Feeding problems and weight in infants and children with Down syndrome

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Submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctor of Philosophy

August 2024

Acknowledgements

First and foremost, I would like to express my deepest gratitude to all of the participants who have taken part in the research studies within this thesis. I am incredibly grateful not only for your time, but for your vulnerability, honesty and willingness to share your stories. The most enjoyable part of this PhD has been the individuals I have met along the way- I can't thank you enough.

I would also like to acknowledge and express gratitude to my supervisory team, Dr Silvana Mengoni, Dr Amanda Ludlow, Dr Samantha Rogers and Dr Karen Irvine. I am thankful for all of your guidance, commitment and support that you have so generously given me. I am lucky to have had the opportunity to learn from such inspiring and hardworking individuals.

Last but not least, thank you Guy. Thank you for your belief in me, for taking care of me and generally holding me together throughout this PhD. I truly could not have done it without you.

Abstract

Childhood overweight and obesity is a significant global public health concern with significant consequences for health. In children with Down syndrome, prevalence of overweight and obesity is higher than the typically developing population. This is problematic because children with Down syndrome are at a higher risk of various negative health outcomes, which can be worsened by excess weight, making proper nutrition particularly crucial for this group. However, these children are also more prone to feeding difficulties that can adversely affect their nutrition and diet. The current understanding of how feeding issues and weight develop in these children is limited. This thesis aims to address this gap by exploring factors associated with feeding problems, weight management, and parental support needs during the early years (from birth to five years old).

A mixed-methods approach was taken to explore these issues. This included conducting a scoping review of relevant literature, longitudinal studies, parent questionnaires and interviews, and video-recorded mealtime observations. The findings reveal that feeding difficulties and weight are influenced by a complex interplay of factors, including sensitivity to food textures, underlying health conditions, motor delays, sensory issues, children's eating behaviours, and parental feeding practices. As a result, early and comprehensive interventions are crucial for addressing feeding, eating, and weight concerns in order to prevent development of secondary issues like oral aversions. To facilitate this, feeding and eating behaviours should be part of routine developmental assessments for children with Down syndrome. Currently, mothers face barriers in accessing high quality support which meets their needs, leading to significant distress. Mothers need access to specialists with expertise in Down syndrome and ongoing, proactive support, especially during critical stages like breastfeeding and introducing complementary foods. Ultimately, the findings of this thesis indicate a need for policy changes and increased funding to enhance early intervention

programs, ensure consistent quality of feeding support, and address disparities in support across different regions in the UK.

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Chapter 1. Introduction

Childhood overweight and obesity are escalating global health issues with profound physical and psychological consequences. Understanding the complexities of child eating and the factors which influence it is essential for fostering lifelong healthy eating habits and promoting long-term positive health outcomes. This is particularly important for children with developmental disabilities, such as Down syndrome, who are more likely to experience various health, feeding and weight related difficulties. This thesis aims to explore feeding problems and weight for children with Down syndrome, focussing on the early years, and to identify parental support needs to promote better health outcomes for these children.

1.1. Milk feeding in early life: the benefits of breastfeeding

It is recommended by the World Health Organisation (WHO) and UNICEF that infants are exclusively breastfed for the first six months of life and are offered milk feeds alongside complementary foods until at least two years of age (WHO, 2023). Breastfeeding offers a variety of health and developmental benefits for both infants and their mothers. Breast milk contains the ideal proportions of nutrients, fats, proteins and carbohydrates to promote optimal growth and nutrition in infants and its composition behaves dynamically, constantly changing and adjusting to meet the infant's needs over time (Muro-Valdez et al., 2023). Breast milk offers many short- and long-term benefits for infant health and immunity because it is rich in antibodies, white blood cells and also helps to establish a healthy gut microbiome (Lyons et al., 2020). This results in a reduced risk of some illnesses such as ear infections, respiratory infections, and diarrhoea (Chęcińska-Maciejewska et al., 2024). Breastfeeding is also associated with a lower risk of sudden infant death syndrome (Hauck et al., 2011). Additionally, breastfed infants have a lower risk of developing chronic conditions later in life, such as asthma, allergies, type 1 diabetes, and certain types of cancer (Fewtrell, 2004). Rates of obesity are lower in childhood and later life for breastfed infants, with a dose-

response effect observed according to duration of breastfeeding (Ferreira et al., 2021). Optimal levels of hormones which are responsible for appetite regulation (and thus promote healthy body weight in infants) are associated with breastfeeding (Chęcińska-Maciejewska et al., 2024).

During breastfeeds (compared to bottle feeds), infants are more in control of their food intake. It can be more difficult for caregivers to know how much milk the infant has taken, and infants can match their milk consumption to their energy requirements. This offers continued benefits throughout childhood; Brown and Lee (2012) identified a significant association between breastfeeding duration and levels of satiety responsiveness in children aged 18-24 months. This effect can contribute to lower levels of food overconsumption later in life, reducing the risk of overweight and obesity (Chęcińska-Maciejewska et al., 2024).

Many important developmental advantages may also be observed in infants who receive breast milk. Enhanced cognitive, communication and social development have been observed in infants who were breastfed for at least four months (Choi et al., 2018). Breastfed infants have also been shown to have better motor development at three to four months of age compared to infants who were no longer breastfeeding (Petry et al., 2022). Additionally, a study conducted with nine-month-old infants demonstrated that gross motor, fine motor, problem solving, and social skills were improved in children who had been breastfeed for any duration (McCrory and Murray, 2013).

However, methodological issues have been identified in some studies which imply a causal relationship between receiving breast milk and developmental advantages (as identified by Anderson and Burggren, 2013; Yum et al., 2007). Additionally, research which has identified cognitive benefits associated with breast milk using several measures of cognitive development indicate that benefits are observed on some but not all measures of cognitive development (Grevet et al., 2024; Yum et al., 2007). Where developmental benefits of breast

milk feeding are found, in some cases this effect is very small. For example, Bellando et al., (2020) identified an association between breastfeeding and small, statistically significant differences in verbal intelligence, expressive communication, and auditory comprehension between children ages three and five years. However, the authors question the clinical relevance of these small differences.

Breastfeeding also offers a variety of benefits for maternal wellbeing. In the short-term, breastfeeding can promote maternal recovery after birth, as the oxytocin produced during breastfeeding contributes to reduced postpartum bleeding and encourages the uterus to return to its pre-pregnancy size more quickly (Almutairi et al., 2021; Saxton et al., 2015). Additionally, breastfeeding is associated with lower levels of depression and stress in new mothers (Pope and Mazmanian, 2016). Long-term maternal benefits include reduced risk of type 2 diabetes, breast, ovarian and endometrial cancers, and cardiovascular diseases (Chęcińska-Maciejewska et al., 2024; Masi and Stewart, 2024).

1.2. Barriers to meeting mothers' breastfeeding goals

Mothers may face significant barriers to breastfeeding, which are frequently outside of their control, such as perceived insufficient milk supply, pain, and returning to work (Dutheil et al., 2021; Tomori, 2022). Breastfeeding prevalence estimates suggest that women in the UK are rarely able to meet their breastfeeding goals. Despite over 80% of new UK mothers reporting a desire to breastfeed, rates suggest only one third are giving their infant any breast milk at all by six months (Brown, 2017; McAndrew et al., 2010; Victoria et al., 2016). Stopping breastfeeding before mothers want to can be devastating and is associated with feelings of guilt, failure, regret and post-natal depression (Brown et al., 2016).

Breastfeeding is a learned skill for both mothers and infants; it can be difficult to establish and take time to master (Volk, 2009). Research suggests as many as one in every two new mothers experience problems during early breastfeeding (Johansson et al., 2010; Kronborg et al., 2009). Adjusting to motherhood whilst recovering from birth and learning to breastfeed can be an overwhelming time, and access to support during this period is essential (Finlayson et al., 2020). For some mothers, breastfeeding may be relatively straightforward and successful from the first feed. However, some infants may have difficulties establishing a successful latch and effective suck (Whipps et al., 2022). Breastfeeding can be physically uncomfortable, with some mothers reporting enduring feeds whilst crying in pain due to sore or cracked nipples (Kronborg et al., 2015). If the infant experiences difficulties effectively removing enough milk from the breast, this can lead to uncomfortable inflammatory conditions such as mastitis, which is estimated to occur in 30% of lactating women worldwide (NICE 2024). Worries around inadequate milk supply are common and can lead to maternal anxieties about their babies not thriving as a result (Kronborg et al., 2015). Maternal confidence regarding breastfeeding ability and milk supply are significant factors for successful breastfeeding (Brown and Lee, 2012). As such, it is essential that mothers receive emotional and practical feeding support to help them navigate this potentially difficult period and assist them to meet their breastfeeding goals (Kronborg et al., 2015).

The WHO (2003) have recommended initiating a first breastfeed within one hour of a baby's birth, and advocate that mothers breastfeed their infants on demand. However, there are circumstances in which this may not be possible or may be difficult to achieve. Infants who are born prematurely (before 37 weeks' gestation) and/or are unwell at birth may require emergency care. This can lead to mother-infant separation which makes it difficult to initiate breastfeeding shortly after birth and sustain it thereafter (Brødsgaard et al., 2022). Mothers of infants who are admitted to a neonatal intensive care unit (NICU) face extra barriers to

meeting their breastfeeding goals. Efforts to establish breastfeeding may be difficult to juggle alongside medical needs of infants who are very unwell and fragile (Hookway et al., 2023). Additionally, maternal feelings such as worry and distress may negatively impact milk supply, which can further exacerbate feelings of anxiety and stress (Septianingrum et al., 2020). In such cases, mothers are particularly reliant on the support of health professionals to assist them to establish breastfeeding but staffing issues and skill shortages may also prevent them from receiving this support (Redshaw and Hamilton, 2006).

Despite the many benefits of breastfeeding, some mothers may feel that it is not the right option for themselves and their families. For example, they may choose to offer formula milk to their baby via a bottle or may choose to express breast milk and give this via bottle. Some mothers may use a combination of methods to feed their child milk (National Childbirth Trust, 2024). It is important that mothers are supported to meet their feeding goals, and to recognise that feeding goals may differ between mothers and families (Radzyminski and Callister, 2016). Simultaneously, it is essential that mothers who want to breastfeed receive adequate support to overcome barriers and achieve this goal.

1.3. Introduction of solid foods during the complementary feeding period

Following the period of milk feeding, WHO (2022) recommend that infants first begin to receive complementary solid foods at six months of age, alongside breast milk. Between the ages of six and 24 months, infants transition from an exclusively milk-based diet to one consisting mainly of solid foods, with the amount and variety of foods offered gradually increasing throughout this time (WHO, 2022). Complementary feeding is an important period in early eating development, whereby children begin to develop their self-feeding skills and satiety cues and move towards becoming independent eaters. The complementary feeding

period is influential for developing long-term eating behaviours and food preferences, which can impact later health outcomes (Thompson, 2023).

There are risks associated with introducing complementary foods both too early and too late. Beginning complementary feeding before a child is developmentally ready increases risk of choking, picky eating, obesity and diabetes (Clayton et al., 2013). However, if children begin complementary feeding too late, they may be at an increased risk of malnutrition, stunted growth and micronutrient deficiencies (Green et al., 2017). It is recommended that parents offer children a range of gradually increasing textures and flavours, introduced at a developmentally appropriate rate (NHS, 2022). This aims to advance the child's tolerance of increasingly difficult food textures and encourage the development of oral-motor skills (Alcock, 2006; Schwartz et al., 2011). Importantly, findings from Coulthard and colleagues' 2009 UK Avon Longitudinal Study of Parents and Children found that typically developing (TD) children who were introduced to solid, lumpy textured food late (after 9 months) ate a less varied diet and had more eating problems at seven years of age than children who began to eat this texture earlier, i.e. between six and nine months of age. In support of this, Northstone et al., (2008) found that children who were introduced to lumpy food textures earlier consumed a greater variety of foods at 15 months of age. Children who were exposed to lumpy food textures at age 10 months or older were reported to be more difficult to feed by parents, with increased picky eating behaviours. Taken together, the work of Coulthard et al., (2009) and Northstone et al., (2008) suggests that there could be a sensitive period for the introduction of lumpy textured foods between the ages of six and nine months. This highlights the importance of not only beginning complementary feeding at the appropriate time, but also the progression of food textures once this has begun. If food texture progression is delayed, there appears to be important implications for later child eating and dietary variety.

1.4. The importance of healthy weight in childhood

Globally, rates of childhood overweight and obesity are increasing at an alarming pace, now reaching epidemic levels (Flegal et al., 2010). The WHO state that incidence of adolescence obesity rates have quadrupled since 1990 (WHO, 2024). There are various short and long-term health risks in children with excess weight. Children with obesity are more likely to experience psychological challenges such as low self-esteem and behavioural problems (Moradi et al., 2020; Reilly et al., 2003; Wang and Veugelers, 2008). Specifically, obesity appears to impact child perceptions of their physical competence, appearance and social functioning (Griffiths et al., 2011). Evidence suggests that risk of psychological morbidity in children with obesity increases as children get older (Reilly et al., 2003).

Children who are overweight or obese are more likely to be overweight or obese as adults (Singh et al., 2008; WHO, 2024). Childhood and adolescent overweight and obesity is associated with increased adult morbidity and premature mortality, as well as increased risk of diabetes, stroke, coronary heart disease and hypertension in adulthood (Reilly and Kelly, 2011). Adults with overweight or obesity have elevated risk of several serious health conditions such as cardiovascular diseases, diabetes, cancers, neurological disorders, chronic respiratory diseases and digestive disorders (Murray et al., 2020).

Childhood overweight and obesity are major problems that pose serious risks to both the physical and mental health of children, with implications that extend into adulthood. Some groups of children are disproportionately affected by overweight and obesity, such as children with intellectual and developmental disabilities, and this increased risk has been identified in children as young as three years old (Emerson, 2009; Schenkelberg et al., 2023). In particular, children with Down syndrome experience increased rates of overweight and

obesity, with prevalence estimates of up to 62.5% compared to 18.5% in TD peers (Bertapelli et al., 2016; Hales et al., 2017; Polfuss et al., 2023).

1.5. Child eating behaviours

During the complementary feeding period, individual differences in child eating behaviours become evident, and also continue to be shaped. Costa and Oliveira (2023) describe eating behaviours as individual predispositions and tendencies towards food which encompass hunger, satiety and influence responses to food. Some children may have more of an avid appetite and exhibit more food approach behaviours such as food responsiveness and enjoyment of food (Costa and Oliveira, 2023). Conversely, some children may be more food avoidant, and exhibit more behaviours such as slowness in eating, food refusal and food fussiness (Kininmonth et al., 2021). Eating behaviours interact with environmental factors and this interaction impacts food choices and consumption (Scaglioni et al., 2018). As such, child eating behaviours have important implications for overall diet quality and weight. For example, children who demonstrate a food avoidant eating behaviour profile tend to consume less food overall and have a less varied diet including reduced consumption of fruit and vegetables (Jalkanen et al., 2017; Vilela et al., 2018; Syrad et al., 2016). Whereas rates of overweight and obesity are higher in children who demonstrate more food approach behaviours (Kininmonth et al., 2021). Behaviours such as lower responsiveness to internal satiety signals, eating faster during meals, and increased sensitivity to external food cues are more common in children with obesity compared to children of a healthy weight (Webber et al., 2009). Additionally, some eating behaviours are associated with risk of being underweight, such as lower responsiveness to food cues, lower emotional eating, higher satiety responsiveness and greater food fussiness (Viana et al., 2008). Research indicates that child eating behaviours are relatively stable throughout childhood (Ashcroft et al., 2008).

Given the relationship between eating behaviours and weight, and evidence for childhood obesity tracking into adulthood, child eating behaviours have important consequences for long-term health outcomes (Singh et al., 2008).

Understanding child eating behaviours and the factors that influence them is crucial for promoting lifelong healthy eating habits. Child eating behaviours appear to be influenced by a complex interplay of biological, psychological and social factors. For example, child temperament has been linked to eating behaviour, whereby children with more emotional temperaments have been reported to display more food avoidant eating behaviours (Haycraft et al., 2011).

There is evidence for some genetic contribution to eating behaviour (e.g. Llewellyn et al., 2013), but it is also shaped in response to environmental factors such as parental feeding practices. It is recommended that parents adopt a responsive feeding style and this applies to both milk feeding and eating of solid foods (Unicef, 2017). Responsive feeding practices include responding to a child's hunger and satiety cues in a sensitive and supportive manner. This involves recognising the child's signals of hunger and fullness and allowing the child to regulate their own food intake (Hodges et al., 2013). Responsive feeding fosters a positive mealtime environment and encourages healthy eating behaviours (Black, 2011). In contrast, nonresponsive feeding practices are controlling, coercive, or emotionally charged (Fernandes et al., 2023). Nonresponsive practices can undermine a child's ability to regulate food intake based on hunger and satiety cues (Black and Aboud, 2011). For example, using food as a reward or to soothe emotions may teach children to value food beyond its nutritional purpose, potentially leading to emotional overeating. Additionally, excessively restricting access to favourite foods may increase a child's desire for them (Costa et al., 2021). To evidence this, controlling feeding practices have been associated with eating in the absence of hunger in typically developing (TD) children (O'Neill et al., 2005). Parental pressure to eat has been

identified as a predictor of emotional overeating and slowness in eating in pre-school children and has been associated with higher levels of food fussiness (Kininmonth et al., 2023; Jansen et al., 2017). Additionally, restrictive parental feeding practices have been shown to negatively affect children's liking of fruits and vegetables (Boots et al., 2019). Child temperament and eating behaviours can also influence parental feeding practices, whereby parents adapt their feeding style in response to their child. For example, parents of children with more emotional temperaments are less likely to use restrictive feeding practices, and more likely to use foods to soothe their child (Farrow et al., 2018; McMeekin et al., 2013).

1.6 What is Down syndrome?

Down syndrome is a genetic condition which most commonly occurs when a person has an extra copy of chromosome 21 and can be diagnosed during pregnancy or after birth. Down syndrome occurs in approximately 1.0-1.5 out of every 1000 live births (Morris and Alberman, 2009; Strippoli et al., 2019) and about 750 babies with Down syndrome are born every year in the UK (Learning Disability Today, 2021). Down syndrome is the most common genetic cause of intellectual disability. Whilst there are some features which are common among individuals with Down syndrome, people with Down syndrome will be affected by their diagnosis in different ways, and will not all experience the same challenges, or to the same extents (Fidler et al., 2008). Individuals with Down syndrome will have some degree of intellectual disability and may have a range of anatomical, oral-motor and structural differences (Cooper-Brown et al., 2008; Field et al., 2003). The types of support services which may be involved in the care of a young child with Down syndrome include specialist breastfeeding support, dietetics, occupational therapy, speech and language therapy, physiotherapy (NHS, 2024).

Children with Down syndrome are at a higher risk of various health problems, such as cardiovascular diseases, autoimmune disorders, coeliac disease, type 1 diabetes, obesity, chronic constipation and dental problems (Bergholdt et al., 2006; Bermudez et al., 2019; Oliveira et al., 2010; Pavlovic et al., 2017). Individuals with Down syndrome are also more likely to have thyroid dysfunction, higher risk for infections, and obstructive sleep apnoea (Consortium et al., 2020). Many of the health comorbidities associated with Down syndrome are exacerbated by overweight and obesity, meaning that appropriate nutrition is of particular importance in this group, in order to promote optimal long-term health outcomes and quality of life (Dierssen et al., 2020; Fonseca et al., 2005).

Additionally, other neurodevelopmental diagnoses commonly co-occur in individuals with Down syndrome, such as autism and attention deficit hyperactivity disorder (ADHD, Startin et al., 2020). Prevalence estimates of co-occurring autism in children with Down syndrome range from 5% to 39% (Spinazzi et al., 2023), and ADHD is thought to occur in around 34%-44% of children with Down syndrome (Ekstein et al., 2011; Oxelgren et al., 2016). As such, health professional services that are made available early in life are crucial for fostering the physical and intellectual abilities of infants and children with Down syndrome (National Down Syndrome Society, 2024).

1.7. Feeding problems in children with Down syndrome

Feeding problems are defined and assessed variably within the existing literature (Hielscher et al., 2023). In this thesis, the term "feeding problems" encompasses a broad spectrum of challenges associated with feeding. This includes developmentally inappropriate eating patterns, such as a reliance on softer textures due to various underlying factors. The term also addresses functional components of feeding, such as swallowing and chewing difficulties, as

well as behavioural issues like food refusal. Furthermore, it captures contextual factors that may complicate mealtimes, including oral sensory sensitivities and challenging mealtime behaviours, such as negative affect or food/utensil throwing. Consequently, unless explicitly stated (e.g. in Chapters 3 and 4 where a screening tool is used) "feeding problems" is utilised throughout this thesis to denote any aspect that may hinder the feeding and eating experience for children and their parents, rather than being restricted to issues which are classified as feeding problems solely through the use of assessment and screening tools.

Children with Down syndrome may experience more challenges regarding milk feeding and eating solid foods than TD children. It is estimated that the frequency of feeding problems in children with Down syndrome is 50-80% (Anil et al., 2019) compared to around 25% in TD children (Manikam and Perman, 2000) and attainment of early feeding milestones such as the introduction of solid foods can occur 10-35% later in infants with Down syndrome (Nordstrom et al., 2020). Moreover, as children with Down syndrome progress through childhood and the feeding skills required become more complex, they become increasingly delayed in comparison to their TD peers (Nordstrom et al., 2020). Feeding problems also have a negative impact on various emotional, functional and physical aspects of life and development. Aversions to specific food items, dislike of being dependent on others for feeding, temper tantrums, and the need for specific utensils during meals can cause emotional stress for the individual. These challenges also hinder important elements of social development related to food, such as eating with peers in school (Anil et al., 2019).

1.8. Features of Down syndrome which can affect feeding in early life

There are various characteristics associated with Down syndrome that can contribute to difficulties around feeding in early life. For example, children with Down syndrome are more likely to be born prematurely, and at a lower weight than TD babies (Down's Syndrome

Association, 2015). Prematurity itself is a risk factor for increased feeding problems and adverse health outcomes in early life (Kamity et al., 2021). As a result of early feeding and health challenges, it is estimated that between 13% and 40% of infants with Down syndrome will require nasogastric (NG) tube feeding to ensure their nutritional needs are met (Nordstrom et al., 2020). Additionally, between 40-60% of infants with Down syndrome are born with a congenital cardiac anomaly, which can disrupt early feeding development, particularly if surgical intervention is required (Marder et al., 2015; Pisacane et al., 2007). Within this, 15% to 20% of infants with Down syndrome that have cardiac problems will require corrective surgery (Down Syndrome UK, 2024). The presence of a cardiac anomaly may contribute to infants tiring more easily during feeds, being less likely to display feeding cues, and being difficult to wake for regular feeds.

Furthermore, some infants and children with Down syndrome may present with hypotonia (low muscle tone) which can lead to difficulties with positioning during milk feeding and sitting upright when introducing solid foods. Other challenges caused by hypotonia include poor lip seal, difficulty sucking and an inefficient swallow which can lead to choking and aspiration (where food or liquid is inhaled and enters the lungs, Agostini et al., 2021). Children with Down syndrome may also present with anatomical differences such as a larger tongue and smaller oral cavity which can lead to abnormal tongue movement (e.g. tongue thrust), pocketing of food and food loss during meals (Ooka et al., 2012).

Delayed motor skill development is also commonly observed in children with Down syndrome, as highlighted by Malak et al., (2015). Oral-motor skills may be particularly affected, which are crucial for developing the chewing patterns necessary for safely eating solid foods and effectively manipulating food in the mouth (Nordstrom et al., 2020; Overland, 2011). Furthermore, delays in gross and fine motor skills can impede the acquisition of self-feeding abilities, such as using utensils—skills that research indicates are

often delayed in some children with Down syndrome (Anil et al., 2019; Frank and Esbensen, 2015).

In addition to motor skill delays, difficulties with sensory processing are also common among children with Down syndrome. Conditions such as oral hyposensitivity and hypersensitivity—where there is a reduced or heightened response to oral sensory input—can lead to a range of feeding challenges. These include food refusal, reluctance to swallow, selectivity by food type and texture, picky eating habits, and the tendency to overstuff food in the mouth (Field et al., 2003; Nordstrom et al., 2020). Moreover, behavioural feeding issues, such as food refusal and refusal to swallow, can further complicate successful feeding (Field et al., 2003).

1.9. Breastfeeding infants with Down syndrome

Estimates of breastfeeding prevalence and duration vary across different countries for children with Down syndrome; a review conducted by Magenis et al., (2022) reported breastfeeding prevalence ranged from 43%-100%, and the proportion of infants whose breastfeeding duration was six months or longer was between 40%-70%. In a UK study undertaken by Williams et al., (2022), 21% of children with Down syndrome were exclusively breastfed at six weeks compared to 23% of infants in the general population. Mothers express a desire to breastfeed their infants with Down syndrome, but they are likely to require more feeding support in order to establish successful breastfeeding, and where this is available, breastfeeding rates are higher (Sooben, 2012). So, it is important that where they encounter early challenges with this, they are supported to manage them (Estrem et al., 2016). In addition to the nutritional benefits for their infants, research has consistently shown that the quality of feeding support for new mothers is important for good maternal mental health (Chaput et al., 2016). For example, poor feeding support is associated with reduced

breastfeeding duration and increased risk of post-natal depression symptoms amongst new mothers (McFadden and Renfrew, 2017). Furthermore, the risk of depression, grief and trauma increases when mothers end breastfeeding earlier than planned due to difficulties encountered (Brown and Shenker, 2021). Lack of early feeding support can have consequences for the infant, including low dietary variety, inadequate daily total energy intake, limited weight gain and increased duration of mealtimes (Hopman et al., 1998, Lewis and Kritzinger, 2004).

1.10. Weight concerns in children with Down syndrome

In early life, infants with Down syndrome frequently have a lower birth weight and length than TD children, and early feeding problems leading to caloric deficiency can make weight gain and growth difficult (Bull et al., 2022; Nordstrom et al., 2020). As a result, it is estimated that between 13% and 40% of infants with Down syndrome will require nutritional support via nasogastric (NG) tube feeding (Nordstrom et al., 2020). Children with Down syndrome grow more slowly than TD children and frequently have a shorter stature as adults. Reflecting this difference, specific growth charts have been developed for use with children with Down syndrome (e.g. Down Syndrome Medical Interest Group and Royal College of Paediatrics and Child Health, 2011).

Whilst feeding problems and difficulties gaining weight are common in the early part of life, older children, adolescents and adults with Down syndrome are more likely to be overweight or obese than their TD peers, with prevalence estimates between 23% and 70% (Basil et al., 2016; Bertapelli et al., 2016; NHS, 2022; Ptomey et al., 2023). Some research has suggested that overweight and obesity rates begin to increase in children with Down syndrome after 2 years of age and remain elevated throughout childhood and adulthood (Bertapelli et al., 2016; Basil et al., 2016; Pierce et al., 2019; Ptomey et al., 2023). In line with this, increased rates of

overweight and obesity have been observed in children with Down syndrome, with prevalence estimates of up to 62.5% compared to 18.5% in TD peers (Bertapelli et al., 2016; Hales et al., 2017; Polfuss et al., 2023).

Currently, neither the critical time periods nor predictive factors for becoming overweight or obese during childhood and adolescence, have been clearly identified.

Amongst the general population, many factors have been identified which increase the risk of childhood overweight and obesity. Examples include maternal and paternal weight, early weaning and complementary feeding, non-responsive feeding practices, sedentary lifestyle, low socioeconomic status, psychosocial stressors, and low consumption of fruit and vegetables (Nogueira-de-Almeida et al., 2024). In addition to this, some characteristics of Down syndrome may also make individuals more likely to be overweight or obese, including hypotonia, cardiac anomalies, respiratory problems, digestive problems, motor skill delays and hypothyroidism (Basil et al., 2016; Cañizares-Prado et al., 2022; Slining et al., 2010; Watts and Vyas, 2013; Wentz et al., 2021). Other potential causes of overweight and obesity in individuals with Down syndrome which have been explored such as reduced physical activity levels, increased leptin levels, lower resting energy expenditure and unfavourable diet (Bertapelli et al., 2016). As discussed, overweight and obesity increase the risk of a variety of negative health outcomes and given that children with Down syndrome are already predisposed to a variety of health complications, there is a need to better understand which factors affect weight outcomes in this group, in order to improve long-term health. However, despite the elevated incidence of feeding, weight and nutrition related concerns, research on this topic is sparse, and the development of eating patterns in children with Down syndrome is not well understood (Schelkenberg et al., 2023).

1.11. Parental feeding practices and weight in children with Down syndrome

A large body of literature has examined the relationship between parental feeding practices and weight outcomes in TD children, with some mixed findings. For example, controlling parental-feeding practices have been associated with higher child body mass index (BMI, O'Neill et al., 2005). However, in contrast, research conducted by Haycraft and Blissett (2008) did not find a relationship between controlling parental feeding practices and child BMI and instead found a relationship between parent BMI, observed and self-reported feeding practices. Whereas a systematic review conducted by Shloim et al., (2015) identified a clear link between parental feeding practices and child weight. Specifically, restrictive/controlling feeding practices were generally linked to higher child BMI and pressure to eat was associated with lower child BMI (Shloim et al., 2015). Whilst research in this area is largely correlational and more longitudinal research is needed (Ruzicka et al., 2020), some existing longitudinal studies have demonstrated that the relationship between parental feeding practices and child weight may be reciprocal. Jansen et al., (2014) and Webber et al., (2010) identified that the parental use of pressure to eat was a response to low child BMI, and Child BMI at two years of age could predict parental use of restriction and pressure to eat.

Literature exploring feeding practices of parents of children with Down syndrome specifically is sparse, but emerging evidence indicates that parents of children with Down syndrome employ different feeding practices than parents of TD children and that feeding practices by parents of children with Down syndrome may be linked to child weight outcomes (Polfuss et al., 2017). For example, during complementary feeding, parents of children with Down syndrome are less likely use responsive feeding practices than TD (Thompson et al., 2024). Rogers et al., (2022) found that parents of children with Down

syndrome reported lower levels of involvement, emotional regulation and teaching about nutrition than TD parents, but higher levels of monitoring. Additionally, research by O'Neill et al., (2005) found that parents of children with Down syndrome employed different feeding practices than with their TD children and that these different practices are correlated with differences in child BMI. Parents of children with Down syndrome express greater concerns about their child's ability to regulate their food intake, which leads to worries about their child becoming overweight, and parents manage this by using more controlling feeding practices (Thompson et al., 2024). Where parents of children with Down syndrome are concerned about child overweight, and also have lower expectations of their child becoming independent eaters, use of restrictive feeding practices are more pronounced (Polfuss et al., 2021).

Whilst there is preliminary evidence indicating weight related differences, the impact of parental feeding practices such as, rewarding children for eating choices (what, when, and how much to eat) and perceptions of the child's weight status on the development of obesity in youth with Down syndrome has not been fully explored (Bertapelli et al., 2016). More longitudinal research into child feeding practices of parents of children with Down syndrome specifically is required to address this phenomenon and better understand the developmental trajectory of individuals with Down syndrome in regard to feeding and weight outcomes. Additionally, it is essential to better understand the developmental trajectory of feeding and weight outcomes in this population and to pinpoint critical periods and areas for early intervention.

1.12. Thesis aims and objectives

Appropriate nutrition would help to promote optimal weight and therefore lead to more positive health outcomes for children with Down syndrome. Unfortunately, feeding problems in early life can have negative impacts on diet and nutritional intake (Cooke et al., 2017). However, there is a scarcity of research examining the intricacies of the feeding journey and the problems which can occur for children with Down syndrome. It is important to address this in further detail so that individuals and families of individuals with Down syndrome can better be supported and better health outcomes promoted. This thesis aims to address this, by exploring factors related to feeding problems, weight, and identifying subsequent parental support needs throughout the early years (birth to five years old).

Chapter 2 details a scoping review which was conducted in order to better understand what the complementary feeding period looks like for children with Down syndrome, including the timing of first introduction of complementary foods, and barriers to eating progression thereafter. This scoping review sought to identify and synthesise the relevant existing literature which describes feeding problems and early eating experiences relating to the period of complementary feeding for children with Down syndrome. In particular, factors which contribute to the development of feeding problems during this period are explored, including the difficulty of different food textures, oral-motor skills, gross and fine motor skills, sensory difficulties and parental feeding practices. Key research gaps were also identified which helped to inform research objectives of later chapters.

In Chapters 3-6, a mixed-methods longitudinal study is presented which aimed to identify longitudinal predictors and factors associated with feeding problems and weight for children with Down syndrome compared to TD children. This study consisted of online parent report questionnaires, height and weight measurements of parents and children, video-recorded mealtime observations and semi-structured parent interviews. Chapter 3 presents the growth

and questionnaire data collected at Time 1, including group differences in factors related to weight and feeding problems. In Chapter 4, Time 2 growth and questionnaire data is explored, and longitudinal predictors of feeding problems and weight are presented for children with Down syndrome and TD children. Chapter 5 aimed to explore how mealtime behaviours and parent-child mealtime interactions differ between children with Down syndrome and TD children, including whether these factors change over time, and how they relate to feeding problems and weight. This was investigated using video-recorded mealtimes carried out during home visits at both Time 1 and 2.

In Chapter 6, data is presented from semi-structured interviews which were carried out with parents of children with Down syndrome at Time 2. Interviews aimed to provide detail on the wider context around feeding and eating in order to better understand families' subjective experiences, perceptions and practices related to feeding children with Down syndrome.

The qualitative study outlined in Chapter 7 sought to understand parents' experiences of feeding their child with Down syndrome during the COVID-19 pandemic. In particular, this study aimed to identify how feeding support services changed throughout and since the pandemic, and how mothers of infants with Down syndrome were impacted. As a result, this chapter provides insight on the wider context of feeding and feeding support for infants with Down syndrome.

In Chapter 8, the use and impact of NG feeding tubes for children with Down syndrome was investigated. This study aimed to address growing concerns about potential overuse of NG tubes for children with Down syndrome, and lack of support to transition away from NG feeding (Positive About Down Syndrome, 2022). Interviews were conducted with parents of children with Down syndrome who had been fed via NG tube within the last five years.

Resultant analysis of interviews provided information about decision-making processes, exit-planning, and the impact of NG tubes on feeding, eating and drinking. Additionally, the psychosocial impact of NG tube feeding is explored, alongside understanding parental support needs, and consequences when these are not met.

In summary, children with Down syndrome are at an increased risk of various negative health outcomes which can be exacerbated by excess weight, and so appropriate nutrition is particularly important for this group. However, children with Down syndrome are more likely to experience feeding problems which can negatively impact nutrition and diet. Additionally, rates of overweight and obesity are higher in children with Down syndrome. Currently, the development of both feeding problems and weight in children with Down syndrome are not well understood. This thesis seeks to address this gap by exploring factors related to feeding difficulties, weight management, and the parental feeding support needed during the early years (birth to five years old). To achieve this, a variety of research methods were used. Ultimately, feeding problems and weight were seen to be influenced by a complex mix of factors such as food texture sensitivity, underlying health issues, motor delays, sensory problems, child eating behaviours, and parental feeding practices.

1.13. Methodological considerations

Overall, the research within this thesis followed a mixed methods approach and this facilitated a flexible and pragmatic approach to addressing complex research questions. For the qualitative elements of the research programme, a critical realist stance was adopted to explore the experiences of participants and the underlying systemic factors influencing those experiences (Maxwell, 2022).

A mixed-methods approach was taken because it facilitated the collection of rich data, and allowed a more nuanced, comprehensive understanding of feeding problems and weight in children with Down syndrome, in line with the overall aims of this thesis. For example, in the longitudinal study outlined in Chapters 3-6, triangulation resulted in the use of varied research methods within the same study: online questionnaires, video-recorded mealtimes and semi-structured interviews. Integration of findings generated using different research methods allowed for cross-verification and the identification of inconsistencies/contradictions too (Denzin, 2017). Quantitative data collected via parent questionnaires in Chapters 3 and 4 could be compared to the findings of the scoping review undertaken in Chapter 2. Interview data collected in Chapter 6 could be compared to mealtime observations detailed in Chapter 5, providing contextual information for observed behaviours. In Chapter 7, a survey of pandemic-related changes to health services could be compared to parent descriptions of access to feeding support and health services during COVID-19. Additionally, as the study outlined in Chapter 7 was the first study to be conducted during the PhD, the findings regarding parental feeding challenges and support needs helped to shape and inform interpretation of findings in later studies (by providing some contextual information). More directly, the findings of Chapter 7 informed the development of interview schedules used in Chapters 6 and 8.

For the interview studies in Chapters 6, 7 and 8, reflexive thematic analysis (RTA) was used (Braun and Clarke, 2006, 2022). RTA is widely used within applied health and psychology research, and many resources exist which detail both the theoretical underpinnings of the approach, and how to conduct it (Braun and Clarke, 2023). RTA was chosen above other thematic analysis (TA) approaches because it offers a more flexible and dynamic approach whilst facilitating deep engagement with the data (Braun and Clarke, 2021) For example, when conducting RTA, both inductive and deductive coding of data is used. A benefit of this

is the integration of new codes based solely within present data, but also the production of codes which are informed by existing research and theory which facilitates a more rigorous analytical process (Fereday, 2006; Proudfoot, 2023).

The interview studies aimed to develop a deep understanding of participants' individual experiences and reflections, but also to explore patterns across the dataset, whilst considering the wider socio-cultural context that personal experiences are situated in. RTA is well suited for this purpose, as it seeks to produce rich themes which reflect patterns of shared meaning that are underpinned by a central organising concept (Braun and Clarke, 2020). In comparison, other TA approaches (e.g. coding reliability approaches) produce more descriptive summaries of data collected which would not fulfil the research aims (Braun and Clarke, 2020). Other qualitative analysis methods were considered, such as interpretative phenomenological analysis (Smith et al., 2009). However, in order to maximise research impact, an important goal of the interview studies was to produce actionable insights with clear implications for practice, which RTA is better suited for (Braun and Clarke, 2020).

1.14. Positionality statement

In conducting RTA, I recognise that various personal factors such as my background and personal engagement with the Down syndrome community have inevitably influenced my interpretation of the data in each of the qualitative studies undertaken. Throughout this PhD, my priority has been to raise awareness of the challenges faced by the Down syndrome community regarding feeding difficulties, whilst identifying barriers to achieving optimal care outcomes. My previous professional experience working with families of children with special educational needs has provided me with a deep understanding of how feeding and eating challenges can profoundly affect family life and daily functioning. These experiences

have strengthened my conviction that appropriate support is crucial to addressing these challenges effectively.

In addition to this, my engagement with the Down syndrome community throughout this PhD has allowed me to gain further insight into their unique struggles and research priorities. This deeper understanding, accumulated throughout the course of my research, especially influenced my interpretation of the data in later chapters of my PhD (Chapters 6, 8, and 9). By this stage, my knowledge of the community's needs and perspectives had grown, and this undoubtedly shaped my approach to identifying and constructing the themes that emerged from these later studies.

Furthermore, my approach to the qualitative research in this thesis has been informed by a critical realist epistemological stance. I acknowledge that the experiences shared by participants reflect real challenges they face in their daily lives; however, I also recognise that these experiences are shaped by broader social and systemic factors. I sought to explore not only the immediate realities of feeding difficulties but also the underlying mechanisms - such as healthcare structures and service provision - that influence these experiences. This perspective enabled me to go beyond surface-level interpretations, aiming to identify deeper structures and systems that contribute to the challenges described by participants.

