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Ethical and legal considerations when supporting children engaging in eating and drinking with acknowledged risk in New Zealand

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Abstract

Purpose: Children and families choose eating and drinking with acknowledged risk, often while receiving support from professionals, such as paediatricians and speech-language pathologists. These decisions may fall inside the *zone of parental discretion*, where decisions are deemed to be ‘good enough’ for a child and may not prioritise physical health but would not cause significant harm. Often a contentious space, health professionals may feel uncertain of their ethical or legal obligations when supporting these families and children. Further complicated when children attend education and are fed by school staff, school-based speech-language pathologists may feel unsure how to support these children and families. Much of the literature surrounding paediatric feeding disorders comes from the US; however, these studies do not consider the legal context of New Zealand.

Result: This article attempts to outline laws, legal principles, and ethical principles applicable to this topic, in the hopes of highlighting health professionals’ obligations and options when supporting these families.

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Keywords: *eating and drinking with acknowledged risk (EDAR); shared decision-making; zone of parental discretion; paediatric feeding disorder (PFD); ethics*

Introduction

Paediatric feeding disorder (PFD) is common with studies suggesting that 20-50% of typically developing children and 80% of children with disabilities will experience PFD-related difficulties in their lifetime (Benjasuwantep et al., 2013; Lindberg et al., 1991; Pados et al., 2021; Sullivan et al., 2000; Udall, 2007). For those with complex needs, often with dysphagia and swallow safety concerns, their journey often starts in a hospital setting, with a wide range of health professionals supporting families to make informed decisions about their child’s PFD. These decisions include enteral tube placement, dietary modifications, and whether to eat and drink orally. Much of the literature informing PFD practice comes from hospital-based multidisciplinary teams with access to resources and expertise (Homer, 2016; Huffman & Owre, 2008; Lefton-Greif & Arvedson, 2007). As medical interventions have improved over the decades, an increasing number of children with complex medical conditions survive. Health professionals have also seen a shift in healthcare delivery models from institutionalised care and hospital-based inpatient stays to community-based care. Subsequently, in New Zealand, many children with chronic PFD, including dysphagia and swallow safety concerns, receive ongoing support from community speech-language pathologists (SLPs) employed by the Ministry of Education, early intervention providers, or specialist schools (Jackson et al., 2019). While families are often the primary providers of food and drink to these children in the early years, they soon spend time in early childhood centres and schools where paid staff support the child’s feeding. Families find themselves needing to make decisions that balance health, practicality, the child’s preferences, and health and safety requirements (D’Angelo, 2018; Huffman & Owre, 2008; Nottingham & O’Donoghue, 2017; O’Donoghue & Dean-Claytor, 2008).

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Not surprisingly, feeding decisions can be ethically and medically complex given the cultural, emotional, and social significance of eating and drinking, the number of professionals involved, and health professionals' understanding of the national law and the health professional's ethics. In this narrative review, we discuss how ethics, legal principles, and New Zealand laws impact how community SLPs support families and children with PFD. Specifically, we refer to children with dysphagia and swallow safety concerns. With a focus on community SLPs working in schools, we propose a need for team-based, ethical decisions with fully informed and engaged families and offer a list of recommendations to paediatric SLPs to support respectful best practices.

Defining risk while considering adverse health outcomes

In the adult literature, eating and drinking with acknowledged risk (EDAR), previously called risk feeding or comfort feeding, encompasses situations where a person or their caregiver decides not to modify food or drink or to continue oral intake rather than enteral tube feeding despite a health professional's assessment that eating and drinking may increase the risk of aspiration, dehydration, and/or malnutrition (Royal College of Speech Language Therapists, 2021; Soar et al., 2021; Speech Pathology Australia [SPA], 2019; The University of Auckland & Hutt Valley District Health Board, 2016). This is typically seen in palliative care settings or in people with chronic or progressive diseases. In children with complex needs and chronic PFD (specifically dysphagia), one could argue for a broader definition with the majority of children with complex needs who eat and drink orally, likely doing so with some degree of risk.

The term 'risk' in EDAR has been controversial, as risk has negative connotations and inappropriately implies that the removal 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. It should be noted that risk is poorly defined and quantified in dysphagia and particularly 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; Miller, A. et al., 2024). A risk is often determined by the observation (only possible with instrumental assessment) that food or drinks enter 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; Miller, A. et al., 2024; Rosenbek et al., 1996).

