836. https://doi.org/10.1044/2015_JSLHR-L-15-0302

Dumont, E., Jansen, A., Duker, P. C., Seys, D. M., Broers, N. J., & Mulkens, S. (2022). Feeding/eating problems in children who refrained from treatment in the past: Who did (not) recover? *Frontiers in Pediatrics, 10*, Article 860785. https://doi.org/10.3389/fped.2022.860785

Durie, M. H. (1985). A Māori perspective of health. *Social Science and Medicine, 20*(5), 483-486. https://doi.org/10.1016/0277-9536(85)90363-6

Education Counts. (2023, Oct). *School rolls.* https://www.educationcounts.govt.nz/statistics/school-rolls

Feint, G., Aghajanzadeh-Langeroudi, H., & Smith, C. (2022, Feb 3-4). *Delphi study for clinical consensus of a care bundle for children who are eating and drinking with acknowledged risk.* [Poster presentation] UK Swallow Research Conference, online.

Feint, G., & Langeroudi, H. (2021, March 21). *Paediatric risk feeding: The current climate.* [Paper presentation] London Paediatric Dysphagia CEN, London, England. https://pdcen.org/wp-content/uploads/2021/07/PDCEN-risk-feeding-study-day-presentation-March-2021.pdf

Felicetti, C., Richardson, K., & Mansolillo, A. (2020). Dysphagia management in schools: A survey of speech-language pathologists. *Perspectives of the ASHA Special Interest Groups, 5*(2), 527-546. https://doi.org/10.1044/2020_PERSP-19-00091

Forsgren, E., Åke, S., & Saldert, C. (2022). Person-centred care in speech-language therapy research and practice for adults: A scoping review. *International Journal of Language and Communication Disorders, 57*(2), 381-402. https://doi.org/10.1111/1460-6984.12690

Gillam, L. (2016). The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics, 11*(1), 1-8. https://doi.org/10.1177/1477750915622033

Goday, P. S., Huh, S. Y., Silverman, A., Lukens, C. T., Dodrill, P., Cohen, S. S., Delaney, A. L., Feuling, M. B., Noel, R. J., Gisel, E., Kenzer, A., Kessler, D. B., Kraus de Camargo, O., Browne, J., & Phalen, J. A. (2019). Pediatric feeding disorder: Consensus definition and conceptual framework. *Journal of Pediatric Gastroenterology and Nutrition, 68*(1), 124-129. https://doi.org/10.1097/MPG.0000000000002188

Gosa, M. M., Carden, H. T., Jacks, C. C., Threadgill, A. Y., & Sidlovsky, T. C. (2017). Evidence to support treatment options for children with swallowing and feeding disorders: A systematic review. *Journal of Pediatric Rehabilitation Medicine, 10*(2), 107-136. https://doi.org/10.3233/PRM-170436

Hagermoser Sanetti, L. M., & Collier-Meek, M. A. (2019). Increasing implementation science literacy to address the research-to-practice gap in school psychology. *Journal of School Psychology, 76*, 33-47. https://doi.org/10.1016/j.jsp.2019.07.008

Hall, A., & Manins, M. (2001a). In loco parentis and the professional responsibilities of teachers. *Waikato Journal of Education, 7*, 117-128. https://doi.org/10.15663/wje.v7i1.436

Hall, A., & Manins, M. (2001b). Some limitations of in loco parentis. *Teachers and Curriculum, 5*, 79-84.

Haynes, W. O., & Johnson, C. E. (2009). *Understanding research and evidence-based practice in communication disorders: A primer for students and practitioners* (1st ed.). Pearson.

Health and Safety at Work Act 2015, (N.Z.). https://www.legislation.govt.nz/act/public/2015/0070/latest/DLM5976660.html

Hollaar, V., van der Maarel-Wierink, C., van der Putten, G.-J., van der Sanden, W., de Swart, B., & de Baat, C. (2016). Defining characteristics and risk indicators for diagnosing nursing home-acquired pneumonia and aspiration pneumonia in nursing home residents, using the electronically-modified Delphi method. *BMC Geriatrics, 16*, Article 60. https://doi.org/10.1186/s12877-016-0231-4

Homer, E. M. (2008). Establishing a public-school dysphagia program: A model for administration and service provision. *Language, Speech, and Hearing Services in Schools, 39*(2), 177-191. https://doi.org/10.1044/0161-1461(2008/018)

Homer, E. M. (2016). *Management of swallowing and feeding disorders in schools* (1st ed.). Plural Publishing.