Chapter 2. Scoping Review: Complementary feeding and early eating experiences of children with Down syndrome

*This chapter has been published: Hielscher, L., Irvine, K., Ludlow, A. K., Rogers, S., & Mengoni, S. E. (2023). A Scoping Review of the Complementary Feeding Practices and Early Eating Experiences of Children with Down Syndrome. *Journal of Pediatric Psychology*, *48*(11), 914-930. Doi: https://doi.org/10.1093/jpepsy/jsad060

Although the content of this chapter is largely the same as the published paper, some formatting changes for consistency of the thesis have been made.

2.1. Introduction

Given the importance of the complementary feeding period for significant eating, developmental and health outcomes (as outlined in Chapter 1), and the increased likelihood of feeding problems and health complications for children with Down syndrome, this is an important research area which needs to be further explored.

Research suggests that infants with Down syndrome are likely to be introduced to complementary foods later than TD children (Cochran et al., 2022; Hopman et al., 1998). Yet, no official guidelines exist for the introduction of complementary foods for infants with Down syndrome specifically, neither does a gold standard exist of how to address feeding problems should they occur during this important phase in development. Whilst several reviews have been undertaken regarding breastfeeding infants with Down syndrome (Magenis et al., 2022; Sooben, 2012) offering insights into barriers, facilitators and helpful implications for policy and practice, the same is not the case for complementary feeding. There is little existing research which has explored complementary feeding and early experiences of eating solid foods for infants with Down syndrome. Additionally, research

indicates that existing feeding support services do not meet the needs of some mothers of infants with Down syndrome (Cartwright and Boath, 2018; Hielscher et al., 2022) and families of infants with Down syndrome are more likely to report unmet care needs generally (McGrath et al., 2011). Therefore, this scoping review aimed to identify and synthesise the relevant existing literature which describes feeding problems and early eating experiences relating to the period of complementary feeding for children with Down syndrome.

2.2. Method

An initial literature search helped to inform the research questions and test search terms for suitability. This identified a lack of studies which have investigated complementary feeding in infants with Down syndrome. As a result, it was determined that a scoping review would be most suitable to provide a broad overview of this research area and identify research gaps. The protocol for this scoping review was developed using the framework for conducting scoping reviews outlined by Arksey and O'Malley (2005), with enhancements from Levac et al. (2010). The protocol was pre-registered on the Open Science Framework (and can be accessed at: https://osf.io/v5q6k). The study was conducted and reported in line with the PRISMA extension for scoping reviews (Tricco et al., 2018).

At the time of pre-registration, it was intended that this review would investigate the very first introduction of solid foods to infants with Down syndrome and feeding problems during this time specifically. However, once searches began, only two studies which have specifically explored this topic were identified, which would have been insufficient to conduct a full review. As such, a decision was made to expand the focus of this review to encompass the complementary feeding period more widely (the gradual introduction of new textures and flavours, and gradual reduction of milk consumed after solid foods are first offered to the child) and feeding development during this time.

This scoping review aimed to address 4 research questions:

1. What is the reported process of introducing complementary foods in this population?
2. What are the reported feeding difficulties that occur during complementary feeding for infants with Down syndrome?
3. What are contributing factors associated with increased or reduced feeding problems?
4. What are the research and knowledge gaps in this area?

2.2.1 Search strategy

Searches were initially conducted in June 2021 and were re-run in June 2022 using Scopus, PubMed, Medline, Web of Science and Psychinfo. The same search terms were also input into Google Scholar and the first 200 results were reviewed (in line with recommendations by Haddaway et al., 2015 regarding the use of Google Scholar as part of evidence reviews). Search alerts were set-up using the same search terms and databases, and they were monitored for new publications between the time that the database searches were conducted and the publication of this review (June 2022 to February 2023). The search terms used are outlined in Table 2.1.

Table 2.1. *Search terms used to conduct database searches*

Search term 1	Search term 2	Search term 3
Search operator:	*AND*	*AND*
Down syndrome	Infant	Feeding problems
Down's syndrome	Child	Feeding disorders
Trisomy 21	Children	Feeding difficulties
Intellectual disability		Introduction of solid foods
		Introduction of solids
		Complementary feeding
		Child feeding practices
		Weaning
		Eating behaviour

Furthermore, the websites of relevant organisations (e.g. The Down's Syndrome Association, Positive About Down Syndrome, Down Syndrome Medical Interest Group, Down Syndrome UK) were searched to identify articles and information relevant to the study aims. Key journals were manually searched. Reference lists of articles obtained using the search terms were manually scanned to identify further relevant articles.

2.2.2 Study selection

All of the search results were imported into Rayyan (an online tool used to aid literature searches). Duplicate records were removed using an online de-duplication tool called Systematic Review Accelerator. Article titles and abstracts were then screened according to the following inclusion criteria:

- Studies which have investigated factors relating to, or which refer to, the complementary feeding period and early eating experiences (relevant to solid foods).

- Studies with participants of any age (although the focus is on complementary feeding, this can occur at varied ages), gender, or geographical location, who are reported to have Down syndrome. As many individuals with Down syndrome have comorbid neurodevelopmental or psychiatric disorders, data from individuals was included regardless of the presence of comorbid disorders. Studies may include parent-report on behalf of the individual with Down syndrome.
- Original articles published in English with either quantitative or qualitative study methodology or study design e.g. intervention studies, interviews, case studies. This does not include review articles.
- Studies which also included groups with other diagnoses were included in the review providing that the findings related to the participants with Down syndrome were reported separately.

Articles published prior to 1990, not in the English language or not using human participants, and review articles were excluded from the review. The cut-off date of 1990 was selected because initial searches identified that research published before this date was limited and outdated regarding weaning practices described.

Initial preliminary searches identified various studies which investigated some elements of feeding in children with Down syndrome that were relevant to this review's aims, but the age range of participants was very broad (e.g. 2-18 years). In such cases, these studies were checked to see if they referred to the complementary feeding period (for example reporting the age at first introduction to solid foods). If they did not explicitly refer to this, and the study results were also not reported separately according to age sub-groups, studies were excluded from the review. Whilst it is recognised that children with Down syndrome may begin complementary feeding at varied ages, the present review aims to explore early eating

experiences and feeding development throughout the complementary feeding period specifically, which would be expected to occur within the pre-school years. As such, in terms of inclusion criteria, it was necessary that the age range remained broad enough to capture all studies which may describe the complementary feeding period (for example some studies included older participants, but gathered retrospective data about early eating experiences), but papers which investigated some element of feeding in older children (e.g. age 5 years- 18 years) without referring to complementary feeding or eating development in relation to solid foods specifically, were excluded on the basis that it could not be justified that the findings were relevant to the aims of this study- early eating experiences and complementary feeding in infants with Down syndrome. In some studies, references to complementary feeding were a small part of what was presented. Where this occurred, only the information relevant to the review's aims were extracted.

Initial title and abstract screening was conducted by the primary researcher, and 10% of the titles were shared with an independent reviewer to screen to ensure inter-rater reliability. Following the initial screening, full-text articles were retrieved and reviewed to make a final decision of inclusion. Once again, 10% of full-text articles were reviewed by an independent reviewer. Any disagreements regarding the inclusion of articles were resolved by discussion with the wider research team. A quality assessment tool was not used during this process. Quality assessment is not part of the framework outlined by Arksey and O'Malley (2005), nor the advancements set out by Levac et al., (2010) for scoping reviews. Due to a preliminary search identifying limited and heterogenous research in this area, it was judged that quality assessment would not affect inclusion in the review and any concerns or observations regarding methodological quality were noted during the data extraction phase instead, and the review findings are considered in light of this.

2.2.3 Data Analysis

A data extraction table was created using MS excel to extract relevant information from the studies included in the review (see Table 2.2. for a summary of selected studies). The primary researcher piloted this table using three studies, to identify any table headings which may need improvement and to validate the table. The extracted data was then reviewed and organised according to several themes which were determined using the research questions, and then further developed based upon the findings of the included studies. The themes were: age at starting complementary feeding, difficulty of different food textures, factors affecting eating development during the introduction of solids, parental feeding practices and their impact on feeding development. In order to identify research gaps in this area, the included studies were then appraised regarding their methodologies, findings and recommendations for future research made in the discussion section of each paper. This was reviewed to identify patterns and commonalities across the available research on this topic and identify what is missing. This is incorporated in the discussion section of this report.

2.3. Results

2.3.1 Included Studies

Initial searching of electronic databases produced 2307 records. Three hundred and ninety-four duplicates were removed, leaving 1903 records to be screened. The titles and abstracts of the records were screened to assess relevance and based on this, 1845 records were excluded. Fifty-eight full text articles were retrieved and assessed for inclusion eligibility. During this process, 16 records were found to meet the inclusion criteria and a further 42 records were excluded. The references of the 16 records were screened and one article (van Dijk and Lipke-Steenbeek, 2018) was subsequently retrieved for screening and then included in the

review. Another record was identified via an automated publication alert (Ross et al., 2022) which occurred shortly after the database searches were conducted (June 2022) and was subsequently screened and included in the review. In total, 18 records were included in the review. Figure 2.1 shows an overview of the study selection process.

2.3.2 Study Characteristics

Table 2.2. presents the characteristics of the 18 studies included in the review. Study designs included parent report questionnaires/surveys, of which six used these only (Al-Sarheed, 2005; Barreiro et al., 2021; Collins et al., 2003; Collins et al., 2004; Rogers et al., 2021; Ross et al., 2019) and four studies utilised other methodologies such as conducting interviews with parents, alongside parent-report questionnaires (Anil et al., 2019; Mohamed et al., 2013; Osaili et al., 2019; Roccatello et al., 2021). Two studies reported anthropometric measurements (Osaili et al., 2019; Hopman et al., 1998). Mealtimes were video-recorded in four studies (Anil et al., 2019; Ross et al., 2022; Spender et al., 1996; van Dijk and Lipke-Steenbeek, 2018). Other methodologies reported include a case study (Shaw et al., 2006), and a review of records for children who had previously been assessed for feeding (Field et al., 2003; Ooka et al 2012).

Six of the studies included in the review were conducted in the US (Barreiro et al., 2021; Cochran et al., 2021; Field et al., 2003; Ross et al., 2019; Ross et al., 2022; Shaw et al., 2006). Two of the studies were conducted in the Netherlands (Hopman et al., 1998; van Dijk and Lipke-Steenbeek, 2018). Four of the studies were carried out in the UK (Collins et al., 2003; Collins et al., 2004; Rogers et al., 2021; Spender et al., 1996). Two of the studies were conducted in Saudi Arabia (Al-Sarheed, 2005; Mohamed et al., 2013). Other countries that the studies in this review originate from were India (Anil et al., 2019); Italy (Roccatello et al., 2021); Japan (Ooka et al., 2012); and the UAE (Osaili et al., 2019).

2.3.3 Participants

All 18 studies included children with a diagnosis of Down syndrome and/or their parents/caregivers and in total, 1276 children with Down syndrome were represented across all of the included studies. Collins et al., (2003) and Collins et al., (2004) report data and findings collected from the same sample, at the same time. In eight of these studies, only the parents/caregivers were the research participants (Al-Sarheed, 2005; Barreiro et al., 2022; Collins et al., 2003; Collins et al., 2004; Mohamed et al., 2013; Roccatello et al., 2021; Rogers et al., 2021; Ross et al., 2019;). In one study, participants included parents/caregivers of children with Down syndrome and healthcare professionals (Cochran et al., 2021). In seven studies, both the parents/caregivers and the children with Down syndrome were the research participants (Anil et al., 2019; Hopman et al., 1998; Ooka et al., 2012; Osaili et al., 2019; Ross et al., 2022; Spender et al., 1996; Van-Dijk and Lipke-Steenbeek., 2018).

In two of the included studies, TD siblings of children with Down syndrome were also represented (Collins et al., 2003; Mohamed et al., 2013) and three of the studies included children with other developmental disabilities (and/or their parents) including Autism, Cerebral Palsy and Cri Du Chat syndrome (Ooka et al., 2012, Collins et al., 2003; Field et al., 2003). Three of the studies used data collected in previous studies to provide a TD comparison group (Barreiro et al., 2022; Spender et al., 1996; Van Dijk and Lipke-Steenbeek, 2018).

The ages of children represented ranged from 0-19 years across the studies, but the majority of studies included children in early childhood. Of the studies which report an age range for participants, eight included children with Down syndrome aged five years and under (Cochran et al., 2021; Hopman et al., 1998; Ooka et al., 2012; Rogers et al., 2021; Ross et al.,

2019; Ross et al., 2022; Spender et al., 1996; Van Dijk and Lipke-Steenbeek, 2018), with the remaining eight including older children

Five of the studies reported medical comorbidities amongst children with Down syndrome in the sample. Cochran et al., (2021) note that the parents of 22 children with Down syndrome aged 14-59 months who took part in their study reported that 18 (82%) of the children with Down syndrome had at least one medical comorbidity. Two of the children (9%) had gastronomy feeding tubes in place, and 16 (72%) of the children had previously undergone at least one surgical procedure requiring sedation prior to participating in the study. Ten children had dysphagia (45%), nine (41%) children had cardiac anomalies, and four (18%) children had obstructive sleep apnoea. Field et al., (2003) report that of the 21 children with Down syndrome in their sample, 14 (66.7%) had gastro-oesophageal reflux and 14 (66.7%) had cardiopulmonary disease. In the case study conducted by Shaw et al., (2003) Martin is described as previously experiencing difficulties with lung infections and choking, vomiting and diarrhoea. Overall, little detail is provided about how data on medical comorbidities was collected in these studies.

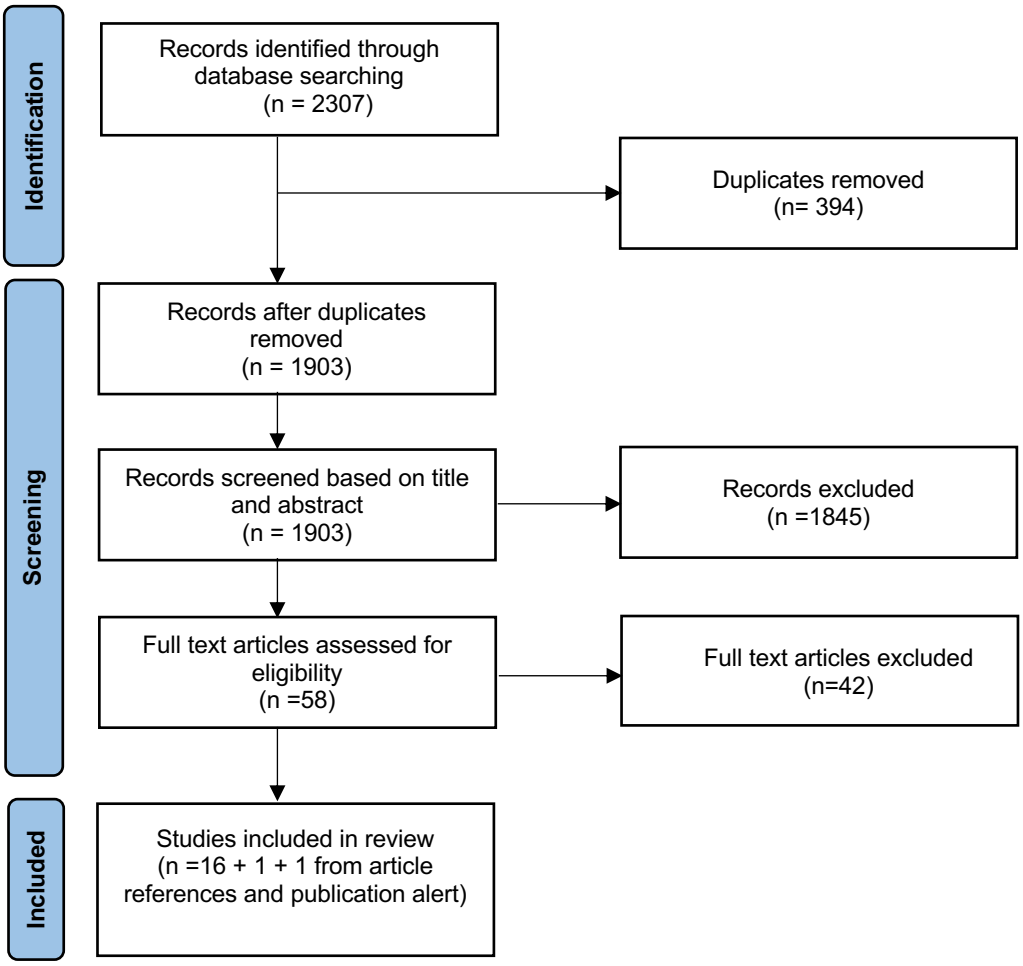

Figure 2.1. *Overview of the study selection process*

Table 2.2. *Summary of research relating to complementary feeding and early eating experiences in children with Down syndrome.*

Author(s), (year of publication)	Participants, gender, age, diagnosis	Purpose	Method	Results
Al-Sarheed (2005)	225 parents of a school-age child with Down syndrome[a]. Mothers' mean age 37.92 years, ***SD*****=** 7.89 years, Fathers' mean age 45.38 years (***SD*****=** 11.29 years).	Investigate breastfeeding patterns and introduction to solid foods for children with Down syndrome.	Parent report questionnaire	Solid foods introduced at mean age of 7.73 months (no SD provided). 16.40% (n=37) of parents introduced solid foods to their child with Down syndrome at less than six months of age. 45.80% (n=103) introduced solid foods between six and nine months of age. 37.80% (n=85) introduced solid foods between nine and 12 months.
Anil et al., (2019)	17 children with Down syndrome aged 2-7 years[b] (7 males, 10 females) and their parents; 47 TD children (27 males, 20 females) and their parents. Groups matched according to age and socioeconomic status.	Assess feeding and swallowing problems of children with Down syndrome Assess the impact of feeding problems on the physical, functional and emotional domains in children with Down syndrome.	Parent report questionnaires (including a newly developed questionnaire to assess feeding problems and two standardised measures; the Com-DEALL checklist to assess oromotor skills in toddlers and the Feeding Handicap Index for	Children with Down syndrome were observed to: 1) have significantly more feeding problems than TD children in all phases of swallow and a variety of problems were present which resulted from reduced oral motor skills and oral hyposensitivity. 2) have difficulty transitioning to varied textured food (35.30%) and chewing solid and semi-solid foods (47%). 3) have a developmentally immature chewing pattern (52.90%).

			Children), video-recorded mealtime	4) have more difficulty manipulating food in the mouth and swallowing. 5) have greater difficulty chewing and biting solid foods than with liquids. 5) have more physical, functional and emotional difficulties with feeding than TD group.
Barreiro et al., (2021)	68 children with Down syndrome aged 2-7 years (***M*****=** 4.6 years, ***SD*****=** 1.80 years***;*** 41 males, 27 females) and their parents.	Examine self-reported feeding practices of parents of children with Down syndrome, and compare this to previous research conducted with TD populations Identify any relationships between parent ethnicity and demographic factors and child feeding practices Determine whether feeding practices are correlated with child weight.	Parent report questionnaire (updated version of Child Feeding Questionnaire and demographics questions).	Parents of children with Down syndrome reported higher perceived responsibility, lower concern about child weight and restriction in comparison to data reported amongst the literature for TD children. Hispanic/Latino parents of children with Down syndrome reported higher perceived responsibility and monitoring compared to non-Hispanic/Latino parents of children with Down syndrome.
Cochran et al., (2022)	22 Parents of children with Down syndrome aged 1-5 years[b], 8 health professionals	Explore caregiver experiences of introducing complementary foods to children with Down syndrome	Interviews with parents and health professionals	Parental themes: 1) Differences in feeding practices for children with Down syndrome; 2) Limited guidance and decisions to not specifically follow recommendations; 3) Feeding

		Describe training received by health professionals on introducing complementary foods and advice they give.		difficulties and related stress; 4) Gross motor milestone acquisition related to feeding milestones. Health professionals' themes: 1) Limited practitioner resources/training; 2) Providing similar recommendations as for children without Down syndrome; 3) Desire for training/resources.
Collins et al., (2003)[c]	262 children with Down syndrome aged 2-18 years (***M***=7.99 years, ***SD***= 4.18 years), and their TD siblings (N=167), 107 children with ASD (and TD siblings (n=69)), 36 children with Cri Du Chat syndrome (and TD siblings (n=14)). Participants split into age groups for analysis: 2-4.99 years, 5-9.99 years and 10-19.9 years.	Assess eating behaviours of children with certain diagnoses compared to TD siblings Describe eating behaviours, ability to cope with range of textures in family diet and self-feeding/drinking skills and assess implications for development of oral-motor and communication skills.	Parent report questionnaire	Children with Down syndrome aged 2-4.99 years: had poorer self-feeding skills than TD siblings and older children. 15% of this age group were reported to finger feed or need feeding, and 10% of children with Down syndrome in this age range reported to have mastered drinking skills. 15% of children with Down syndrome aged 2-4.99 years reported to swallow without chewing (TD siblings less likely to do this). Children with Down syndrome more likely to display problem behaviour during mealtimes e.g. eating too slow/fast, playing with food, taking food from others' plates, than TD siblings.

Collins et al., (2004)[c]	262 children with Down syndrome aged 2-18 years (***M***=7.99 years, ***SD***= 4.18 years), and their TD siblings (N=167), 107 children with Autism Spectrum Disorder (and TD siblings (n=69), 36 children with Cri Du Chat syndrome and TD siblings (n=14). Participants split into age groups for analysis: 2-4.99 years, 5-9.99 years and 10-19.9 years.	Describe usual meal, snacking patterns and food choices of sample.	Parent report questionnaire	Children with Down syndrome in 2-4.99 years age group reported to eat four or five snacks/meals per day. Food choice was often of soft, sticky, sweet food and sweet beverages. Of the children with Down syndrome aged 2-4.99 years, 48.50% (n=66) were reported to eat ice-cream every day compared to 26.30% of their TD siblings. 43.80% of children with Down syndrome aged 2-4.99 years rarely or never ate sweet biscuits and 44.40% (n=63) rarely or never ate sweets/candy. Across all age groups children with Down syndrome who consumed sweet biscuits more often were also likely to eat chocolate, sweets, fruit squash and carbonated drinks more often.
Field et al., (2003)	349 children with and without developmental disabilities aged 1 month-12 years[a] who were assessed for feeding problems in clinic (200 male, 149 female). 225 of 349 children were identified as having a	Identify possible predisposing factors for specific childhood feeding problems.	Review of clinic medical records of children who were assessed for feeding problems over a 30-month period.	Many children with Down syndrome refused to chew despite being able to and so ate low textured purees. Prevalence of different problems for children with Down syndrome were: • Oral motor delays – 80% • Selectivity by texture – 45% • Dysphagia – 36%

	developmental disability of which type and severity varied widely. Three sub-groups of developmental disability analysed separately: Autism (n=26), Down syndrome (n=21), Cerebral palsy (n=44.) Authors report that 81% of sample were aged 5 years or younger. Groups were not age matched.			• Food refusal – 6% • Selectivity by type – 5% Issues with oral motor delays and selectivity by texture were higher than the other groups.
Hopman et al., (1998)	44 children with Down syndrome aged 0-4 years (22 male, 22 female, ***M*****=** 21 months, ***SD***= 11 months), 37 TD children (19 male, 18 female, ***M*****=** 22 months, ***SD*****=** 13 months)	Investigate nutritional status, breastfeeding patterns, age of introduction to solids, energy and nutrient intakes of children with Down syndrome compared to TD children.	Height/weight measurements, parental interview with nutritionist, dietary history method and analysis.	Children with Down syndrome had delayed introduction of solid foods (across various food types and textures measured). Mean daily energy intake of children with Down syndrome was 27% below recommended daily allowance, compared to 9% below in TD group. Children with Down syndrome group received significantly more energy from carbohydrates than recommended daily allowance.
Mohamed et al.,(2013)	108 parents of children with Down syndrome aged 5-12 years [b] Mean age for males within the Down syndrome group: ***M*****=** 8.20 years, ***SD*****=** 1.70 years, mean age for	Investigate dietary practice and physical activity among children with Down syndrome.	Parent report questionnaire and interview	Children with Down syndrome introduced to solid foods later than TD siblings.

	females within Down syndrome group: ***M***= 7.90 years, ***SD***= 1.50 years) and 113 TD siblings. Mean ages of males and females across Down syndrome and TD groups not significantly different.			
Ooka et al., (2012)	17 Children with Down syndrome (9 male, 8 female, ***M*****=** 2 years 9 months, ***SD*****=** 9 months). 16 children with autism, 20 children with intellectual disability (age range across all groups was 2 years 2 months-5 years 2 months). Groups did not differ significantly regarding mean age or gender.	Analyse feeding problems reported by caregivers Evaluate child feeding function.	Review of notes from feeding consultation.	Children with Down syndrome had difficulties with food capturing, chewing, and self-feeding functions. Frequency of self-feeding among children with Down syndrome was lower than other groups. Tongue thrust only seen in children with Down syndrome. Chewing and inappropriate 'form of meal' (relating to food texture e.g. pureed, mashed, soft) most frequently reported feeding problems in Down syndrome group.
Osaili et al., (2019)	83 individuals with Down syndrome[b] aged 2-19 years (55 males, 28 females) and their parents. Median age of 9 years, interquartile range 8 years. Participants split into age groups for some analyses: 2-4.99 years (n=13), 5-	Assess the physical status, feeding problems, parent-child feeding relationship and weight outcome in children and adolescents with Down syndrome in the UAE.	Questionnaires (standardised measures include STEP-CHILD screening tool for feeding problems and Child Feeding Questionnaire) and anthropometric measurements.	More children with Down syndrome aged 2-4.99 years reported to be dependent on caregivers when eating (84.60%) and to push food away or leave food (53.80%) than all other age groups. Total scores of STEP-CHILD screening tool for feeding problems highest in 2-4.99 years age group.

	8.99 years, 9-11.99 years, 12-19.99 years.			Chewing problems significantly associated with age and decreased as age increased.
Roccatello et al., (2021)	Parents of 34 children with Down syndrome[b] (median age 7 years, 12 female, 22 male) aged 1-16 years. Children grouped into 3 age groups: 1-6 years (n=13), 7-12 years (n=16), 13-16 years (n=5).	Investigate eating and lifestyle habits of children with Down syndrome.	Parent report questionnaire (which included recall of foods eaten across 3-day period), interviews with a dietician	73% of overall sample first introduced to complementary foods at mean age of 7.50 months (***SD***= 2 months). For remaining 27% of sample this occurred later (not specified) but delay explained as being due to disruption of surgery in early life. Within this 27% there were difficulties with food texture; 4 children only ate pureed foods until 3-4 years of age, 2 children had specific difficulties with meat, raw vegetables or fruit. Reported causes of delayed introduction of complementary foods were: lack of appetite and unwillingness to chew (50%), food refusal due to taste aversion (18%), finding foods hard to chew (18%). Large variation in age at which sippy cups/drinking glasses introduced (***M***=23 months, ***SD***=16 months). 21% of sample (n=7) able to independently drink by recommended age (24 months). 53% parents received specific

				nutrition counselling after initiating introduction of complementary foods, 47% received support from elsewhere including the internet, paediatricians and other health professionals, other parents. 52% parents reported difficulties with solid, hard consistencies e.g. raw vegetables, dried fruit, 48% reported difficulties with dual-textured meals such as pasta and beans. Liquid and puree/mashed foods easier to eat. 45% parents reported fibrous, sticky, or smelly foods to be difficult for their children. 85% of children completed entire portion sizes offered to them.
Rogers et al., (2021)	40 parents of children with Down syndrome aged 6 months- 5 years (***M***= 30.30 months, ***SD***= 15.70 months, 18 female, 22 male) and 40 parents of TD children (***M***=30.50 months, ***SD***=16.0 months, 18 female, 22 male) Groups pairwise matched for age and gender.	Explore feeding problems in young children with Down syndrome, related eating behaviours and parental feeding practices, compared to TD children.	Parent report questionnaire (standardised measures include Baby Eating Behaviour Questionnaire, Child Eating Behaviour Questionnaire, Montreal Children's Hospital Feeding Scale, Child	Children with Down syndrome had more feeding problems and solid foods introduced later (***M***= 6.20 months, ***SD***= 1.71 months). Feeding problems negatively associated with general appetite and breast milk duration but positively associated with slowness in eating during exclusive milk feeding. Correlation between feeding problems and food avoidant behaviours in both Down syndrome and TD group.

			Feeding Practices Questionnaire).	No relationship between feeding problems and parental feeding practices. Feeding problems not related to age of introduction to complementary foods.
Ross et al., (2019)	157 parents of children with Down syndrome aged 11-58 months (***M***= 31.50 months, SD not stated, 98 male, 59 female).	Investigate which textures were reported to be easy for the children to eat and which textures were reported to be difficult to eat.	Parent report questionnaire	As children got older, dry and hard textures more likely to be reported as easy. As they got older, lumpy, gooey, mushy, wet textures were less likely to be described as easy. Chewy and firm more often reported as difficult.
Ross et al., (2022)	111 parents and children with Down syndrome aged 11-58 months. Children characterised as texture sensitive (TS) or non-texture sensitive (NTS). Mean age of TS children with Down syndrome was 33.90 months, ***SD***= 13.10 months, mean age of NTS children with DS was 29.40 months, ***SD***= 13.10 months. 107 parents and TD children. Mean age of TD TS group was 28.90 months (***SD***= 8 months), mean age of NTS group	Understand mealtime behaviours and identify preferred food textures of children with Down syndrome, using commercial food products.	Video-recorded mealtimes	Children with Down syndrome less likely to interact with and touch the food overall, compared to TD group. Children with Down syndrome ate less of the food samples overall and were more likely to mouth/suck on food compared to TD group. TS children with Down syndrome showed low disposition towards foods that had loose particles, were grainy, dense, or hard; preferring products that were crispy and dissolvable. Children with Down syndrome who were not texture sensitive liked crisp and dissolvable products with an oily mouthcoating and that were salty and cheesy.

	was 28.20 months (***SD***=10.50).			
Shaw et al., (2003)	One child with Down syndrome aged 6 years (male).	Describe multi-disciplinary treatment approach to complex feeding disorder.	Case study/ clinical observations	Solid food introduced after intervention (aged 6 years), variety of foods, tastes and textures accepted, able to eat without distractions and complete meals within reduced time frame (30-minute intervals), able to self-feed at school, speech and language improved, weight increased in line with growth charts at 6 months after treatment.
Spender et al., (1996)	Parents of 14 children with Down syndrome aged 11-34 months [b] (8 female, 6 male). The children with Down syndrome were matched to data from TD children in a previous study on developmental age (assessed using the Bayley Scales of Infant Development)	Investigate various elements of feeding and related factors in infants with Down syndrome in comparison to a TD group.	Video recorded mealtimes during home visits, including research offering food. Assessed using Feeding Interaction Scale. the Schedule for Oral Motor Assessment. Parent interview. Measurement of weight and height Questionnaires (Bates 13-month questionnaire for child temperament; General Health Questionnaire for	Higher proportion of oral-motor dysfunction observed for children with Down syndrome than TD group. Children with Down syndrome had greater challenges regarding oral motor control and co-ordination of chewing and biting movements. Children with Down syndrome commonly retained food in the mouth without swallowing, showed food loss and were less likely to self-feed than TD comparison group. Seven (50%) mothers described their child with Down syndrome as a fussy eater. TD comparison group more accepting of different types of food.

			parental mental health).	Mealtimes did not significantly differ in length between groups. More parents of children with Down syndrome had sought advice regarding feeding problems Seven (50%) mothers of children with Down syndrome reported difficulties introducing complementary foods. Parents of children with Down syndrome more likely to display non-verbal controlling feeding practices.
Van Dijk and Lipke-Steenbeek (2018)	32 parents of children with Down syndrome aged 1-3 years (***M*****=** 21.53 months, ***SD*****=** 7.08 months, 23 males, 9 females).	Compare feeding problems reported by caregivers, in comparison to research conducted with TD children Compare reported feeding problems with observed feeding skills.	Interview, questionnaire (SEP- the Dutch version of the MCHFS, to measure feeding problems), video-recorded mealtime	Parents of Down syndrome group did not report higher feeding problems than TD norms. Significant association between total score on questionnaire and occurrence of 'refusal per second' and 'negative affect per second' during video-recorded mealtime. Children with Down syndrome displayed little self-feeding and high levels of tongue protrusion whilst chewing during the recorded mealtime. However, this was not correlated with parental report of feeding problems in the questionnaire.

Notes

[a] *Age range, mean and standard deviation for children with Down syndrome not reported*

[b] *Mean age for children with Down syndrome not reported*

[c] *Collins et al., (2003) and Collins et al., (2004) report data and findings collected from the same sample, at the same time.*

TD = typically developing

TS= texture sensitive

2.4. What is the complementary feeding period like for children with Down syndrome?

2.4.1 Age at starting complementary feeding

Seven studies commented on the timing at which parents began to offer complementary foods to their children. All of the studies which measured the age of introduction of complementary foods to infants with Down syndrome reported that for the majority of children this was happening later than six months of age. For example, Mohamed et al., (2013) found that the largest proportion of their sample of children with Down syndrome (42.70%) were introduced to complementary foods at seven months of age or later. In comparison, their TD siblings were most commonly introduced to complementary foods at four months of age (53.30%). Al-Sarheed (2005) reported the mean age of introduction to complementary foods was 7.73 months in their sample and 37.80% of the sample began complementary feeding after nine months. Similarly, Roccatello et al., (2021) reported that 73% of their sample were introduced to complementary foods at 7.50 months or later, with surgery in early life being a common reason for delaying beyond this age. Furthermore, Rogers et al., (2021) reported that children with Down syndrome were introduced to solid foods significantly later than age-matched TD children, at a mean age of 6.20 months compared to 5.49 months. Cochran et al., (2021) also reported the introduction of complementary foods occurring later for children with Down syndrome (6.20 months) compared to their TD siblings (5.10 months), but do not state whether this difference is statistically significant. They found that 60% of the parents/caregivers who had multiple children reported initiating the introduction of complementary foods at an older age than for their TD siblings. Parents recall introducing complementary foods ‘differently’ for their children with Down syndrome, with one parent

reporting that they adopted a more cautious approach than they had previously employed with their TD child.

Hopman and colleagues (1998) found that infants with Down syndrome were generally introduced to a variety of solid foods at a later age than TD children. For example, the infants with Down syndrome were first introduced to bread at 12 months, compared to 8 months for the TD group. Hard pieces of fruit were introduced at 30 months of age, compared to 12 months for the TD group. The first mixed meal which required chewing (described by the authors as containing vegetables and/or meat and/or starch) was introduced to infants with Down syndrome at 24 months, compared to 12 months for the TD group.

One case study (Shaw et al., 2006) described a child with Down syndrome (Martin) who was introduced to solid foods as late as 6 years of age, following extensive multi-disciplinary treatment to address his aversion to solid foods. Before treatment, Martin was exclusively fed PediaSure (a nutritional supplement drink) via a bottle. Martin very occasionally sampled some solid foods (e.g. ice cream or licking potato chips), but otherwise ate no solid food. His aversion had been exacerbated by previous traumatic medical experiences during attempts to introduce solid foods; such as choking, dehydration, lung infections and multiple blood tests.

2.4.2 Difficulty of different food textures

Nine papers commented on how children with Down syndrome were impacted by different food textures when starting to eat solid foods. Some textures were found to be particularly challenging, and some textures significantly easier than others, which impacted the overall diet of the children.

Spender et al., (1996) reported that children with Down syndrome aged 11-34 months had greater difficulties with all solid textures measured (puree, semi-solid, solid and crackers)

than a TD comparison group, however this difference was not statistically significant. Roccatello et al., (2021) described four children in their sample who ate only puree textures until three to four years of age and also noted that meat, raw vegetables, fruit and dual-textured meals were commonly reported as difficult to eat. Additionally, Ross et al., (2019) found that easier textures included creamy, crispy, crunchy, puree and soft foods, whereas more difficult textures included chewy and firm. The sample of children ranged from 11 to 58 months, and it was observed that as children grew older, some textures became less likely to be reported as easy to eat (such as wet, lumpy, mushy) and some textures such as dry and hard would become easier to eat.

In a later study, Ross et al., (2022) used a brief assessment tool to characterise children with Down syndrome as either texture sensitive (TS) or non-texture sensitive (NTS). The assessment tool included statements such as "my child prefers one texture of food" and "my child would rather drink than eat", and parents rated the frequency of which that statement was true for their child. Those in the TS group preferred foods with crispy or dissolvable textures and disliked foods which were grainy, dense or had loose particles. Children without texture sensitivity were found to tolerate a larger number of textures overall than children with texture sensitivity.

There was wide variation about the extent of problems related to textures reported across the studies. Field et al (2004) reported that 45% of the sample of children with Down syndrome showed food selectivity regarding different textures, whereas Anil et al., (2019) reported that 35.3% of children with Down syndrome demonstrated difficulty in transitioning to varied textured food. Some of the parents interviewed by Cochran et al., (2021) described the difficulties that their children with Down syndrome experienced with food textures, as demonstrated by Kristina: "He got really constipated at the beginning. And then that whole

spoon in his mouth, he didn't like that… Dry textures is a huge aversion and anything too chunky. He does gag sometimes if there's too many pieces, or too chunky, or too thick.". Hopman et al., (1998) also found that young children with Down syndrome consume more foods that require less chewing and eat foods requiring higher chewing skills such as meat, less often than TD children.

In contrast, Collins et al., (2003) described the majority of the children with Down syndrome aged 2-4.99 years were mostly able to cope with the usual family diet (and therefore did not need foods to be mashed or pureed) and there was a small group of parents in Cochran et al., (2021) who reported that their children were eating very well.

2.5. Contributing factors associated with increased or reduced feeding problems during complementary feeding

Twelve of the studies described feeding problems in infants with Down syndrome. For example, in Cochran et al., (2021) 45% of parents reported feeding difficulties when complementary foods were introduced to their child with Down syndrome. Spender et al., (1996) reported that seven out of 11 parents of children with Down syndrome described difficulties when introducing complementary foods. Feeding problems were defined and measured differently across studies, and some feeding problems appear to be interrelated.

2.5.1 Oral-motor Skills

Hopman and colleagues (1998) state that delayed oral-motor skills can be both a cause and consequence of delayed introduction to solid foods. This was reiterated by Roccatello et al., (2021) who noted that a 'lazy' chewing pattern led to delays regarding the introduction of complementary foods in 45% of children with Down syndrome. Oral-motor delays were

linked to food loss, holding food in the mouth longer without chewing, swallowing before food has been chewed sufficiently, incomplete swallowing, difficulties taking an active bite, texture selectivity and choking or vomiting (Anil et al., 2019, Shaw et al., 2006; Spender et al., 1996). Furthermore, in the case study described by Shaw et al., (2006), Martin's ability to tolerate increasingly difficult and varied food textures was linked to the development of his oral motor skills. However, when infants with Down syndrome are given simpler textures e.g. soft, pureed foods over a prolonged period of time, their oral-motor development is hindered. Field et al., (2003) report that 82% of their sample of children with Down syndrome had oral-motor delays, and also that a large proportion of the sample ate only pureed or low-textured foods. In some cases, children would refuse to chew despite having the ability to do so, and so their diets consisted mainly of foods which didn't require chewing. In their discussion, the authors hypothesised that these children may have developed an aversion to chewing because they associate it with earlier experiences of gagging, vomiting, or choking.