The risk of aspiration stems from the adverse health outcomes it can result in including aspiration pneumonia, cobblestoning of the trachea, and bronchiectasis (Imdad et al., 2023; Wallis & Ryan, 2012). Aspiration pneumonia is a respiratory infection commonly thought to result from recurrent aspiration, though there is contention about how significant a role aspiration alone plays (Langmore et al., 1998). It is well-established that aspiration pneumonia can be fatal; however, some children who aspirate regularly experience no pathological changes or observed effects from the aspiration (Imdad et al., 2023; Miller, A. et al., 2024; Murray et al., 2019; Wallis & Ryan, 2012). Health outcomes associated with aspiration are multifactorial and are thought to be impacted by a multitude of factors including:

- Swallow function indicated by videofluoroscopic objective measures (e.g. laryngeal penetration, 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 versus 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).

Reducing risk of respiratory complications is not as simple as removing oral intake. Enterally-fed children and adults continue to develop respiratory infections. This is thought to be caused by aspiration of bacteria in saliva or reflux (Murray et al., 2019; Wallis & Ryan, 2012). Oral health is challenging for people who are not eating and drinking, and volume reflux is a common challenge with enteral tube feeding. Therefore, elimination of oral diet may eliminate the risk of aspiration of oral food and drink but does not necessarily eliminate the risk of adverse respiratory health outcomes.

Additionally, the elimination of an oral diet reduces the child's ability to develop their swallowing skills, as outlined in the principle of 'exercise specificity'. A well-founded concept in motor learning, this principle suggests that the nervous system best learns a skill by practicing that exact skill (Clark, 2003; Langmore & Pisegna, 2015; van den Engel-Hoek et al., 2017). While children can complete exercises to stimulate the swallowing mechanisms, this does not have the same impact as swallowing foods or fluids. Subsequently, complete elimination of an oral diet can prevent the swallow skill from maturing, further perpetuating the risk associated with eating and drinking orally.

Internationally, health professionals experience a range of difficulties when supporting families and children engaging in EDAR (Feint & Langeroudi, 2021; Jackson et al., 2022). SLPs struggle to identify risk, which is unsurprising as it is poorly defined and quantified in PFD (Imdad et al., 2023; Miller et al., 2024; Murray et al., 2019; Wallis & Ryan, 2012). Some suggest 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 repeated 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). These concepts can be difficult to distinguish between and require expertise from the multidisciplinary team and child's carers to provide a holistic understanding of the child.

Muddy waters: the concoction of ethics, law, and PFD decisions

In New Zealand, as in many countries, all health professionals must abide by their own Code of Ethics. The New Zealand Speech-language Therapists' Association (NZSTA) Principles and Code of Ethics (NZSTA, 2020) stipulates several principles relevant to working with PFD (Table I).

These ethical principles quickly become familiar to professionals, such as SLPs working with PFD, as recommending the 'right' feeding plan for a child is complex. SLPs frequently support families and children to make decisions about oral versus enteral tube feeding, or texture-modified diet versus shared family meals. Families may agree or disagree with professional recommendations, a legally protected right of health and disability consumers in New Zealand (New Zealand Government, 1996).

At times, SLPs may feel that the family's decisions impact their own ability to adhere to their professional, ethical principles, such as non-maleficence, where SLPs seek to prevent harm and beneficence, where an SLP's professional actions should benefit others (Huffman & Owre, 2008; NZSTA, 2020). Radford et al. (2020) discussed that to align with the ethical principles of beneficence and non-maleficence, SLPs should not support oral feeding if doing so would cause harm to the child yet should not prevent oral feeding if children or families receive benefit, quality, or comfort from it. Additionally, SLPs should not discharge families who choose to pursue EDAR, as when doing so, they are left without support to minimise any risks or potential harm. Subsequently, it is not uncommon for SLPs to question how they can continue supporting families ethically when the family makes a decision that the SLP considers 'risky' and contrary to their own often more cautious recommendations.

Taking a holistic view of health

Of note, healthcare providers are sometimes criticised for narrowly viewing a person's health as synonymous with physical health, often described as viewing someone through a medical model. This has the tendency to overlook how culture, preferences, and beliefs affect a person's 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 II.

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

Table I. Ethical principles in the NZSTA code of ethics in relation to PFD.