Homer, E. M., & Carbajal, P. (2015). Swallowing and feeding services in the schools: From therapy to the dinner table. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia), 24*(4), 155-161. https://doi.org/10.1044/sasd24.4.155

Hudson, N., Spriggs, M., & Gillam, L. (2019). Telling the truth to young children: Ethical reasons for information disclosure in paediatrics. *Journal of Paediatrics and Child Health*, *55*(1), 13-17. https://doi.org/10.1111/jpc.14209

Huffman, N. P., & Owre, D. W. (2008). Ethical issues in providing services in schools to children with swallowing and feeding disorders. *Language, Speech, and Hearing Services in Schools, 39*(2), 167-176. https://doi.org/10.1044/0161-1461(2008/017)

Hutchins, T. L., Gerety, K. W., & Mulligan, M. (2011). Dysphagia management: A survey of school-based speech-language pathologists in Vermont. *Language, Speech, and Hearing Services in Schools, 42*(2), 194-206. https://doi.org/10.1044/0161-1461(2011/10-0057)

Individuals with Disabilities Education Act, 20 U.S.C § 1400 (2004). http://uscode.house.gov/view.xhtml?path=/prelim@title20/chapter33&edition=prelim

Imdad, A., Wang, A. G., Adlakha, V., Crespo, N. M., Merrow, J., Smith, A., Tsistinas, O., Tanner-Smith, E., & Rosen, R. (2023). Laryngeal penetration and risk of aspiration pneumonia in children with dysphagia: A systematic review. *Journal of Clinical Medicine, 12*(12), Article 4087. https://doi.org/10.3390/jcm12124087

Ingham-Broomfield, R. (2016). A nurses' guide to the hierarchy of research designs and evidence. *The Australian Journal of Advanced Nursing, 33*(3), 38-43.

Jackson, B. N., Helier, T., Exley, K., Hampton Edwards, B., Johnston, S., Keesing, M., Lyons, J., Musgrave, J., O'Hare, M., Olah, Z., & Setchell, C. (2019). *New Zealand* *speech-language therapy therapy clinical practice guideline on children's feeding and swallowing difficulties (paediatric dysphagia)*. New Zealand Speech-Language Therapists' Association.

Jackson, B., Wong, C., & Miles, A. (2022). Health professionals' perceptions of complex feeding decision-making in school-aged children. *Journal of Paediatrics and Child Health*, *58*(5), 791-795. https://doi.org/10.1111/jpc.15834

Jones, E., Southwood, H., Cook, C., & Nicholson, T. (2020). Insights into paediatric tube feeding dependence: A speech-language pathology perspective. *International Journal of Speech-Language Pathology, 22*(3), 327-337. https://doi.org/10.1080/17549507.2020.1754910

Kaizer, F., Spiridigliozzi, A.-M., & Hunt, M. R. (2012). Promoting shared decision-making in rehabilitation: Development of a framework for situations when patients with dysphagia refuse diet modification recommended by the treating team. *Dysphagia, 27*, 81-87. https://doi.org/10.1007/s00455-011-9341-5

Kelly, K., Cumming, S., Kenny, B., Smith-Merry, J., & Bogaardt, H. (2018). Getting comfortable with "comfort feeding": An exploration of legal and ethical aspects of the Australian speech-language pathologist's role in palliative dysphagia care. *International Journal of Speech-Language Pathology, 20*(3), 371-379. https://doi.org/10.1080/17549507.2018.1448895

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice, 24*(1), 120-124. https://doi.org/10.1080/13814788.2017.1375092

Langmore, S. E., Skarupski, K. A., Park, P. S., & Fries, B. E. (2002). Predictors of aspiration pneumonia in nursing home residents. *Dysphagia*, *17*(4), 298-307. https://doi.org/10.1007/s00455-002-0072-5

Langmore, S. E., Terpenning, M. S., Schork, A., Chen, Y., Murray, J. T., Lopatin, D., & Loesche, W. J. (1998). Predictors of aspiration pneumonia: How important is dysphagia? *Dysphagia*, *13*(2), 69-81. https://doi.org/10.1007/PL00009559

Lanspa, M. J., Peyrani, P., Wiemken, T., Wilson, E. L., Ramirez, J. A., & Dean, N. C. (2015). Characteristics associated with clinician diagnosis of aspiration pneumonia: A descriptive study of afflicted patients and their outcomes. *Journal of Hospital Medicine*, *10*(2), 90-96. https://doi.org/10.1002/jhm.2280

Larcher, V., & Hutchinson, A. (2010). How should paediatricians assess Gillick Competence? *Archives of Disease in Childhood*, *95*(4), 307-311. https://doi.org/10.1136/adc.2008.148676