2.5.2 Gross and Fine Motor Skills

Gross and fine motor skills were reported to affect various elements of self-feeding e.g. eating with fingers or spoon, drinking using straws, not spilling food during meals (Anil et al., Collins et al., 2003; 2019, Shaw et al., 2006; Spender et al., 1996). Children with Down syndrome were also found to have increased difficulties using utensils (compared to TD controls) and required specific utensils and positions whilst feeding and eating (Anil et al., 2019). Importantly, during parent interviews, Cochran et al., (2021) identified a theme which highlighted relationships between acquisition of gross motor and feeding milestones, for example Julia described her son beginning to crawl at 10 or 11 months old, stating it was also "about the time he started getting better at eating." When reflecting on their results in their discussion, Collins et al., (2003) highlighted how a child's ability to cut food into small

mouthfuls using a knife and fork may also indirectly impact chewing ability, explaining that small mouthfuls will be much easier to chew and swallow.

2.5.3 Sensory Difficulties

Oral hypo- and hypersensitivity were also seen to lead to feeding problems. Anil et al., (2019) observed that children with Down syndrome in their sample showed poor or reduced awareness of food on lips and tongue and stuffing of food in the mouth and this was attributed to oral hyposensitivity. Additionally, Ross et al., (2022) described that the children with Down syndrome in their study were more likely to mouth or suck on food than TD children. They also noted several behaviours amongst their sample which are associated with oral hypersensitivity e.g. being less likely to touch food with their hands, bite into the food, chew/munch on food or touch food to lips or tongue. In their results, Anil et al., (2019) found that sensory difficulties hindered eating development by making it more difficult for children with Down syndrome to transition to food of different textures.

2.5.4. Parental feeding practices and their impact on eating development

Eight studies described parental feeding practices and how they may differ for children with Down syndrome during the period of introducing solid foods. Cochran et al., (2021) found that some parents approached introducing complementary foods to their child with Down syndrome differently than their TD siblings, exercising more caution. One participant, Donna, explained that she became fearful of introducing complementary foods to her child following feeding problems in the child's early life, and as a result she introduced complementary foods to her child with Down syndrome nine months later than she did with her TD children. Similarly, when discussing their findings Collins et al., (2003) and Shaw et al., (2003) reflected that parental anxiety (e.g. fear of choking, weight loss or dehydration)

may have led to parents restricting the types of food they offer their child, or prevented them from addressing existing feeding routines which are problematic, including an overreliance on foods of age inappropriate textures or negative behavioural responses to solid foods.

In the study carried out by Osaili et al., (2019), 67.10% of parents reported feeling either very or fairly concerned about their child with Down syndrome becoming overweight. Parental concern about child weight was significantly associated with restrictive feeding behaviours. Interestingly, Barreiro et al., (2021) stated that parents of children with Down syndrome reported higher perceived responsibility regarding their child's weight but lower concern about child weight in comparison to a previously studied control group. The authors also found a significant positive correlation between perceived child weight and concern for child weight. Additionally, in Rogers et al., (2021) parents of children with Down syndrome scored significantly higher than parents of TD children for monitoring feeding behaviours, and lower for involvement, emotional regulation and teaching about nutrition, but parental feeding practices were not significantly correlated with children's eating behaviours. Spender et al., (1996) found that parents of children with Down syndrome demonstrated more controlling non-verbal behaviours during mealtimes than a TD comparison group.

2.6. Discussion

This scoping review aimed to identify and synthesise research which has explored the early eating experiences of children with Down syndrome, in relation to the complementary feeding period and eating of solid foods during this time. Eighteen studies met the inclusion criteria and were subsequently included in the review. Overall, the results of this review suggest that the complementary feeding period looks different for children with Down syndrome than TD children.

Children with Down syndrome tend to be introduced to solid foods at a later age than TD children and WHO recommendations. There are several factors which may influence this, including delayed oral-motor development and chewing abilities, parental anxiety (e.g. regarding risk of choking or weight loss) and surgical or medical intervention in early life which can disrupt early feeding development and also lead to food aversions (Cochran et al., 2022; Hopman et al., 1998; Roccatello et al., 2021; Rogers et al., 2021). Once complementary feeding has begun, children with Down syndrome may progress to more challenging textures at a slower rate than TD children and development of self-feeding skills may be delayed. These findings are in agreement with the results of a recent review conducted by Nordstrom et al., (2020) focusing on nutrition in children and adolescents with Down syndrome, which also reports that as required feeding and eating skills become more advanced, children with DS show increasing delays in feeding abilities and self-feeding skills compared to TD peers.

Another finding from the present review is that during the period of complementary feeding, children with Down syndrome are more likely to experience feeding problems than TD children. Examples of feeding problems reported during this time include difficulties with chewing and swallowing, difficulty manipulating food whilst it is in the mouth, food loss, holding food in the mouth without chewing, swallowing before food has been chewed sufficiently, incomplete swallowing, choking, vomiting, picky eating, food aversions, reduced awareness of food on lips and tongue and stuffing of food in the mouth. Some feeding problems can be seen to be secondary to other factors. For example, underlying oral-motor delays, and texture sensitivity appear to be contributing factors which may influence the presence of feeding problems during complementary feeding. This means that these are key areas which could be targeted for intervention at an early age to limit the development of secondary feeding problems. This is especially pertinent in light of recent research conducted

by Cañizares-Prado et al., (2022) which identified difficulties regarding the introduction of new flavours for 60% of their sample of adults with Down syndrome and difficulties introducing new consistencies for more than 75% of the sample. The authors also describe poor chewing amongst the participants, and that these factors led to limitations in their diets. This demonstrates that challenges regarding chewing, flavours and textures can be long lasting and may not improve over time, highlighting the importance of monitoring and addressing any feeding problems as early as possible to avoid the potential of consolidating problems that emerge in childhood.

Another finding from the present review is that parental feeding practices differ for children with Down syndrome compared to TD children. Parents of children with Down syndrome report employing more restrictive, cautious or controlling feeding practices and more concern about their child becoming overweight (Barreiro et al., 2021; Cochran et al., 2021; Collins et al., 2003; Osaili et al., 2019; Rogers et al., 2021; Shaw et al., 2003; Spender et al., 1996). Some parental feeding practices may arise as a consequence of feeding problems. Parents may limit the difficulty of textures that they offer their child out of fear or anxiety regarding risk of choking or vomiting, which may have developed as a consequence of previous adverse experiences resulting from feeding problems. However, limiting the difficulty of the textures that they offer their child may inhibit the development of their child's chewing abilities (Schwartz et al., 2011). This demonstrates the importance and necessity of readily available, timely feeding support for parents throughout the complementary feeding period.

It can be incredibly difficult for parents/caregivers when their child with Down syndrome is experiencing problems with feeding and swallowing, and it is important that parental concerns and wellbeing are taken into account when a care plan is being developed (Arslan, 2022). However, families of infants with Down syndrome are a group which are already

noted to have difficulties accessing feeding and medical support that meets their needs (Hielscher et al., 2022; McGrath et al., 2011). To improve feeding support services moving forwards, early and ongoing guidance and feeding support from health professionals is vital for parents throughout the complementary feeding period. This should be available before the first complementary foods are introduced and throughout this period to give parents an opportunity to express any concerns (e.g. regarding safe swallowing), and a place to seek reassurance. This would facilitate early intervention regarding the progression of texture difficulties (if necessary), prevent further delays and encourage optimum development of eating abilities. Garcia et al., (2019) have highlighted that parents of TD children report unmet needs and a desire for further information regarding complementary feeding for their child. Given the additional feeding challenges and developmental delay that can be associated with Down syndrome, it is of particular importance that families of children with Down syndrome are appropriately supported regarding introducing complementary foods to their child.

The final aim of the present review was to identify any gaps in this area of research. Only 18 studies met the inclusion criteria for this review, which demonstrates the paucity of research which has explored the early eating experiences and complementary feeding period for children with Down syndrome. When considering the studies which have been included in this review, several gaps become evident. Only one study (Cochran et al., 2022) included health professionals who support families of children with Down syndrome. In light of the findings of this review, this is a valuable area which could be further explored, particularly around support offered to parents who experience challenges during the complementary feeding period. There were only two studies included in this review which explore interventions for children experiencing feeding problems during complementary feeding, and their outcomes (Cochran et al., 2022; Shaw et al., 2006). Furthermore, there is little research

which has explored in-depth how parents have adapted to any challenges around feeding in this period. There is also no longitudinal research examining early eating experiences and complementary feeding for children with Down syndrome. Furthermore, whilst several of the included studies describe texture sensitivities and how they may impact feeding, there is no research which has explored how texture sensitivities develop over time in Down syndrome, nor how they may be effectively addressed. For example, although some studies reported that parents may have offered their children developmentally 'easier' textures, there is little rich data around the concerns of parents, where/if they sought support throughout this time, and what strategies they tried to employ in response to difficulties. These gaps represent valuable areas that future research could explore.

It is important to consider the limitations of the studies included in this review. One limitation that can be identified is that many of the studies include relatively small sample sizes, although this can be a common practical difficulty when conducting research with populations with developmental disabilities. Despite this, there is agreement between the studies regarding the key findings of this review. There is large variation in terms of how feeding will be affected for children with Down syndrome, and it may be the case that parents of children who have experienced more problems with feeding may be more motivated to participate in research than parents of children with Down syndrome who have had a relatively unproblematic feeding journey. Six of the 18 articles included in the review recruited their participants with Down syndrome via feeding clinics or another medical setting relevant to feeding intervention, and this may have influenced the studies' findings, although the findings of these studies do not vastly contrast the findings of studies whereby participants were recruited via different methods.

Furthermore, there is a lack of consistency regarding how feeding problems are both defined and assessed across the different studies included in the review. For example, Anil et al., (2019) developed a new questionnaire to assess feeding problems as part of the study protocol, whereas van Dijk and Lipke-Steenbeek (2018) and Rogers et al., (2021) used a validated feeding problem questionnaire (MCHFS; Ramsay et al., 2011). This presents challenges when attempting to assimilate and compare results across different studies. However, Anil et al., (2019) conducted a small pilot study to validate their measure, and their study findings are in agreement with Rogers et al., (2021) which identified a higher number of feeding problems for children with Down syndrome than TD children. Additionally, alongside the newly developed questionnaire, Anil et al., (2019) used the Feeding Handicap Index for Children (Swapna and Srushti, 2017) which assessed the extent to which parents felt feeding problems had a handicapping effect on their child. The latter is a previously validated measure and across both questionnaires children with Down syndrome scored significantly higher than TD controls, indicating a greater presence of feeding problems.

Regarding limitations of the review process itself, the selection of studies for inclusion in the review presented challenges. It was difficult to identify an age range of study participants and determine a cut off age whereby studies would be describing childhood eating generally, and not the complementary feeding period specifically. The WHO suggest that the complementary feeding period lasts from six months to two years of age in TD children. Research suggests that this can occur later for children with Down syndrome, but given the sparsity of this research area, it is not known definitively how much later or in which percentage of children it occurs later. Therefore, it was difficult to determine a cut-off point in terms of age, whereby children would be expected to be developmentally beyond the complementary feeding period. The majority of the studies included in the review describe children with Down syndrome in the pre-school years. Studies with relevant methodology

which included children older than this were included if they made reference to the complementary feeding period or the eating/introduction of solid foods specifically. Studies which included participants with wide age ranges were included in the review if study results were presented separately for the younger and older children in the sample.

2.6.1 Conclusions

Children with Down syndrome tend to be introduced to complementary foods later than TD children and WHO recommendations. Once the complementary feeding period begins, progression to more challenging food textures occurs at a slower rate than TD and the development of self-feeding skills may be delayed in comparison. Parents may limit difficulty of textures out of fear and anxiety of choking or vomiting. Throughout the complementary feeding period children with Down syndrome are more likely to experience feeding problems than TD children. Parents of children with Down syndrome employ more restrictive, cautious or controlling feeding practices and are more concerned about their child becoming overweight than TD siblings and peers.

2.6.2 Implications

Written guidelines for the introduction of complementary foods that are specific to children with Down syndrome are required. Parents should receive guidance regarding the introduction of complementary foods before this begins and should have ongoing support from health professionals during the complementary feeding period. This would allow parents to express concerns and facilitate early intervention if problems occur. This may also help parents who are anxious about introducing complementary foods to their child with Down syndrome to feel more confident and attempt to introduce them earlier. Future research should aim to explore the complementary feeding period for children with Down syndrome in

further detail. In particular, how texture sensitivities develop over time, how parents adapt to feeding challenges, their concerns during this time, where they access support and to what extent support received meets their needs.

Chapter 3. Longitudinal predictors of feeding problems and weight in children with and without Down syndrome- Time 1

3.1. Introduction

There are several factors which could lead to the development of feeding problems and weight outcomes in children with Down syndrome (see Chapters 1 and 2 for a full exploration). Some of these include eating behaviours, delays in motor skills and sensory processing (Birch and Ventura, 2009; Blissett and Fogel, 2012; Field et al., 2003; Rogers et al., 2021; Slining et al., 2010). For example, research conducted by Rogers et al., (2021) found that children with Down syndrome who scored higher on a measure for feeding problems were perceived by parents to have reduced enjoyment of solid food and be less responsive to it, and to be fussier, more satiety responsive and eat more slowly. Feeding problems such as food selectivity, swallowing without chewing sufficiently, and continued eating in the presence of food can make weight management more difficult for children with Down syndrome by impacting the types and quantities of foods they consume (Ptomey et al., 2023).

Delays in the development of motor skills (commonly reported amongst children with Down syndrome; Malak et al, 2015) can limit self-feeding, effective chewing patterns and the ability to manipulate food in the mouth, which can in turn lead to restriction of food textures offered to children with Down syndrome (Anil et al., 2019; Field et al., 2003; Roccatello et al., 2021; Ross, 2023). Furthermore, delayed motor skill development is associated with being overweight and high subcutaneous fat levels in TD children (Slining et al., 2010). Oral sensory processing may impact nutrition and weight for children with Down syndrome by reducing the number of textures and foods that the child will eat (Cochran et al., 2022; Field

et al., 2023; Ross et al., 2022). For example, in a study conducted by Roccatello et al., (2021), children with Down syndrome were reported to have difficulties with hard textures, meals with dual textures and sticky, smelly foods. This limited intake of foods such as raw vegetables, dried fruit, meat, and fish.

There is some evidential support for the suggestion that parental feeding practices may be linked to child weight outcomes in both Down syndrome and TD children (see Chapter 1 for an exploration of TD literature). For example, research by O'Neill et al., (2005) found that parents employed different feeding practices with their child with Down syndrome than with their TD child and that these different practices were correlated with differences in child body mass index (BMI). Parents reported greater use of restriction, greater feelings of responsibility for feeding and concern about child weight status, and lower pressure to eat for children with Down syndrome than for their TD siblings. Additionally, controlling parental-feeding practices (namely restriction) were associated with higher child BMI and were employed more frequently for children with Down syndrome than their TD siblings (O'Neill et al., 2005). Similarly, more recent research has found that parents of children with Down syndrome reported more monitoring of feeding behaviours, and this is related to increased child weight (Barreiro et al., 2022; Osaili et al., 2019; Polfuss et al., 2017). However, the impact of parental feeding practices and perceptions of the child's weight status on the development of obesity over time in children with Down syndrome has not been fully explored (Bertapelli et al., 2016).

Existing research suggests that there are differences for children with Down syndrome compared to TD children in relation to weight related factors and feeding problems, but research in this area is largely correlational and cross-sectional, meaning that causality and change over time cannot be examined. As such, more longitudinal research into predictors of

feeding problems and weight in infants with Down syndrome is required, to better understand the developmental trajectory of this population regarding feeding and weight outcomes, and to identify areas to target for early intervention.

3.1.1. Aims

This study aimed to build upon previous cross-sectional research conducted by Rogers et al., (2021) whereby relationships between feeding problems, eating behaviours and parental feeding practices were explored in children with Down syndrome aged 6-months to 5 years. The present study aimed to explore potential longitudinal predictors of feeding problems and weight outcomes in young children with Down syndrome, including how this is different to TD children. Potential predictors included infant milk feeding behaviour, child eating behaviour, sensory processing, parental feeding practices, motor skills and mealtime behaviours. Data collection was undertaken at two timepoints and aimed to explore how feeding, weight and potentially related factors change over time. Parent interviews conducted at the second timepoint (Time 2, Chapter 6) explored feeding support needs, feeding problems and eating development for children with Down syndrome.

At Time 1, analysis aimed to identify how children with Down syndrome and TD children may differ regarding feeding problems, weight and other exploratory variables relevant to eating and weight. This research also aimed to understand which factors are related to feeding problems and weight for each group, and to identify key differences. As such, at Time 1, cross-sectional data is presented and relationships between feeding problems and weight will were explored.

The primary aim of Time 2 data analysis was to identify potential predictors of feeding problems and weight for each group. Time 2 analysis also aimed to explore how feeding

problems, weight and other relevant factors changed over time, including whether group differences remained stable between Time 1 and Time 2. Therefore at Time 2 (Chapter 4) longitudinal data will be presented, and potential predictors of feeding problems and weight will be investigated.

3.2. Method

3.2.1 Design

A mixed-methods, longitudinal, between-groups design was used whereby data was collected at two time points roughly seven months apart. Quantitative and qualitative data was collected using questionnaires, anthropometric measurements, video-recorded mealtimes and interviews. At both timepoints there were two groups: whether participants were a parent of a child with a diagnosis of Down syndrome, or the parent of a TD child (control group). At Time 1, outcome measures were feeding problems and weight and exploratory variables included children's eating behaviours during exclusive milk feeding, eating behaviours after the introduction of solid food, sensory processing, parental feeding practices, gross and fine motor skills and mealtime behaviours. At Time 2, an additional variable of food texture sensitivity was added, and data analysis aimed to identify variables which could predict feeding problems and weight. Semi-structured interviews were also conducted at Time 2 to understand how parents perceive feeding problems, potential determining factors, any consequences along with the support needed.

3.2.2 Participants

Parents of 49 children aged between 12 and 51 months participated in the study. Initial target sample size was parents of 30 children with Down syndrome and 30 TD children. This was determined based on practical considerations such as feasibility of completing data collection

across two time points for the whole sample within the PhD timeframe. Target sample size was also informed by previous literature, and the achieved sample size is larger than or similar to many studies which have included young children with Down syndrome (Anil et al., 2019; Ooka et al., 2012; Spender et al., 1996; van Dijk and Lipke-Steenbeek, 2018).

Parents were eligible to take part if they lived in the UK and had a child who was older than 12 months but younger than 5 years at Time 1 and who either had a diagnosis of Down syndrome or who did not have a diagnosis of a developmental disorder which may affect eating development. Data was collected from 46 parents; three parents participated with two eligible children (in the TD group) and 43 parents participated with one eligible child. All of the parents identified as female and described themselves as the child's biological mother. Further demographic and background information is shown in Table 3.1. All 46 parents completed the online questionnaire, 30 responses were recorded for the Vineland-3 (15 children with Down syndrome, 15 TD) and video-recorded mealtimes were conducted for 23 children (nine children with Down syndrome, 14 TD).

The group of children with Down syndrome (n=25) consisted of 15 males and 10 females aged 12 months to 51 months (*mean age*= 28.60 months). The TD control group (n=24) consisted of 14 males and 10 females aged 12 months to 51 months (*mean age*= 31.33 months). The two groups did not significantly differ in mean age. Of the children with Down syndrome, eight (32%) received the diagnosis of Down syndrome before birth and 14 (56%) were diagnosed with Down syndrome after birth, data was missing for three children with Down syndrome. Sixteen (64%) of the children with Down syndrome were diagnosed with a cardiac anomaly shortly after birth and three children underwent surgery early in life to address this. One male with Down syndrome had a comorbid diagnosis of Klinefelter

syndrome (i.e. an extra X chromosome). Comorbid diagnoses amongst the TD children include milk protein allergy (***n***=1) and dairy intolerance (***n***=1).

Table 3.1. *Descriptive demographic and background information*

	Group with Down syndrome (n=25) N (%) / mean (SD)	**Typically developing group (n=24)** N (%) / mean (SD)
Respondent ethnicity- N (%)		
White British	17 (68)	14 (58)
Other White	4 (16)	5 (21)
Asian Indian	1 (4)	0
Black African	0	1 (4)
Other Black	0	1 (4)
Mixed (not specified)	1 (4)	2 (8)
Missing data	2 (8)	1 (4)
Respondent education- N (%)		
Left school between 13 and 16 years	1 (4)	0
Further secondary education (16-18 years)	1 (4)	5 (21)
Secretarial/technical qualification	0	1 (4)
University course not completed	2 (8)	0
Professional qualification without degree	2 (8)	0
Degree	10 (40)	12 (50)
Further degree	9 (36)	6 (25)
Annual household income- N (%)		
£20,000-£29,000	9 (36)	4 (17)
£30,000-£39,000	0	1 (4)
£40,000-£49,000	3 (12)	1 (4)
£50,000-£59,000	2 (8)	3 (13)
£60,000-£69,000	2 (8)	4 (17)
£70,000-£79,000	2 (8)	3 (13)
£80,000 or more	7 (28)	8 (33)
Respondent BMI- mean (SD)	25.5 (7.7)	26.02 (5.94)
Child gender- N (%)		
Male	15 (60)	14 (58)
Female	10 (40)	10 (42)
Child ethnicity- N (%)		
White British	16 (64)	17 (71)
White Irish	1 (4)	0
Other White	4 (16)	2 (8)

Asian Indian	1 (4)	0
Other Asian	0	1 (4)
Black African	0	1 (4)
Mixed White and African	0	1 (4)
Mixed Ugandan/German	0	1 (4)
Mixed (not specified)	3 (12)	1 (4)
Childcare setting- N (%)		
Pre-school	2 (8)	4 (17)
Nursery	16 (64)	5 (21)
Nanny	1 (4)	1 (4)
Childminder	1 (4)	10 (42)
No childcare setting reported	5 (20)	4 (17)
Childcare frequency N (%)		
Part-time	17 (68)	17 (71)
Full-time	2 (8)	3 (13)
Missing data	1 (4)	0
Pre-natal plan to milk feed- N (%)		
Breastfeed	20 (80)	19 (79)
Formula	0	1 (4)
Combination of breastfeeding and formula	2 (8)	3 (13)
Unsure/hadn't decided	2 (8)	1 (4)
Missing data	1 (4)	0
Primary method of milk feeding from birth to six months- N (%)		
Breastfeed	11 (44)	15 (63)
Expressed breastmilk via bottle	2 (8)	1 (4)
Formula	1 (4)	3 (13)
Combination of breastfeeding and formula	5 (20)	5 (21)
Combination of expressed breastmilk via bottle and formula	1 (4)	0
Via NG tube	3 (12)	0
Combination of breastfeeding, expressed breastmilk via bottle, formula and NG tube feeding	1 (4)	0
Missing data	1 (4)	0

3.2.3 Measures

An online questionnaire was constructed to collect data about infant feeding behaviour, child eating behaviour; sensory processing and parental feeding practices. At the beginning of the online questionnaire, demographic information for both parent and child were collected (Table 3.1). Participants then completed several questions about infant feeding- relating to their plans to milk feed before birth, primary method of milk feeding during the first six months, and the additional methods in which their child had previously received milk (e.g. expressed breast milk in a bottle, formula, NG tube feeding), age of introduction to solid foods and whether/how their child currently receives milk. Participants were then asked to enter current height and weight details for themselves and their child. Participants then completed the following standardised measures:

Montreal Children's Hospital Feeding Scale (MCHFS, Ramsay et al., 2011)

The MCHFS is a 14-item specific measure of feeding problems which is completed by parents about their child. The MCHFS has been validated for use with children aged 6-months to 6-years (Ramsay et al., 2011). Each question is answered on a 7-point Likert scale where response options vary according to the question. For example, for the question 'When does your child start refusing to eat during mealtimes? Response options range from 'at the beginning' (1) to 'at the end' (7). For the question 'How are your child's chewing/sucking abilities?' response options range from 'good' (1), to 'very poor' (7), and for the question 'How does your child's feeding influence your relationship with him/her', response options were 'very negatively' (1), to 'not at all' (7). Total scores range from 14 to 98. A raw score of 45 or above indicates the presence of feeding problems. Scores between 45 and 52 indicate mild feeding problems, whereas scores ranging from 53-58 indicate moderate feeding problems and 59 or above indicate severe feeding problems are present. The MCHFS has

been demonstrated to have moderate-to-good internal consistency (from .48 to .87) by Ramsay et al., (2011). Rogers et al., (2021) demonstrated very good internal consistency for MCHFS total score (Cronbach's α was .84) in previous research with young children with Down syndrome. In the present study, the MCHFS total score achieved moderate internal consistency (Cronbach's α was .75).

Baby Eating Behaviour Questionnaire (BEBQ, Llewellyn et al., 2011)

The BEBQ aims to assess infant appetite during the period of exclusive milk-feeding. Participants completed the BEBQ retrospectively. Participants were required to consider the extent to which each statement applied to their child's feeding style at a typical daytime feed during the period of exclusive milk-feeding and select an answer from a 5-point Likert scale which ranges from never (scored as one), rarely (scored as two), sometimes (scored as three), often (scored as four) and always (scored as five).There are 18 items on the BEBQ and five subscales: enjoyment of food (four items), food responsiveness (six items), slowness in eating (four items), satiety responsiveness (three items) and general appetite (one item,). A mean score is calculated for each subscale and higher scores for each subscale indicate greater expression of that eating behaviour. Examples of items on the BEBQ include 'My baby seems contented while feeding', 'My baby gets full up easily', 'My baby is always demanding a feed' and 'If given the chance, my baby would always be feeding'. The BEBQ has been shown to have good internal reliability by Llewellyn et al. (2011) whereby Cronbach's α ranged from .73 to .81. At Time 1, Cronbach's α for BEBQ subscales ranged from .60 to .89.

Children's Eating Behaviour Questionnaire (CEBQ, Wardle et al., 2001)

The CEBQ assesses childhood eating behaviours (relating to solid foods) and is completed by parents on behalf of their children. There are 35 items which describe eating behaviours such as 'my child loves food', 'my child eats more when annoyed' and 'my child eats less when upset'. Parents rate the extent to which statements are true of their child using a 5-point Likert scale where response options range from 1 (never) to 5 (always). There are eight subscales in total and four relate to food approach behaviours: food responsiveness (five items), enjoyment of food (4 items), desire to drink (three items) and emotional overeating (four items). Four subscales assess food avoidant behaviours: satiety responsiveness (five items), slowness in eating (four items), emotional undereating (four items), food fussiness (six items). Mean scores are calculated for each subscale and higher scores indicate that children display that eating behaviour to a greater extent. The CEBQ has been shown to have good reliability when used with children from 12 months of age (Rogers and Blissett, 2017; Shneider-Worthington et al., 2020). The CEBQ had good internal consistency in the present study, with Cronbach's α ranging from .77 to .94.

Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman & Holub, 2007)

The CFPQ is a self-report questionnaire which assesses parental feeding practices. There are 49 items in total which consist of 12 subscales. To assess each subscale, questions describe specific attitudes or behaviours about child feeding and parents select the response option that is most appropriate. Response options range from never (1) to always (5) or disagree (1) to agree (5). The subscales are monitoring (four items), emotional regulation (three items), child control (five items), encourage balance and variety (four items), healthy environment (four items), involvement (three items), pressure to eat (four items), restriction for weight control

(eight items), food as reward (three items), restriction for health (four items), teaching about nutrition (three items) and modelling (four items). Higher mean scores for each subscale indicate greater prevalence of the feeding practice. Examples of questions include "How much do you keep track of the sweet foods (sweets, ice cream, cake, biscuits, pastries) that your child eats?", "Do you give this child something to eat or drink if s/he is upset even if you think s/he is not hungry?", and "I try to eat healthy foods in front of my child, even if they are not my favourite". The CFPQ was initially developed for use with children between the ages of two and eight years but it has previously been used with children from 12 months of age (Rodgers et al., 2013; Rogers et al., 2018, 2021). The CFPQ subscale scores have moderate to high internal consistency (with Cronbach's α ranging from .58 to .81) as assessed by Musher-Eizenman and Holub (2007). In the present study, Cronbach's α ranged from .52 to .79. CFPQ subscales which had low internal consistency at Time 1 include encouraging balance and variety (Cronbach's α was .52), and food environment (Cronbach's α was .54).

Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002)

The ITSP is a 48-item measure of sensory processing suitable for completion by parents of children up to 36 months of age. The ITSP was only completed by parents in the sample whose children were aged 36 months or younger. The ITSP consists of six sections: general processing (three items, total scores ranged from 3-15), auditory processing (10 items, 10-50), visual processing (seven items, 7-35), tactile processing (15 items, 15-75), vestibular processing (relating to detection of movement and gravity; six items, 6-30) and oral sensory processing (seven items, 7-35). A raw score is produced for each section and then within this, individual items relate to four specific sub-domains of behaviour: low registration (the degree to which the child misses sensory input; 11 items, 11-55), sensation seeking (14 items, 14-

70), sensory sensitivity (11 items, 11-55) and sensation avoidance (12 items, 12-60). Example questions include 'my child tries to escape from noisy environments', 'my child does not recognise self in the mirror', 'my child is unaware of food/liquid left on lips'. Parents are asked to select the response that best describes the frequency with which their child does a described behaviour. Response options are 'almost always' (90% of the time or more, scored as 1), 'frequently' (75% of the time or more, scored as 2), 'occasionally' (50% of the time or more, scored as 3), 'seldom' (25% of the time or more, scored as 4), or 'almost never' (10% of the time or less, scored as 5). As such, higher total scores indicate that a child demonstrates that sensory behaviour less than the norms (hyposensitivity) and lower scores indicate that a child demonstrates that sensory behaviour more than others (hypersensitivity). The ITSP subscales have been shown to have overall adequate internal consistency (Cronbach's α for subscales and quadrants ranged from .42 to .79, Eeles et al., 2012). In the present study, the visual processing subscale demonstrated poor internal consistency- Cronbach's α was .39. However, all other subscales achieved moderate to very good internal consistency, ranging from .66 to .89.

Short Sensory Profile 2 (SSP-2, Dunn et al., 2014)

The SSP-2 follows a similar format to the ITSP but it is suitable for use with children older than 36 months and younger than 15 years old. As such, it was only completed by the parents in the sample whose child was older than 36 months. The SSP-2 consists of 34 items split into two sections: sensory processing (14 items, total scores ranged from 0-70), and behavioural (responses associated with sensory processing; 20 items, 0-100). The SSP-2 produces scores for the same subdomains as the ITSP: registration (eight items, 0-40), sensation seeking (seven items, 0-35), sensation avoidance (nine items, 0-45) and sensory sensitivity (10 items, 0-100). Response options are similar to the ITSP but are scored in the opposite direction; 'almost always' is scored as 5 and 'almost never' is scored as 1. Parents

are also given the option of selecting 'does not apply', which was initially scored as 0 and then coded as missing data for analysis purposes. In contrast to the ITSP, higher total scores indicate that the child demonstrates the sensory behaviour more than others (hypersensitivity) and lower scores indicate hyposensitivity compared to age norms. Example questions include: 'my child tunes me out or seems to ignore me', 'my child loses balance unexpectedly when walking on an uneven surface', 'my child resists eye contact from me or others' and 'my child struggles to pay attention'. Simpson et al. (2019) found SSP-2 subscale internal consistency ranged from .69 to .83 when used with children with Autism aged 4-11 years. In the present study, SSP-2 subscales achieved very good internal consistency (Cronbach's α ranged from .88 to .95).

Vineland Adaptive Behaviour Scales, third edition (Sparrow et al., 2016)

The Vineland-3 measures adaptive behaviours across several domains: communication, daily living, social skills and relationships, motor skills and problem behaviours. Internal consistency across all Vineland-3 domains is excellent, with Cronbach's α ranging from .94 and .99 (Pepperdine and McCrimmon, 2017). For the present study, only the motor skills domain was used, and this was via the comprehensive parent/caregiver form. The Vineland-3 is suitable for use with individuals aged 1-99 years and has previously been used with children with developmental disabilities (Odeh et al., 2022). Previous versions of the Vineland have also been frequently been used with children with developmental disabilities (Fidler et al., 2005; Licari et al., 2020). The motor skills domain of the Vineland-3 consists of 43 items which assess gross motor skills and 34 items which measure fine motor skills. Statements describe specific behaviours and parents must consider whether their child can perform that behaviour without help or reminder. Response options are 'usually/often' (2), 'sometimes' (1) and 'never' (0). If parents are unsure or are estimating their answer, there is a tick box to indicate this. Questions begin describing behaviours suitable for younger children

(0-1 years on the gross motor scale and 0-3 years on the fine motor scale) and gradually become more complex, describing behaviours that may be appropriate for children up to nine years old. Parents continue answering each question until either they reach the end of the questions or they have answered with five 'never' responses in a row. Basal and ceiling scores are calculated as the participant progresses through the questionnaire. To achieve this in the present study, LH read questions to parents during visits, or over the phone, instead of participants completing the Vineland-3 as part of the online questionnaire. A raw score is then calculated which is converted to a standardised age-norm v-score for each subdomain of gross and fine motor skills. A combined overall standard motor score is then calculated using both of these scores to give an indication of overall motor skill proficiency. For subdomain v-scores (fine and gross motor), the mean score is 15, and standard deviation is 3. As such, a score of 15 denotes gross/fine motor skill proficiency that is similar to the typical population of the same age. Scores of 12 or lower signify delayed motor skill development. For overall standard motor score, the mean score is 100 and standard deviation is 15. Scores of 85 or lower represent delayed overall motor skill proficiency compared to the typical population of the same age. At Time 1, overall standard motor skill scores assessed using the Vineland-3 demonstrated moderate internal consistency (Cronbach's α was .73).

Examples of questions which assess gross motor skills are 'rolls over from his/her back to his/her stomach', 'crawls up stairs' and 'squats or bends down to pick something up without falling'. Questions which assess fine motor skills include 'takes an object out of a box or other container', 'unwraps small objects', 'opens and closes scissors with one hand, does not have to cut with them'.

3.2.4 Procedure

Ethical approval to conduct the study was granted by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (approved protocol number: aLMS/PGT/UH/04883(4)). Time 1 data collection was conducted between July 2022 and November 2022 and Time 2 data collection occurred between February 2023 and August 2023. A purposive sampling method was used to recruit participants and information about the study was shared with relevant local services (including family centres, libraries and children's groups), local and national charities and support groups used by parents of children with and without Down syndrome. Details of the study were also shared via social media and physical copies of study flyers were distributed throughout the local area. Participants were encouraged to contact the lead researcher (LH) by email if they were interested in taking part in the study or if they would like further information. Participants were asked whether they would prefer hybrid (partially in-person) or completely virtual participation. Participants were eligible for partially in-person participation if they lived two hours or less from the researcher. Following this, participants were sent a link to a Qualtrics webpage which contained the participant information sheet and an opportunity to provide informed consent before proceeding to the study questionnaire. The consent form contained options for participants to select which parts of the study they would like to take part in (questionnaire, mealtime observation and an interview which was conducted at Time 2). Participants were given a participant ID to use when completing the questionnaire so that they would not be identifiable from the questionnaire data. At this point, if participants were taking part in-person, a date was arranged for the first home visit. Some participants completed the online questionnaire before the home visit took place, and some participants completed it afterwards.

Upon arrival at the home visit LH gave an overview of the study aims and provided the opportunity for the participant to ask any questions or express any concerns. Height and weight of both caregiver and child were taken using equipment issued by the university which LH had brought to the visit. If children participating in the study were unable to support their own weight whilst standing, a laying length measure and infant scale were available for use. Both height and weight were taken in whichever area of the participant's home was most stable and flat. Shoes and heavy clothing were removed prior to measurements being taken.

If participants had opted to take part in video-recorded mealtimes, these were conducted next. Full details of the video-recorded mealtimes are presented separately in Chapter 5. The next step entailed completion of the Vineland-3 gross and fine motor domain. LH first explained the aim of the questionnaire and briefly explained how scoring worked, then the gross motor scale was conducted, followed by the fine motor questions. Afterwards participants were asked to sign a paper payment agreement form and were thanked for their time. Participants were notified that they would be emailed a code to download a £15 Love2Shop voucher as remuneration for their time. LH advised that the second visit would be due in roughly seven months and described what Time 2 participation would include. Participants were again asked if they had any questions and were notified about how to withdraw from the study if they should wish to at any point.

Virtual participants reported height and weight measurements for themselves and their child when completing the online questionnaire. Virtual participants were asked if they would like to complete the Vineland-3 motor questions and if so, this was done via telephone or video-call. Virtual participants were not eligible to take part in video-recorded mealtimes due to practical challenges establishing video quality, consistency and adherence to study protocol

when conducted virtually. Electronic payment agreement forms were emailed to participants and voucher codes were sent to all participants once a completed form had been received and all parts of Time 1 participation (as indicated in their consent form) were complete.

3.2.5 Time 1 Data Analysis

At Time 1, data analysis aimed to identify group differences regarding feeding problems, weight and other potentially related factors. Analysis also aimed to explore which factors are related to the outcome measures of feeding problems and weight for each group, and how this differs.

Descriptive analysis was first conducted to understand sample demographics and identify frequencies of missing data. Where possible, weight and height measurements obtained during home visits were used for data analysis. Where this was not available (for example for participants taking part in the study virtually), self-reported weight and height provided during questionnaire completion was used. In cases where height and weight measurements were taken during home visits and parents also reported this data during questionnaire completion, measurements taken during home visits were used instead of self-reported data. As child weight is a key outcome measure in the present study, analysis was conducted to assess the reliability of self-reported weight data. A two-tailed Pearson's correlation demonstrated that self-reported weight was strongly correlated with weight measurements taken during home visits ($r(14)= 1$, $p<.001$, indicating that self-reported weight was reliable.

Group differences were then explored using independent samples t-tests. Similar to Rogers et al., (2021), t-tests were used instead of ANOVAs in an attempt to minimise inflation of the familywise error rate due to repeated testing and multiple comparisons drawn (Cramer et al., 2016). Due to the large volume of data collected and comparisons drawn, the Bonferroni

correction was applied to select priority comparisons which were most important for addressing the studies' aims. The priority research aim of the study was to investigate group differences regarding feeding problems and weight, and the secondary aim was to explore relationships between these measures and other potentially related factors. As such, the main outcome measures of the study are feeding problems and weight for children with Down syndrome and TD children. To ensure that confidence in findings related to these measures is as high as possible, Bonferroni corrections were applied to the following priority analyses:

1. MCHFS raw score for children with Down syndrome and TD (measure of feeding problems, t-test)
2. Time 1 weight of children with Down syndrome and TD (t-test).
3. Weight for age centile for children with Down syndrome and TD at time 1 (t-test).

Analysis which explored group differences regarding other measures (set out in section 3.2.3) and factors associated with feeding problems and weight for each group was conducted to address secondary research aims and thus viewed as supplementary. The Bonferroni correction was not applied to supplementary analysis (t-tests or correlations- Tables 3.2 and 3.3), as due to the large number of statistical tests this may have been too stringent and increased likelihood of Type II error (Barnett et al., 2022). However, the statistical tests which would have been affected if it had been applied to supplementary data analysis are outlined in the study results.

T-tests assessed whether the two groups significantly differed in terms of background factors (such as age, gestation at birth, weight at birth), outcome measures (feeding problems, Time 1 weight) and potential predictors (baby and child eating behaviour, parental feeding practices, sensory sensitivity, motor skills and mealtime behaviours). Participant recruitment

was limited by several practical factors and thus sample sizes in the present study were relatively low. As such, post-hoc power analysis was conducted for all t-tests and interpretation of study power was informed by Rogers et al., (2021) and Onwuegbuzie and Leech (2004). Observed group differences were interpreted with confidence if $1 - \beta = .80$ or higher. Where study power was between .60 and .80, findings were treated with less confidence and if study power was less than .60 observed group differences were interpreted with caution. Missing questionnaire data was omitted from analyses (pairwise deletion) and is noted in the results tables. Cronbach's alpha was calculated for all measures used to assess internal consistency achieved.