Principle	Example of principles in an area of PFD management
Beneficence and non-maleficence	SLPs 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	Paediatric-based SLPs will recognise the extent of their PFD knowledge and skills, seeking support from appropriate sources when required.
Promotion and development of the profession	SLPs will run training for teams to explain various aspects of PFD, enabling teams to understand the SLP's role in supporting PFD and how the PFD affects the child and family.
Professional integrity	If families and children make informed decisions to not follow SLP's feeding recommendations, SLPs will treat a client/family with respect, upholding the family's/child's dignity when discussing their case with other professionals.
Fairness	SLPs will allocate more resources to support families/children with complex PFD 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.

Note. NZSTA = New Zealand Speech-language Therapists' Association; PFD = paediatric feeding disorder; SLP = speech-language pathologist.

Table II. 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
Psychological 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	PFD 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

Note. PFD = paediatric feeding disorder

in a medical model may recommend options that prioritise physical health over other areas. Contrastingly, families whose children have lived with chronic PFD for most of their lives may choose to focus on other areas of health, such as psychological or spiritual. Their differing priorities are likely due to the heightened stress and anxiety experienced when a child requires enteral feeding, alongside a loss of identity as a mother and connection to their child, a well-documented phenomenon in the literature (Wilken, 2012). To clinicians, these choices may appear to carry unnecessary risks for the child but are considered appropriate and even essential risks to fulfil family or child goals, who sometimes have differing priorities than those of health professionals. Supporting these families may also increase clinician stress, who are encouraged to use Te Whare Tapa Whā to manage their own wellbeing. It is not within the scope of this article, or its authors, to provide a thorough discussion of the Māori health model and its applicability to complex PFD decisions, but we encourage health professionals to seek additional resources for a more in-depth discussion.

Zone of parental discretion

As health professionals shift towards a more holistic view of health, more space has been created for families to disagree with and decline to follow professional recommendations, frequently focused heavily on physical health. Askren and Leslie (2019) highlighted that children or families who decide to prioritise psychological, spiritual, or family health over physical health 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. Additionally, these terms align with the best interests test where decisions are made to safeguard the child's best interest. Many ethicists consider this test to be overly subjective and prefer the use of the *harm principle*, focusing on whether decisions will cause the child harm (Gillam, 2016).

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 health does not have to be optimised (Radford et al., 2020). Decisions that are good enough may not prioritise physical health but would not cause significant harm. An often-contentious space, the ZPD will almost always require an element of interpretation. As part of this, Gillam (2016) advocated that health professionals consider how the child and the family's psychological, spiritual, and family health will be affected if their decisions were overridden. While some decisions may be safer for a child's physical health, they can be equally damaging to other areas of a person's well-being (Figure 1).

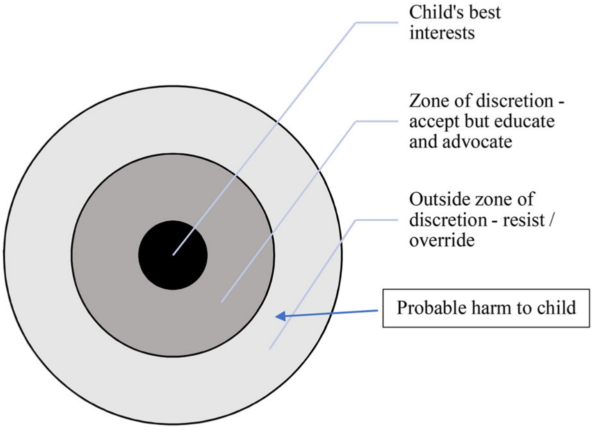

Figure 1. Zone of parental discretion (Gillam, 2016).

Legal considerations for EDAR – the right to make an informed choice

When families or children make choices with increased perceived risk, that differ from recommendations focused on physical health, 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. Right 7 describes how those receiving health and disability services have the right to make an informed choice and give informed consent. While the Code provides no definition for informed consent, it does define a *choice* as a decision to "either (a) receive services, (b) refuse services, or (c) withdraw consent to services".

Families and children have the right to be fully informed and to fully understand their options and the potential outcomes of their options (New Zealand Government, 1996). The Code 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. Therefore, the type of information that health professionals provide each family/child should change depending on their background, culture, and personal preferences.