Lefton-Greif, M. A., & Arvedson, J. C. (2008). School children with dysphagia associated with medically complex conditions. *Language, Speech, and Hearing Services in Schools*, *39*(2), 237-248. https://doi.org/10.1044/0161-1461(2008/023)

Lefton-Greif, M. A., & Arvedson, J. C. (2007). Pediatric feeding and swallowing disorders: State of health, population trends, and application of the International Classification of Functioning, Disability, and Health. *Seminars in Speech and Language*, *28*(3), 161-165. https://doi.org/10.1055/s-2007-984722

Lindberg, L., Bohlin, G., & Hagekull, B. (1991). Early feeding problems in a normal population. *The International Journal of Eating Disorders*, *10*(4), 395-405.

https://doi.org/10.1002/1098-108X(199107)10:4<395::AID-EAT2260100404>3.0.CO;2-A

Mabry-Price, L. R. (2015). Treating dysphagia in schools: Making it easy to swallow. *The ASHA Leader, 20*(2), 36-37. https://doi.org/10.1044/leader.SCM.20022015.36

Mandak, K., & Light, J. (2018). Family-centered services for children with ASD and limited speech: The experiences of parents and speech-language pathologists. *Journal of Autism and Developmental Disorders., 48*(4), 1311-1324. https://doi.org/10.1007/s10803-017-3241-y

McCarthy, E., & Guerin, S. (2022). Family-centred care in early intervention: A systematic review of the processes and outcomes of family-centred care and impacting factors. *Child: Care, Health, and Development, 48*(1), 1-32. https://doi.org/10.1111/cch.12901

McNiff, J., & Whitehead, J. (2011). *All you need to know about action research* (2nd ed.). Sage.

Melnyk, B. M., & Fineout-Overholt, E. (2023). *Evidence-based practice in nursing and healthcare: A guide to best practice* (5th ed.). Wolters Kluwer.

Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science, 6,* Article 42. https://doi.org/10.1186/1748-5908-6-42

Miles, A., Wong, C., & Jackson, B. (2021). Barriers and facilitators to implementation of a guideline for school-aged children with feeding difficulties. *Journal of Intellectual and Developmental Disability, 46*(3), 217-226. https://doi.org/10.3109/13668250.2021.1877645

Miles, M. B., Huberman, A. M., & Saldana, J. (2018). *Qualitative data analysis: A methods sourcebook* (4th ed.). Sage.

Miller, A. L., Miller, C. K., Fei, L., Sun, Q., Willging, J. P., de Alarcon, A., & Pentiuk, S. P. (2024). Predictive value of laryngeal penetration to aspiration in a cohort of pediatric patients. *Dysphagia*, *39*, 33-42. https://doi.org/10.1007/s00455-023-10589-8

Miller, C. K. (2009). Optimizing collaboration between medical and school-based speech-language pathologists managing pediatric dysphagia. *Perspectives on Swallowing and Swallowing Disorders, 18*(3), 91-96. https://doi.org/10.1044/sasd18.3.91

Ministry of Education. (2024, Feb 09). *Specialist schools.* https://www.education.govt.nz/school/student-support/special-education/specialist-schools-for-students-with-high-needs/

Ministry of Education. (2023a, Dec 17). *Ministry funding deciles.* https://parents.education.govt.nz/secondary-school/secondary-schooling-in-nz/deciles/#:~:text=Decile%20ratings%20are%20based%20on,5%20years%2C%20after%20each%20Census.

Ministry of Education. (2023b, April 28). *The New Zealand curriculum.* Te Kete Ipurangi. https://nzcurriculum.tki.org.nz/The-New-Zealand-Curriculum#collapsible7

Ministry of Education. (2023c, Nov 01). *Resources for students in Ongoing Resourcing Scheme (ORS).* https://www.education.govt.nz/school/student-support/special-education/ors/resources-for-students-in-ors/

Ministry of Education. (2011). *Welcome to the ongoing resource scheme (ORS).* https://parents.education.govt.nz/assets/Documents/Special-Education/Welcome-To-The-ORS.pdf

Ministry of Education. (n.d.). *Informed consent guidelines.* https://parents.education.govt.nz/assets/Documents/Special-Education/Informed-Consent-Guidelines.pdf

Mitchie, S., Atkins, S., & West, R. (2014). *The behaviour change wheel: A guide to designing interventions* (1st ed.). Silverback Publishing.