To clarify the need to control for any covariates which have previously been shown to be related to feeding problems and weight (child current age, birth weight, gestation at birth, breastfeeding duration, age of introduction to solid foods, respondent age and BMI), two-tailed Pearson's correlations were conducted for the overall sample and results of this analysis are detailed in the results section. Birth weight, child age and gestation at birth were significantly associated with MCHFS total score and/or Time 1 weight and so were controlled for during subsequent analysis. A series of two-tailed partial correlations were conducted to assess the relationships of both MCHFS and Time 1 weight with breast milk duration, age of introduction of solid foods, BEBQ, CEBQ, CFPQ, ITSP, SSP-2 and Vineland-3 motor domain scores (Table 3.3).

3.3. Time 1 Results

Table 3.2. *N, mean, SD,* t, p-*values (two-tailed) of background questions, feeding, weight, height, and predictor variables for children with Down syndrome and typically developing (TD) children.*

	N		Mean (SD)			95% confidence interval of the group difference					
Measures	**Down syndrome**	**TD**	**Down syndrome**	**TD**	**df**	**Lower**	**Upper**	**Cohen's D**	**Power (1-β)**	***t***	***p***
Age (months)	25	24	28.60 (11.41)	31.33 (12.56)	47	-4.16	9.62	.23	.12	.80	.429
Gestation at birth (weeks)	25	24	37.36 (2.48)	40.04 (1.32)	47	1.53	3.83	1.34	.96	4.70	**.000[a]**
Weight											
Birth weight (kg)	25	24	2.99 (.72)	3.65 (.47)	47	.31	1.02	1.09	.96	3.81	**.000[a]**
Child Time 1 weight (kg)	21	24	10.98 (2.01)	14.19 (3.07)	43	1.61	4.79	1.22	.98	4.07	**.000[a,b]**
Weight for age centile	21	24	21.79 (23.5)	64.75 (30.46)	43	26.42	59.5	1.57	>.99	5.24	**.000[a,b]**
Parent weight (kg)	23	24	69.64 (20.54)	72.01 (16.04)	45	-8.44	13.17	.13	.07	.44	.661
Height											
Child current height (cm)	20	24	80.75 (7.51)	91.81 (11.07)	42	5.18	16.94	1.15	.96	3.93	**.000[a]**
Parent height (cm)	25	24	165.24 (4.30)	166.56 (5.15)	47	-1.41	4.04	.28	.16	.97	.336
Parent BMI[c]	23	24	25.5 (7.74)	26.02 (5.94)	45	-3.52	4.57	.08	.06	.26	.795
Feeding											

Breastfeeding duration (months)	15	20	11.48 (6.58)	11.03 (7.26)	33	-4.33	5.23	.07	.05	.19	.849
Expressed milk duration (months)	17	11	4.49 (2.91)	5.89 (4.05)	26	-1.30	4.10	.41	.18	1.07	.295
Formula duration (months)	13	14	15.12 (7.81)	9.89 (5.97)	25	-10.73	.25	-.76	.47	-1.97	.060
Age of introduction to solid foods (months)	24	23	6.29 (1.52)	5.90 (.65)	45	-1.08	.30	-.33	.20	-1.15	.261
MCHFS[d]											
Total score	25	24	36.52 (14.57)	26.46 (8.09)	47	-13.84	-2.80	-.60	.54	-2.11	**.042[a,b]**
BEBQ[e]											
Food responsiveness	25	24	2.17 (.82)	2.60 (.95)	47	-.07	.95	.49	.39	1.72	.092
Enjoyment of food	25	24	3.85 (1.02)	4.21 (.63)	47	-.03	.95	.54	.46	1.92	.062
Satiety responsiveness	25	24	2.59 (.77)	1.97 (.47)	47	-.98	-.25	-.96	.91	-3.37	**.002[a]**
Slowness in eating	25	24	2.97 (.79)	2.93 (.68)	47	-.47	.38	-.06	.05	-.20	.839
General appetite	25	24	3.28 (1.34)	3.88 (.8)	47	-.04	1.23	.54	.46	1.90	.065
CEBQ[f]											
Food responsiveness	24	24	2.91 (1.25)	2.98(.9)	46	-.56	.71	.07	.06	.24	.813
Emotional overeating	24	24	1.53 (.75)	1.76 (.72)	46	-.20	.66	.31	.18	1.08	.288
Enjoyment of food	24	24	3.90 (1.1)	3.99 (.75)	46	-.45	.64	.10	.06	.35	.731
Desire to drink	24	24	2.24 (.73)	2.51 (.75)	46	-.15	.71	.38	.25	1.30	.200
Satiety responsiveness	24	24	2.54 (.77)	2.95 (.5)	46	.03	.79	.63	.57	2.17	**.036[a]**
Slowness in eating	24	24	2.93 (.73)	2.94 (.72)	46	-.41	.43	.01	.05	.05	.960
Emotional undereating	24	24	3.01 (1.15)	3.02 (.73)	46	-.55	.57	.01	.05	.04	.970
Food fussiness	24	24	2.25 (.82)	2.20 (.78)	46	-.51	.42	-.06	.05	-.21	.834
CFPQ[g]											
Monitoring	24	24	4.01 (1.16)	4.06 (.61)	46	-.48	.59	.06	.05	.20	.846

Emotional regulation	24	24	2.14 (.75)	2.10 (.77)	46	-.48	.40	-.06	.05	-.19	.850
Child control	24	24	2.22 (.64)	2.53 (.78)	46	-.10	.73	.45	.33	1.54	.130
Encourage balance and variety	24	24	4.24 (.6)	4.04 (.62)	46	-.55	.16	-.32	.19	-1.12	.269
Food environment	24	24	3.58 (.58)	3.58 (.46)	46	-.30	.30	.00	.05	.00	1.00
Involvement	24	24	1.90 (.96)	2.58 (.82)	46	.16	1.2	.77	.74	2.65	**.011**[a]
Pressure	24	24	2.73 (.8)	2.54 (.72)	46	-.63	.26	-.25	.14	-.85	.399
Restriction for weight control	24	24	1.59 (.56)	1.43 (.37)	46	-.44	.11	-.35	.22	-1.22	.231
Food as reward	24	24	1.82 (.85)	1.83 (.87)	46	-.49	.51	.02	.05	.06	.956
Restriction for health	24	24	2.56 (1.2)	2.8 (.96)	46	-.39	.87	.22	.12	.76	.449
Teach about nutrition	24	24	2.35 (1.19)	2.97 (.88)	46	.02	1.23	.60	.53	2.07	**.044**[a]
Modelling	24	24	3.73 (1.03)	3.93 (.63)	46	-.30	.70	.23	.12	.80	.427
ITSP[h]											
General processing	16	13	9.00 (4.84)	11.46 (4.31)	27	-5.6	1.07	-.53	.28	-1.43	.165
Auditory processing	16	13	33.44 (6.21)	35.77 (12.27)	27	-9.53	4.87	-.25	.10	-.67	.160
Visual processing	16	13	16.94 (3.64)	15.92 (7.1)	27	-3.56	5.59	.19	.08	.47	.646
Tactile processing	16	13	49.13 (12.06)	52.85 (8.68)	27	-11.91	4.47	-.35	.15	-.93	.359
Vestibular processing	16	13	16.56 (4.88)	15.58 (4.29)	27	-2.67	4.62	.21	.08	.55	.586
Oral sensory processing	16	13	21.19 (6.47)	25.23 (5.59)	27	-8.71	.63	-.66	.40	-1.78	.087
Low registration	16	13	38.63 (7.29)	40.85 (8.87)	27	-8.37	3.93	-.28	.11	-.74	.465
Sensation seeking	16	13	24.19 (5.08)	29.31 (8.25)	27	-10.24	-.00	-.77	.51	-2.05	**.050**[a]
Sensory sensitivity	16	13	40.13 (9.29)	40.15 (8.15)	27	-6.78	6.72	-.00	.05	-.02	.993
Sensation avoidance	16	13	43.31 (9.98)	47 (9.16)	27	-11.06	3.69	-.38	0.17	-1.03	.314
SSP-2[i]											
Sensory processing	8	11	27 (9.86)	22.27 (5.69)	17	-2.81	12.27	.62	.24	1.32	.203
Behavioural	8	11	36 (14.38)	30.55 (11.04)	17	-6.82	17.73	.44	.14	.94	.362

Registration	8	11	12.50 (6.59)	9.55 (4.56)	17	-2.38	8.29	.54	.20	1.17	.258
Sensory sensitivity	8	11	19 (6.23)	15.45 (4.50)	17	-1.64	8.73	.67	.28	1.44	.167
Sensation seeking	8	11	13.50 (6.05)	10.73 (4.36)	17	-2.25	7.80	.54	.20	1.17	.260
Sensation avoidance	8	11	16.50 (5.13)	15.82 (4.85)	17	-4.19	5.55	.14	.06	.30	.771
Vineland-3[j]											
Gross motor raw score	15	15	36.73 (13.25)	46.93 (9.85)	28	-18.93	-1.47	-.87	.64	-2.39	**.024[a]**
Fine motor raw score	15	15	25.13 (5.54)	28.47 (6.29)	28	-1.10	7.77	.56	.32	1.54	.135
Gross motor v-score	15	15	9.33 (2.44)	12.53 (2.45)	28	1.37	5.03	1.31	.97	3.59	**.001[a]**
Fine motor v-score	15	15	12.73 (1.49)	14.33 (1.91)	28	.32	2.99	.93	.80	2.56	**.016[a]**
Motor domain standard score	15	15	78.8 (8.19)	90.73 (12.04)	28	4.23	19.63	1.16	.93	3.18	**.004[a]**

Notes

[a]Significant at α level of <.05. [b] Bonferroni adjusted p-value α level of <.016,; [c]Body mass index, [d]Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011), [e]Baby Eating Behaviour Questionnaire (Llewellyn et al., 2011), [f]Children's Eating Behaviour Questionnaire (Wardle et al., 2001), [g]Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman & Holub, 2007), [h]Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002), [i]Short Sensory Profile 2 (SSP-2, Dunn et al., 2014), [j]Vineland Adaptive Behaviour Scales, third edition (Sparrow et al., 2016).

3.3.1 Descriptive statistics

Mean MCHFS score was significantly higher for children with Down syndrome (*M*=36.50, *SD*= 14.57) than for TD (*M*=26.46, *SD*= 9.09), *t*(47)=-2.11, *p*=.042 (power= .54). The relatively low power indicates this finding must be interpreted cautiously. Seven children with Down syndrome (28%) met the clinical cut off for feeding problems. Five of these children (20%) reached the threshold for mild feeding problems, one child (4%) had moderate feeding problems and one child (4%) met the cut-off for severe feeding problems. No children in the TD group had feeding problems as indicated by MCHFS score.

Children with Down syndrome were born at a significantly younger gestational age (*M*= 37.36 weeks, SD= 2.48 weeks) than TD (*M*=40.04 weeks, *SD*= 1.32), *t*(47)=4.70, *p* <.001 and weighed significantly less at birth (*M*=2.99kg, *SD*=.72kg) than TD (*M*=3.65kg, *SD*=.47kg), *t*(47)=3.81, *p*<.001. At the time of the questionnaire completion, three (12%) children with Down syndrome and one (4%) child in the TD group were being breastfed. One (4%) parent of a child with Down syndrome reported that their child was receiving expressed breast milk and three (12%) children with Down syndrome were receiving formula milk.

Mean Time 1 weight for children with Down syndrome (*M*=10.98kg, *SD*=2.01kg) was significantly less than TD (*M*=14.19kg, *SD*=3.07), *t*(43)=4.07, *p*<.001. Additionally, mean current height for children with Down syndrome (*M*=80.75cm, *SD*=7.51cm) was significantly less than TD (*M*=91.81cm, *SD*=11.07cm), *t*(42)=3.93, *p*<.001.

It was not possible to calculate Body Mass index (BMI) for many of the children in the sample at Time 1. This was due to either missing data or child age being less than two years at the point of data collection (BMI z-scores and charts are suitable for use with children

from age two years). Instead, weight for age centiles were calculated using WHO (2023) growth charts using data obtained during home visits where possible, and self-reported data where not. Mean weight for age centile was significantly lower for children with Down syndrome (*M*= 21.79, *SD*=23.50) than TD (M=64.75, *SD*=30.46), *t*(43)= 5.24, p<.001. In the group of children with Down syndrome, 19% (n=4) of children were below the 2nd centile, indicating low weight for age. Mean BMI for parents for both groups of parents of children with Down syndrome (M=25.50, SD= 7.74) and TD (M=26.02, SD= 5.94) is within the overweight range (NHS, 2023). All of these findings had a high level of power at .90 or above despite some missing data (Table 3.2).

3.3.2 Covariates

For both groups combined, MCHFS score was negatively associated with birth weight (*r*= -.52, *p*<.001), and gestation at birth (*r*= -.37, *p*=.010) indicating that more feeding problems were associated with lower birth weight and gestation. Time 1 weight was positively associated with child current age (*r*= .71, *p*<.001), gestation at birth (*r*= .29, *p*=.050) and birth weight (*r*= .32, *p*=.033). This means that higher weight at Time 1 was associated with older age, greater gestation at birth and higher birth weight. As such, these variables were controlled for when conducting partial correlations (Table 3.3).

3.3.3 Infant feeding and eating behaviours

Twenty-one children with Down syndrome (84%) had received breast milk (either via breastfeeding or expressed milk via bottle, for any duration). Twenty-three (95%) children in the TD group had received breastmilk. Breastfeeding duration did not significantly differ for children with Down syndrome compared to TD. Ten (40%) children with Down syndrome had previously been fed via NG tube and the duration of this ranged from one week to 10

months (*M*= 3.78 months, *SD*= 3.41 months) whereas only one child (4%) in the TD group had ever been fed this way, the duration of which was two weeks. Mean age of introduction to solid foods was not significantly different for children with Down syndrome compared to TD. Children with Down syndrome scored significantly higher on the BEBQ subscale of satiety responsiveness than TD, $t(47)=-3.37$, $p<0.01$. Overall, early feeding practices were generally similar between children with Down syndrome and TD children, but children with Down syndrome had a higher prevalence of NG tube feeding and greater satiety responsiveness during milk feeding.

Analysis also identified group differences regarding factors associated with feeding problems and weight for children with Down syndrome and TD children (Table 3.3). Partial correlations were conducted to explore relationships between infant feeding and eating behaviours, MCHFS score and Time 1 weight . MCHFS score was negatively associated with age of introduction to solid foods for TD, $r(15)= -.55$, $p=.023$, but not for children with Down syndrome (Table 3.3). For children with Down syndrome, Time 1 weight was positively associated with infant food responsiveness $r(16)=.49$, $p=.040$, but not for TD. MCHFS score was negatively associated with enjoyment of food ($r(16)=-.46$, $p=.036$) and general appetite for children with Down syndrome, $r(16)=-.49$, $p=.024$ but not for TD. Time 1 weight was positively associated with general appetite for children with Down syndrome, $r(16)=.53$, $p=.027$, but not for TD.

3.3.4 Children's eating behaviours

Children with Down syndrome scored significantly lower than TD children for the CEBQ subscale of satiety responsiveness, $t(46)=2.17$, $p=.036$, but power was relatively low at .57. MCHFS score was negatively associated with enjoyment of food for both children with Down syndrome, $r(19)= -.64$, $p<.01$ and TD, $r(19)=-.65$, $p<.01$. MCHFS score was positively

associated with food fussiness for children with Down syndrome, $r(19)=.71$, $p<.001$ and for TD children, $r(19)=.77$, $p<.001$. Time 1 weight was negatively associated with food fussiness for TD, $r(19)= -.47$, $p=.033$, but not for children with Down syndrome.

3.3.5 Parental feeding practices

Differences were observed regarding parental feeding practices reported by parents of children with Down syndrome and TD parents (Table 3.2), whilst associations between MCHFS scores and parental practices, such as monitoring and encouraging balance, varied between groups (Table 3.3). Parents of children with Down syndrome scored significantly lower for involvement ($t(46)= 2.65$, $p=.011$) and teaching about nutrition than parents of TD children ($t(46)=2.07$, $p=.044$) but power was low for teaching about nutrition (power=.53). MCHFS score was positively associated with monitoring for TD ($r(19)=.55$, $p=.011$) but not for children with Down syndrome. MCHFS score was negatively associated with encouraging balance and variety for both children with Down syndrome ($r(19)=-.44$, p=.045) and TD ($r(19)=-.49$, $p=.024$). Time 1 weight was positively associated with modelling for children with Down syndrome ($r(15)=.51$, $p=.035$).

3.3.6 Sensory processing- ITSP and SSP-2

Twenty-nine participants completed the ITSP for their child and nineteen responses were recorded for the SSP-2. For children with Down syndrome, mean scores were below typical performance for all ITSP subscales, indicating sensory hypersensitivity. For TD children, mean scores were below typical performance for auditory, visual, vestibular processing and sensory sensitivity. TD children scored within the typical performance range for all other ITSP subscales. Children with Down syndrome scored significantly lower than TD on the subscale of sensation seeking but this finding had low power (power = .51) indicating low

confidence in this result. Both children with Down syndrome and TD children scored within typical performance ranges for all SSP-2 subscales. Mean scores for SSP-2 subscales did not significantly differ between groups.

MCHFS score was positively associated with the ITSP subscale of low registration for children with Down syndrome ($r(11)=.56$, $p=.045$) indicating that more feeding problems were associated with greater registration of sensory input. However, for TD, higher MCHFS score was negatively correlated with low registration, $r(7)=-.69$, $p=.038$, meaning that more feeding problems were associated with a greater tendency to miss sensory input. MCHFS score was also negatively associated with both oral sensory processing ($r(7)=-.70$, $p=.035$) and sensation avoidance ($r(7)=-.76$, $p=.017$) for TD but not for children with Down syndrome. This shows that for TD children, higher MCHFS scores were associated with increased oral sensory sensitivity and sensation avoidance.

Time 1 weight was negatively associated with tactile processing for children with Down syndrome ($r(11)=-.68$, $p=.030$) but not for TD, showing that for children with Down syndrome, higher weight at Time 1 was associated with tactile sensory sensitivity. For children with Down syndrome, Time 1 weight was negatively associated with oral sensory processing ($r(11)= -.64$, $p=.046$ but for TD it was positively associated, $r(7)=.88$, $p<.01$. Children with Down syndrome who weighed more at Time 1 had more oral sensory sensitivity, whereas TD children who weighed more at Time 1 had less oral sensory sensitivity. There were no significant associations between MCHFS score or Time 1 weight and the SSP-2.

3.3.7 Motor skills

In total, 30 responses (15 children with Down syndrome and 15 TD) were received for the Vineland-3 motor skills domain. Children with Down syndrome scored significantly lower than TD for both subdomains of gross and fine motor skills, and also for overall motor skill proficiency (motor domain standard score in Table 3.2). For children with Down syndrome, fine, gross and overall motor skill proficiency scores were lower than same age norms. For children with Down syndrome, there was a positive association between gross motor skill v-scores and weight at Time 1, but this was not observed for the TD group (Table 3.3).

3.3.8 Bonferroni adjustments

Given the large number of comparisons made throughout data analysis (Tables 3.2 and 3.3), if Bonferroni adjustments had been made to all comparisons, then an alpha level of $p<.000$ would be required to observe any significant group differences. This would impact several findings including group differences observed relating to BEBQ and CEBQ satiety responsiveness, CFPQ measures of involvement and teaching about nutrition, the ITSP subscale of sensation seeking, and Vineland-3 gross, fine and overall motor domain standard scores. This would also impact significant associations observed between MCHFS scores and BEBQ, CFPQ subscales for children with Down syndrome only, and significant relationships with ITSP subscales for both groups. Significant associations were observed between Time 1 weight and BEBQ, CFPQ, ITSP and Vineland-3 subscales (children with Down syndrome only), as well as CEBQ subscales (TD only).

Table 3.3. *Partial correlations between background questions, feeding problems, weight, and predictor variables (two-tailed) for children with Down syndrome and typypically developing (TD) children. Covariates include birth weight, child age and gestation at birth.*

	MCHFS[a] Raw score				Time 1 Weight			
	Down Syndrome		TD[b]		Down syndrome		TD[b]	
	r	*p*	*r*	*p*	*r*	*p*	*r*	*p*
Breast milk duration	-.34	.278	-.01	.972	.28	.502	.40	.109
Age introduced to solid food	-.40	.192	**-.55**	**.023**[c]	-.30	.467	-.42	.097
BEBQ[d]								
Food responsiveness	-.35	.116	.10	.659	**.49**	**.040**[c]	.13	.57
Enjoyment of food	**-.46**	**.036**[c]	-.06	.782	.24	.329	.10	.66
Satiety responsiveness	.12	.610	-.04	.871	-.27	.285	.04	.870
Slowness in eating	.12	.595	-.00	.993	-.07	.796	-.06	.795
General appetite	**-.49**	**.024**[c]	-.34	.132	**.53**	**.027**[c]	.28	.212
CEBQ[e]								
Food responsiveness	-.35	.12	-.12	.612	.36	.157	.14	.543
Emotional overeating	-.31	.179	.04	.881	.29	.256	.07	.754
Enjoyment of food	**-.64**	**.002**[c]	**-.65**	**.002**[c]	.43	.082	.39	.084
Desire to drink	-.13	.568	-.03	.883	.25	.343	.20	.389
Satiety responsiveness	.42	.08	.24	.295	-.22	.401	-.29	.199
Slowness in eating	.15	.523	.41	.066	-.22	.396	-.10	.654
Emotional undereating	.08	.735	.31	.176	.45	.073	.11	.631
Food fussiness	**.71**	**.000**[c]	**.77**	**.000**[c]	-.06	.822	**-.47**	**.033**[c]
CFPQ[f]								
Monitoring	-.20	.377	**.55**	**.011**[c]	.29	.258	-.29	.211
Emotional regulation	.10	.680	.06	.807	.04	.887	.20	.394

Child control	.14	.553	-.06	.801	.17	.508	.01	.976
Encourage balance and variety	**-.44**	**.045[c]**	**-.49**	**.024[c]**	.40	.110	.13	.586
Food environment	-.19	.420	.38	.094	.39	.127	.00	.996
Involvement	-.17	.462	-.05	.833	.13	.620	.14	.535
Pressure	.07	.759	-.06	.809	.32	.215	.16	.501
Restriction for weight control	-.27	.240	-.08	.727	.46	.065	-.33	.149
Food as reward	.02	.945	-.08	.741	-.16	.535	.28	.228
Restriction for health	-.03	.895	-.06	.806	-.07	.802	.22	.340
Teach about nutrition	-.29	.197	-.10	.678	-.03	.907	.14	.554
Modelling	-.29	.205	-.39	.083	**.51**	**.035[c]**	.15	.514
ITSP[g]								
General processing	.27	.379	-.44	.242	-0.50	.140	-0.10	.795
Auditory processing	.10	.738	-.44	.236	.08	.822	-.09	.815
Visual processing	.41	.168	-.52	.155	-.23	.520	.33	.390
Tactile processing	.25	.418	-.63	.072	**-.68**	**.030[c]**	.66	.053
Vestibular processing	.17	.569	-.49	.182	-.51	.129	.66	.051
Oral sensory processing	.31	.310	**-.70**	**.035[c]**	**-.64**	**.046[c]**	**.88**	**.002[c]**
Low registration	**.56**	**.045[c]**	**-.69**	**.038[c]**	-.38	.277	.36	.341
Sensation seeking	.40	.174	-.63	.071	-.57	.088	.54	.134
Sensory sensitivity	.19	.545	-.64	.062	-.60	.070	.42	.263
Sensation avoidance	.17	.575	**-.76**	**.017[c]**	-.61	.062	.43	.252
SSP-2[h]								
Sensory processing	.57	.321	.47	.235	-.58	.420	-.36	.382
Behavioural	.25	.688	.56	.151	.95	.051	-.29	.494
Registration	.29	.638	.13	.753	-.04	.965	-.31	.457
Sensory sensitivity	.63	.258	.53	.173	.53	.469	.22	.608
Sensation seeking	.01	.982	.69	.061	.45	.553	-.43	.304

Sensation avoidance	.37	.539	.42	.297	.89	.106	-.31	.461
Vineland-3[i]								
Gross motor raw score	-.16	.636	-.02	.945	.42	.202	.20	.539
Fine motor raw score	.07	.745	-.38	.220	.17	.395	.06	.863
Gross motor v-score	-.15	.653	.25	.433	**.61**	**.035[c]**	.27	.405
Fine motor v-score	-.17	.628	-.45	.145	-.06	.866	.06	.864
Motor domain standard score	-.23	.488	-.14	.654	.56	.059	.35	.268

Notes

[a]Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011), [b]typically developing children, [c] Significant at α level of <.05, [d]Baby Eating Behaviour Questionnaire (Llewellyn et al., 2011), [e]Children's Eating Behaviour Questionnaire (Wardle et al., 2001), [f]Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman & Holub, 2007), [g]Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002), [h]Short Sensory Profile 2 (SSP-2, Dunn et al., 2014), [i]Vineland Adaptive Behaviour Scales, third edition (Sparrow et al., 2016)

3.3.9 Summary of results: feeding problems

A greater prevalence of feeding problems was observed in children with Down syndrome, with 28% of the Down syndrome group meeting the clinical cut-off for feeding difficulties compared to no children in the TD group. In children with Down syndrome, feeding problems were associated with lower general appetite and lower enjoyment of food during milk feeding. Regarding childhood eating of solid foods, feeding problems were associated with lower enjoyment of food and higher levels of food fussiness for children with Down syndrome. Additionally, for children with Down syndrome feeding problems were associated with lower levels of parental encouragement of dietary balance and variety and greater registration of sensory input (measured by the ITSP).

In TD children, higher MCHFS scores were associated with earlier introduction of solid foods, lower childhood enjoyment of solid foods, higher levels of food fussiness, increased parental monitoring and lower parental encouragement of dietary balance and variety. Additionally, higher feeding problem scores were associated with ITSP measures of higher oral sensory sensitivity, lower registration of sensory input, and greater sensation avoidance.

3.3.10 Summary of results: weight

Regarding weight, children with Down syndrome weighed less than TD children both at birth and at Time 1. Children with Down syndrome were also more likely to be a low weight in comparison to weight norms for their age. In children with Down syndrome, Time 1 weight was associated with increased food responsiveness and general appetite during milk feeding, higher levels of parental food modelling, ITSP measures of increased tactile and oral sensory sensitivity as well as better gross motor skills.

For TD children, weight at Time 1 was associated with lower food fussiness during childhood eating of solid foods, and lower oral sensory sensitivity (ITSP).

3.4. Discussion

Data collected at Time 1 aimed to explore relationships between feeding problems, weight and potentially related factors for children with and without Down syndrome. Feeding problems were only observed in the group of children with Down syndrome, and children with Down syndrome were both significantly lighter and shorter than the TD group despite not significantly differing in age. Several group differences were observed, with parents of children with Down syndrome reporting significantly higher levels of satiety responsiveness during milk feeding than TD, but significantly lower levels of satiety responsiveness during solid food eating. Parents of children with Down syndrome also reported significantly lower levels of involvement during mealtimes and teaching about nutrition than TD parents. Overall, children with Down syndrome were observed to have delayed motor skill acquisition compared to TD children and their same age norms. Moreover, parents reported sensory hypersensitivity compared to same age norms for children with Down syndrome aged up to 36 months. For children with Down syndrome, feeding problems were associated with lower general appetite during milk feeding, lower enjoyment of solid foods, more food fussiness, less parental encouragement of balance and variety and increased registration of sensory stimuli. In children with Down syndrome higher weight at Time 1 was associated with higher food responsiveness and larger general appetite during milk feeding, higher levels of parental modelling in relation to food and mealtimes, hypersensitivity regarding tactile and oral sensory processing, and gross motor skill proficiency.

Twenty-one (84%) children with Down syndrome had previously received breastmilk (direct from the breast or via bottle, for any duration). This is similar to research conducted by Rogers et al. (2021) whereby 85% of the sample of children with Down syndrome had ever received breast milk. In the present study, breastfeeding duration was similar for children with Down syndrome and TD children. This is in contrast with previous research which has commonly reported that breastfeeding rates are lower for children with Down syndrome, and that children with Down syndrome are breastfed for shorter durations (Mohamed et al., 2013; Pisacane et al., 2003) but is in line with more recent findings by Williams et al., (2022) and Rogers et al. (2021). Successful breastfeeding for parents and infants with Down syndrome has been linked to the provision of effective and timely multi-disciplinary feeding support from healthcare professionals and has shown that when this is available, it is possible to meet breastfeeding goals even if there are early feeding problems (Barros da Silva et al., 2018; Sooben et al., 2012; Zhen et al., 2021).

Children with Down syndrome were more likely to have been fed via NG feeding tube than TD (with 40% of the children with Down syndrome and 4% of the TD group reporting to have ever been fed this way). A 2020 review conducted by Nordstrom et al. found that 13-40% of infants with Down syndrome may require NG tube feeding for some period of time and the findings of the current study are in line with the upper range reported. The mean length of NG tube use was 3.78 months. Prolonged use of NG tube feeding has been linked with increased rates of childhood feeding problems (Mason, Harris & Blissett, 2005). Whilst the period of time that an NG tube will be in place will be context dependent and determined on a case by case basis, Dunitz-Scheer et al., (2009) recommend that NG feeding tubes should be in place for a maximum of two months in order to prevent tube dependency and feeding problems, such as oral aversions. Based on the recommendations put forth by Dunitz-Scheer et al (2009), mean NG tube feeding duration for the children with Down syndrome in

the present study could be considered prolonged. This is a factor which could have influenced the increased prevalence of feeding problems amongst the children with Down syndrome in the sample.

Children with Down syndrome were introduced to solid foods later than TD; however, the difference was not statistically significant. Previous research has shown that the age at which children with Down syndrome are introduced to solid foods varies from 6.20 to 7.73 months, but generally suggests they are introduced to solid foods later than TD children, with parents reporting a more cautious approach to the process (Al-Sarheed,2006; Cochran et al., 2022; Mohamed et al., 2013; Hielscher et al., 2023; Hopman et al., 1998; Roccatello et al., 2021; Rogers et al., 2021).

In the present study, the TD group were introduced to solid foods at a mean age of 5.9 months, which is in line with WHO recommendations (which advise beginning the introduction of solids at 6 months of age) but later than observed in several other studies such as Cook et al., (2020), Rogers et al., (2021) and Santorelli et al., (2014) which all showed that UK parents introduced children to solid foods earlier than recommended by the WHO. The mean age of the cohort of children included in the present study indicates that many were born around the COVID-19 pandemic which began in 2020 (whereas Cook et al., 2020, Rogers et al., 2021 and Santorelli et al., 2014 completed data collection prior to the pandemic). Throughout the pandemic, UK maternity and infant health services were impacted, with parents reporting a reduction in feeding support during this time (Brown and Shenker, 2020; Coxon et al., 2020; Vazquez-Vazquez et al., 2021). It is possible that parents of TD children in the present study may have approached introducing solid foods more cautiously or introduced solid foods slightly later due to reduced feeding support. However, this is speculation and further follow up research would be necessary to confirm this.

More children with Down syndrome experienced feeding problems than the TD group, but this finding was no longer significant after applying a Bonferroni adjustment. However, it was expected that children with Down syndrome would experience more feeding problems than TD as this is widely reported amongst existing literature (Anil et al., 2019; Cochran et al., 2022; Rogers et al., 2022; Spender et al., 1996). Using the MCHFS, 28% of children with Down syndrome scored above the clinical cut off for feeding problems, whereas no child in the TD group scored in this range. Similar rates were observed in Rogers et al., (2021) whereby feeding problems were detected in 30% of the children with Down syndrome sampled, using the same measure.

Interestingly, 20% of the sample of children with Down syndrome were born before 37 weeks' gestation, which is classed as preterm (WHO, 2023), whereas all of the TD children sampled were full-term. Preterm infants are at higher risk for paediatric feeding problems than infants born after 37 weeks and feeding difficulties can be long-term (Thompson 2023). This is likely, therefore, to have contributed to the higher incidence of feeding problems amongst the group of children with Down syndrome. This could possibly explain why children with Down syndrome were found to be significantly shorter and lighter in weight than the TD children, despite a very similar mean age for both groups of children. Children with Down syndrome were lower on weight for age centiles, with four (19%) children with Down syndrome classed as low weight for age, whereas all TD children fell within expected ranges.

For children with Down syndrome, more feeding problems were associated with lower general appetite during the milk feeding period, but this was not true for TD. During the milk feeding period, children with Down syndrome were also more responsive to satiety than TD

which means that children with Down syndrome would get full sooner during milk feeds, which can make it more challenging for infants to receive adequate nutrition and reach optimal weight/growth targets (Marder et al., 2015, Pisacane et al., 2007). This finding is consistent with Rogers et al., (2021) who found that infants with Down syndrome who were reported to have more feeding problems were perceived by parents to have smaller appetites during milk feeding. One reason for this might be that children with Down syndrome with a cardiac anomaly are more likely to become exhausted during feeds and to cope with this by feeding for shorter durations (Hookway et al., 2021; Lewis and Kritzinger, 2004; Marder et al., 2015; Pisacane et al., 2003). In the present study, 64% of the children with Down syndrome were reported to have some cardiac anomaly at birth, which may partly explain these findings.

In contrast, children with Down syndrome were found to have *lower* levels of satiety responsiveness than TD during childhood eating of solid foods. Satiety responsiveness was not significantly related to either MCHFS score or weight during Time 1 analysis. However, given this contrast, it will be of particular interest to further explore whether children with Down syndrome have lower levels of satiety responsiveness than TD at Time 2, and whether this can predict weight gain between Time 1 and Time 2. Existing research conducted with young TD children has demonstrated that eating behaviours such as low satiety responsiveness are associated with BMI and can predict later obesity risk (Viana et al., 2008; Webber et al., 2009).

For both children with Down syndrome and TD, more feeding problems were associated with higher levels of food fussiness and lower enjoyment of solid foods. This is also consistent with Rogers et al., (2021) who concluded that greater food avoidance traits in childhood may indicate risk for feeding problems in both children with and without Down syndrome.

Parents of children with Down syndrome display different feeding behaviours to those with TD. Both parents of children with and without Down syndrome who had more feeding problems reported encouraging dietary balance and variety less. Additionally, parents of children with Down syndrome also reported lower levels of involvement and teaching their child about nutrition than parents of TD children. Previous research has observed a similar trend in TD children whereby parents who reported more feeding problems also reported lower encouragement of dietary balance and variety (Rogers et al., 2018). It is possible that when parents perceive their child to enjoy solid foods less, they may prioritise encouraging their child to consume a sufficient amount of food during mealtimes, as opposed to prioritising variety and balance of foods consumed. Food fussiness, texture sensitivity and food refusal have been commonly reported amongst children with Down syndrome and can limit the variety of foods which a child will accept (Field et al., 2003; Ross et al., 2022). Additionally, feeding problems in early life, delayed oral motor skills and increased worries around risk of choking, may lead some parents of children with Down syndrome to limit the foods offered to their child (Cochran et al., 2022; Collins et al., 2003; Field et al., 2003; Shaw et al., 2003). As such, parents of children with Down syndrome who experience more feeding problems may prioritise other things above encouraging dietary balance and variety during mealtimes.

Using the ITSP, sensory hypersensitivity was observed in children with Down syndrome aged up to 36 months across all subscales. More feeding problems were associated with increased sensory registration (awareness of all types of sensory sensation) for children with Down syndrome aged up to 36 months and parents reported increased sensation seeking behaviour in comparison to TD. TD children were observed to have normal sensory sensitivity for all subscales except for auditory, visual and vestibular processing, where

hypersensitivity was reported. This finding was unexpected, as it had been anticipated that the TD group would score within normal ranges for all sensory processing subscales. It is possible that parents of TD children who experience more challenges related to sensory sensitivity may have been more motivated to participate in the study.

Children with Down syndrome aged up to 36 months who had more sensitivity regarding tactile and oral sensory processing weighed more at Time 1. However, for TD children higher weight at Time 1 was associated with less oral sensory sensitivity. Challenges associated with sensory processing such as texture sensitivity have been shown to impact food preferences for children with Down syndrome by reducing the number of textures and foods that children will consume (Cochran et al., 2022; Field et al., 2023; Ross et al., 2022). This can impact overall nutrition and weight. For example, Roccatello et al (2021) describe how children with Down syndrome who experienced texture sensitivities were less likely to consume foods such as raw vegetables, dried fruit, meat, and fish. Research conducted with children with other developmental disorders such as Autism has also identified how sensory sensitivity can lead to restriction of accepted foods and contribute to an obesogenic diet (Cermak et al., 2010).

Parents of children older than 36 months completed the SSP-2 instead of the ITSP to assess their child's sensory processing. It is interesting to note that both children with Down syndrome and TD children scored within normal ranges of sensory processing for all SSP-2 subscales, despite the younger group of children with Down syndrome scoring in the hypersensitivity range for all subscales. The SSP-2 has previously been used to detect sensory processing challenges in children with Down syndrome (Will et al., 2019). There were no significant differences between groups or relationships between the SSP-2 and either feeding problems or Time 1 weight, but it is possible that this was due to low power. The SSP-2 was completed by a subset of participants whose child was older than 36 months, but

this produced a very small sample of respondents in each group (eight children with Down syndrome and 11 TD children). It is possible that the sample was too small to detect any group differences in sensory processing for children over 36 months of age. Therefore, sensory processing data collected at Time 2 will be of particular interest in terms of observing how patterns of hypersensitivity detected at Time 1 change over time. Additionally, future studies could include larger, more equal samples of parents of children with Down syndrome and TD completing the ITSP and SSP in order to increase power and confirm age/development related changes to sensory processing before and after three years of age. Furthermore, it would be valuable to explore what factors may be related to a reduction in sensory hypersensitivity for children with Down syndrome as they age, and how this could be different for children who remain hypersensitive throughout childhood.

Children with Down syndrome had delayed gross and fine motor skills, and overall lower motor skill proficiency compared to both the TD children sampled and same-age norms, and these findings had a high level of power. The children with Down syndrome were more delayed in gross motor skill proficiency than fine motor skills, which indicates that gross motor skill acquisition could be a specific challenge in this population. These findings are consistent with existing research which has identified motor skill delays in children with Down syndrome, and other developmental disabilities including autism (Hauck et al., 2020; Malak et al., 2015, Odeh et al., 2020).

Previous research has linked gross motor skill development with feeding abilities in children with Down syndrome (Anil et al., 2019; Cochran et al., 2022) and being overweight in TD children (Slining et al., 2010). In the present study, children with Down syndrome with better gross motor skill proficiency were seen to weigh more at Time 1. This is in contrast to findings reported for TD children by Slining et al., (2010), suggesting that gross motor

development may have a different relationship with weight for children with Down syndrome than it does for TD children. Previous research has also identified associations between gross motor skill acquisition and development of other skills such as cognitive, language and social development (Hauck et al, 2020), which are particular developmental concerns for children with Down syndrome. Taken together, these findings highlight the necessity to better understand the developmental profile of gross motor skills for children with Down syndrome, and their relationship with other important developmental outcomes. Further analyses of data collected at Time 2 will help to better understand the relationship between motor skills, feeding problems and weight, and how these change over time for children with Down syndrome.