SLPs in New Zealand describe lacking confidence in their skills to guide families with children with PFD to make informed decisions (Miles et al., 2021). 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. SLPs' use of language may enable families and children to view themselves as active decision-makers instead of passive healthcare recipients. Additionally, SLPs 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 in addition to the potential safety benefits of modified diets. This is because families and children cannot make fully informed decisions if differing points of view are not discussed. Skegg and Paterson (2015) recognise that clinicians are not expected to discuss all possible outcomes with clients and suggest that clinicians should choose how to discuss risk by weighing up the consequence of the risk with the likelihood of its occurrence. For example, if the consequences of the risk are severe (e.g. possible death), but the chance of it happening is low, the risk should be explained in a way that does not unnecessarily deter the family from making a decision. A short case study of this is provided which is an exemplar derived from experiences during the research (Table III).

SLPs can also draw from informed consent guidelines published by individual organisations, such as the Ministry of Education (2015n.d.) and Health New Zealand - Te Whatu Ora (2015n.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

Table III. Case example of informed consent and shared decision-making.

Case study
Kalea is a five-year-old with a diagnosis of Cerebral Palsy and GMFCS level 5. She recently started attending a specialist school. She had a Mic-Key button inserted before attending school due to a multi-phase dysphagia, receiving all nutrition and hydration through this. Kalea requires a suction machine to manage her secretions, particularly when unwell. Additionally, she has epilepsy that is not well controlled and has seizures regularly throughout the week. In a school enrolment meeting, her mother reported that their primary goal for Kalea was to have food orally. At home, Kalea's mother fed her small amounts of ice cream and pureed foods as this allows participation in family events, and she enjoys the taste of them.
The school SLP emailed the paediatrician to discuss Kalea's health and potential dysphagia management options. The paediatrician reported that Kalea was often unwell and considered palliative by the medical team. The SLP reported that the family utilised EDAR at home and suggested that she discuss a more formalised school-based tastes program with the family, considering their goal around oral eating and EDAR practices. The paediatrician agreed this was appropriate. As Kalea was enrolled in school, she was not supported by a health SLP. However, the school SLP emailed the local health SLP to ask for any frameworks or handouts they had on tastes and EDAR. The health SLP sent several documents, which included risk minimisation strategies when EDAR, such as monitoring the child's interest, posture, breathing, and state.
The school SLP made time to discuss dysphagia management options with the family. The school SLP explained the risk of aspirating on food and fluids, including increased risk of aspiration pneumonia, which could result in bronchiectasis, hospital admissions, and fatality. However, the school SLP explained that it was difficult to quantify these risks for Kalea and acknowledged that this option reduced Kalea's psychosocial opportunities. The family knew these facts as they had been in the health system for many years. The school SLP discussed EDAR as an alternative dysphagia management strategy, which the family were currently doing at home, outlining risk minimisation strategies, and textures. For example, the school SLP recommended not using ice cream, as the consistency changed when it melted, additionally reinforcing their use of purees due to Kalea's reduced oral motor skills. The SLP allowed the family to discuss these options before formalising a plan with them.
After the discussion with the family, the school SLP informed the paediatrician and health SLP of their discussion and requested to send a safe feeding plan to the health SLP for review, which the health SLP agreed to. The paediatrician requested to be updated with the family's decision, so they could discuss it at their next review.

Note. GMFCS = Gross Motor Function Classification System; SLP = speech-language pathologist; EDAR = eating and drinking at acknowledged risk.

with PFD, even though the information is specifically related to the use of modified diets for adults.

Children's roles and rights in the decision-making process

Another legal consideration when supporting children is who makes the decision, particularly when the decision lies within the ZPD. For decisions within the ZPD, the Code 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 PFD 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 aged 16 years old and above can make medical and health-based decisions (Skegg & Paterson, 2015; New Zealand Government, 1996). However, mature minors, under age 16 years old, can be deemed Gillick Competent, meaning they can consent to or refuse consent to medical and health-based treatments. 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 refer to 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 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 (Askren, A., & Leslie, 2019). 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, such as a child reaching out to show interest in family mealtimes. For other children, however, alternative forms of communication may be required, such as visuals, talking mats, and communication systems, amongst others.