Mitchie, S., Richardson, M., Johnston, M., Abraham, C., Francis, J., Hardeman, W., Eccles, M. P., Cane, J., & Wood, C. E. (2013). The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus for the reporting of behavior change interventions. *Annals of Behavioral Medicine, 46*(1), 81-95. https://doi.org/10.1007/s12160-013-9486-6

Murray, A., Mulkerrin, S., & O'Keeffe, S. T. (2019). The perils of 'risk feeding'. *Age and Ageing., 48*(4), 478-481. https://doi.org/10.1093/ageing/afz027

Neubauer, N. P., & Singleton, N. C. (2023). What plays a role in perceived confidence for managing pediatric feeding disorders in the public school. *Language, Speech, and Hearing Services in Schools*, *54*(3), 856-872. https://doi.org/10.1044/2023_LSHSS-22-00074

New Zealand Speech-Language Therapists' Association. (2020). *NZSTA principles and rules of ethics*. New Zealand Speech-Language Therapists' Association.

https://speechtherapy.org.nz/assets/Uploads/NZSTA-Principles-Rules-of-Ethics-Dec-2020.pdf

Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation Science*, *10*, Article 53. https://doi.org/10.1186/s13012-015-0242-0

Norwood Jr, K. W., Slayton, R. L., Council on Children With Disabilities, & Section on Oral Health. (2013). Oral health care for children with developmental disabilities. *Pediatrics*, *131*(3), 614-619. https://doi.org/10.1542/peds.2012-3650

O'Donoghue, C. R., & Nottingham, E. E. (2017). Dysphagia management in the schools: Past, present, and future. *Seminars in Speech and Language*, *38*(2), 126-134. https://doi.org/10.1055/s-0037-1599110

O'Donoghue, C. R., & Dean-Claytor, A. (2008). Training and self-reported confidence for dysphagia management among speech-language pathologists in the schools. *Language, Speech, and Hearing Services in Schools*, *39*(2), 192-198. https://doi.org/10.1044/0161-1461(2008/019)

O'Keeffe, S. T., Leslie, P., Lazenby-Paterson, T., McCurtin, A., Collins, L., Murray, A., Smith, A., & Mulkerrin, S. (2023). Informed or misinformed consent and use of modified texture diets in dysphagia. *BMC Medical Ethics*, *24*, Article 7. https://doi.org/10.1186/s12910-023-00885-1

Olswang, L. B., & Prelock, P. A. (2015). Bridging the gap between research and practice: Implementation science. *Journal of Speech, Language, and Hearing Research*, *58*(6), S1818-S1826. https://doi.org/10.1044/2015_JSLHR-L-14-0305

Ortega, O., Sakwinska, O., Combremont, S., Berger, B., Sauser, J., Parra, C., Zarcero, S., Nart, J., Carrión, S., & Clavé, P. (2015). High prevalence of colonization of oral cavity by respiratory pathogens in frail older patients with oropharyngeal dysphagia. *Neurogastroenterology and Motility, 27*(12), 1804-1816. https://doi.org/10.1111/nmo.12690

Owre, D. W. (2006). Dysphagia management in schools: Survey results – issues and barriers. *Perspectives on Swallowing and Swallowing Disorders, 15*(3), 27-28. https://doi.org/10.1044/sasd15.3.27

Pados, B. F., Hill, R. R., Yamasaki, J. T., Litt, J. S., & Lee, C. S. (2021). Prevalence of problematic feeding in young children born prematurely: A meta-analysis. *BMC Pediatrics, 21*, Article 110. https://doi.org/10.1186/s12887-021-02574-7

Pizzorni, N., Schindler, A., Castellari, M., Fantini, M., Crosetti, E., & Succo, G. (2019). Swallowing safety and efficiency after open partial horizontal laryngectomy: A videofluoroscopic study. *Cancers, 11*(4), Article 549. https://doi.org/10.3390/cancers11040549

Power-deFur, L. (2009). Dysphagia services in schools: Applying special education requirements to a health service. *Perspectives on Swallowing and Swallowing Disorders, 18*(3), 86-90. https://doi.org/10.1044/sasd18.3.86

Power-deFur, L. A. (2023). Legal issues and opportunities associated with serving children with pediatric feeding disorders in schools. *Language, Speech, and Hearing Services in Schools*, Advance online publication. https://doi.org/10.1044/2023_LSHSS-23-00018

Radford, C., Marshall, J., Herbert, A., Irving, H., & Weir, K. (2020). Risk feeding: An Australian pediatric palliative care perspective. *Perspectives of the ASHA Special Interest Groups, 5*(2), 515-521. https://doi.org/10.1044/2020_PERSP-19-00032