Limitations of the overall longitudinal study will be fully considered in Chapter 4 but there are several limitations relating to the first phase of this study (Time 1) which should be considered. Firstly, extensive statistical testing has been conducted using a relatively small pool of data. Conducting numerous statistical tests (t-tests and correlations in this case) increases the likelihood of a Type-I error occurring. It was necessary to conduct many statistical tests to fully address the numerous aims of the present study, and to explore in-depth factors which may be linked to feeding problems and weight in this population. In an attempt to manage the likelihood of Type-I error in the present study, post hoc Bonferroni adjustments were applied to priority comparisons which addressed the study's primary research aim (outlined in the introduction section of this chapter) and are reported in the study results. Given the stringency of the Bonferroni adjustment, and the large number of supplementary comparisons in this study, it would be impractical to apply it to all supplementary comparisons as this may limit the ability to detect significant findings and in-turn increase the likelihood of Type-I I error (Barnett et al., 2023). For transparency, the

supplementary comparisons which would be affected if Bonferroni adjustments were applied to those also are outlined in the study results.

Study sample size was limited by practical considerations such as time commitments required to conduct home visits across two time points. The data collection process was flexible, and participants could choose whether to take part partially in-person or completely virtually, and could choose which parts of the study they would like to participate in. These considerations were made in order to make it as easy as possible for participants to take part in the study (and therefore encourage participation) and to maximise the number of participants it was practically possible to collect data from during the time available. The achieved sample size is larger than or similar to many studies which have included young children with Down syndrome (Anil et al., 2019; Ooka et al., 2012; Spender et al., 1996; van Dijk and Lipke-Steenbeek, 2018). Additionally, some findings from this study are consistent with research which has included larger samples of children with Down syndrome (e.g. Rogers et al., 2021) as outlined earlier in this discussion. However, given that for some variables, measures were completed by only a subset of participants, in order to further increase confidence in the study findings, post hoc power was calculated for all statistical tests conducted.

A further limitation of Time 1 data collection is that there was no measure to assess oral-motor skills specifically, only gross and fine motor skills. Oral-motor skill delays are common in children with Down syndrome and have been linked to increased feeding difficulties and delayed introduction of solid foods and this may impact the types of foods that parents offer their children (Anil et al., 2019; Hielscher et al., 2023; Roccatello et al., 2023). As such, it would have been valuable to explore group differences relating to oral-motor skill proficiency, as well as how this relates to the MCHFS measure of feeding problems, weight, and other related factors. At the time of study design, there was no

available measure of oral-motor skills which could be completed by parents. It was beyond the scope of the present study to include clinician assessments of oral-motor skills and so it was not possible to include this specific variable. In order to collect some information about oral-motor skills specifically, parents of children with Down syndrome who took part in interviews at Time 2 were asked about their child's oral-motor skills, any challenges relating to this, and if/how parents felt this affected their child's eating development and feeding problems (see Chapter 6 for findings). Future research could build on this by including clinician assessments of oral-motor skill proficiency for children with Down syndrome and explore how abilities develop over time.

Another limitation of this study is the poor internal consistency of some of the measures used. For example, the CFPQ subscales of encouraging balance and variety and food environment, as well as the ITSP visual processing subscale. This suggests that the items within the subscale may not reliably capture the factors which they aim to measure. In contrast, a significant association was found between feeding problems and parental report of encouraging balance and variety for children with Down syndrome. The poor reliability of this subscale indicates that this finding should be accepted with caution and/or confirmed using a different measure in future research. However, visual processing and food environment did not significantly differ between groups, nor were they significantly associated with any of the main outcome measures. As such, the poor internal consistency of these subscale does not appear to have affected the overall findings or interpretations of the study.

3.4.1 Implications

Factors which are related to increased feeding problems in children with Down syndrome specifically should be monitored throughout infancy and the early years. It is important that

health professionals ask parents about their child's eating behaviours, sensory processing and motor skills as these factors could signpost potential targets for early intervention in order to promote positive feeding and eating developmental outcomes. Also, it is vital that health professionals supporting families to feed children with Down syndrome are aware of eating and drinking challenges unique to this group. Parents of children with Down syndrome often report a desire for information from health professionals that is specific to children with Down syndrome, and not information about TD children applied to their child (Mengoni et al., 2023). Health professionals who are aware of the ways in which eating, drinking and related factors may differ for children with Down syndrome (compared to TD) will be able to offer more effective, relevant and timely support.

3.4.2 Conclusions

The present study suggests differences exist between children with Down syndrome and TD children regarding factors that are related to feeding problems and weight in the early years, such as infant eating behavior during milk feeding, child eating behavior, parental feeding practices, sensory processing and motor skill proficiency.

Chapter 4. Longitudinal predictors of feeding problems and weight in children with and without Down syndrome – Time 2

4.1. Introduction

As discussed in the scoping review (Chapter 2) and Time 1 results (Chapter 3) numerous complex factors can influence feeding development and weight in children with Down syndrome. However, the exact nature of these relationships and how they evolve over time remains unclear. Most existing research on feeding problems and weight-related factors in children with Down syndrome is cross-sectional and correlational. This type of research does not allow for disentangling the complex and often interrelated factors related to weight and feeding problems or identifying key predictors related to important feeding outcomes, which is desired in order to promote optimal health for children with Down syndrome (Rogers et al., 2021).

Moreover, current interventions aimed at addressing overweight and obesity in children with Down syndrome primarily focus on exercise and have shown mixed results in terms of efficacy (Bertapelli et al., 2016; Li et al., 2013; Medina-Rebollo et al., 2023; Nordstrom et al., 2020). Therefore, more longitudinal research is needed to better understand causality and identify predictors of feeding problems and weight in infants and children with Down syndrome. This research is essential to better understand the developmental trajectory of feeding and weight outcomes in this population and to pinpoint critical periods and areas for early intervention. The present study aimed to address this by repeating data collection at a second interval, seven months after Time 1 data collection.

4.1.1 Aims

Time 2 analysis aimed to explore how feeding problems, weight and other relevant factors changed over time, including whether observed group differences remained stable between Time 1 and Time 2. Additionally, Time 2 data analysis aimed to identify potential predictors of feeding problems and weight for each group.

4.2. Method

4.2.1 Participants

Parents of 48 children between the ages of 18 and 59 months participated in the study. Across the whole sample, only one parent of a child with Down syndrome did not complete the online questionnaire at Time 2, indicating a retention rate of 98% of study participants. The group of children with Down syndrome (*n*=24) consisted of 15 males and 9 females (*mean age at T2*= 35.54 months). The TD control group (*n*=24) consisted of 14 males and 10 females (*mean age at T2*= 39.04 months). The two groups did not significantly differ in mean age at Time 2. Forty-two parents completed the online questionnaire, and 27 responses were recorded for the Vineland-3 (12 children with Down syndrome, 15 TD). See Table 4.1 for full sample demographics. The weight of six parents was not recorded and included in analysis at Time 2 due to pregnancy.

Table 4.1. *Time 2 descriptive demographic and background information.*

	Group with Down syndrome (n=24) N (%) / mean (SD)	**Typically developing (n=24)** N (%)/ mean (SD)
Respondent ethnicity- N (%)		
White British	17 (71)	14 (58)
Other White	3 (13)	5 (21)
Asian Indian	1 (4)	0
Black African	0	1 (4)
Other Black	0	1 (4)
Mixed (not specified)	1 (4)	2 (8)
Missing data	2 (8)	1 (4)
Respondent education- N (%)		
Left school between 13 and 16 years	1 (4)	0
Further secondary education (16-18 years)	1 (4)	5 (21)
Secretarial/technical qualification	0	1 (4)
University course not completed	1 (4)	0
Professional qualification without degree	2 (8)	0
Degree	10 (42)	12 (50)
Further degree	9 (38)	6 (25)
Annual household income- N (%)		
£20,000-£29,000	8 (33)	4 (17)
£30,000-£39,000	0	1 (4)
£40,000-£49,000	3 (13)	1 (4)
£50,000-£59,000	2 (8)	3 (13)
£60,000-£69,000	2 (8)	4 (17)
£70,000-£79,000	2 (8)	3 (13)
£80,000 or more	7 (29)	8 (33)
Respondent BMI- mean (SD)	25.5 (7.7)	26.02 (5.94)
Child gender- N (%)		
Male	14 (58)	14 (58)
Female	10 (42)	10 (42)
Child ethnicity- N (%)		
White British	16 (66)	17 (71)
White Irish	1 (4)	0
Other White	3 (13)	2 (8)
Asian Indian	1 (4)	0
Other Asian	0	1 (4)
Black African	0	1 (4)
Mixed White and African	0	1 (4)

Mixed Ugandan/German	0	1 (4)
Mixed (not specified)	3 (13)	1 (4)
Childcare setting- N (%)		
Pre-school	2 (8)	4 (17)
Nursery	15 (63)	5 (21)
Nanny	1 (4)	1 (4)
Childminder	1 (4)	10 (42)
No childcare setting reported	5 (20)	4 (17)
Childcare frequency N (%)		
Part-time	16 (67)	17 (71)
Full-time	2 (8)	3 (13)
Missing data	2 (8)	0
No childcare setting reported	4 (16)	4 (17)

4.2.2 Measures

At Time 2, minimal changes were made to the parent completed online questionnaire used at Time 1. The BEBQ was removed as it is a retrospective measure, and removal avoided duplicated data collection from Time 1. Other redundant retrospective questions were removed including questions around plans to milk feed before birth and feeding in early infant life. Participants were then asked to enter height and weight details for themselves and their child, and complete the standardised measures outlined in Chapter 3. An additional measure was included within the online questionnaire at Time 2, in order to assess child food texture sensitivity.

The five questions established by Ross et al., (2022) aim to classify a child as either texture sensitive, or non-texture sensitive, in regard to food and eating. The questions are; 1) "My child limits themselves to certain food textures", 2) "My child is a picky eater, especially about food textures", 3) "My child prefers one texture of food", 4) "My child would rather drink than eat", 5) "When you introduce new textures into your child's diet, do you feel

confident that he/she will accept these foods?". Questions 1-4 are answered using a 5-point Likert scale, whereby parents reflect upon the extent to which each statement is true for their child. Response options range from almost always (5), frequently (4), sometimes (3), infrequently (2), almost never (1). Question 5 is answered using the response options of yes or no. Scores are generated using a binary coding system. For questions 1-4, responses of almost always and frequently were coded as a 1, with all other response options coded as 0. For question 5, a response of 'No' was coded as 1, and 'Yes' was coded as 0. Total scores are then calculated, with a score of 2 points or more needed to classify a child as food texture sensitive. Ross et al., (2022) used this measure to classify both children with and without Down syndrome from four to 58 months of age as either texture sensitive or non-texture sensitive.

4.2.3 Procedure

The Time 1 data collection protocol outlined in Chapter 3 was repeated at Time 2. Participants were re-contacted seven months after their Time 1 participation and asked if they would like to participate in Time 2 data collection. If so, a link to access the online questionnaire was sent to the participant, and if applicable, a date was arranged for the second home visit, which was then carried out. During home visits, height and weight measurements, video-recorded mealtimes (outlined in Chapter 5) and the Vineland-3 were repeated. Following this, all parents of children with Down syndrome were invited to take part in a virtual interview which aimed to explore their experiences around feeding, any concerns, challenges faced and their support needs. Details of the interviews are presented in Chapter 6. Once all parts of Time 2 data collection were complete, each participant was emailed a second voucher code for taking part, as well as debrief information about the study.

4.2.4 Time 2 data analysis

Data analysis first aimed to identify group differences regarding feeding problems, weight and related factors (Table 4.3). Data analysis also explored differences between Time 1 and Time 2 for both children with Down syndrome and TD children. As such, descriptive analysis was first conducted and is presented in Table 4.2. Similar to Time 1, group differences were identified using independent samples t-tests (Table 4.3) and Bonferroni adjustments were applied to the variables of MCHFS raw score, child weight and child BMI centiles (NHS).

Paired-samples t-tests were then used to identify significant changes between Time 1 and Time 2 for each group (Table 4.4). Given that food texture sensitivity has previously been linked to problematic feeding and eating in children with and without Down syndrome (Ross et al., 2022), a Chi-square test of independence was used to explore the relationship between texture sensitivity and feeding problems (see section 4.3.3 for results). Given the large number of analyses undertaken in this chapter, Tables 4.3 and 4.4 only include full t-test results of comparisons which showed a significant difference, to promote clarity around the study findings. Details of non-significant comparisons are included in Table 4.2 and in section 4.3.

Following this, analysis aimed to identify potential predictors of feeding problems and weight for children with Down syndrome and TD. Therefore, Pearson's correlations were carried out next, to identify variables which were related to (and thus potential predictors of) both Time 2 MCHFS total score (Table 4.5) and Time 2 child weight (Table 4.6). This approach was taken in order to preserve statistical power when running regressions, due to the large number of variables compared to sample sizes (Haycraft et al., 2012). Pearson's correlations

also identified variables with high levels of multicollinearity which were then excluded from further analysis (these variables are denoted in Tables 4.5 and 4.6). For example, parent weight at Time 1 was strongly associated (r=.8 or higher) with parent BMI at Time 1, and so only parent weight at Time 1 was included in subsequent analysis, due to its stronger association with the outcome measure of Time 2 child weight. Time 1 and Time 2 Vineland-3 gross and fine motor raw scores were highly associated and so only Time 1 scores were included in the analysis.

Four separate stepwise regressions were then conducted to identify significant predictors of Time 2 MCHFS total score and Time 2 child weight. Stepwise regressions were selected to facilitate identification of the best predictors of feeding problems and weight (Ruengvirayudh and Brooks, 2016). This method has been used in previous studies which utilise a similar research design and measures to the present study (e.g. Haycraft and Blissett, 2012; Holley et al., 2018). Two separate regressions were conducted to identify predictors of Time 2 MCHFS total score, using the data collected from children with Down syndrome and TD children separately. This same approach was taken to explore predictors of Time 2 child weight. VIF statistics were examined to check again for multicollinearity and scatterplots were produced to satisfy the existence of a linear relationship between variables and outcome variables. Further scatterplots of residuals versus predicted values were produced to satisfy the assumption of homoscedasticity. Histograms were created and checked to ensure normal distribution of residuals

4.3. Time 2 Results

4.3.1 Feeding problems

Analysis aimed to understand how feeding problems changed between Time 1 and Time 2 for both groups (Table 4.4), and to identify any group differences at Time 2 regarding feeding problems (Table 4.3). MCHFS score remained relatively stable and did not significantly change from Time 1 to Time 2 for either children with Down syndrome ($t(22)=.65$, $p=.525$) or TD children ($t(23)=.53$, $p=.603$). However, at Time 2, mean MCHFS score was significantly higher for children with Down syndrome ($M= 38.96$, $SD= 9.02$) than for TD ($M=30.6$, $SD= 8.77$), $t(46)=-3.25$, $p=.002$ (power=.88) and this significance remained after applying a Bonferroni adjustment (which did not happen at Time 1).

At Time 2, seven children with Down syndrome (30%) met the clinical cut off for feeding problems. For six of these children (86%), these were classified as mild feeding problems, and one child (14%) had moderate feeding problems. Within this, four children with Down syndrome who had feeding problems at Time 1 also had them at Time 2, and three children who met the threshold for feeding problems at Time 1 did not meet it at Time 2. Three children with Down syndrome who did not have feeding problems at Time 1 did meet the threshold for feeding problems at Time 2. In all of these cases, scores were very close to the clinical cut off for classification of feeding problems at both Time 1 and 2, and this does not represent a large score change across time points. No children in the TD group had feeding problems at Time 2.

4.3.2 Weight

Weight and height data was analysed to identify changes which occurred between Time 1 and 2 for each group (Table 4.4)., and to identify group differences in weight at Time 2 (Table 4.3). For children with Down syndrome, weight increased by 1.53 kg from Time 1 to Time 2 (*M*= 12.89kg, *SD*= 2.57kg) and this difference was significant, $t(18)=-6.77$, $p<.001$ .Additionally, mean height for this group significantly increased by 4.45cm (*M*=87.77cm, *SD*= 8.79cm), $t(13)=-4.2$, $p<.001$.

For the TD group, Time 2 weight increased by 1.69kg between Time 1 and Time 2 (*M*=15.91kg, *SD*= 2.98kg) and this difference was significant, $t(22)=-6.95$, $p<.001$. Similarly, mean TD height significantly increased by 5.9cm between Time 1 and Time 2, $t(21)=-8.76$, $p<.001$. Between Time 1 and Time 2, both groups gained a similar amount of weight, but TD children grew more in height between time points than children with Down syndrome.

Similarly to Time 1, children with Down syndrome weighed significantly less than TD at Time 2 $t(45)=3.69$, $p<.001$ (power=.95) and were significantly shorter than TD at Time 2, $t(37)=3.13$, $p=.003$ (power= .86). At Time 2, the TD group were 3.01kg heavier and 9.19cm taller than the children with Down syndrome.

Table 4.2. *Descriptive statistics for background factors and non-significant group differences on variables of interest.*

	N		Mean (SD)	
Measures	**Down syndrome**	**TD**	**Down syndrome**	**TD**
Age (months)	24	24	35.54 (11.8)	39.04 (12.28)
Weight				
Parent T2 weight (kg)	20	21	71.61 (19.34)	70.51 (13.76)
Height				
BMI[a]				
Parent T2 BMI	23	24	25.5 (7.74)	26.02 (5.94)
Child T2 BMI centile (NHS)	15	20	78.67 (24.5)	63.15 (24.26)
Child T2 BMI centile (DSMIG)	15	-	61.8 (33.72)	-
MCHFS[b]				
Feeding problems present (n)	7 (28%)	0		
Texture sensitivity				
Texture sensitive	6 (24%)	3 (12%)		
Not texture sensitive	16 (64%)	22 (88%)		
CEBQ[c]				
Food responsiveness	23	25	2.8 (.99)	2.67 (.9)
Emotional overeating	23	25	1.77 (.75)	1.75 (.71)
Enjoyment of food	23	25	3.79 (1.1)	3.95 (.8)
Desire to drink	23	25	2.16 (.82)	2.53 (.94)
Slowness in eating	23	25	2.95 (.71)	2.89 (.66)
Emotional undereating	23	25	2.85 (1.01)	2.97 (.96)
Food fussiness	23	25	3.12 (.82)	2.79 (.89)
CFPQ[d]				
Monitoring	23	25	3.64 (1.32)	3.76 (.83)
Emotional regulation	23	25	1.93 (.72)	2.13 (.71)
Child control	23	25	2.46 (.58)	2.53 (.78)
Encourage balance and variety	23	25	4.25 (.62)	4.12 (.51)
Food environment	22	25	3.48 (.67)	3.6 (.46)
Pressure	23	25	2.87 (.79)	2.95 (.84)
Restriction for weight control	22	25	1.63 (.53)	1.38 (.34)
Food as reward	22	25	1.89 (.84)	2.22 (1.07)
Restriction for health	22	25	2.8 (.92)	2.79 (1.01)
Modelling	22	25	3.87 (.62)	3.98 (.58)
ITSP[e]				
General processing	13	11	10.85 (2.3)	11 (3.44)
Visual processing	13	11	15.46 (4.7)	18.82 (3.79)
Vestibular processing	13	11	13.69 (4.99)	16.45 (4.66)
Sensation seeking	13	11	23.92 (6.47)	33.45 (8.5)
Sensory sensitivity	13	11	36.15 (10.55)	40.73 (9.69)

SSP-2[f]				
Sensory processing	10	14	42.2 (9.73)	44.36 (17)
Behavioural	10	14	64.4 (8.15)	62.07 (25.5)
Registration	10	14	25.8 (7.7)	24.29 (14.07)
Sensory sensitivity	10	14	28.3 (6.73)	32.07 (4.50)
Sensation seeking	10	14	21.3 (5.01)	21.29 (10.25)
Sensation avoidance	10	14	31.2 (4.76)	28.79 (10.49)

Notes

[a]Body mass index, [b]Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011), [c]Children's Eating Behaviour Questionnaire (Wardle et al., 2001), [d]Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman & Holub, 2007), [e]Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002), [f]Short Sensory Profile 2 (SSP-2, Dunn et al., 2014).

Table 4.3. *Time 2 Significant group differences on variables of interest (Independent measures t-tests).*

	N		Mean (SD)				95% confidence interval of the group difference					
Measures	**Down syndrome**	**TD[a]**	**Down syndrome**	**TD[a]**	**df**	**Mean difference**	**Lower**	**Upper**	**Cohen's D**	**Power (1-β)**	***t***	***p***
Weight												
Child T2 weight (kg)	22	25	12.89 (2.57)	15.91 (2.98)	45	3.01	1.37	4.66	1.08	.95	3.69	**.001[b]**
Height												
Child T2 height (cm)	16	23	87.77 (8.79)	96.89 (9.18)	37	9.19	3.23	15.14	1.02	.86	3.13	**.003[c]**
MCHFS[d]												
T2 Total score	23	24	38.96 (9.02)	30.6 (8.77)	46	8.36	-13.53	-3.19	-.94	.88	-3.25	**.002[b]**
CEBQ[e]												
Satiety responsiveness	23	25	2.53 (.6)	2.86 (.45)	46	.33	.02	.64	.62	.56	2.12	**.040[c]**
CFPQ[f]												
Involvement	22	25	2.3 (.77)	2.93 (.96)	45	.63	.11	1.14	.72	.67	2.46	**.018[c]**
Teach about nutrition	22	25	2.68 (.75)	3.19 (.82)	45	.50	.04	.97	.64	.43	2.18	**.034[c]**
ITSP[g]												
Auditory processing	13	11	27.31 (8.44)	34.27 (7.27)	22	6.97	.23	13.7	.88	.54	2.14	**.043[c]**
Tactile processing	13	11	42.92 (13.48)	53.45 (10.46)	22	10.53	.17	20.9	.86	.52	2.11	**.047[c]**
Oral sensory processing	12	11	16.83 (4.93)	25.91 (5.96)	21	9.08	4.35	13.8	1.67	.97	3.99	**.001[c]**

Low registration	13	11	28.69 (10.92)	38.91 (9.9)	22	10.22	1.39	19.04	.98	.63	2.4	**.025**[c]
Sensation avoidance	13	11	37 (12.19)	46.82 (10.08)	22	9.82	.24	19.4	.87	.53	2.13	**.045**[c]
Vineland-3[h]												
Gross motor raw score	12	15	41.25 (10.49)	51.4 (9.58)	25	10.15	2.18	18.12	1.02	.72	2.62	**.015**[c]
Fine motor raw score	12	15	26.58 (5.76)	32 (6.81)	25	5.42	.33	10.5	.85	.56	2.2	**.038**[c]
Gross motor v-score	12	15	9.17 (1.75)	10.8 (1.21)	25	1.63	.46	2.81	1.11	.79	2.87	**.008**[c]
Fine motor v-score	12	15	11.42 (1.62)	12.8 (1.42)	25	1.38	.18	2.59	.91	.62	2.36	**.026**[c]
Motor domain standard score	12	15	75.25 (6.17)	81.53 (6.96)	25	6.28	1	11.56	.95	.65	2.45	**.022**[c]

Notes

[a]Typically developing group, [b]significant at α level of <.016 (Bonferroni adjusted p-value); [c]Significant at α level of <.05, [d]Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011), [e]Children's Eating Behaviour Questionnaire (Wardle et al., 2001), [f]Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman & Holub, 2007), [g]Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002),[h]Vineland Adaptive Behaviour Scales, third edition (Sparrow et al., 2016).

4.3.3 Texture sensitivity

Twenty-four percent (n=6) of children with Down syndrome were texture sensitive, and 12% (n=3) of TD children were texture sensitive. Of the children with Down syndrome who were texture sensitive, three met the cut-off for feeding problems. None of the TD children who were classed as texture sensitive had feeding problems. A chi-square test of independence was performed to evaluate the relationship between texture sensitivity and feeding problems. The relationship between these variables was significant, χ^2 (*df*=2, *N*=47) = 6.17, *p*= .046. Across the sample, children who were classed as texture sensitive were more likely to have feeding problems than those who were not texture sensitive.

4.3.4 BMI

In order to consider child weight in the context of wider health and wellbeing, and to understand differences between children with Down syndrome and TD regarding this, child BMI was calculated and analysed. Using the NHS child BMI centiles (NHS 2024), mean BMI centile at Time 2 for children with Down syndrome was 78.67 (*SD*=24.5) and for TD it was 63.15 (*SD*=24.26) and this difference was not statistically significant. Ninety-five percent (n=19) of TD children were a healthy weight, and 5% (n=1) were classed as 'overweight'. Forty percent (n=6) of children with Down syndrome were at a healthy weight, 33% (n=5) were 'overweight' and 27% (n=4) of children with Down syndrome were 'very overweight'.

However, when using BMI centiles that are specific to children with Down syndrome, established by the Down syndrome Medical Interest Group and Royal College of Paediatrics and Child Health (2011), mean BMI centile for children with Down syndrome was significantly less than when using NHS BMI centiles (*M*=61.8, *SD*=33.72), *t*(14)=2.99,

p=.001. Using this, 67% (n=10) of children with Down syndrome were classed as being a healthy weight, 27% (n=4) were 'overweight', and 7% (n=1) were classed as 'very overweight'.

Mean BMI for both groups of parents of children with Down syndrome (*M= 25.5 SD= 7.74*) and TD (*M*=26.02*, SD*= 5.94) did not significantly differ at Time 2, and were within the overweight range (NHS, 2022)

Table 4.4. *Significant mean score differences from Time 1 to Time 2 for both children with Down syndrome and TD children (paired samples t-tests).*

	Mean score difference from T1 to T2	*p*
Children with Down syndrome		
Weight (kg)	+1.53	**.000**[a]
Height (cm)	+4.45	**.001**[a]
CEBQ[b]		
Emotional overeating	+.3	**.035**[a]
Food fussiness	+.85	**.000**[a]
CFPQ[c]		
Involvement	+.47	**.016**[a]
ITSP[d]		
Vestibular processing	-3.33	**.027**[a]
SSP-2[e]		
Sensory processing	+13.67	**.010**[a]
Behavioural	+23	**.018**[a]
Low registration	+15.33	**.011**[a]
Sensation avoidance	+13.17	**.012**[a]
Vineland-3[f]		
Fine motor raw score	+1.92	**.026**[a]
Fine motor v-score	-1.42	**.001**[a]
Motor domain standard score	-5	**.016**[a]
Typically developing children		
Weight (kg)	+1.69	**.000**[a]
Height (cm)	+5.9	**.000**[a]
CEBQ[b]		
Food fussiness	+.6	**.001**[a]
Food responsiveness	-.32	**.018**[a]
CFPQ[c]		
Food as reward	+.31	**.042**[a]
Monitoring	-.3	**.014**[a]
Pressure	+.41	**.003**[a]
SSP-2[e]		
Sensory processing	+25.18	**.001**[a]
Behavioural	+39	**.000**[a]
Registration	+18.27	**.000**[a]
Sensation seeking	+12.82	**.002**[a]
Sensory sensitivity	+19.55	**.000**[a]
Sensation avoidance	+14.82	**.002**[a]
Vineland-3[f]		
Gross motor raw score	+4.36	**.005**[a]
Fine motor raw score	+4.14	**.003**[a]
Gross motor v-score	-1.86	**.008**[a]
Fine motor v-score	-1.29	**.033**[a]
Motor domain standard score	-9	**.005**[a]

Notes

[a]Significant at α level of <.05, [b]Children's Eating Behaviour Questionnaire (Wardle et al., 2001), [c]Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman &

Holub, 2007), [d]Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002, [e] [f]Short Sensory Profile 2 (SSP-2, Dunn et al., 2014), [f]Vineland Adaptive Behaviour Scales, third edition (Sparrow et al., 2016).

4.3.5 Child eating behaviours

CEBQ scores were explored to understand whether and how children with Down syndrome and TD children's eating behaviours changed from Time 1 to Time 2 (Table 4.4), and how eating behaviours were different between groups at Time 2 (Table 4.3). At Time 2, children with Down syndrome scored significantly lower than TD children for only the CEBQ subscale of satiety responsiveness, $t(46)=2.12$, $p=.040$, but power was relatively low at .5. The mean difference in satiety responsiveness scores between children with Down syndrome and TD children was relatively similar from Time 1 (.41) to Time 2 (.33).

For children with Down syndrome, scores on the CEBQ subscale of food fussiness increased significantly from Time 1 to Time 2 $t(22)=-7.04)$, $p<.001$, as did emotional overeating, $t(22)=2.25$, $p=.035$ (Table 4.4). For TD children, food fussiness also significantly increased from Time 1 to Time 2 $t(23)=-4$, $p<.001$, and food responsiveness significantly decreased from Time 1 to Time 2, $t(23)=2.56$, $p=.018$.

4.3.6 Parental feeding practices

Analysis of CFPQ data revealed some changes in reported parental feeding practices over time (Table 4.4), and between groups (Table 4.3). At Time 2, parents of children with Down syndrome reported significantly lower levels of involvement, $t(45)=2.46)$, $p=.018$, and teaching about nutrition than parents of TD children, $t(45)=2.18)$, $p=.034$. Mean difference in involvement between groups was .68 at Time 1 and at Time 2 it was .63, indicating that this

group difference remained similar over time. Regarding teaching about nutrition, the mean difference between groups reduced from .62 at Time 1 to .51 at Time 2.

At Time 2, parents of children with Down syndrome reported significantly higher levels of involvement than at Time 1, $t(21)=-2.61)$, $p=.016$.

Between Time 1 and Time 2, a significant increase of using food as a reward, $t(23)=2.15)$, $p=.042$, and pressure to eat, $t(23)=3.28)$, $p=.003$, was observed for parents of TD children, whereas monitoring reduced between timepoints, $t(23)=2.66)$, $p=.014$.

4.3.7 Sensory processing- ITSP and SSP-2

Sensory processing data was analysed to understand how sensory processing changed and developed over time (Table 4.4), and where groups differed at Time 2 (Table 4.3). Twenty-four participants completed the ITSP for their child at Time 2 (13 parents of children with Down syndrome and 11 TD). The SSP-2 was completed by twenty-four participants which consisted of 10 parents of children with Down syndrome, and 14 parents of TD children. ITSP and SSP-2 scores are interpreted differently (see Chapter 3, Time 1 for a further details). Using the ITSP, lower scores indicate higher levels of sensory sensitivity. Conversely, using the SSP-2, higher scores indicate higher levels of sensory sensitivity.

For children with Down syndrome, mean scores were below typical performance for all ITSP subscales, indicating increased levels of sensory sensitivity than typical norms. For TD children, mean scores were below typical performance for auditory, visual, vestibular processing, low registration and sensory sensitivity. TD children scored within the typical performance range for all other ITSP subscales.

At Time 2, children with Down syndrome scored significantly lower than TD children on the ITSP subscales of auditory, tactile and oral sensory processing, low registration and sensation avoidance indicating more sensitivity on these subscales than the TD group (Table 4.3). However, power was low for auditory processing (.54), tactile processing (.52) and sensation avoidance (.53), indicating low confidence in these findings. Levels of hypersensitivity significantly increased on the ITSP subscale of vestibular processing between Time 1 and Time 2 for children with Down syndrome (Table 4.4).

Both children with Down syndrome and TD children scored above typical performance ranges for all SSP-2 subscales, indicating hypersensitivity. Mean scores for SSP-2 subscales did not significantly differ between groups. In comparison to Time 1, parents of children with Down syndrome reported significantly higher levels of sensitivity regarding the SSP-2 subscales of sensory processing, behavioural, low registration and sensation avoidance at Time 2 (Table 4.4). At Time 2, parents of TD children reported significantly higher levels of sensitivity for all SSP-2 subscales in comparison to Time 1.

Mean group differences appeared to increase between Time 1 and Time 2 for the ITSP subscales, indicating growing group differences in sensory processing over time. However, at Time 2 no significant group differences were observed on SSP-2 subscales, indicating that sensory processing differences may be greater between children with Down syndrome and TD children under 36 months of age. As parents completed either the ITSP or SSP-2 depending on their child's age, it is possible that this trend may be reflective of different sample sizes between Time 1 and Time 2. For example, at Time 1 the ITSP was completed by 30 participants (n= 16 parents of children with Down syndrome, n= 13 TD), and the SSP-2 was completed by a smaller group of 19 participants (n= 8 parents of children with Down syndrome, n= 11 TD). Whereas at Time 2, the ITSP was completed by 24 participants (n= 13

parents of children with Down syndrome, n= 11 TD), and the SSP-2 was also completed by 24 participants (n=10 parents of children with Down syndrome, n=14 TD).

4.3.8 Motor skills

Analysis aimed to map motor skill proficiency over time (Table 4.4) and to identify whether children with Down syndrome and TD children differed regarding gross and fine motor skills at Time 2 (Table 4.3). At Time 2, 27 responses were collected for the Vineland-3 motor skills domain. Children with Down syndrome scored significantly lower than TD for both subdomains of gross and fine motor skills, and also for overall motor skill proficiency (motor domain standard score in Table 4.2). For children with Down syndrome, fine, gross and overall motor skill proficiency scores were lower than same age norms at Time 2. For TD children, gross and overall motor skill proficiency scores were lower than same age norms at Time 2.

Unexpectedly, differences observed between Time 1 and Time 2 for children with Down syndrome indicate a significant reduction in fine and overall motor skill proficiency scores (Table 4.4). For TD children, significant reductions were observed for gross, fine and overall motor skill proficiency scores between Time 1 and Time 2.

4.3.9 Predicting feeding problems at Time 2

Next, analysis aimed to identify potential predictors of Time 2 feeding problems and weight for children with Down syndrome and TD children. Related variables were first identified to highlight possible predictors, and this was explored using multiple regressions.

4.3.9.1 Children with Down syndrome

Pearson's correlations (Table 4.5) identified the following variables as significantly associated with Time 2 MCHFS raw scores for children with Down syndrome: Time 1 MCHFS raw scores, parent BMI at Time 2 and texture sensitivity. A stepwise multiple linear regression was then run to identify whether any of these variables could predict feeding problems at Time 2 for children with Down syndrome, and the significance of the overall model. Only Time 1 MCHFS scores significantly predicted feeding problems at Time 2 (β= .54, t=4.75, p<.001) and this accounted for 59% of the variance in feeding problems at Time 1 (R^2= .59, F(1,16)=22.53, p<.001).

As feeding problems at Time 1 significantly predicted feeding problems at Time 2, predictors of Time 1 were also explored. The correlates of MCHFS raw scores identified at Time 1 (Table 3.3, Chapter 3) were entered into a stepwise multiple linear regression: infant enjoyment of food and general appetite, childhood enjoyment of food and food fussiness, parental encouragement of balance and variety and low sensory registration (ITSP). Only childhood enjoyment of food significantly predicted feeding problems at Time 1(β= -5.93, t=-2.23, p=*.042*) and this accounted for 26% of the variance in feeding problems at Time 1 (R^2= .26, F(1,14)=4.99, p=*.042*).

Figure 4.1. outlines key relationships between variables and feeding problems at Time 1 and Time 2 for children with Down syndrome.

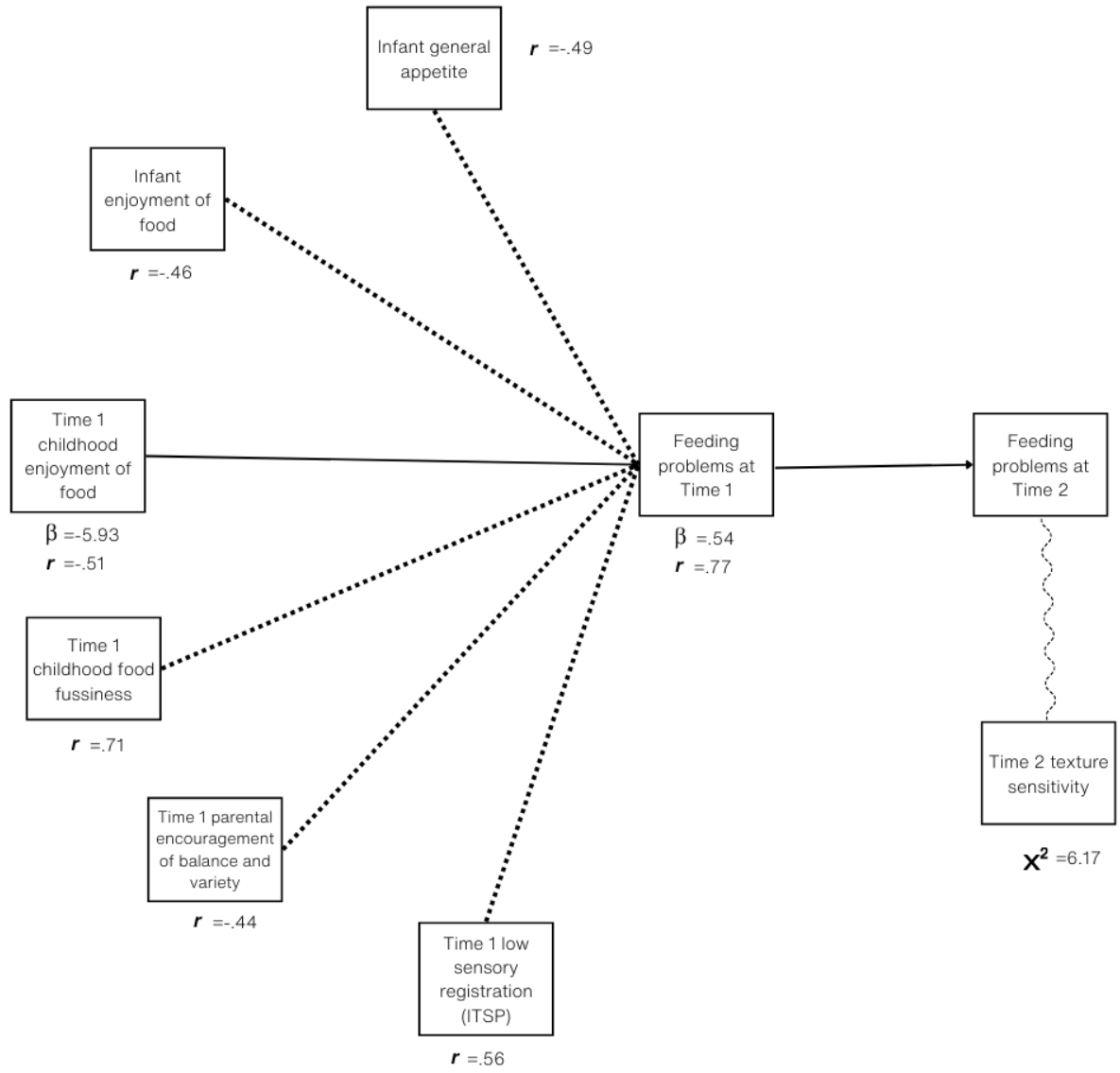

Figure 4.1. *Significant relationships between variables and feeding problems at Times 1 and 2 for children with Down syndrome.*

Notes

Dashed straight lines denote significant correlates of Time 1 feeding problems (identified in Table 3.3, Chapter 3) and solid arrows depict significant predictors of feeding problems at both Time 1 and 2. The wavy dashed line portrays the significant association between texture sensitivity status and feeding problems.