Legal considerations for EDAR – health and safety at school

Families will inevitably make decisions about how they feed their child at home. However, children with chronic PFD are often supported differently at school compared to at home, and families sometimes use practices that differ from SLP feeding recommendations (Miles et al., 2021). The recognition of, and advocacy for, shared decision-making between families and health professionals has increased over the years as studies have indicated that clients and their families have a wide range of adherence to dysphagia plans, likely linked to what aspect of health they prioritise (e.g. physical health versus family health). To support students with PFD, collaboration is consistently recognised as essential, yet Miller (2009) aptly described the process as "elusive".

In New Zealand, school-based SLPs are employed by the education sector and do not have access to medical records. These SLPs are encouraged to routinely collaborate with health teams to gather clinical information, attend instrumental assessments, discuss SLP recommendations, and request support for students' complex PFD. In conjunction with this, health teams rely on school-based SLPs 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, 2007; Miller, C. K., 2009). School-based SLPs often rely on families to provide general medical information regarding their child's PFD. As students with chronic PFD 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.

However, school SLPs' collaborative practices vary greatly and often depend on their knowledge and confidence levels (Felicetti et al., 2020; Neubauer & Singleton, 2023). School SLPs have been shown to experience difficulties with collaboration practices, such as obtaining the appropriate documentation from health teams and collaborating with external medical professionals (Miles et al., 2021). SLPs describe challenging conversations with families and difficulties ensuring 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 does not always occur, the finding signifies difficulties with the home-school relationship. Additionally, in a recent paper, school SLPs did not consistently create mealtime plans in a collaborative manner that involved families and classroom staff who supported the child during mealtimes (Miles et al., 2021). They also did not feel confident supporting a conflict resolution process

Table IV. *Risk ratings (Ministry of Education, 2017).*

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

when disagreements occurred between the family and school team. Not all families had access to SLP support in the home despite accessing school SLP support. Subsequently, these families sometimes chose EDAR without the knowledge and skill to minimise risk (Erlam, 2024). Out of these situations arise complex decisions and dilemmas where ethics, legal considerations, and setting restraints collide.

In loco parentis

Internationally, different approaches have been recommended. At schools in the US, SLPs supporting students with PFD in school settings have a duty to act ‘in loco parentis’ (Power-deFur, 2024). 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 has been prevalent in New Zealand education guidelines in past years and was often related to behavioural discipline. New Zealand legal experts criticised in loco parentis for not considering students’ wishes and not aligning with legislation such as the Code (Hall & Manins, 2001a, 2001b). More recent informed consent guidelines stipulate that in loco parentis is no longer considered relevant in the school environment and that families must provide informed consent (Ministry of Education, 2001n.d.), as specified by the Code. Subsequently, in loco parentis is no longer used within the New Zealand 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 to health and safety for staff and students. The *Health and Safety at Work Act 2015* stipulates that schools must provide training, instruction, and supervision necessary to protect staff and students. To support the implementation of this Act, The Ministry of Education (2017) released guidelines for school leaders and board of trustees. These guidelines distinguish 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 (Table IV).

Minimising consequences or minimising the risk

As previously discussed, risk is poorly defined and quantified in PFD, which complicates the use of risk ratings when supporting students with PFD in school settings. An extreme risk hazard could be students with poor oral motor skills and a tendency to overstuff their mouths when eating solid foods, potentially resulting in a choking incident causing death or permanent injury. For this reason, The Ministry of Education (2017) encourages introducing alternate activities to reduce the risk of extreme-level risk hazards. One such high-risk hazard could be students with PFD wanting to eat food different from their recommended diet levels. The student may aspirate and develop respiratory complications that might require medical treatment. However, much of the associated risk with this case is assumed risk, and, as discussed, multiple factors impact the development of aspiration pneumonia and adverse health outcomes. The Ministry of Education (2017), 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-risk hazards if controls were introduced, and it was deemed the best solution by the family and student.

Supporting EDAR: Where to look

While children and families make informed decisions, such as EDAR, there is little policy or protocols for how SLPs should support families in these situations. As is common in fields with sparse literature, paediatric SLPs can borrow principles from adult EDAR literature. Internationally, various authors recommend that SLPs work collaboratively within multi- or interdisciplinary teams, utilise person-centred care, explicitly document all aspects of intervention, assess a person’s capacity, and work within ethical principles (Royal College of Speech Language Therapists, 2021; SPA, 2019; The University of Auckland & Hutt Valley District Health Board, 2016). Additionally, The University of Auckland and Hutt Valley District Health Board (2016) specify the

Table V. Top five statements for a care bundle for SLTs supporting families and children engaging in EDAR.