Rosenbek, J. C., Robbins, J. A., Roecker, E. B., Coyle, J. L., & Wood, J. (1996). A penetration-aspiration scale. *Dysphagia, 11*, 93-98. https://doi.org/10.1007/BF00417897

Royal College of Paediatrics and Child Health. (2021). *Models of care: The future.* Paediatrics 2040: Forecasting the future. https://paediatrics2040.rcpch.ac.uk/our-evidence/models-of-care/future/#page-section-15

Royal College of Speech and Language Therapists. (2021). Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process (adults), 1-23. https://www.rcslt.org/wp-content/uploads/2021/09/EDAR-multidisciplinary-guidance-2021.pdf

Saldaña, J. (2021). *The coding manual for qualitative researchers* (4th ed.). Sage.

School Dysphagia Policy. (2020).

Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., & Pascoe, E. (2012a). Family-centred care for hospitalised children aged 0-12 years. *Cochrane Database of Systematic Reviews, 10*, Article CD004811. https://doi.org/10.1002/14651858.CD004811.pub3

Shields, L., Zhou, H., Taylor, M., Hunter, J., Munns, A., & Watts, R. (2012b). Family-centred care for hospitalised children aged 0-12 years: A systematic review of quasi-experimental studies. *JBI Database of Systematic Reviews, 10*(39), 2559-2592. https://doi.org/10.11124/jbisrir-2012-32

Silverman, A. H., Erato, G., & Goday, P. (2021). The relationship between chronic paediatric feeding disorders and caregiver stress. *Journal of Child Health Care, 25*(1), 69-80. https://doi.org/10.1177/1367493520905381

Simione, M., Dartley, A. N., Cooper-Vince, C., Martin, V., Hartnick, C., Taveras, E. M., & Fiechtner, L. (2020). Family-centered outcomes that matter most to parents: A pediatric feeding disorders qualitative study. *Journal of Pediatric Gastroenterology and Nutrition., 71*(2), 270-275. https://doi.org/10.1097/MPG.0000000000002741

Simione, M., Harshman, S., Cooper-Vince, C. E., Daigle, K., Sorbo, J., Kuhlthau, K., & Fiechtner, L. (2023). Examining health conditions, impairments, and quality of life for pediatric feeding disorders. *Dysphagia*, *38*, 220-226. https://doi.org/10.1007/s00455-022-10455-z

Skegg, P., & Paterson, R. (2015). *Health law in New Zealand* (1st ed.). Thomson Reuters New Zealand.

Soar, N., Birns, J., Sommerville, P., Lang, A., & Archer, S. (2021). Approaches to eating and drinking with acknowledged risk: A systematic review. *Dysphagia*, *36*, 54-66. https://doi.org/10.1007/s00455-020-10107-0

Somerville, M. M. (2014). Participatory action research: Improving professional practices and local situations. *Sage research methods cases part 1* (pp. 1-15). Sage. https://doi.org/10.4135/978144627305014534165

Sullivan, P. B., Lambert, B., Rose, M., Ford-Adams, M., Johnson, A., & Griffiths, P. (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford feeding study. *Developmental Medicine and Child Neurology, 42*(10), 674-680. https://doi.org/10.1111/j.1469-8749.2000.tb00678.x

Taylor, C., Kong, A. C., Foster, J., Badawi, N., & Novak, I. (2021). Caregivers’ feeding experiences and support of their child with cerebral palsy. *Journal of Child and Family Studies, 31*, 819-830. https://doi.org/10.1007/s10826-021-02123-x

Te Whatu Ora. (n.d). *Informed consent.* https://www.waitematadhb.govt.nz/patients-visitors/your-safety-in-hospital/informed-consent/

Udall, J. N. (2007). Infant feeding: Initiation, problems, approaches. *Current Problems in Pediatric and Adolescent Health Care, 37*(10), 374-399. https://doi.org/10.1016/j.cppeds.2007.09.001

The University of Auckland, & Hutt Valley District Health Board. (2016). *Risk feeding guideline.*

Wallis, C., & Ryan, M. (2012). Assessing the role of aspiration in pediatric lung disease. *Pediatric Allergy, Immunology, and Pulmonology, 25*(3), 132-142. https://doi.org/10.1089/ped.2012.0148

Whitehead, A., Torresi, K., Johnson, T., Dutton, B., Earle, D., Harrison, C., Jinks, A., Krikheli, L., Nund, R., Pearse, W., Radford, C., Smart, S., & Thermos, S. (2019). *The role of the speech pathologist in supporting informed choice and shared decision making in dysphagia: Working with 'risk feeding'*. Speech Pathology Australia.