Table 4.5. *Significant Pearson's correlation coefficients between predictors and MCHFS total score at Time 2 for both children with Down syndrome and TD children.*

	Children with Down syndrome		TD children	
	r	***p***	***r***	***p***
Background factors				
Time 1 parent weight[a]	-.49	**.026**[b]	-	-
Time 1 parent BMI[a]	-.54	**.012**[b]	-	-
Time 2 parent BMI	-.50	**.029**[b]	-	-
CEBQ[c]				
Enjoyment of food (T1)	-	-	-.50	**.013**[b]
Enjoyment of food (T2)	-	-	-.66	**.000**[b]
Emotional overeating (T1)	-	-	.41	**.044**[b]
Food fussiness (T1)	-	-	.58	**.003**[b]
Food fussiness (T2)	-	-	.74	**.000**[b]
CFPQ[d]				
Child control (T2)	-	-	.48	**.015**[b]
Food as a reward (T2)	-	-	.41	**.042**[b]
ITSP[e]				
Sensation avoidance (T1)	-	-	-.55	**.049**[b]
SSP-2[f]				
Sensation avoidance (T2)	-	-	-.77	**.001**[b]
Time 1 MCHFS[g] **total score**	.77	**.000**[b]	.46	**.025**[b]
Texture sensitivity	.57	**.008**[b]	.55	**.005**[b]

Notes

[a] Variables which were not included in multiple linear regression analyses due to high multicollinearity (r=.8 or higher) with other variables associated with the outcome measures, [b]Significant at α level of <.05, [c]Children's Eating Behaviour Questionnaire (Wardle et al., 2001), [d]Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman & Holub, 2007), [e]Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002, [f]Short Sensory Profile 2 (SSP-2, Dunn et al., 2014), [g]Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011).

4.3.9.2 TD Children

Pearson's correlations identified several potential predictors of Time 2 feeding problems for the TD group (Table 4.5), and so a stepwise multiple linear regression was conducted to identify any significant predictors from the following: Time 1 feeding problems, childhood enjoyment of food (both Times 1 and 2), emotional overeating at Time 1, food fussiness (both Time 1 and Time 2), sensation avoidance (ITSP, Time 1), the parental feeding practices of child control and food as a reward (Time 2), sensation avoidance at Time 2 (SSP-2), and texture sensitivity. Both feeding problems at Time 1 (β= .47, t=2.88, p=.016) and the Time 2 SSP-2 measure of sensation avoidance (β= -.63, t=-5.03, p=.001) were significant predictors of Time 2 feeding problems for TD children. This model accounted for 78% of the variance in feeding problems at Time 2 (R^2= .78, F(2,10)=17.29, p=.001).

Predictors of Time 1 feeding problems for TD children were then explored using the correlates of Time 1 MCHFS raw scores identified in Chapter 3, Table 3.3: age of introduction to solid foods, child enjoyment of food and food fussiness, the parental feeding practices of monitoring and encouraging balance and variety, and the ITSP measures of oral sensory sensitivity, low registration and sensation avoidance. Only food fussiness was identified as a significant predictor of feeding problems at Time 1 for TD children (β= 7.43, t=3.21, p=.009) and this accounted for 51% of the variance in Time 1 feeding problems scores for TD children (R^2= .51, F(1,10)=10.32, p=.009).

Figure 4.2. outlines key relationships between variables and feeding problems at Time 1 and Time 2 for TD children.

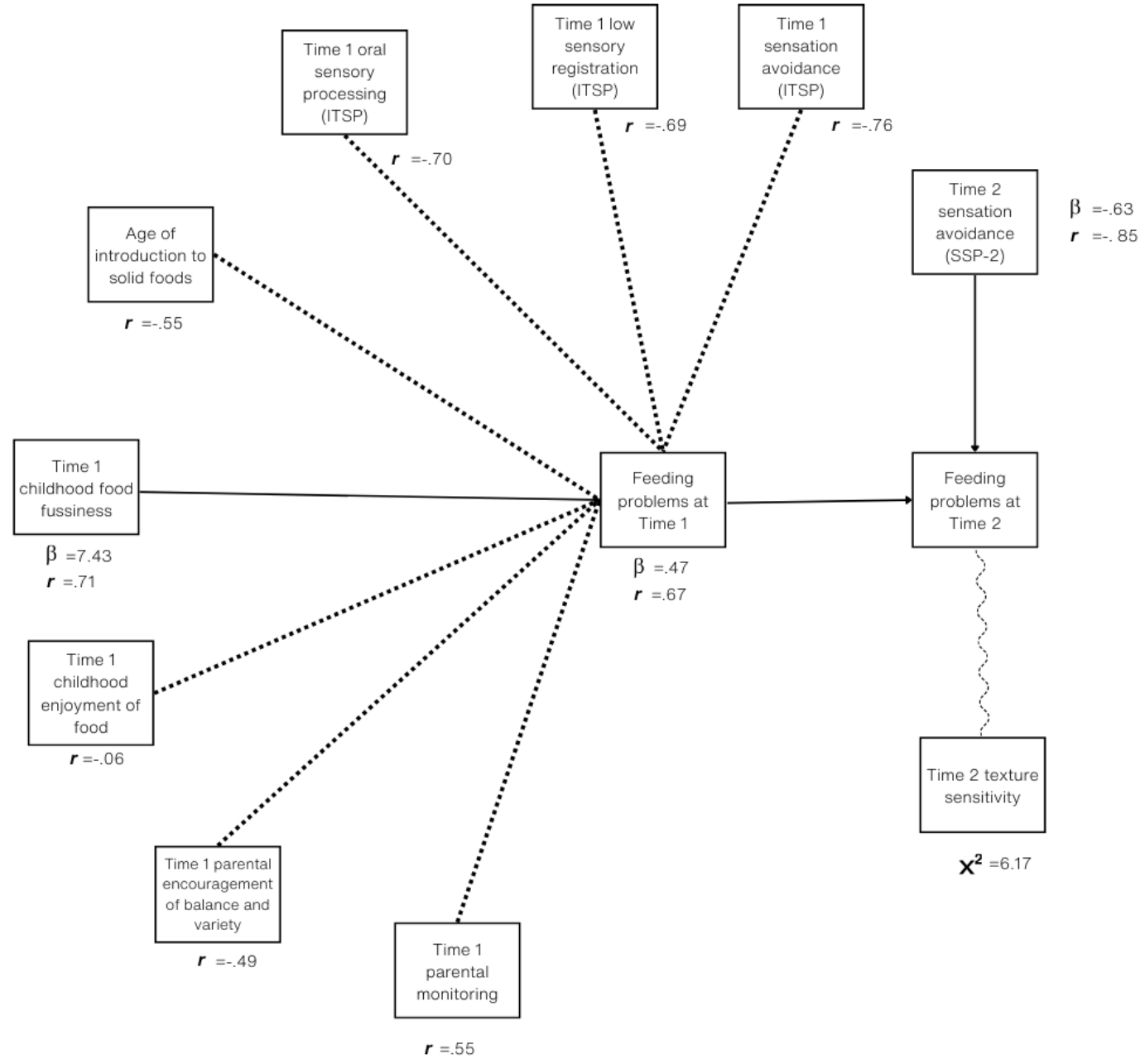

Figure 4.2. *Significant relationships between variables and feeding problems at Times 1 and 2 for TD children.*

Notes

Dashed straight lines denote significant correlates of Time 1 feeding problems (identified in Table 3.3, Chapter 3) and solid arrows depict significant predictors of feeding problems at

both Time 1 and 2. The wavy dashed line portrays the significant association between texture sensitivity status and feeding problems.

Table 4.6. *Significant Pearson's correlation coefficients between predictors and Time 2 child weight for children with Down syndrome and TD children.*

	Children with Down syndrome		**TD children**	
	r	***p***	***r***	***p***
CEBQ[a]				
Food responsiveness (T2)	.53	**.014[b]**	-	-
CFPQ[c]				
Involvement (T1)	-	**-**	.47	**.020[b]**
Monitoring (T1)	-	**-**	-.43	**.037[b]**
Monitoring (T2)	-	**-**	-.52	**.007[b]**
Teaching about nutrition (T1)	-	**-**	.57	**.004[b]**
ITSP[d]				
Sensation seeking (T2)	-.60	**.038[b]**	-	**-**
SSP-2[e]				
Behavioural (T1)[f]	-.79	**.036[b]**	-	**-**
Registration[f]	.83	**.022[b]**	-	**-**
Vineland-3[g]				
Gross motor raw score (T1)	.65	**.016[b]**	.56	**.028[b]**
Fine motor raw score (T1)[f]	-	**-**	.64	**.010[b]**
Gross motor v-score (T1)[f]	-	**-**	-.7	**.004[b]**
Fine motor v-score (T1)[f]	-	**-**	-.61	**.004[b]**
Motor domain standard score (T1)	-	**-**	-.64	**.011[b]**
Gross motor raw score (T2)[f]	-	**-**	.67	**.000[b]**
Fine motor raw score (T2)[f]	-	**-**	.7	**.000[b]**
Time 1 MCHFS[h] total score	-.54	**.012[b]**	-	**-**
Time 1 child weight	.89	**.000[b]**	.92	**.000[b]**

Notes

[a]Children's Eating Behaviour Questionnaire (Wardle et al., 2001), [b]Significant at α level of <.05, [c]Comprehensive Feeding Practices Questionnaire (CFPQ, Musher-Eizenman & Holub, 2007), [d]Infant Toddler Sensory Profile (ITSP, Dunn et al., 2002), [e]Short Sensory

Profile 2 (SSP-2, Dunn et al., 2014), [f] Variables which were not included in multiple linear regression analyses due to high multicollinearity (r=.8 or higher) with other variables associated with the outcome measures. [h] Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011).

4.3.10. Predicting child weight at Time 2

4.3.10.1 Children with Down syndrome

Following Pearson's correlations (Table 4.6), a stepwise multiple linear regression was conducted to explore whether any of the following variables were significant predictors of child weight at Time 2 for children with Down syndrome: child weight at Time 1, Time 1 MCHFS raw scores, Vineland-3 gross motor raw scores measured at Time 1, and food responsiveness at Time 2. For children with Down syndrome, weight at Time 2 was significantly predicted by the CEBQ subscale of food responsiveness at Time 2 (β= 1.42, t=12.61, p<.001), Time 1 weight (β= .59, t=7.55, p<.001) and gross motor raw scores measured by the Vineland-3 at Time 2 (β= .08, t=7.17, p<.001). This model accounted for 99% of the variance in child weight at Time 2 (R^2= .99, F(3,9)=268.04, p<.001).

Given that Time 1 weight was a significant predictor of Time 2 weight for children with Down syndrome, further analysis was conducted to explore whether any correlates of child weight which were identified at Time 1 (Table 3.3, Chapter 3) could significantly predict child weight at Time 1. As a result, a stepwise multiple linear regression was conducted to explore whether any of the following variables were significant predictors of child weight at Time 1 for children with Down syndrome: infant food responsiveness and general appetite, the parental feeding practice of modelling, tactile sensitivity (measured by the ITSP), oral

sensory processing (measured by the ITSP), gross motor v-scores. However, no significant predictive relationships were found, and the overall model was not significant.

Figure 4.3 outlines key relationships between variables and weight at Time 1 and Time 2 for children with Down syndrome.

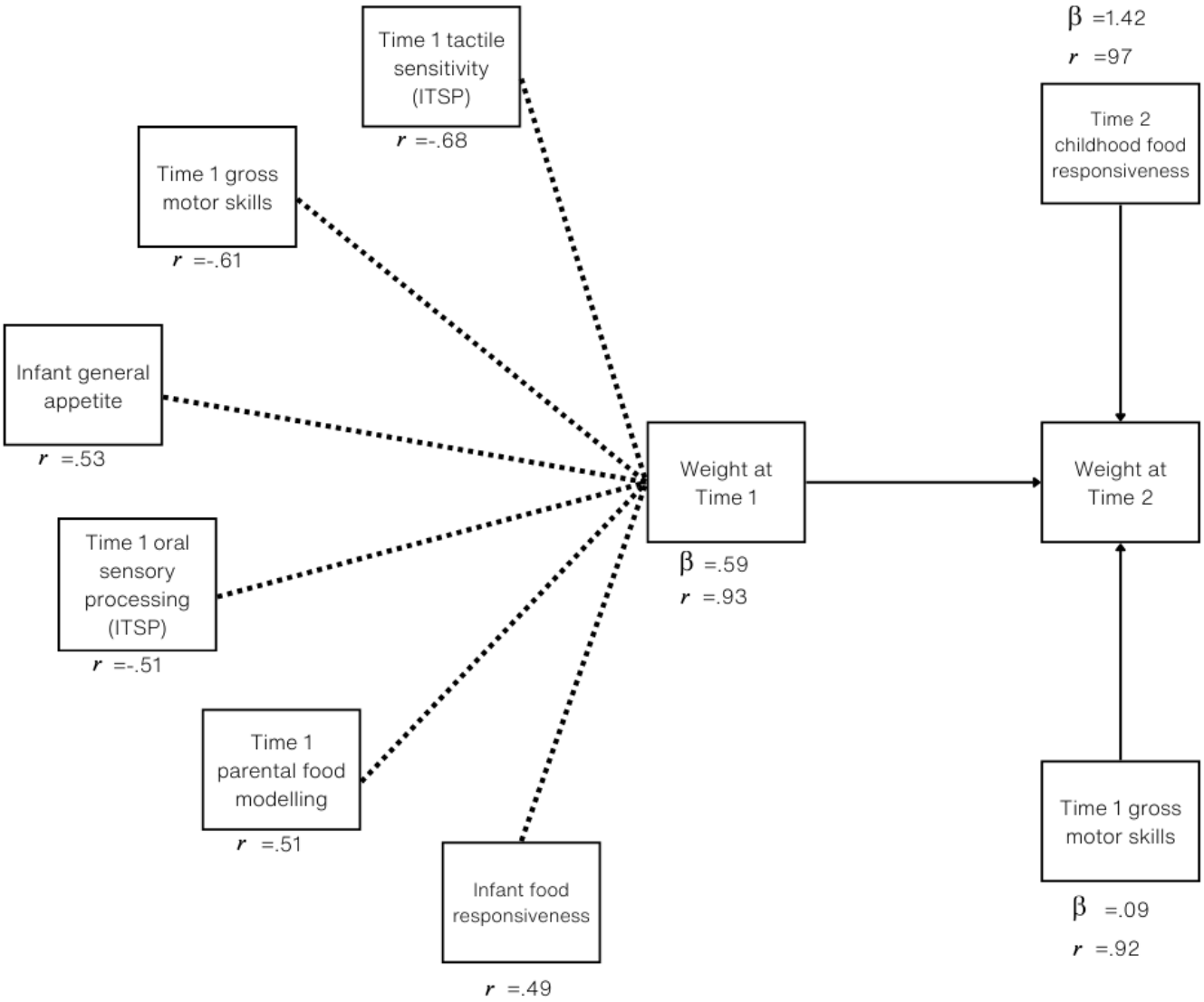

Figure 4.3. *Correlates and predictors of weight for children with Down syndrome.*

Notes

Dashed arrows denote significant correlates of Time 1 weight (identified in Table 3.3, Chapter 3) and solid arrows depict significant predictors of weight at Time 2.

4.3.10.2 TD children

For the TD group, a stepwise multiple linear regression was conducted to identify potential predictors of Time 2 child weight from Time 1 weight, gross motor raw scores at Time 1, overall motor standard scores at Time 1, the parental feeding practices of involvement (Time 1), monitoring (Time 1 and Time 2) and teaching about nutrition (Time 1).

Time 2 weight was significantly predicted by Time 1 weight (β= 1.24, t=36.53, p<.001), gross motor raw scores at Time 1 (β= -.17, t=-15.21, p<.001) and the Time 1 parental feeding practice of monitoring (β= -1.63, t=-13.3, p<.001). This model accounted for 99% of the total variance in TD child weight at Time 2 (R^2= .99, F(3,11)= 689.99, p<.001).

Further analysis was then undertaken to identify whether any of the correlates of TD child weight identified at Time 1 (Table 3.3, Chapter3) could predict TD child weight at Time 2. A stepwise multiple linear regression was conducted to identify potential predictors of Time 1 child weight from child food fussiness (Time 1), and oral sensory processing (ITSP, Time 1). However, no significant predictive relationships were found, and the overall model was not significant.

Figure 4.4 outlines key relationships between variables and weight at Time 1 and Time 2 for TD children.

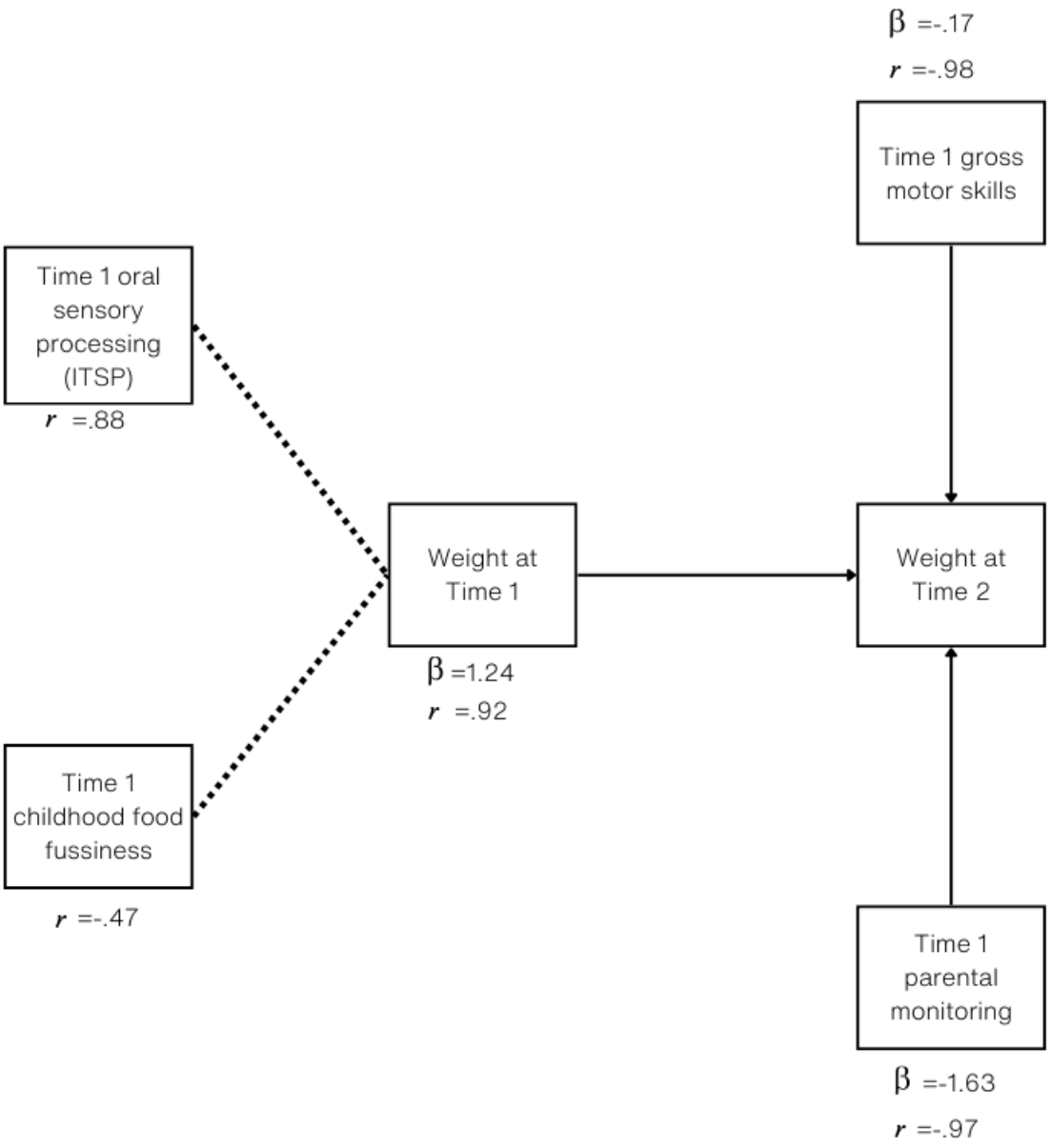

Figure 4.4. *Correlates and predictors of weight for TD children.*

Notes

Dashed arrows denote significant correlates of Time 1 weight (identified in Table 3.3, Chapter 3) and solid arrows depict significant predictors of weight at Time 2.

4.4. Discussion

The present study aimed to explore potential longitudinal predictors of feeding problems and weight outcomes in young children with Down syndrome, including how this is different to TD children. The findings from this study provide a comprehensive analysis of feeding problems, weight, texture sensitivity, BMI, child eating behaviours, parental feeding practices, sensory processing and motor skills in children with Down syndrome compared to TD children. The results underscore significant differences between the two groups, highlighting areas of concern and potential intervention.

Children with Down syndrome exhibited higher feeding problems scores compared to TD children, which remained stable over time. Notably, 30% (n= 7) of children with Down syndrome met the clinical cut-off for feeding problems, primarily classified as mild. This is consistent with existing research which has explored feeding problems in children with Down syndrome (Anil et al., 2019; Cochran et al., 2022; Rogers et al., 2021; Spender et al., 1996). At Time 1, the same number of children with Down syndrome met the clinical cut off for feeding problems, however, unlike at Time 2, the mean difference between groups in MCHFS raw score was no longer significant once a Bonferroni adjustment was made. At both Time 1 and Time 2, none of the TD children were reported to have feeding problems. These findings indicate a pronounced disparity that necessitates targeted support for children with Down syndrome to address their unique feeding challenges.

Both groups showed significant increases in weight and height over time. However, children with Down syndrome were significantly lighter and shorter than TD children at Time 1 and Time 2. This discrepancy highlights potential growth and nutritional concerns for children with Down syndrome (Charleton et al., 2014). Additionally, when using standard BMI

centiles, a higher proportion of children with Down syndrome (60%, n= 9) fell into the overweight or very overweight categories compared to TD children. However, using Down syndrome-specific BMI centiles (DSMIG and RCPCH, 2011), a larger proportion of children were classified as having a healthy weight, (67%, n=10) suggesting the importance of using appropriate growth charts for accurate assessments. Although, even when using the Down syndrome specific growth charts, rates of overweight and obesity were higher (33%, n= 5) than for TD (5%, n=1), demonstrating that achieving a healthy weight is of particular concern for children with Down syndrome.

There is some conflict amongst the literature about which BMI measure is most suitable for use with toddlers with Down syndrome. For example, Zemel et al., (2015) suggest that typical, widely used BMI charts (such as CDC, 2000) are not appropriate for use in children with Down syndrome as they do not take into consideration the shorter stature that is typical of children with Down syndrome, and therefore weight category classifications such as overweight or healthy are not reliable. In contrast, Hatch-Stein et al., (2016) argue that CDC (2000) BMI growth charts are a more reliable measure of excess adiposity than Down syndrome specific BMI charts as their analysis revealed that CDC (2000) BMI growth charts were more sensitive and able to detect excess adiposity in children with Down syndrome. It is unclear how best to measure BMI in this group, or whether BMI is a useful or appropriate measure for this group at all. As such, BMI should be considered amongst a range of other observations, and not be solely relied upon to determine whether or not a child with Down syndrome is at a healthy weight.

A larger percentage of children with Down syndrome (29%) and a smaller percentage of TD children (12%) exhibited texture sensitivity, and this was associated with feeding problem scores (as shown by Chi-squared). This suggests that texture sensitivity plays a crucial role in

feeding difficulties, particularly for children with Down syndrome as rates of texture sensitivity were higher than for TD. This finding is consistent with existing research which has identified food texture sensitivity as a particular challenge for children with Down syndrome (Bernhard, 2019; Field et al., 2003). Food texture sensitivity has been shown to strongly influence eating behaviours and food preferences in children with Down syndrome (Ross et al., 2024), which highlights the important role it may play in the development of both feeding problems and weight (Hielscher et al., 2023). Parents of young children with Down syndrome who are texture sensitive may limit the types of food textures they offer their child due to anticipation of rejection from the child as a result of textural aversions or difficulties safely managing certain challenging food textures (Anil et al., 2019; Cochran et al., 2022; Hopman et al., 1998; Hielscher et al., 2023; Roccatello et al., 2021). However, exposure to varying food textures which gradually increase in difficulty during the complementary feeding period is important as the development of oral anatomy and processing skills (such as co-ordination of chewing and improved muscle control) is reliant on experience (Forde and Tournier, 2023). As such, the significant association between texture sensitivity and feeding problems underscores the need for early identification and sensory-based interventions to help manage these sensitivities and encourage a wider acceptance of foods in children with Down syndrome, in turn encouraging optimal oral processing skills. Chapter 2 (scoping review) explores in more detail factors and practices which may promote optimal eating development in this group, including texture acceptance.

A limitation of the present study is that texture sensitivity was only assessed at Time 2. Given the relationship between texture sensitivity and feeding problems, it would be helpful to know at what point during early childhood did texture sensitivity become apparent, and how stable this is over time. It was not possible to include the texture sensitivity questions during data collection at Time 1 because they were first published after the Time 1 research protocol

had already been designed. However, future research should aim to establish the earliest point at which food texture sensitivity can be detected for young children with Down syndrome, in order to identify critical periods for intervention. Ross et al., (2022) have used the questions to identify texture sensitivity in TD children as young as four months old, and so it is possible that incorporating this assessment into future longitudinal research which includes a wider age range than the present study would provide beneficial further information about the role that texture sensitivity plays in the development of feeding problems.

Children with Down syndrome again scored lower on satiety responsiveness than TD children and showed significant increases in food fussiness and emotional overeating over time. In TD children, food fussiness also increased, but food responsiveness decreased. These changes over time are consistent with existing literature which has shown that food neophobia and associated picky/fussy eating increases to reach peak levels between the ages of two and six years of age (Dovey et al., 2008). These findings indicate evolving eating behaviours in both groups, with children with Down syndrome exhibiting more pronounced changes that could impact their dietary intake and overall health.

Parents of children with Down syndrome reported lower levels of involvement and teaching about nutrition compared to parents of TD children. However, involvement increased from Time 1 to Time 2, suggesting growing awareness and engagement. For parents of TD children, there was a significant increase in using food as a reward, monitoring, and pressure to eat, reflecting changes in parental strategies that may influence children's eating behaviours. Powell et al., (2011) previously found that mothers who report higher levels of child food fussiness also report using more pressure to eat and parental use of food as a reward was related to increases in child food fussiness. Therefore, it may also be the case that parents are adapting their feeding practices in response to increased food fussiness and

responsiveness observed in the TD children, highlighting the bidirectional relationship between child eating behaviours and parental feeding practices (Costa and Oliveira, 2023; Roberts et al., 2018).

Children with Down syndrome exhibited higher sensitivity across various sensory processing subscales compared to TD children, with significant increases in hypersensitivity observed over time. This heightened sensory sensitivity may have contributed to the feeding and eating challenges observed (Yi et al., 2015). Both groups showed increased sensitivity on the SSP-2 subscales, indicating a broader trend of rising sensory processing issues that need to be addressed. It is interesting that both children with Down syndrome and TD children were observed to have high levels of sensory sensitivity, and this was not expected for the TD group in particular. The mean age of the sample indicates that this cohort of children were born during and in the aftermath of the COVID-19 pandemic. An emerging body of research has highlighted the myriad ways in which child development may have been negatively impacted as a result of the pandemic. Increased pre and post-partum stress, anxiety and depression measured during the pandemic have been linked to increased levels of child sensory avoidance at 18 months of age (Aubin et al., 2024). Additionally, the closure of many early education and care services during the pandemic represent a loss of many important early childhood experiences and have been shown to impact child socio-emotional development negatively (Egan et al., 2021). Pandemic related deprivation of important sensory experiences during early life (particularly during critical developmental periods) can hinder sensory processing and integration abilities (Purpura et al., 2023). It is reasonable to speculate that the atypical early experiences of this generation may be a contributing factor to the increased sensory sensitivity observed in the present study, but larger scale, further research is needed to confirm this and to better understand this phenomenon.

Motor skill proficiency was significantly lower in children with Down syndrome compared to TD children, with notable reductions observed over time in both groups, indicating an increasing delay for children with Down syndrome. It was particularly unexpected that parents of TD children reported lower levels of motor skill proficiency at Time 2. There is existing research which suggests that parent report both is, (e.g. Federico et al., 2021; Humble et al., 2024) and is not an accurate measure of child motor skills compared to clinician or direct observation assessments (e.g. Zysset et al., 2017). Evidence suggests that parents are more likely to over report than under report their child's motor abilities (Stoiber, 1992). The Vineland-3 offers three potential response options for parents to choose from in relation to whether their child can complete a motor task without help or reminder and these are 'never', 'sometimes' or 'usually or often'. For parents trying to consider how frequently their child performs an obscure skill (e.g. gross motor item 41: 'catches a tennis sized ball from two or three feet away. May catch with two hands or one but must catch away from the body instead of trapping the ball against the body), the difference between an answer of 'sometimes' and 'usually' may have seemed ambiguous. It is possible that when completing the Vineland-3 at Time 1, parents may have responded in a more optimistic manner and potentially overestimated motor abilities, which could have been corrected at Time 2, as opposed to an actual worsening of motor skills over time.

This same phenomenon could have applied to other broad concepts which this study attempted to measure. For example, when parents were asked to assess how often their child exhibits food fussiness (using the CEBQ), the distinction between response categories such as "sometimes" and "usually" may be unclear. As a result, parents may have initially responded with an optimistic bias, reporting that their child is less fussy than they truly are, especially if they are trying to project positive eating habits. Over time, as parents become more aware of their child's eating patterns or reflect on their prior responses, they might have adjusted their

assessments more accurately in later measures. This could have lead to the appearance of increased food fussiness at Time 2, not because the child's behaviour has changed, but because parents are correcting their initial overestimation. This highlights the potential for response bias when parents are asked to provide subjective assessments of their child's behaviour, particularly in areas like food fussiness where daily variability is common.

The finding that children with Down syndrome were again seen to have lower motor skill proficiency than TD children has highlighted the ongoing motor development challenges in this group. This is consistent with extant research that has identified motor delays in this group (Malak et al., 2015). Oral-motor skill delays can negatively impact several elements of feeding and eating such as limiting self-feeding abilities, hindering the development of effective chewing patterns and the ability to manipulate food in the mouth (Anil et al., 2019; Field et al., 2003; Roccatello et al., 2021; Ross, 2023). Additionally, motor skill delays have been associated with increased rates of overweight in TD children (Slining et al., 2010). Early and continuous motor skill interventions are essential for children with Down syndrome. These interventions not only promote optimal eating abilities, and therefore a more diverse diet, but also encourage physical activity, such as sports, which can help maintain a healthy weight (Marquis and Baker, 2015).

Given that it is already widely known that children with Down syndrome may experience more challenges co-ordinating tongue and mouth movements during eating (Ross et al., 2022), a limitation of the present study is that oral-motor skills were not specifically measured. While gross and fine motor skills were assessed using the Vineland-3 to gauge overall motor proficiency, a specific assessment of oral-motor skills would have offered even more detailed insights into which motor skills are most relevant to the development of feeding problems and how they influence these issues. An oral-motor skill assessment

conducted through observation or clinician assessment would have been optimal. However, this was beyond the scope of the present study due to the PhD timeline. It was not possible to find a parent-report measure of oral-motor skills suitable for both children with and without Down syndrome. Therefore, including such assessments would enhance future research.

The study identified that the feeding problems at Time 1 were a significant predictor of feeding problems at Time 2 for both groups, explaining a substantial portion of the variance. Additionally, across the sample texture sensitivity status was significantly associated with presence of feeding problems, and for TD children sensory avoidance significantly predicted Time 2 feeding problems, emphasising the role of sensory factors in feeding difficulties. Since feeding problems remained stable between Time 1 and Time 2, and Time 1 feeding problems strongly predicted those at Time 2, it suggests that the factors related to feeding problems are established early. This underscores the necessity of early intervention for factors associated with feeding problems. For children with Down syndrome, feeding problems at Time 1 were predicted by child enjoyment of food, and were associated with (as shown by partial correlations) infant general appetite and enjoyment of food, childhood food fussiness, parental encouragement of balance and variety, and sensory registration. For TD children, Time 2 feeding problems were predicted by sensory avoidance and Time 1 feeding problems. Time 1 feeding problems were predicted by food fussiness and associated with (as shown by partial correlations) enjoyment of food, age of introduction to solid foods, parental monitoring and encouragement of balance and variety, as well as sensory processing. Therefore, these factors represent potential areas for intervention and support to reduce future feeding problems.

Regarding weight, children with Down syndrome consistently showed lower weight outcomes at both Time 1 and Time 2 compared to TD children but despite this, increased

rates of overweight and obesity were observed at Time 2, indicating distinct growth patterns in this group. For children with Down syndrome, predictors of weight at Time 2 included weight at Time 1, food responsiveness and gross motor skills. No predictors of Time 1 weight were identified, but Time 1 weight was associated with several factors such as infant food responsiveness and general appetite, oral sensory processing and tactile sensitivity, parental food modelling and gross motor skills. For TD children, some differences were observed regarding predictors of weight outcomes and associated factors. Weight at Time 2 was predicted by Time 1 weight, gross motor skills and parental food monitoring. Similar to children with Down syndrome, no predictors of Time 1 weight were identified, but associated factors included oral sensory processing and food fussiness. Overall, it is clear that some factors which are related to weight outcomes differ for children with Down syndrome compared to TD children. As such, early and comprehensive support that is tailored to children with Down syndrome is crucial to establish healthy weight trajectories early on, as these children face an increased risk of overweight and obesity starting from a young age (Bertapelli et al., 2016).

Several factors in early life, such as dietary habits, parental feeding practices, breastfeeding, introduction of nutritious foods, infant sleep duration, and family meals, have been linked to weight outcomes in infants and toddlers (Dattilo et al., 2012). Therefore, it is essential to identify and address weight-related challenges early, providing timely information and support to parents. Interventions should focus on factors identified in this study, such as childhood food responsiveness and gross motor skills and aim to promote protective factors like physical activity and exercise. Despite the importance of early interventions to promote healthy habits and prevent obesity in children with developmental disabilities, research on effective interventions specifically targeting weight and nutrition outcomes in this population remains limited (Mirza et al., 2014; Schenkelberg et al., 2023). Equipping parents with

resources and education on nutrition and physical activity can help mitigate obesity risks and enhance overall health outcomes for children with Down syndrome.

This study is limited by the fact that data collection was repeated only seven months apart. It is possible that this may not have allowed sufficient time to capture significant developmental changes in feeding problems, weight, or related factors in children with Down syndrome and TD children. Feeding difficulties and growth patterns can evolve over longer periods, and a brief time frame might miss important transitions or obscure longer-term trends. Additionally, this limits the ability to observe whether feeding problems resolve or persist, making it difficult to distinguish between short-term and chronic issues. The short interval may also have restricted the study's capacity to establish causal relationships between early feeding behaviours and later weight outcomes, as some predictors may not have had enough time to show measurable effects. The follow-up period was restricted by the overall PhD timeline, seven months was the longest gap possible which also allowed data collection for all chapters to be completed within the overall timeline. However, extending the follow-up period in future research would provide a more comprehensive understanding of the developmental trajectories of feeding and growth in children with Down syndrome.

Furthermore, a key limitation of the study sample is the lack of cultural diversity, with the majority of participants identifying as White British, particularly in the Down syndrome group (71%). While there was some representation from other ethnic groups, such as Other White, Asian Indian, and Black African, these numbers were relatively small, limiting the generalisability of the findings to more culturally diverse populations. This lack of diversity is important, as cultural background may influence feeding practices, parental attitudes towards food, and broader developmental outcomes (Pak-Gorstein et al., 2009). Future research would benefit from recruiting a more culturally varied sample to explore how these

factors might differ across ethnic and cultural groups, thereby providing a more comprehensive understanding of feeding issues in children with Down syndrome and TD children.

4.4.1 Implications

Timely identification and assessment of early-life risk factors (e.g. dietary habits, eating behaviours, parental feeding practices) that contribute to weight outcomes in children with Down syndrome is very important. Targeted interventions which aim to address these factors and promote healthy weight trajectories from early childhood are necessary. Additionally, proactive and early screening for texture sensitivity challenges in children with Down syndrome is important and it is necessary to develop strategies that could help to manage texture aversions and improve feeding behaviours in order to prevent the worsening of feeding problems. There is a clear need for parental access to comprehensive support programs that integrate interventions and services targeting feeding problems, sensory sensitivities, motor skills, and parental feeding practices to address the multifaceted needs of this population effectively. Future longitudinal research could include larger participant samples, include oral motor and texture sensitivity assessments throughout and span a longer time period in order to identify critical periods for intervention relating to feeding problems and weight. Addressing these research implications can contribute to advancing knowledge, improving clinical practices, and enhancing the quality of life for children with Down syndrome by addressing their unique challenges related to feeding, sensory processing, motor skills, and weight management.

4.4.2 Conclusions

The findings of this study illustrate the complex interplay between feeding problems, sensory and texture sensitivities, weight, eating behaviours, parental feeding practices, and motor

skills in children with Down syndrome compared to their TD peers. The study highlights the need for tailored interventions addressing sensory processing, feeding difficulties, and motor skill development to support the development of optimal eating abilities and practices, and to promote a healthy weight and therefore reduce the risk of adverse health outcomes for children with Down syndrome. Future research should focus on longitudinal studies to further explore these relationships and the effectiveness of targeted interventions.

Chapter 5. Observations of mealtime behaviour for young children with Down syndrome.

5.1. Introduction

Much of the limited pool of research which has explored feeding problems in children with Down syndrome has been of a quantitative nature (Cartwright and Boath, 2018). However, quantitative measures such as self-report parent questionnaires may be somewhat limited as it is not possible to ascertain to what extent parental responses reflect actual as opposed to idealised behaviours (Burgmeier et al., 2015), Furthermore, it is difficult to capture bi-directional parent-child interactions during mealtimes using self-report quantitative methods alone. Existing research which has utilised both mealtime observation protocols and parent-report questionnaires in conjunction have identified that parents do not always report all feeding problems, for example where issues are expected due to developmental delays (Spender et al., 1996; van Dijk and Lipke-Steenbeek, 2018). Conversely, mealtime observations conducted in a naturalistic environment offer the opportunity to capture rich data about elements of feeding and eating which participants may not be aware of, or think to report (Pesch and Lumeng, 2017).

Previous use of mealtime observations has provided valuable insights about eating and mealtime behaviours for young children with Down syndrome. Anil et al., (2019) identified delayed chewing patterns and increased emotional difficulties during mealtimes for children with Down syndrome. When using mealtime observations in conjunction with caregiver completed assessments of texture sensitivity, Ross et al., (2022) observed differences in how frequently young children with Down syndrome interact with different foods, and how much food they consume during mealtimes. Additionally, van Dijk and Lipke-Steenbeek (2018) and Spender et al., (1996) noted particular challenges for children with Down syndrome

regarding oral-motor control, food refusal, negative affect and reduced self-feeding. Mealtime observations can also provide useful information about parental feeding practices for parents of children with Down syndrome. This was highlighted in the study conducted by Spender et al., (1996) whereby mealtime observations showed that parents of children with Down syndrome used more controlling non-verbal feeding practices than parents of TD children during mealtimes. Evidently, mealtime observations are a valuable tool in exploring feeding and eating for children with Down syndrome, however, they are not frequently used in practice. The literature search presented in Chapter 2 identified only four studies which included mealtime observations within their methodology. It is possible that observational methods are underused in feeding research because they are time consuming to conduct and analyse (Morgan et al., 2017).

Regarding feeding problems specifically, the use of observations in research mirrors parents' desire for health professionals to watch their child eat in order to understand their feeding challenges. Our research found that parents believed this would be more informative than telephone consultations or virtual services, particularly where parents feel they are not able to accurately describe elements of feeding or eating (Hielscher et al., 2022). With this in mind, it was determined that video-recorded mealtimes would provide a valuable and rich context to quantitative data collection carried out at Times 1 and 2 (Chapters 3 and 4).