Documentation of actions taken to minimise risks of EDAR.
Prompt questions to ensure the paediatric client’s and/or caregiver’s views have been considered.
A section to enable SLP eating and drinking recommendations to be documented and shared with MDT.
Capacity assessment prompts to establish the paediatric client’s capacity to make an EDAR decision.
A written form to enable EDAR recommendations to be communicated to paediatric clients/caregivers.

Note. EDAR = eating and drinking at acknowledged risk; SLP = speech-language pathologist; MDT = multi-disciplinary team.

importance of involving a lead doctor in EDAR decisions, as they hold responsibility for the person’s overall health. Working in an interdisciplinary manner is made more complex when community SLPs do not have good ties to the health team and do not have guidance when health team input is required. Two New Zealand studies found that families’ decisions, such as practicing EDAR at home, were not consistently documented, even when school SLPs were aware of the decision. Additionally, the lead doctor, often a paediatrician, was rarely informed of these decisions (Erlam, 2024; Miles et al., 2021). While it is recognised that every family does not live near a specialist paediatrician, interdisciplinary collaboration and support is important and a local general practitioner may be a useful additional team member.

School staff hypothesised that families practiced EDAR at home because they did not understand the rationale for the PFD recommendations set by the school SLP, often centred around a student’s physical health (Miles et al., 2021). This viewpoint does not give families space to make informed decisions prioritising other areas of wellbeing over physical health. Adult EDAR guidelines recognise that people may choose 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 Language Therapists, 2021; The University of Auckland & Hutt Valley District Health Board, 2016; SPA, 2019).

Regardless of a family’s reason for EDAR, SPA specifies that people who choose EDAR should not be denied SLP input if a clinician disagrees with their decision (SPA, 2019). Instead, they advocate for people to be allowed to change their minds at any point, thus ensuring their needs are met.

To enable clinicians to better support children engaging in EDAR, Feint and Langeroudi (March 21, 2021) developed an EDAR care bundle and piloted this with community SLPs working with PFD in the Evelina London catchment area. The EDAR care bundle included information sheets, flowcharts, and proforma for families and SLPs to complete together to document the EDAR plan. Using a questionnaire, the authors gathered feedback from SLPs who appreciated the ‘structured and objective’ procedure, enabling the team to analyse the risks and benefits of EDAR. The SLPs valued having documentation and procedures to guide conversations, ensuring no information was overlooked or forgotten. Langeroudi et al. then completed a Delphi study to establish a clinical consensus of what components would be helpful in a care bundle for SLPs supporting families and children practicing EDAR. Thirty-one expert PFD SLPs agreed on the statements in Table V. enabling SLPs to consider those documents useful in clinical practice.

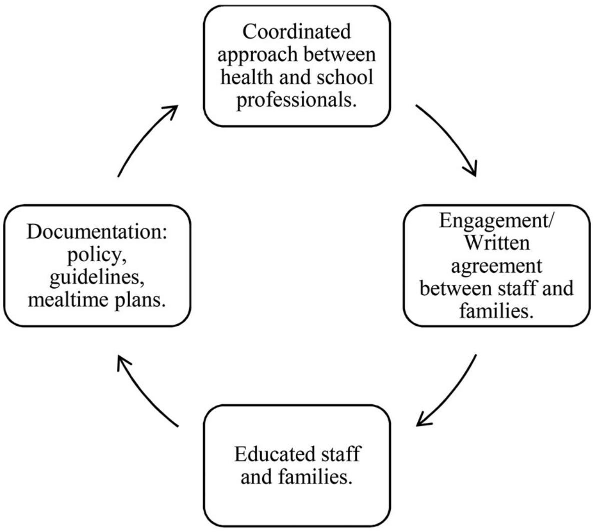

Figure 2. Best care for children with PFD in schools.

These findings indicate how increased documentation and procedures when working with children practicing EDAR are recognised as needed in the field. However, in the absence of paediatric-specific documentation or guidelines, SLPs may wish to utilise principles from adult guidelines and be aware of local laws and regulations whilst supporting families and children to make and review decisions inside the ZPD.