5.1.1 Aims

This study aimed to explore how mealtime behaviours and parent-child interactions during mealtimes differ between children with Down syndrome and TD children. Additional objectives included identifying whether mealtime behaviours and parent-child interactions

change over time for either group, and how mealtime behaviours relate to feeding problems and child weight.

This study is a core element of the wider longitudinal study detailed in Chapters 3 and 4, but is presented separately to aid clarity, and because only a sub-sample of participants from the wider study took part in mealtime observations.

5.2. Method

5.2.1 Study design

This was an observational study exploring eating behaviours, feeding problems and parent-child interactions during mealtimes for children with and without Down syndrome. Naturalistic video-recorded mealtimes were conducted during home visits and the videos were analysed to explore the behaviours of interest.

5.2.2 Participants

Participants were recruited from the wider study outlined in Chapters 3 and 4. At Time 1, video recorded mealtimes were conducted for nine children with Down syndrome (from nine separate families) between the ages of 17 and 51 months (*mean age* = 30 months, *SD*= 10.97 months) and 14 typically developing (TD) children aged 12-47 months (*mean age* = 29.15 months, *SD*= 12.68 months). At Time 2, video-recorded mealtimes were repeated for six children with Down syndrome (*mean age*= 40 months, *SD*= 12.11 months, *range*= 24-58 months) and 13 TD children (*mean age*= 36.08 months, *SD*= 12.7 months, *range*= 19-54 months). There were fewer observations at Time 2, as some parents opted for remote participation.

The mean ages of the group of children with Down syndrome and the TD children were similar to that of the wider study sample at both Time 1 and Time 2. However, only one child with Down syndrome (11%) who took part in the mealtime observations had feeding problems at Time 1, and none of the children with Down syndrome who took part in the mealtimes had feeding problems at Time 2. This is different to the overall study sample, where 28% of children with Down syndrome met the criteria for a classification of feeding problems at Time 1, and 30% had feeding problems at Time 2. Similarly, Time 2 questionnaire data indicates that one child in each group were classed as texture sensitive, representing 17% of the children with Down syndrome who took part in mealtime observations at Time 2 and 8% for TD children. In the wider study sample these percentages were higher- 29% of children with Down syndrome were texture sensitive compared to 12% of TD children.

5.2.3 Procedure

Ethical approval to conduct the study was granted by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (approved protocol number: aLMS/PGT/UH/04883(4)). As outlined in Chapter 3, when parents were provided with participant information for the overall study, they were asked to select which parts of the study (questionnaire, mealtime observations, interviews) they would like to take part in. Parents who were happy to participate in the mealtime observations indicated their consent by selecting the option that corresponded with this. All parents who took part in home visits were eligible to participate in mealtime observations, but participants who took part virtually were not eligible due to practical considerations. During home visits, height and weight measurements of parent and child were taken first, and mealtimes took place after this. Participants were asked where mealtimes would usually take place at that time of day and the video camera was set up in the least intrusive place possible, whilst still in full-view

of the parent and child. Participants were advised to have their meal however was usual practice for them. Some parents asked if there is anything in particular that they should do for the purpose of the recording, and they were advised to do what they would usually do if the researcher was not present. The video recording began when food was first placed in front of the child and then the researcher would wait in a separate room out of view. Participants notified the researcher once they believed their child had finished the meal, and the recording was stopped. At each timepoint, only one observation was conducted per family, even if the parent was taking part with multiple children. In such cases, videos were coded twice, focussing on one child each time.

5.2.4 Coding and data analysis

Analysis of video-recoded mealtimes aimed to provide information about mealtime behaviours of each group and was based on the coding scheme used by van Dijk and Lipke-Steenbeek (2016, 2018). This coding scheme was selected because it has previously been used with toddlers with and without Down syndrome of a very similar age to the children who took part in the present study (van Dijk and Lipke-Steenbeek, 2016, 2018). Additions were made to the coding scheme following feedback from parents of children with Down syndrome about their concerns around feeding (which emerged during home visits) and both the adapted coding scheme used in this study, and the original coding scheme are presented in Appendix A. The coding scheme was amended after Time 1 mealtime recordings took place, but before analysis of recording began. Additional codes include instances of throwing (whether this was food, utensils, cups etc), bites taken using utensils and offering of food or drink by the caregiver (either verbally or physically). In van Dijk et al., (2016, 2018) only caregiver instructions were coded and this included offers of food but in the present study explicit instances of offering food (e.g. “would you like some apple?”, “do you want a yoghurt instead?”) were coded separately to general instructions (e.g. “sit down and eat

nicely", "slow down, don't put too much in your mouth at a time"). This was due to feedback from parents of children with Down syndrome about the challenges faced encouraging their child to eat at mealtimes. It was noted if children with Down syndrome displayed tongue protrusion during the mealtime and instances of coughing or choking were also noted. In total, there were 11 codes; reject, negative affect, drink, self-feed, use utensils, throw, instruction, offer, tongue protrusion, coughing, choking. Unstructured qualitative coding of the video recordings was also conducted throughout, to capture anything of interest relating to mealtime behaviour, context or parent-child interactions.

Coding began when food first became available to the child, either by having a plate placed in front of them, or by being offered a bite by their caregiver. Some parents did not place the plate of food in front of the child, and instead kept the plate of food out of reach, feeding the child bites using a fork, spoon or their hands.

Coding ended when the caregiver announced that the child had finished eating, when food was finished, or the child's plate was taken away. Mealtime duration was calculated, and absolute frequencies of observed behaviours were recorded. Bites fed by caregiver, self-fed using hands and self-fed using utensils were initially coded separately and then combined to give a total number of bites per meal and to indicate how these bites were being taken. Bites per minute were calculated based on total number of bites taken and mealtime duration.

At Time 1, mealtime data was analysed to obtain descriptive statistics such as mean, SD and range values for each group. Independent samples t-tests were conducted to assess statistical significance of observed group differences and study power was calculated. Due to the smaller number of comparisons made (compared to Chapters 3 and 4), and few statistically significant groups differences identified, Bonferroni adjustments were not applied. Pearson's

correlations were then used to explore associations between mealtime behaviour, feeding problems and weight.

Similarly, at Time 2 independent samples t-tests were used to explore group differences in mealtime behaviours, but then paired samples t-tests were also used to examine how mealtime behaviours changed between Time 1 and Time 2 for children with Down syndrome and TD children. Study power was then calculated for all t-tests undertaken. Pearson's correlations were also used to identify relationships between Time 2 mealtime behaviours, feeding problems and weight at both Time 1 and Time 2. Following this, additional exploratory analysis aimed to identify whether any Time 1 mealtime behaviours were associated with Time 2 outcome measures (MCHFS score and weight, Table 5.5) and whether Time 2 mealtime behaviours were associated with Time 1 outcomes for either group (Table 5.6).

Analysis of Time 2 video-recorded mealtimes occurred after the coding of Time 2 interviews (Chapter 6) and therefore mealtime coding at Time 2 was also informed by challenges, experiences and coping mechanisms described by parents during interviews. Examples of factors which were noted include child demeanour, general interest in meal, parent-child interactions, chewing pattern and utensil control. A narrative report of behavioural observations and group differences was then compiled and is presented alongside results of quantitative analysis conducted at Time 2.

Table 5.1. *Mean, SD and range of observed frequencies of behaviours of interest for video recorded mealtimes.*

	Time 1 mean (SD)		**Time 1 range**		**Time 2 mean (SD)**		**Time 2 range**	
	Down syndrome (n= 9)	**TD (n= 14)**	**Down syndrome (n=9)**	**TD (n=14)**	**Down syndrome (n=6)**	**TD (n=13)**	**Down syndrome (n=6)**	**TD (n=13)**
Mealtime duration	20:04 (06:25)	36:38 (06:28)	07:26-27:58	06:28-43:06	19:20 (09:42)	20:16 (06:28)	10:52-37:03	09:48-30:30
Child behaviour								
Bites per minute	3.91 (1.44)	4.46 (1.64)	2-5.92	1.64-6	4.06 (1.68)	2.61 (1.86)	1.76-5.80	1.12-4.69
Reject (frequency)	9 (11.24)	5.50 (4.53)	2-33	1-15	10.60 (12.66)	7.50 (6.36)	2-33	3-12
Negative affect	7.33 (5.51)	3.50 (3.79)	1-11	1-9	10.67 (8.08)	0	2-18	0
Drink	6.29 (4.89)	3.46 (2.03)	1-14	1-9	4 (1.83)	5.33 (4.04)	2-6	3-10
Self-feed	60.44 (38.7)	70.14 (40.95)	18-146	16-140	67.17 (61.13)	26 (26.89)	11-181	9-57
Use utensils	16 (14.31)	26.55 (28.42)	1-36	3-100	51.80 (53.03)	12 (19.08)	8-138	0-34
Throw	7.25 (4.35)	0	1-11	0	4.50 (1.73)	0	2-6	0
Tongue thrust (n)	9	0			6	0		
Choking/coughing (n)	5	6			2	0		
Parent behaviour								
Instruction	9.33 (6.56)	10.67 (13.22)	4-22	2-43	10.40 (13.3)	6 (6.25)	2-34	1-13
Offer (verbal and physical)	36.78 (30.25)	12.07 (10.87)	8-99	2-34	19.20 (11.56)	8 (6.02)	5-34	4-15

Table 5.2. *Results of independent samples t-tests conducted to explore group differences in Time 1 and Time 2 mealtime behaviours for children with Down syndrome and typically developing children.*

	Mean difference between groups	***df***	***t***	***p***
Time 1				
Mealtime duration	16:34	21	.24	.815
Child behaviour				
Bites per minute	.50	21	.82	.421
Reject	3.07	21	.90	.384
Negative affect	3.83	21	1.10	.321
Drink	2.82	21	1.46	.082
Self-feed	9.70	21	.57	.577
Use utensils	4.86	21	.49	.630
Parent behaviour				
Instruction	1.33	21	.28	.785
Offer (verbal and physical)	24.71	21	2.35	**.042**[a]
Time 2				
Mealtime duration	0:56	17	.25	.803
Child behaviour				
Bites per minute	1.44	17	1.18	.278
Reject	3.10	17	.32	.764
Drink	1.33	17	.60	.576
Self-feed	41.17	17	1.09	.314
Use utensils	39.8	17	1.22	.268
Parent behaviour				
Instruction	4.4	17	-.53	.617
Offer (verbal and physical)	11.2	17	-1.52	.179

Notes

[a]Significant at α level of <.05.

Values could not be calculated for Time 1 throwing, Time 2 throwing or Time 2 negative affect because means and standard deviations for the typically developing group were 0.

5.3. Time 1 results

For the children with Down syndrome, all recorded mealtimes were lunchtimes. For the TD children, three of the recorded mealtimes were evening meals and 11 were lunchtimes. Type of food did not seem to differ according to whether the meal took place at lunch time or dinner time, as two TD children (siblings eating at the same time) had a dinner consisting of 'finger foods' which they could pick up and eat with their hands, and so were eaten without utensils, whereas one TD child ate fish and vegetables using utensils. Similar variation in food type was observed across lunches too.

Due to the naturalistic setting of the mealtimes, some participants had their meals with both parents and siblings present, and for some it was one caregiver and the child present. For the group of children with Down syndrome, the child was the only person eating during seven (78%) of the mealtimes, and in two cases (22%) the parent was also eating during the meal. For TD children it was more common for the parent and/or siblings to also eat during the meal, and this occurred in 71% (n=10) of cases. At four of the TD mealtimes (29%) the child was the only person eating.

5.3.1 Quantitative analysis

Quantitative analysis at Time 1 aimed to identify differences in mealtime behaviours and parent-child interactions between children with Down syndrome and TD children. There was large variation in the duration of mealtimes for both groups (Table 5.1) but mean mealtime duration for TD children was longer (*M*=36:38 minutes, *SD*= 06:28 minutes) than for children with Down syndrome (*M*=20:04 minutes, *SD*= 06:25 minutes) however, the difference between the groups was not significant (Table 5.2).

Observed frequencies (Table 5.1) show that children with Down syndrome took fewer bites per minute, showed more instances of rejection and negative affect during mealtimes than TD children. Whilst the two groups showed similar levels of self-feeding, more of the self-feeding was done using utensils for TD children, whereas for children with Down syndrome the majority of self-feeding was with their hands. Children with Down syndrome took more drinks during their meals than TD children. All of the children with Down syndrome showed tongue thrust whilst eating, to varying extents. Four children with Down syndrome threw food or other objects during the mealtime, whereas no children in the TD group were seen to do this. However, none of these observed group differences were statistically significant (Table 5.2).

Regarding parental behaviour during mealtimes, parents of children with Down syndrome offered food or drink to their child significantly more often than parents of TD children, $t(21)=2.35$, $p=.042$. Power was .77 indicating moderate confidence in this finding. There were no significant associations between mealtime behaviours and either Time 1 feeding problems or Time 1 weight for children with Down syndrome or TD (Table 5.4).

5.3.2 Qualitative analysis

It was commonly noted that children with Down syndrome exhibited challenges with self-feeding using utensils and difficulties clearing a bite from a utensil with their mouth were also common. Food loss was a frequent problem for children with Down syndrome and children would often help food back onto a utensil with their hands or opt to self-feed using their hands instead when this happened. Although, food loss was also common when children with Down syndrome were self-feeding using their hands. In some cases, mothers would encourage their child with Down syndrome to use their utensil to take a bite, instead of self-feeding with hands. Mothers would sometimes do this by loading a bite onto a utensil and

handing this to the child, or by guiding the child's hand over hand to show them how to pick food up using the utensil. Sometimes children became frustrated when their mothers would encourage them to use utensils instead of their hands. Negative affect was most commonly noted after a child with Down syndrome had been encouraged to use a utensil or had been offered food or drink by the parent but did not want it.

Several children with Down syndrome appeared to enjoy rubbing their mouth/lips with a utensil after they had taken the food from it. Behaviours such as touching and playing with food were also common, particularly towards the end of a meal. Instances of throwing or playing with food tended to occur towards the end of the meal. Parents appeared to find this problematic and they responded to these behaviours by moving food and objects out of reach of the child.

For some children, bites taken per minute fluctuated depending on what part of the meal they were eating. For example, for one child with Down syndrome the first part of their lunch was a boiled egg and toast which they self-fed using their hands, after this they were spoon-fed a yoghurt by their mother and whilst eating the yoghurt (where the pace was dictated by the mother) bites per minutes increased. Sometimes, children with Down syndrome overloaded utensils, or tried to eat bites which were too large. Where this occurred, mothers responded by staying attentive to this behaviour and encouraging smaller or slower bites, keeping plates of food within their own reach and offering it to children a small bit at a time. Parents of children with Down syndrome regularly offered their child drinks during the meal, whereas TD children often drank without parental prompts.

Both children with Down syndrome and TD children were noted to cough during their meal, but for TD children this did not appear to cause concern for parents and was generally brief

and resolved quickly. For one child with Down syndrome, a bout of coughing led to the child vomiting.

5.4. Time 2 results

Typically, children with Down syndrome were the only ones eating during the meal, with only one parent (17%) eating at the same time, compared to 46% (n=6) of TD parents. No siblings were present at mealtimes for children with Down syndrome, but for six TD children siblings were also present and eating. Similar to Time 1, for TD children three of the observations were evening meals (the same children as at Time 1) and ten meals were lunchtimes. For children with Down syndrome all of the mealtime recordings took place during lunchtimes.

Table 5.3. *Mean mealtime behaviour differences from Time 1 to Time 2 for both children with Down syndrome and TD children (paired samples t-tests).*

	Mean score difference from T1 to T2	***p***
Children with Down syndrome		
Mealtime duration	0:44	.631
Child behaviour		
Bites per minute	.15	.461
Reject	1.6	.353
Negative affect	3.34	.449
Drink	2.29	.353
Self-feed	6.73	.867
Use utensils	35.8	.363
Parent behaviour		
Instruction	1.07	.353
Offer (verbal and physical)	17.58	.235
Typically developing children		
Mealtime duration	16:22	.617
Child behaviour		
Bites per minute	1.85	.820
Reject	2	.272
Drink	1.87	.321
Self-feed	44.14	.907
Use utensils	14.55	.791
Parent behaviour		
Instruction	4.67	.373
Offer (verbal and physical)	4.07	.874

5.4.1 Quantitative analysis

Group differences at Time 2

At Time 2, quantitative analysis sought to first identify group differences in mealtime behaviours, but also to compare data to Time 1 in order to understand how mealtime behaviours changed over time for each group. Therefore, independent samples t-tests were conducted to explore differences in mealtime behaviour between children with Down syndrome and TD. Unfortunately, power was very low, ranging from .05 to .25. Subsequently, quantitative analysis (Tables 5.2 and 5.3) identified no statistically significant group differences, but qualitative coding and analysis of mealtime observations identified various behavioural group differences.

Observed frequencies indicate that there was large variation in mealtime duration for both groups (Table 5.1), but the mean mealtime duration was more similar between groups compared to Time 1. Although TD children had fewer bites per minute than children with Down syndrome, the range for bites per minute was relatively similar across both groups. At Time 2, children with Down syndrome appeared to self-feed and use utensils more than TD children, likely due to the type of meal.

Differences in mealtime behaviour over time

Paired samples t-tests were conducted to identify changes in mealtime behaviours between Time 1 and Time 2 for both children with Down syndrome and TD children (Table 5.3). This analysis did not reveal any significant differences between Time 1 and Time 2 mealtime behaviours for either children with Down syndrome or TD children. Statistical power was again very low, ranging from .15 to .42 for children with Down syndrome and .05 to .32 for TD children.

Relationships between mealtime behaviours, feeding problems and weight

An additional aim of Time 2 data analysis was to explore how mealtime behaviours may be related to feeding problems and weight at either timepoint- and whether this is different for children with Down syndrome compared to TD children. Pearson's correlations were conducted to explore relationships between mealtime behaviours, feeding problems and weight at both Time 1 and Time 2 (Table 5.4). First, correlations explored relationships between Time 1 mealtime behaviour data, Time 1 MCHFS scores and Time 1 weight for each group. Then, correlations were conducted using Time 2 mealtime behaviour data, Time 2 MCHFS scores and Time 2 weight. No significant associations were identified and the results of this analysis are outlined in Table 5.4.

Table 5.4. *Pearson's correlation coefficients between mealtime behaviours, MCHFS total score and weight for both children with Down syndrome and TD children.*

	Time 1 MCHFS[a]		Time 1 weight[a]		Time 2 MCHFS[b]		Time 2 weight[b]	
	r	***p***	***r***	***p***	***r***	***p***	***r***	***p***
Children with Down syndrome								
Mealtime duration	.028	.947	-.17	.656	.02	.970	-.22	.680
Child behaviour								
Bites per minute	-.39	.336	-.10	.805	-.13	.840	.28	.597
Reject	.54	.164	-.27	.489	.47	.527	.07	.916
Negative affect	-.08	.844	.64	.067			-.92	.264
Drink	.35	.402	-.35	.356	.48	.681	.61	.393
Self-feed	-.45	.260	.04	.918	-.11	.856	.04	.938
Use utensils	-.04	.921	-.22	.575	.07	.907	.15	.813
Throw	.45	.267	.19	.623	-.98	.151	-.97	**.033**[c]
Parent behaviour								
Instruction	.56	.148	-.34	.376	.06	.94	-.01	.986
Offer (verbal and physical)	.24	.573	-.56	.120	.44	.558	.01	.990
Typically developing children								
Mealtime duration	-.23	.457	-.15	.626	.77	.440	.18	.883
Child behaviour								
Bites per minute	-.14	.642	.06	.838	-.91	.279	-.97	.165
Reject	.23	.452	-.27	.373	N/A	N/A	N/A	N/A
Negative affect	.26	.388	-.38	.199	N/A	N/A	N/A	N/A
Drink	-.08	.783	-.17	.584	.33	.788	.90	.291
Self-feed	-.18	.56	-.02	.939	-.99	.086	-.85	.358
Use utensils	.37	.219	.20	.513	-.97	.154	-.90	.289
Throw	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Parent behaviour								
Instruction	-.18	.562	.05	.861	.82	.391	.26	.835

Offer (verbal and physical)	.13	.677	-.30	.312	.40	.735	.90	.291

Notes

[a]Time 1 mealtime behaviours were used in this analysis. [b]Time 2 mealtime behaviours were used in this analysis. [c]Significant at α level of <.05.

Following this, additional exploratory analysis aimed to identify whether any Time 1 mealtime behaviours were associated with Time 2 outcome measures (MCHFS score and weight, Table 5.5) and whether Time 2 mealtime behaviours were associated with Time 1 outcomes for either group (Table 5.6). Pearson's correlations were conducted between Time 1 and Time 2 mealtime behaviours, feeding problems and weight for both groups.

Low statistical power may have impacted the findings, as in some cases unexpectedly high *r* values (between .9 and 1) were observed, calling reliability of the findings into question (Aggarwal and Ranganathan, 2016). For example, for children with Down syndrome, instances of rejection at Time 2 were positively associated with feeding problems at Time 1 (r= .99, p=.007). Additionally, throwing at Time 2 was negatively associated with weight at both Time 1 (r= -.96, p=.045) and Time 2 (r=-.97, p=.033) for children with Down syndrome.

A negative association was observed between offering at Time 1 and weight at Time 2 for children with Down syndrome (r=-.68, p=.046). Levels of self-feeding at Time 1 were also negatively associated with feeding problems at Time 2 for children with Down syndrome (r=-.82, p=.014).

For TD children, parent offering at Time 2 was positively associated with child weight at Time 1 (r=1, p=.047).

Table 5.5. *Pearson's correlation coefficients between Time 1 mealtime behaviours, Time 2 MCHFS total score and Time 2 weight for both children with Down syndrome and TD children.*

	Time 2 MCHFS[a]		Time 2 weight	
	r	***p***	***r***	***p***
Children with Down syndrome				
Time 1 mealtime behaviours				
Mealtime duration	-.39	.345	-.40	.290
Bites per minute	-.41	.315	.07	.861
Reject	-.46	.215	.19	.653
Negative affect	N/A	N/A	-.92	.264
Drink	.14	.750	-.50	.170
Self-feed	-.82	**.014**[b]	-.01	.991
Use utensils	-.36	.388	-.14	.730
Throw	.54	.171	.07	.850
Instruction	.28	.505	-.53	.140
Offer (verbal and physical)	.02	.970	-.68	**.046**[b]
Typically developing children				
Time 1 mealtime behaviours				
Mealtime duration	-.06	.851	.13	.666
Bites per minute	-.23	.43	-.05	.879
Reject	.12	.695	-.30	.293
Negative affect	.16	.578	-.46	.099
Drink	-.14	.640	-.19	.515
Self-feed	-.19	.507	-.01	.968
Use utensils	.14	.630	.01	.977
Throw	N/A	N/A	N/A	N/A
Instruction	.10	.724	.13	.651
Offer (verbal and physical)	.00	.998	-.29	.322

Notes

[a]Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011), [b]Significant at α level of $<.05$.

Table 5.6. *Pearson's correlation coefficients between Time 2 mealtime behaviours, Time 1 MCHFS total score and Time 1 weight for both children with Down syndrome and TD children.*

	Time 1 MCHFS[a]		Time 1 weight	
	r	***p***	***r***	***p***
Children with Down syndrome				
Time 2 mealtime behaviours				
Mealtime duration	.05	.943	-.12	.821
Bites per minute	-.83	.086	.20	.704
Reject	.99	**.007**[b]	.62	.267
Negative affect	N/A	N/A	-.87	.325
Drink	-.29	.814	.29	.715
Self-feed	-.51	.380	.07	.903
Use utensils	-.28	.651	.19	.761
Throw	-.42	.725	-.96	**.045**[b]
Instruction	-.17	.826	.33	.594
Offer (verbal and physical)	.95	.051	.59	.301
Typically developing children				
Time 2 mealtime behaviours				
Mealtime duration	.87	.334	-.20	.872
Bites per minute	-.83	.384	-.80	.409
Reject	N/A	N/A	N/A	N/A
Negative affect	N/A	N/A	N/A	N/A
Drink	.17	.893	.99	.099
Self-feed	-.96	.191	-.58	.603
Use utensils	-.92	.260	-.67	.534
Throw	N/A	N/A	N/A	N/A
Instruction	.90	.289	-.13	.921
Offer (verbal and physical)	.25	.841	1	**.047**[b]

Notes

[a]Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011), [b]Significant at α level of <.05.

5.4.2 Qualitative analysis

TD children often ate wraps and sandwiches, which required motor handling skills but not utensils. It was common for children with Down syndrome to hold a utensil in one hand, but to use the other hand to eat with, instead of the utensil they were holding. As such, parents would often remind the child to use the utensil, or model the action required to use the utensil effectively.

Children with Down syndrome showed a munching chewing pattern, taking several small bites of handheld foods, whereas TD children took fewer but larger bites. As observed at Time 1, all children with Down syndrome displayed tongue thrust to varying extents while eating. Children with Down syndrome found it more challenging to get food onto utensils, and to control the utensil whilst bringing it to their mouth and clearing food from the utensil. Children would often compensate for this, bringing their faces closer to the plate, and using their other hand to push food onto the utensil, and taking extra bites. Frequently, children resorted to using their hands to self-feed, which they found easier and quicker; this was particularly common after they had just dropped food from a utensil. Once a bite was taken, they demonstrated oral sensory behaviours such as keeping the utensil in their mouth after eating the food, bringing an empty utensil to their mouth, or chewing/sucking on their fingers after eating the food they were holding. Children with Down syndrome sometimes continued to put food into their mouths before swallowing the previous bite or held food in their mouths without swallowing. Some were very interested in their meal and ate quickly, prompting their parents to instruct them to slow down or finish their mouthful before taking another bite. In other cases, they were uninterested in their meal, and parents had to encourage them to eat with physical and verbal prompts. This was less common in the TD group, where parents more frequently allowed their child to independently direct the pace of the meal. This

difference is consistent with the lower observed frequencies of parent offering and instructions seen for the TD group at Time 2 (Table 5.1).

Children with Down syndrome sometimes coughed and choked while eating, some made wheezing sounds while breathing, and had runny/blocked noses which frequently needed wiping, which was not observed for the TD children. They were also more commonly distressed or frustrated during mealtimes, exhibiting negative affect such as crying, shouting, and refusal. They were more likely to throw food or utensils compared to TD children, particularly during periods of frustration or boredom, such as waiting for caregiver attention after finishing their food. Parents often kept the plate or bowl out of reach and offered one bite at a time to manage this behaviour. Parents of children with Down syndrome often used Makaton to aid communication with their child, whereas no TD parent did this. TD children often chatted to parents during their meal, asking questions and talking, whereas for children with Down syndrome the interaction was more focussed on eating and the food itself.

5.5. Discussion

The present study aimed to explore whether and how mealtime behaviours and parent-child interactions differ for children with Down syndrome and TD children. Additionally, this study also sought to identify how mealtime behaviours change over time for both groups, and how they relate to feeding problems and weight outcomes. Video-recorded mealtimes were conducted to better understand both child and parent behaviours during mealtimes, and how these may relate to feeding problems and weight.

Large variation was observed across all coded measures for both children with Down syndrome and TD children. Quantitative and qualitative coding indicate several differences between groups although few group differences reached statistical significance during

quantitative analysis, possibly due to low power resulting from a small study sample. Observed frequencies suggest that mealtimes lasted longer for TD children and that children with Down syndrome behaved differently at mealtimes. For example, observed frequencies suggest that children with Down syndrome were more likely to reject food, demonstrated more negative affect and challenging behaviour such as throwing food, objects or utensils (although these differences did not reach statistical significance). Additionally, qualitative coding demonstrated that children with Down syndrome exhibited more motor challenges (regarding both utensil use and oral-motor control) and displayed more oral-sensory behaviours. Parents of children with Down syndrome offered food to their child significantly more frequently than TD at Time 1, highlighting the more active role they took in encouraging their child to eat during mealtimes.

Parents of children with Down syndrome offered their child food or drink more often during the mealtime than parents of TD children, across both time points. Parents of children with Down syndrome played a more active role in trying to encourage the consumption of foods to children with Down syndrome, and their children were more likely to refuse or reject offers of food. This aligns with previous research whereby parents of children with Down syndrome have reported more monitoring, controlling behaviours regarding their child's consumption of food and concern over the adequacy of their child's dietary intake (Brantley et al., 2023; Collins et al., 2005). Food refusal is a commonly noted feeding problem for children with Down syndrome (Hielscher et al., 2023). Where children frequently exhibit food refusal, this may lead parents to encourage and offer food more frequently during a meal, out of concern that the child eats enough. Statistical analysis appeared to support this, as correlations showed that parents of children with Down syndrome who offered food more at Time 1 weighed less at Time 2. It was observed at both time points that some children with Down syndrome were not very interested in the food and required encouraging to eat their meal. Conversely, some

other children with Down syndrome ate quickly, taking many bites in quick succession and putting more food in their mouth before swallowing the previous bite. Parents responded by encouraging their child with Down syndrome to slow down and take fewer bites. This finding is consistent with Collins et al., (2003) whereby parents of children with Down syndrome report concerns over both eating too fast, and too slowly during mealtimes.

Qualitative coding revealed clear and distinct child eating behaviour profiles in the present study (although statistical analysis did not reflect this, possibly due to low study power), and parents appeared to behave differently during the mealtime as a result. Parents of children with Down syndrome whose child ate very quickly were conscious of their child chewing food effectively and not overloading their mouths, in order to limit the risk of choking. Parents of those children with Down syndrome that demonstrated more food avoidant behaviours were concerned with encouraging their child to eat and drink sufficient quantities during the meal. This suggests that parents' feeding goals, priorities and resulting support needs may be influenced by their child's eating behaviours. As such, early eating behaviours should be assessed and taken into account by feeding support services and professionals, as this could influence the types of feeding problems that children with Down syndrome experience, and the type of support that parents need. This information could also be used to inform health professionals' advice when prescribing interventions, as they could limit the therapeutic benefit.

Mealtimes lasted longer for TD children at both Times 1 and 2. This was unexpected as it was theorised that mealtimes would last longer for children with Down syndrome because longer mealtime duration is linked to the presence of feeding problems (Wolf and Glass, 1992) and feeding problems are more common amongst children with Down syndrome (Anil et al., 2019; Manikam and Perman, 2000). It is possible that the unexpected difference in

mealtime duration reflects the observation that for TD children, mealtimes were a more sociable occasion, with parents and siblings often present and eating at the same time. Additionally, children with Down syndrome showed more negative affect and challenging behaviour during meals, which was more common once they had finished eating and. It is possible that parents responded to this by ending the mealtime sooner.

At Time 1, children with Down syndrome ate more slowly than TD, taking fewer bites per minute, whereas at Time 2 TD children took fewer bites per minute. Children with Down syndrome were observed to take more frequent, smaller bites. Sometimes this was as a result of motor challenges; for example struggling to load food onto a utensil, or eating lots of individual pieces of food, such as grated cheese, one at a time using fingers. Sometimes children with Down syndrome took many bites in quick succession, particularly where they had lost food from a utensil when trying to put it in their mouth- children would commonly then use their free hand to pick up the lost food and quickly eat it. Sometimes this might also be due to sensory reasons. For example, one child with Down syndrome would refuse a bite unless it was very small.

Children with Down syndrome behaved differently to TD children at mealtimes. Only children with Down syndrome were observed to demonstrate negative affect (such as frustration and distress) and challenging behaviour such as throwing food, objects or utensils. This finding is consistent with existing research which suggests that up to 85% of children with developmental disabilities display disruptive mealtime behaviours associated with feeding problems (Burklow, et al., 1998). Challenging mealtime behaviours are a significant stressor for caregivers of children with Down syndrome, making family mealtimes very difficult (Brantley et al., 2023; Lewis and Kritzinger, 2004). Family mealtimes can provide numerous benefits for child development, such as fostering relationships and emotional

bonds, and offering learning opportunities that promote independence and development in fine motor skills, social-emotional growth, and language abilities (Lora et al., 2014; Snow and Beals, 2006; Spagnola and Fiese, 2007; Totterdell, 2006). However, challenging child behaviours can negatively affect the mealtime environment and the quality of parent-child and family interactions, preventing the child from accessing these developmental benefits (Totterdell, 2006).

In the present study, parents responded to behaviours like throwing by keeping plates of food and drinking cups out of reach of the child and offering them small amounts of food at a time. However, this approach may limit the child's exposure to food handling and subsequently hinder the development of self-feeding skills. This highlights the need for alternative strategies to address and manage challenging mealtime behaviours. Intervention strategies based on positive behavioural support principles and implemented by parents in the home setting have demonstrated success in reducing children's challenging mealtime behaviours and problematic eating in other populations such as children with autism (Diaz et al., 2018; Fraser et al., 2004). Future research which assesses the suitability of existing interventions for use with children with Down syndrome would be valuable.

Children with Down syndrome exhibited more motor challenges regarding both utensil use and oral-motor control, which they often compensated for by self-feeding using their hands, which they found easier. This is consistent with existing research which suggests that children with Down syndrome may have delayed self-feeding, increased difficulties using utensils and that gross and fine motor skill delays may impact food spillage during meals (Anil et al., 2019; Collins et al., 2003; Shaw et al., 2006; Spender et al., 1996).

At Time 2, parents of children with Down syndrome frequently encouraged their child to use their utensil and not their hands, and often modelled the actions required to use the utensil, also using words like ‘stab’ and ‘scoop’. Many children with Down syndrome held a utensil in one hand throughout the meal, but mainly ate with their free hand, except when prompted to use the utensil by the parent. It was a clear focus for parents to develop their child’s ability to use utensils during mealtimes, and this may have influenced the choice of food offered during the mealtime (for example by parents choosing a meal which would facilitate the opportunity to practice utensil use). This could explain why at Time 1, TD children were coded to use utensils more frequently, but at Time 2 the opposite was observed. At Time 1, during many of the mealtimes, children with Down syndrome were given meals that consisted of snack type ‘finger foods’ which did not require the use of utensils. As such, they were observed to use utensils less during coding. However, at Time 2 almost all of the children with Down syndrome were offered a meal to eat using utensils. Conversely, at Time 2 TD children were frequently offered meals such as sandwiches and wraps, which require fine motor handling skills, but not utensils.

Furthermore, children with Down syndrome displayed more oral-sensory behaviours during mealtimes. Both oral hypo- and hypersensitivity are commonly observed in children with Down syndrome (Jackson et al., 2024). Examples of sensory-seeking behaviours in this study include sucking on hands and fingers after placing food in the mouth, sucking on empty utensils, and continuing to chew on utensils once the food has been eaten. Examples of oral hyposensitivity included keeping food in the mouth for an extended period without swallowing and food loss during chewing. Oral hypo- and hypersensitivity can influence various eating behaviours and problems, such as food taste and texture preferences and aversions, as well as feeding difficulties (Zulkilfi et al., 2022). Detecting these sensitivities early is important, as targeted support based on oral sensitivity can help parents make

informed food choices, prevent adverse eating experiences and potentially prevent the development of sensory related feeding difficulties.

It is interesting to note that children with Down syndrome were observed to experience unique challenges regarding eating, food handling and behaviour in comparison to TD, even though a very small number of this group had feeding problems or texture sensitivity according to parent questionnaires (Chapter 4). This demonstrates the value of using observational methods alongside screening tools to assess feeding. Additionally, this finding suggests that parents of children with Down syndrome who do not meet the criteria for a classification of feeding problems may still experience difficulties during mealtimes and benefit from support.

A limitation of the present study is that it only used a very small sample, which led to a lack of statistical power. As a result, very few of the observed quantitative group differences reached statistical significance, which was unexpected given that qualitative coding revealed important differences between groups. Additionally, comparisons between time points indicated no significant differences in mealtime behaviours over time for either children with Down syndrome or TD children- this also may have been impacted by low power. Some significant associations were observed between mealtime behaviours, feeding problems and weight but *r* values were extremely high, casting doubt on the reliability of these findings- another factor which may have been influenced by small sample sizes (Aggarwal and Ranganathan, 2016). Therefore, a larger-scale replication of this mealtime observation study is necessary to confirm the findings. This replication should include a larger participant sample and repeated mealtime observations over a longer period. Doing so would allow for a deeper exploration of eating behaviours in children with Down syndrome across broader age ranges (e.g., from birth into childhood) and provide more insight into how their mealtime

behaviours evolve over time. Additionally, if combined with parental questionnaires and/or interviews, such research could identify practices that lead to positive outcomes, such as self-feeding abilities, reduced challenging mealtime behaviours (e.g. throwing, negative affect), and varied food acceptance. This would highlight opportunities to develop more targeted and effective early interventions for feeding and eating in children with Down syndrome.

5.5.1 Implications

Standardised screening for feeding and sensory challenges should be implemented to provide early and appropriate interventions for children with Down syndrome. Interventions need to be multidisciplinary and tailored to address specific issues faced by children with Down syndrome, such as oral-motor control, sensory processing challenges, and self-feeding skills. Additionally, it is necessary to identify successful strategies to increase food acceptance, reduce food refusal and challenging mealtime behaviours, which would help to develop better guidance and support for parents, reducing the stress associated with feeding challenges. Further research should explore whether strategies which are useful in other populations may be effective for children with Down syndrome.

5.5.2 Conclusions

Children with Down syndrome exhibit distinct mealtime behaviours and face unique challenges related to feeding and oral-motor control compared to TD children, leading to greater parental involvement and the use of specific strategies to manage mealtimes. Early and tailored interventions are essential to address these challenges and support the development of healthy eating behaviours and reduce feeding problems in children with Down syndrome. The findings highlight the need for further research with larger groups of

children and improved access to therapeutic services to ensure timely and effective support for these children and their families.

Chapter 6. Mothers' experiences of feeding problems and complementary feeding for young children with Down syndrome.

6.1. Introduction

Given the extensive quantitative data collection involved in the longitudinal study outlined in Chapters 3 and 4, it was determined that also conducting parent interviews would offer many benefits. For example, it would allow the collection of unanticipated data which is not captured by the structured questionnaires and assessment tools used in the online questionnaire (Wasti et al., 2022). It provides the opportunity to collect data about several important factors such as mothers' support seeking behaviour, how well any received support met their needs, barriers to implementing feeding advice, wider concerns about feeding, and the impact of feeding problems on wider family life. It also has the potential to provide vital clarity about how mothers respond to feeding challenges and how they think these issues are linked (e.g. sensory, motor, feeding). There is a bi-directional relationship between child eating behaviours and parental feeding practices (Costa and Oliveira, 2023). Therefore, understanding of the wider context around feeding and eating is vital, beyond just quantitative data, in order to better understand families' subjective experiences, perceptions and practices. As a result, a mixed-methods approach was taken in this thesis, and semi-structured interviews were conducted with mothers of children with Down syndrome in order to facilitate a holistic exploration of feeding problems during early eating.

Parents of children with Down syndrome often face challenges progressing food textures and self-feeding once complementary feeding has begun (Chapters 2 and 8). However, there are no existing guidelines that inform parents how to navigate eating in early childhood (Hielscher et al., 2023; Mohamed et al., 2013; Rogers et al., 2021). There is also no gold standard of how to address feeding problems should they occur during this phase in

development, even though early childhood eating is very important for significant eating, developmental and health outcomes (Ravel et al., 2019). Delayed feeding skills in early life in children with Down syndrome are exacerbated throughout childhood, as required feeding skills become more complex (Nordstrom et al., 2020). Additionally, feeding problems such as selective eating and chewing difficulties can persist into adulthood for people with Down syndrome (Canizares-Prado et al., 2022). This highlights the importance of addressing problematic eating early and understanding how best to support parents to achieve this.