Recommendations for school SLPs to support students with PFD

As described, the role of the SLPs supporting PFD in specialist schools in New Zealand is complex (Cook et al., 2019; Miles et al., 2021). Recommendations for SLPs working in these settings are discussed below (Figure 2). Firstly, teams require a coordinated approach between health and school professionals, where health professionals, school staff, and families should meet regularly to discuss complex cases and problem solve when required. Where lead doctors may be difficult to access due to geographical isolation, team decision-making/interdisciplinary practice with perspectives from health teams is recommended. This consultation enables health and school SLPs to provide holistic, informed support for families and children with PFD. School SLPs should communicate regularly with health professionals that are hospital based to gather key documentation, update health professionals on family decisions when necessary, and request additional services when required.

To increase engagement/written agreements between staff and families, families and children should be viewed holistically, enabling them to share beliefs, values, and preferences freely. Holistic health models, such as Te Whare Tapa Whā (Durie, 1985), promote holistic thinking and create space for families to share health concerns related to all areas of health. When decisions are made, these should be documented and shared with relevant team members, such as paediatricians or dietitians. To aid this engagement, staff and families should be provided with all options, facilitated by SLPs, to provide a balanced discussion of the risks and benefits of potential treatment options (O'Keeffe et al., 2023). When disagreements arise between families and school teams, the school should have processes in place to navigate these, ensuring the family and child's dignity is upheld. SLPs should consider the legal aspects of supporting families in New Zealand contexts, such as informed consent (New Zealand Government, 1996), Gillick competency, the principle of child assent (Hudson et al., 2019), and decisions involving informed/measured risks whilst introducing controls (New Zealand Government, 2015).

Lastly, documentation in the form of policy, guidelines, and mealtime plans is required to best support these students. Where policies or guidelines are unavailable for this population, SLPs must look to adult versions, such as adult EDAR guidelines (Royal College of Speech Language Therapists, 2021; SPA, 2019; The University of Auckland & Hutt Valley District Health Board, 2016). School SLPs should document the family or child's decision regarding EDAR, whether this be in the school or home environment. Additionally, school SLPs should ensure that each child with PFD has a mealtime plan in place, monitoring and reviewing this plan in a consistent manner.

Conclusion

In children with chronic PFD, a broad definition of EDAR is needed, as the majority of children with complex needs who eat and drink orally are likely doing so with some degree of risk. SLPs provide support for these children alongside a range of other professionals. While EDAR guidelines are available to guide the practice of SLPs working with adults practicing EDAR, no paediatric EDAR guidelines are available. Clinicians are encouraged to use principles from adult EDAR guidelines in the absence of paediatric ones; however, additional laws, ethical frameworks, and legal principles apply to paediatric situations. The ZPD is an ethical framework allowing caregivers to make decisions that are 'good enough' for a child. When facilitating decisions, this framework enables clinicians to consider the 'harm principle' instead of defaulting to the best interests test, which may not prioritise physical health but would not cause significant harm (Gillam, 2016). Whether situations fall in the ZPD is a complex decision and should be made within a multi-disciplinary team. Additionally, The Code of Health and Disability Services Consumers' Rights 1996 specifies families' rights when engaging with health and disability services, such as informed consent, Gillick competency, and the principle of child assent.

Similarly, The Health and Safety at Work Act 2015 specifies how schools can reduce risk in work environments yet does not adopt a zero-risk policy in school settings, indicating schools could legally accommodate risk if controls were introduced to reduce the risk, and it was deemed the best solution for the student. Internationally, legal principles such as 'in loco parentis' are common in education settings overseas, where teachers and school staff have 'delegated powers' to look after a child as a parent would. In New Zealand, informed consent overrides in loco parentis when the decisions fall inside the ZPD. Keeping these laws and principles in mind enables SLPs to best support families to make complex feeding decisions.

Recent New Zealand research analysed the management of students with complex PFD in specialist school settings. Some children utilised EDAR practices, yet families and students were not consistently supported in a manner aligning with adult EDAR guidelines. Several recommendations are provided with the hope of assisting collaborative and trusting relationships between families and professionals, that support family and child wishes whilst minimising health consequences. These include: A coordinated approach between health and school professionals, engagement/written agreement between staff and families, documentation, and educated staff and families. Overall, families and children practice EDAR within the ZPD, and this article attempts to provide some guidance for professionals supporting these families.

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