There is very little understanding of how parents interpret and utilise more general information about complementary feeding and eating progression, usually aimed at parents of children without developmental disabilities (Cochran et al., 2022). Parents face the challenge of progressing oral feeding and eating in line with TD age and nutritional guidelines while also considering the child's developmental readiness and motor skills (Cochran et al., 2022). Although there are existing reports of difficulties progressing food textures and flavours, (Chapters 2 and 8) it is also not well known how parents respond to this or what kind of support they receive, although generally families of children with Down syndrome are more likely to report unmet health care needs than the TD population (Hielscher et al., 2022; McGrath et al., 2011).

Overall, there is a paucity of existing research which has explored early childhood eating for children with Down syndrome specifically (Chapter 2, Hielscher et al., 2023). Although, existing (largely quantitative) research has highlighted some differences in early parental feeding practices for children with Down syndrome in comparison to typically developing children (Cochran et al., 2022; Hielscher et al., 2022). Parents report using more restrictive, cautious or controlling feeding practices and have more concern about their child becoming overweight (Barreiro et al., 2022; Cochran et al., 2022; Collins et al., 2003; Rogers et al.,

2021; Shaw et al., 2003; Spender et al., 1996). However, there are contextual factors relating to this which are not understood. For example, parental awareness and intention around their feeding practices, their priorities and challenges faced around feeding, and the impact of child behaviour and needs on their resulting feeding practices. Such information is important and would allow for a deeper understanding of early feeding and eating for young children with Down syndrome and has the potential to better inform both interventions and policy. As such, this study aimed to explore parental experiences of solid food introduction and subsequent progression of eating for their children with Down syndrome. Furthermore, the study sought to identify the challenges parents encountered during this period, their responses to these challenges, and their support needs.

6.2. Method

6.2.1 Study design

Semi-structured online interviews were conducted and analysed using reflexive thematic analysis (Braun and Clarke 2006, 2019) to identify common themes amongst participants' experiences. The reporting of the data analysis process and resultant themes were guided by Braun and Clarke's Reflexive Thematic Analysis Reporting Guidelines (2024).

6.2.2 Participants

Participants were recruited from the wider study outlined in Chapters 3 and 4. All parents of children with Down syndrome were invited to take part in virtual interviews which took place after Time 2 home visits and questionnaires had been completed. Fourteen mothers of children with Down syndrome aged between 29 and 44 years (*mean age*= 38.90 years, *SD*= 4 years) participated in interviews (see Tables 6.1 and 6.2 for demographic information). At the time of interview, participants' children ranged in age from 20 to 38 months (*mean age*=

34.20 months, *SD*= 11.20 months). Five (36%) children with Down syndrome had feeding problems as assessed by the screening tool which parents completed during Time 2 questionnaires and six (43%) children were food texture sensitive (see Chapter 4).

Eight (57%) of the children with Down syndrome had some kind of cardiac anomaly at birth, and two children (14%) underwent surgery in early life to address this. Seven (50%) children with Down syndrome had previously been fed via nasogastric (NG) tube, and mean duration of NG tube feeding ranged from two weeks to 11 months (*mean*= 3.60 months, *SD*= 4.20 months). Mothers first began to offer their children solid foods at a mean age of 6.20 months (SD= 1.10 months) but this ranged from five months to nine months across the sample.

Table 6.1. *Characteristics of individual participants and their children.*

Participant	Age (years)	Mother and child dyad Ethnicity	First time mother?	Child age (months)	Cardiac anomaly present at birth?	Previously fed via NG tube? (duration)	Feeding problems?[a]	Texture sensitive?[b]
Mother 1	43	White British	No	33	Yes	Yes (2 months)	No	Yes
Mother 2	41	White British	Yes	58	No	No	No	Yes
Mother 3	42	Other White British	No	25	Yes	Yes (unknown)	No	No
Mother 4	38	White British	Yes	32	Yes	No	Yes	No
Mother 5	29	Other White British	Yes	20	Yes	No	Yes	No
Mother 6	41	White British	No	30	Yes	No	Yes	Yes
Mother 7	40	White British	No	35	No	No	No	No
Mother 8	46	White British	Yes	42	Yes[c]	Yes (2 weeks)	No	No
Mother 9	37	White Irish	No	22	No	No	Yes	Yes
Mother 10	37	White British	Yes	47	Yes[c]	Yes (1 month)	Yes	Yes

Mother 11	36	Asian Indian	Yes	37	Yes	Yes (6 months)	No	No
Mother 12	44	Mixed	No	26	No	Yes (11 months)	No	Yes
Mother 13	43	White British	Yes	48	No	Yes (1 month)	No	No
Mother 14	35	Mixed	No	24	No	No	No	No

Notes

[a]As measured by the Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011) during completion of questionnaires at Time 2 (see Chapter 4). [b]Assessed using Ross et al's., (2022) five specific questions to classify a child as food texture sensitive, which were completed as part of the Time 2 questionnaires (see Chapter 4). [c]Cardiac anomaly that required surgery to address in early life.

Table 6.2. *Sample characteristics.*

	Mean (SD)/ N (%)
Child's age	34.20 months (11.20 months)
Child age range	20-58 months
Mother's age	38.90 years (4 years)
Mother age range	29-44 years
Mother and child dyad ethnicity:	
White British	8 (57)
White Irish	1 (7)
Other white	2 (14)
Asian Indian	1 (7)
Mixed	2 (14)
First time mothers	7 (50)
Gestation at birth	37.80 weeks (1 week)
Gestation at birth range	36-40 weeks
Premature	2 (14)
Weight at birth	3.20kg (0.46kg)
Weight at birth range	2.50-4.20 kg
Timing of Down syndrome diagnosis:	
Pre-natal	8 (57)
Post-natal	6 (43)
Feeding problems[a]	5 (36)
Texture sensitivity[b]	5 (36)
Age of introduction of solid foods	6.20 months (1.10 months)

Notes

[a]As measured by the Montreal Children's Hospital Feeding Scale (Ramsay et al., 2011) during completion of questionnaires at Time 2 (see Chapter 4). [b]Assessed using Ross et al's., (2022) five specific questions to classify a child as food texture sensitive, which were completed as part of the Time 2 questionnaires (see Chapter 4).

Interview schedule

A semi-structured interview schedule was developed to explore parents' feeding experiences. Specifically, this aimed to understand how parents perceive feeding problems, potential determining factors, consequences and support needed (Appendix B). Mothers were asked about their initial experiences with milk feeding, starting complementary feeding, and advancing to more complex food textures and tastes, as well as any challenges faced, and support needed during this period. The interview schedule was developed using existing literature, and feedback from a parent of a young person with Down syndrome. The interview schedule included open ended questions and more specific prompts and follow up questions.

Key open-ended questions included the following:

- When you were pregnant, how did you plan on feeding (name of child) milk?
- Could you tell me about when you started to introduce (name of child) to solid food?
- What support have you received regarding introduction of solid foods to (name of child), if any?

Examples of follow-up questions and prompts include:

- How prepared did you feel to start introducing solid foods?
- Did you have any worries or concerns before introducing solid foods to (name of child)?
- Does (name of child) experience any preferences or problems with flavour or texture of foods now? If yes, what type of preferences/problems, how do you manage this?

6.2.3 Procedure

Ethical approval to conduct the study was granted by the University of Hertfordshire **Health, Science, Engineering and Technology** Ethics Committee with Delegated Authority (approved protocol number: aLMS/PGT/UH/04883(4)). Participants were provided with detailed information before interviews to allow them to understand the nature of the interview, and the topics to be discussed. This was provided within the participant information that was shared when participants gave consent to take part in the study before Time 1 data collection commenced. As outlined in Chapter 3, when parents were provided with participant information for the overall study, they were asked to select which parts of the study (questionnaire, mealtime observations, interviews) they would like to take part in. Parents who were happy to participate in interviews indicated their consent by selecting the option that corresponded with this. Participant information was also re-shared before interviews took place, due to the time that had elapsed between initially signing up to take part in the study and arranging the interviews. Before interviews commenced, participants were informed that if at any point they felt they wanted to pause or stop the interview, this was encouraged, and they need only to inform the interviewer. Debrief information which included signposting to relevant sources of support was provided to participants after interviews. Interviews lasted between 23:48 minutes and 1:03:28 minutes (*mean* =40:37 minutes, *SD*= 10:37 minutes). Interviews were audio recorded and then transcribed verbatim.

6.2.4 Data analysis

The data analysis process followed Braun and Clarke's six-step process for conducting reflexive thematic analysis (Braun and Clarke 2006, 2022). The lead author read the transcripts and listened to the interview audio recordings multiple times to become familiar

with the dataset. Coding was done using Microsoft Word, incorporating both semantic codes (e.g., descriptions of events) and latent codes (e.g., reflections on the emotional impact of challenges faced). Comments and initial interpretations were also noted during this phase.

Initial themes were generated from these codes and then reviewed and developed in order to determine main themes and subthemes which were compared with direct quotes from the transcripts, to ensure they were supported by and rooted in the data. Themes were then further refined following discussions with the wider research team. Where disagreements occurred regarding themes, this was solved by discussion and comparison with direct source material from the interview transcripts. Theme outlines were then refined and shared with the research team again. This process was repeated until consensus was achieved regarding themes and the team was satisfied that the themes were strongly supported by the interview data. The themes were written up into a narrative account and continued to be refined throughout this stage. To ensure rigour and credibility, member checks were conducted: all participants were given access to the finalised themes and supporting quotes to provide their approval.

6.3. Results

Analysis of 14 semi-structured interviews produced three main themes; (1) *The complex nature of feeding problems*, (2) *Mothers face many barriers to addressing problematic feeding and eating*, (3) *Positive eating progress is possible* (Figure 1).

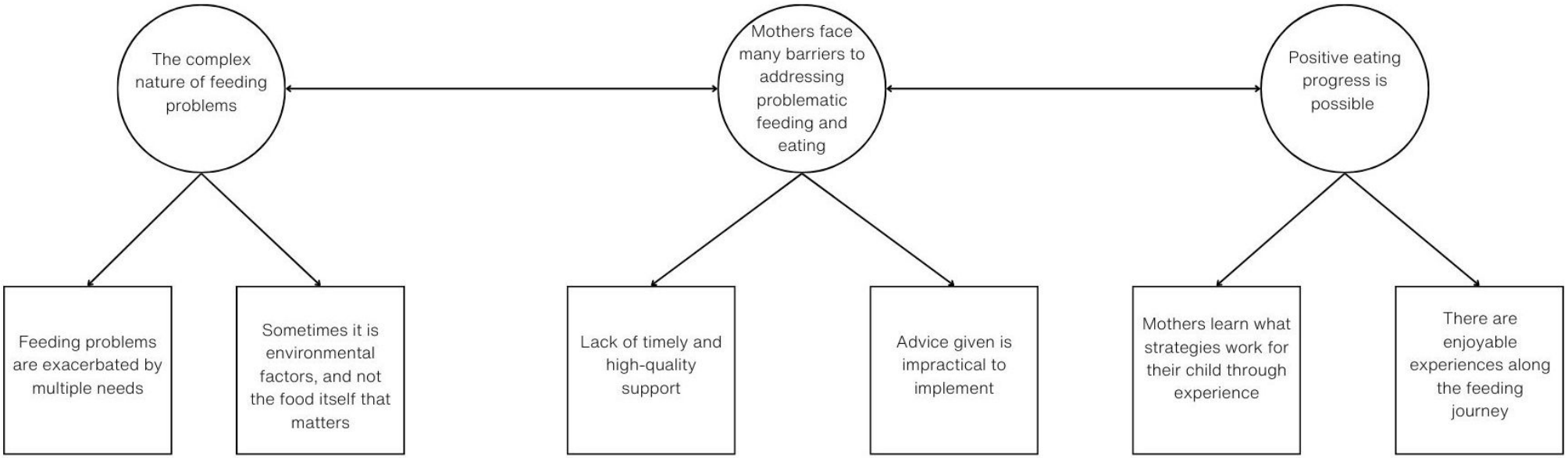

Figure 6.1. *Relationships between main themes and their sub-themes.*

6.3.1 The complex nature of feeding problems

This theme describes the complex challenges faced around mealtimes and eating, and the factors which mothers felt contributed to the presence of feeding problems. All mothers described challenges with feeding problems and food textures, even though not all of their children met the threshold for this using the MCHFS and texture sensitivity questions at Time 2 (see Tables 4.2 and 6.1). Contributory factors were myriad, often interlinked and mothers found it difficult to know how to deal with them. Mothers had to adapt, developing new strategies, experimenting and seeking advice and support to try to address challenges faced with eating and mealtimes.

6.3.1.1 Feeding problems are complex and exacerbated by multiple needs

Frequent illness in early life (in particular respiratory infections which impacted breathing) were very disruptive of early feeding and eating milestones. Periods of illness could undo hard-fought progress with weaning and eating solid foods. "*He weaned a bit before, but he took ill in October time, and he was refusing all food and drink."* (Mother 9). The food available in hospital was often not suitable for very young children, which made it difficult to maintain complementary feeding and as a result mothers tended to stop offering solid foods during periods of hospitalisation and rely on milk feeding instead. *"We were in the hospital so much, and I would not want to feed him hospital food."* (Mother 3). When children were very ill, they would sometimes refuse any oral food or drink at all. This could be long lasting, and disrupt initial progress made with weaning and complementary feeding, with mothers struggling to know how they could manage or address this.

> *"So by October last year, he was on three meals a day, hardly any milk, doing amazing. I was so impressed. And then he got ill because my eldest goes to nursery…So last year, November and December for two months straight, he was ill and I was told that he has bug after bug. He's got several different bugs before one is cleared up. He's probably picked up another one. That's why it's gone on for so long. And pretty much since then, he went off his food and he's never gone back on it."* (Mother 12)

Recurrent illness was such a significant problem that mothers dreaded the winter months, worrying about the impact that bugs would have on their child's health and eating. *"I don't want to hit winter because winter is when she gets really congested. And then she vomits because she can't clear it (food). And if it's stuck in her throat, the tonsils cause her to gag, and so she vomits."* (Mother 7)

Motor challenges were another commonly reported cause of feeding problems. Low oral muscle control and tone (for example relating to tongue control) led to difficulties with manipulating food inside the mouth. *"The food will get stuck, he's got quite a high palate, so the food gets stuck up the top of his mouth and he doesn't really have the control of his tongue to get it out and so he would gag."* (Mother 9). This meant mothers had to pay close attention during mealtimes, in case they were needed to intervene and help their child. *"She couldn't clear her mouth, so I would often be putting my finger in to remove what was at the top of her mouth."* (Mother 7)

Motor challenges also affected chewing, and delayed chewing skills were common. This meant that children were often restricted to softer, easier food textures. *"I think*

sometimes his chewing is not great and we've been told by the speech and language therapist that he needs to chew in a different way, like more like a mature chew." (Mother 3). Where chewing delays were not addressed, they created bigger challenges over time, and mothers worried about how they could progress their child's eating abilities further, due to their child's lack of chewing experience. Mother 10 provided an example of this. Her child was still eating soft, pureed textures at four years old, as a result of eating challenges which had not been addressed.

> *"I'm really worried actually about even trying him on any solids because he's four years old and he doesn't have any experience of chewing. So I just don't really see a way forward there because he doesn't have the experience, but the older he gets, the more difficult to actually get him to understand how to chew and not to choke."* (Mother 10)

Delayed fine-motor skills meant that children found it difficult to develop the co-ordination needed to use utensils effectively, which could be frustrating for children who wanted to be in control of their feeding. *"He wanted to be in control and hold his food, but he didn't really have the motor control, so he just kind of let him hold something."* (Mother 9). Children's ability to co-ordinate the movements required for self-feeding varied across the type of meal given. Offering a utensil for the child to hold during the meal where they were struggling was a common practice that mothers reported.

> *"If we give her a fork, sometimes she'll be great at it. And it just depends on what she's having. But she wouldn't be able to have a chapatti and dip the things in. I don't think she's quite there yet in terms of the dip and the coordination. But*

what we do try is if she struggles with coordination, we'll just give her the fork in her hand (to hold).” (Mother 11)

Low muscle tone also meant that gross motor skills such as body positioning and head support required for safe feeding of solid foods was a challenge.

“A challenge with both purees or proper solids, was the muscle tone again because in all the advice it says the baby needs to be able to sit upright…But because of (child)’s muscle tone, he couldn't sit up. Not even in a chair, his head would have just gone like that (flopped over).” (Mother 10)

Where mothers did not have access to specialist equipment, high chairs designed for typically developing children did not address body positioning challenges. *“I found choosing a high chair really tricky because he just was very slouchy in all the chairs that he sat in.”* (Mother 14)

Sensory challenges were also common and could complicate feeding and mealtimes. *“It’s a visual thing, sometimes she thinks the spoon has got too much on it, even though the spoon, it's fine. If she thinks it won't fit in her mouth or something, she doesn't want anything to touch her face with a funny sensation, like touch her mouth.”* (Mother 13). Sensory challenges also influenced food texture preferences, which lead to refusal of some foods, for example lumpy foods. *“She doesn't like lumpy soups, so it's either smooth or nothing. If something is lumpy and she's not expecting it to be, she'll spit it out.”* (Mother 7). Progressing eating abilities by providing meals of mixed food textures was difficult, as some children would tolerate a variety of food textures, but only if they were separate.

"I think as we were transitioning into sort of proper food, if textures were too mixed, like you could give something that was absolutely crunchy, or something that was absolutely smooth and both would be fine. But give her something that was crunchy with a smooth bit, like bits of fruit in yogurt or something. Something like that would be like, hmm. The clash of textures, she's happily eat a crunchy biscuit. Or she'll happily eat yoghurt. But if you crumble some biscuit crunchy bits into yogurt, that would suddenly become quite problematic." (Mother 12)

Challenging child mealtime behaviours could also be problematic for mothers. In particular, mothers expressed concerns over throwing behaviours. "*She was then throwing things as well, like the spoons, the plates, the food*." (Mother 2). This was something that mothers sought support to address. *"Now we're focusing more behaviours around food, so she's (health professional) helping with like, he will just throw his plate or his cup once he's finished or he'll, take the lid off his cup of juice or milk and just empty it everywhere."* (Mother 4)

Worries around mealtime behaviours were significant and difficult for mothers to address. For example, Mother 9 was apprehensive about offering new foods and textures, and implementing strategies suggested by Speech and Language Therapists, due to concern about her child's behavioural reaction: *"I'm worried about the behaviour, his reactions around that rather than anything else, really. I think it's going to be hard for him. That's a big change."* (Mother 9)

Sometimes communication difficulties and impulsivity could exacerbate challenging behaviour, which could lead to mealtimes feeling chaotic for mothers. *"She can't*

communicate what she wants clearly enough, and she is impulsive. She will grab for something before saying I want it. It's the impulsivity that can often cause chaos. It's her just getting down from the table when she wants." (Mother 7)

Conversely, some mothers struggled to manage children who were very motivated by food, and frequently requested it outside of mealtimes, and in the absence of hunger. "*She is saying every hour 'Mummy, I want food. Mummy, I'm hungry. Mummy. I want (to) eat. Mummy, I want banana. Mummy, I want fruit pouch. Mummy, I want ice cream.'"* (Mother 2)

6.3.1.2 Sometimes it is environmental factors, and not the food itself that matters

Often, feeding problems were difficult for mothers to understand, as sometimes contextual factors around food and mealtimes appeared to influence food acceptance, preferences and eating behaviours more than the food itself.

> *"Quite often actually, it's the context and not the food. So for example, when he was younger, he loved those Ella's (kitchen) pouches which I'd grab when we were out sometimes cause it's really easy. Now he won't eat them out of the pouch, but if I put it in a bowl then he'll eat them."* (Mother 4)

Mothers would often feel frustrated when their child refused to try foods. They could not understand what drove the refusal, particularly when the child enjoyed the food they had previously refused once they eventually tried it. *"It was a lot of saying no, I don't want this or I don't want to try. And that takes us a lot of encouragement and praise. 'Come on, (child). Just try. Just try.' But when she tried, I would say 8 out of 10 times, she liked what we gave her."* (Mother 2)

Similarly, Mother 14 describes unpredictable phases that her child went through whereby his preferences for the presentation of food (and not the food itself) could significantly impact whether or not it was accepted.

> *"There were little phases. I remember there being a time when he would want all food broken into pieces. So, if I gave him toast, it was fine if it was in little pieces. But then, he went through a phase where it had to be big pieces, and if you broke it down, that was really not okay, and the worst thing you could have done. Now, sometimes if you break something in half, he won't eat it. He used to be fine."* (Mother 14)

Children often ate very differently for different caregivers, and across childcare settings. Mothers reported that their child ate a much wider range of foods when they were at nursery for example, compared to at home. *"When I saw in the book what my child has eaten during the day, what was served in the nursery, I was surprised. Are you sure it was my child eating this because at home, she's not eating this and that? And I was like, give me your recipes."* (Mother 2). This effect also applied to self-feeding skills, with mothers frequently describing that at nursery and school their child ate more independently, demonstrating more complex self-feeding skills than they were willing to do in the home setting. It was felt that the presence of other children at mealtimes was helpful for their child's eating development.

> *"So at nursery he sits in a little chair, not a high chair, he doesn't wear a bib. He feeds himself, refuses to be fed. They say most days he eats all of his food. Bring him home and he's refusing not to be fed (by parents), throwing his food*

all over the place. He's in a high chair. I have to put like a full bib on him every time. It's like there's something about coming home to Mummy and Daddy that makes him sort of revert a bit. But when he's around all of the other children (it's different).” (Mother 4)

6.3.2 Mothers face many barriers to addressing problematic feeding and eating

Mothers encountered many barriers outside of their control which made it difficult for them to address and resolve feeding problems. This created feelings of frustration, as actively trying to improve their child's feeding was an important priority for mothers.

6.3.2.1 Lack of timely and high-quality support

Mothers faced difficulties accessing various health and feeding support services. They wanted early intervention in order to improve feeding and eating outcomes but support often came too late.

“In this area speech and language with the NHS won't even consider starting anything until they're two and from my experience, that's a bit late, you know, even for a typical child. So for a child who might take a bit longer to develop, I feel like you have to start earlier.” (Mother 6)

Sometimes underlying health conditions (such as respiratory issues) could hinder eating. Long waiting lists for medical support to address these conditions was problematic, and so some were forced to pay for private healthcare to overcome this. *“We just need the ENT review. So we're going private for it because it's like a 14 month wait just for an initial assessment.”* (Mother 7)

When feeding support was available, it was commonly felt that it was not available at the frequency or regularity necessary for it to fully address mothers' needs.

> *"We are in a speech and language team, but all they did was see him three times at nursery a year ago and they haven't seen him this year, so it's not really good support. They should also support him at school, more like once a week. I almost think it's not enough to have a few appointments where I try to tell them what the situation is, I also show them some videos and they give me tips but you know, it's like actually really properly implementing them, I need a bit more guidance at home as well. Maybe sort of directly observing when here, seeing what's happening and maybe trying some techniques themselves or showing how that could work."* (Mother 10)

Method of information delivery was also important. Mothers wanted a health professional present to demonstrate how to implement advice and struggled to apply guidance when they only had access to written information. *"I think having someone actually coming and doing a bit more coaching with him and us would be better than just telling us like on a piece of paper, just go and do this."* (Mother 3). Furthermore, it was felt that virtual delivery of health services had increased since the COVID-19 pandemic, but that services delivered this way were not always thorough or effective.

> "*Sorry to say this, they've (support services) become lazy since COVID. Everything's just online. You know, how can a dietician just call me and ask me questions and then try to diagnose my child? How can you diagnose a child over*

the phone without meeting that child or seeing that child, seeing how that child eats or swallows?" (Mother 12)

Unfortunately, some mothers felt that the support they received was of poor quality and not helpful at all in addressing their challenges. *"If I'm completely honest, everything has been completely useless."* (Mother 5). They found it difficult to access quality advice and felt that health professionals did not always know how to help them. *"These are the issues that we're having, and no one seems to have any suggestions. No one seems to have any great ideas*." (Mother 12). This left the mothers feeling anxious and unsure about how they could improve their child's feeding and eating. *"We're worried about what the next step is, we're trying to stop the whole minced (food textures)."* (Mother 9)

There was a profound negative impact on mothers who could not access timely and effective support that met their needs. This made it difficult for mothers to feel they could cope with their child's complex health needs and for some mothers this severely harmed their mental and emotional wellbeing.

"About a year and a half ago I ended up being put on antidepressants because I was really struggling. Not just because of this, but you know, I'd wanted a care coordinator involved and I was struggling so much that I couldn't even work out how they could help me… part of the reason why I ended up going to the doctor is because (older child) turned to me and said, 'Mummy, you're just angry all the time.'" (Mother 6)

In contrast to the challenges faced by others in the sample, Mothers 7 and 11 in particular felt very lucky to have received excellent feeding support and provided many examples of what this looks like in practice. A key tenet of quality feeding support was that it was delivered at an appropriate frequency. For Mother 7, monthly private Speech and Language therapy appointments ensured that her child made regular and continuous progress in regard to eating: *"I've loved having the input every month, I feel like I see progression every month in little ways, but definite progression."* Additionally, quick and easy access to feeding support was very beneficial.

> *"Our speech and language therapist was signed off and then she did say if we do need a bit of help, just let her know so I'll normally drop her an e-mail just to say I'm really struggling… I definitely had the support from her, even though she was no longer my speech in the language therapist, she still gave me that support."* (Mother 11)

Multidisciplinary, joined up care was valued very highly. In particular, Mother 11 described the support of an early years team which consisted of speech and language therapists, physiotherapists, occupational therapists. She could attend a monthly support hub to access all of these services in one place, along with other parents of children with Down syndrome. This service also extended to her child's educational setting, with the early years team conducting nursery visits to provide support for both her child and the nursery staff, in order to promote the best possible developmental outcomes for the child.

> *"It's really weird, but I feel very, very lucky and this is why we never want to move because we get to see our physio, speech and language and our early*

years, once a month in one place and we don't need to think to go to disparate sessions, they're just all there. And they go to her nursery as well." (Mother 11)

Another key factor which mothers felt benefitted their child's feeding and eating development was the timely provision of therapeutic equipment by health care professionals. Mother 11's physiotherapist provided a specialist high chair which supported the introduction of solid foods, as it helped her child to be positioned in a way which promoted a safer swallow: *"The one thing that we did get was a tumble form chair which was provided by the physio, which I think allowed her to just sit in the right position, it allowed her to have a safer swallow."* Similarly, Mother 7 was provided with a series of straws which allowed her child to gradually increase her oral-motor strength. *"We have specialist straws from the private speech and language therapists. And as we progressed the strength of her tongue would improve and her whole oral motor skills would all improve, and so did so she."* (Mother 7). Overall, the experiences of mothers 7 and 11 highlight what is possible when issues around accessing high-quality support are not there.

6.3.2.2 Advice given is impractical to implement

Mothers juggled trying to employ strategies which aimed to progress their child's feeding (for example providing opportunities for self-feeding) with the practical demands of everyday family life. Mess was a very big concern for mothers, which often made them apprehensive about employing strategies that aim to promote eating and feeding development. *"I mainly spoon fed because I was a bit nervous about getting dirty, like getting everything everywhere. But I did also give him some stuff to hold… I just need to let loose some. Let him let him go for it really."* (Mother 3)

Mothers were frustrated that health professionals did not consider the practical challenges associated with recommendations such as messy food play, and this often meant that mothers did not carry out their recommendations.

> *"I can't do it anymore. It's really frustrating, the dietician, the feeding specialists don't seem to understand that it obviously gets really messy, without seeing any results. If I knew it would really help, I would do it. But I, like I said I did it for over a year and I just didn't see any progress. He never puts any of it (food) in his mouth."* (Mother 10)

Excessive food waste and the associated financial cost also made it very difficult to implement advice and recommendations given to mothers.

> *"He doesn't eat any snacks and I forever get told, put snacks in front of him, Mummy, and just let him play. Okay, how much food am I supposed to waste here? I don't have a money tree at the back of my house because to a lot of specialists, they think, yes, we have kids with special needs, so we must be made of money. Buy this, buy this, buy this, buy this and we try, we do. But there's got to be a limit."* (Mother 12)

Well-meaning advice and recommendations were often challenging to implement within the wider family context, as it could frustrate the child and negatively affect the mealtime environment. As such, sometimes mothers had to pick and choose when they could apply intervention strategies.

> *"The speech therapist had told us that because his swallow takes longer to clear food, that we should be giving him a spoon of food and then an empty spoon, because the empty spoon will encourage a second swallow to get rid of any of the residue, but obviously he doesn't like the empty spoon coming and so when he sees the empty spoon coming, he just goes berserk sometimes and then that can just ruin meal time….We can't ruin dinner time every day."* (Mother 9)

Furthermore, juggling multiple children made it difficult to access in-person support services and groups, and left some mothers feeling that they were not able to dedicate as much time to their child's needs as other parents with only one child.

> *"One thing I would say is that because we spend a lot of time with other families who have children with Down syndrome, we've noticed that those people who have only got one child do do more with their child because they don't have that other sibling to have to worry about."* (Mother 6)

Time was another significant practical consideration. Mothers were cognizant of their child's need to explore and practice self-feeding skills (both with hands, and with utensils) but acknowledged that this could be very time consuming. As a result, they sometimes chose to feed the child themselves where time was short. "*We are still spoon feeding her which you know, we probably shouldn't really be doing, she's four now…It's just so we can get out the house quicker."* (Mother 13)

6.3.3 Positive eating progress is possible

Some mothers commented that that despite previous feeding problems, their child now ate very well. In these cases, mothers reflected widely on the positive elements of their

feeding journey, highlighting various important factors which they felt made a beneficial difference along the way.

6.3.3.1 Mothers learn what strategies work for their child through experience

Mothers also described effective strategies that they had learned as a result of their own experiences feeding their child. For example, some children benefitted from some independence and freedom to explore food at their own pace during a mealtime, and so mothers tried to adopt a less controlling, and more relaxed approach. *"She enjoyed that little bit of freedom, because obviously when you're giving them a bottle, there isn't an awful lot of input they can have as such. So yeah, I think she just likes being able to play with it (food) and just do what she wanted to do with it."* (Mother 8)

Setting small goals and taking things one step at a time was also helpful for mothers. This could be gradually increasing flavours or textures, or simply focussing on offering solid foods at only one meal at a time. For some, creating a structured framework which allowed them to make incremental progress was helpful.

> *"I just remember picking one meal to focus on at a time, and for me it always worked. Just focusing on breakfast first and every few days introducing a different food, and then as she grasped that meal, reduced the milk on that meal and move on to the next meal…I don't work well with fluidity, I need a framework and I need structure. Otherwise, I just don't know how to follow, I don't know how to make it work. I'm not very good at just being chilled…I think that early structure really helped."* (Mother 7)

For others, taking extra steps to ensure that they were always prepared with food their child could eat helped to make them feel more relaxed about feeding and mealtimes when outside of the house. *"We always have a hand blender with us. That's just a thing that we do now just in case, like if you're out and about."* (Mother 9)

Prioritising eating meals as a family was also viewed as important for child eating development. For some children, the social learning gleaned from eating alongside family members was vital. *"We'll always eat together, which I think made a big impact. I would never feed her first and then we go for food, we'll eat at the same time. She was eating, and I think she was watching all of us eat and that also helped her as well."* (Mother 11)

6.3.3.2 There are enjoyable experiences along the feeding journey

Despite the difficulties faced with feeding problems, and challenges addressing these, where the right support was available it was possible for children with Down syndrome to make good progress and eat very well. There were many elements of feeding that mothers enjoyed as a result, and they were keen to celebrate these. "*I've got some really cute pictures… (it was) a lot of fun."* (Mother 7)

Mothers found enjoyment in experimenting with the foods they offered their child, taking satisfaction in the knowledge that they could provide good nutrition to help their child thrive. "*I enjoyed doing it differently to what I did with my daughter, like I enjoyed doing the vegetable meat combos first and I feel that all of this nutrition from that helped him in a good way. It was quite satisfying knowing that he was getting all that good nutrition."* (Mother 3)

For others, watching their child interact with solid foods during a new phase of development was very fulfilling. *"By introducing solids it was just giving her the experience of enjoying different types of food, introducing new things and it's all part of the development of (child). Just seeing her engage with it and sit around a food table with us…It was really nice."* (Mother 1)

Children with Down syndrome sometimes surprised their mothers, surpassing their early expectations of what feeding and mealtimes could look like.

> *"When we had (child) just in general, it was very like, oh my God, she's never going to walk, she's never going to talk, she's never going to eat a meal with us. It was all very doom and gloom and actually, yeah, okay, we can't have a full-blown conversation with her yet, but her speech is getting there, but she walks, she runs like to the point where we struggle to catch her. We sit, we have meals with her, it is possible to do all that stuff too."* (Mother 8)

Family mealtimes were very important to mothers, and when children reached milestones that meant they could partake in 'typical' family mealtime experiences, this brought mothers joy.

> *"I enjoyed his love of food because he was playing, motivated by it and I remember we went out to a restaurant with the normal high chairs. And I think it was probably around 10 months maybe. But I remember almost crying with joy that he could just sit and join us and munch on his broccoli or whatever… I just*

remember thinking it was going to be ages before he could sit and join us for food and he could so yeah, it was really lovely." (Mother 14)

6.4. Discussion

The results of this study highlight the complex nature of childhood feeding problems. Factors which contributed to feeding problems were often multifaced and interconnected, which made them difficult for mothers to manage. Additionally, mothers struggled to access feeding support which fully met their needs, and advice which was impractical to implement within the family context caused frustration and was not seen as helpful. Sharing family mealtimes was an important goal for mothers, and they felt joy when goals related to this were achieved.

It is interesting to see that whilst not all of the study participants' children met the threshold for categorisation of feeding problems or food texture sensitivity (as measured during Time 2 data collection, Chapter 4), all mothers described feeding difficulties, and challenges relating to food texture. Mothers frequently remarked that feeding problems were the result of multiple, frequently interrelated, underlying factors which could compound over time e.g. motor delays, chewing delays, texture sensitivity, sensory issues. This complexity is well noted throughout existing literature (Mengoni et al., 2023; Usman et al., 2023) and further highlights the importance of timely, high quality and integrated health care and feeding support for families of children with Down syndrome.

However, in line with existing research, mothers frequently reported unmet feeding support needs which related to poor service availability, quality and long waiting lists

(Cartwright and Boath, 2018; Cochran et al., 2022; Hielscher et al., 2022; Mengoni et al., 2023). Generally, high quality support was not available at the right time, and very few mothers received proactive early intervention, which was a priority for them (Mengoni et al., 2023). Amongst the general population, existing literature indicates that information given to mothers about feeding problems is frequently delivered too late and often more focussed on breastfeeding than complementary feeding or increasing food variety (Mitchell et al., 2013; Usman et al., 2023). However, when caregivers are informed about potential feeding problems early (before they develop, for example through pre-natal counselling), the emotional difficulties and associated distress are reduced, which can lead to positive impacts on the nutritional and emotional wellbeing of children too (Mitchell et al., 2013).

In the present study, mothers frequently felt that health professionals did not know how to help their child, sometimes owing to a lack of knowledge about Down syndrome specific issues related to feeding, and this could exacerbate feelings of stress and worries related to eating. This is a theme which is consistently repeated throughout research with mothers of children with Down syndrome (Cartwright and Boath, 2018; Cochran et al., 2022; Hielscher et al., 2022; Mengoni et al., 2023). This highlights a need for further guidance and training for health professionals about how to adapt feeding advice for children with Down syndrome specifically.

Additionally, virtual feeding support services were not viewed as sufficient or in-depth enough to allow health professionals to understand children's eating, and mothers did not feel confident that they understood how to implement advice delivered this way. Telehealth services can offer many benefits to patients who struggle to attend in-person appointments and remain frequently used in the UK since their widespread adoption during the COVID-19 pandemic, with an estimated 85% of primary care consultations

now taking place virtually (Health Foundation, 2021; Neves et al., 2021). However, there are notable barriers of access to telehealth services including poor access to technology and environmental distractions (Lindsay et al., 2023). Virtual healthcare services which are delivered without consideration of patient experience and feedback risk exacerbating health inequalities between different groups of patients (Neves et al., 2021). This is a particular concern considering that children with special educational needs and disabilities were disproportionately affected by reduced access to health and care services throughout the pandemic (Ashworth et al., 2023). Telehealth services may not always be the most effective mode of health care delivery for all patient groups. In cases specifically related to feeding, first-time mothers of children with Down syndrome may struggle to verbally describe practical elements of feeding and eating over the phone which are new to them, which can limit how effectively they can utilise support offered this way (Hielscher et al., 2022). As such, the need for an adaptable and tailored approach to service delivery which takes into consideration patient preferences is essential moving forwards (Lindsay et al., 2023).

Mothers also reported that certain child eating behaviours, such as enjoyment of food, had a very positive impact on feeding and eating. Some mothers enthusiastically described their child as 'definitely a foodie', and felt their child was very interested in and motivated by food. This trait was linked to a higher variety of flavours and textures accepted by the child, more enjoyable mealtimes and overall a more straightforward early childhood feeding journey. Future longitudinal research which aims to understand which factors in early life could predict positive eating behaviours such as enjoyment of food in children with Down syndrome could inform early intervention services and improve subsequent eating outcomes.

The role of feeding and eating as an important and influential function within wider family life was evident throughout the interviews. Feeding did not occur in isolation; it both influenced and was influenced by daily family routines and was also seen to impact on overall family functioning. Similar findings have been observed elsewhere within the literature (e.g. Povee et al., 2012). As such, advice on feeding from health professionals was not helpful if it could not be practically implemented within the family environment. Parents commonly adapt their feeding behaviours in response to practical considerations of family life, and family stressors such as multiple demands on their time (Carnell et al., 2011; Polfuss et al., 2021). For example, parents may use increased encouragement and pressure to eat, so that dinner time is not prolonged and subsequently bed times are not delayed (Carnell et al., 2011). This has important implications for parental feeding interventions aimed at improving child feeding and eating, highlighting the need for a family-centered care approach to address feeding issues, which considers parental stressors and daily family life (Polfuss et al., 2021). The family-centered care model is associated with increased parental engagement and improved child health and development outcomes (Ridgway et al., 2021). Active collaboration between parents and health professionals can facilitate the development of a care plan and goal setting that are compatible with daily family life, promoting adherence.

Contextual and environmental factors played a big role in the food acceptance and self-feeding skills of children with Down syndrome. The presence of peers in childcare settings such as nursery, pre-school or even alternative caregivers was thought to have a positive impact. Mothers reported that their children ate a much wider variety of foods and demonstrated more sophisticated self-feeding skills in alternative settings compared to mealtimes at home. The beneficial influence of peer modelling on child food

acceptance has been established within the typically developing population (Houldcroft et al., 2014). However, this study finding raises the question of to what extent could feeding interventions (e.g. which aim to increase acceptance of a wider range of food flavours and textures or promote self-feeding and utensil use) be applied in childcare settings, and whether beneficial impacts of this could trickle over into home eating too. Forde and Tournier (2023) emphasise the role of experience and exposure to varied food textures on developing children's oral muscle strength, control and chewing abilities, which are areas in which children with Down syndrome commonly experience delays (Anil et al., 2019). This is a cyclical problem, as children with Down syndrome's overall diet and food preferences are shaped in part by the types of food that they can safely eat, as a result of their chewing and oral control skills (Hopman et al., 1998; Roccatello et al., 2021). If children with Down syndrome are not consuming challenging food textures (either due to food refusal or parental feeding practices) then they will not gain the experience necessary to manage varied food textures, and delays will be exacerbated. However, if children with Down syndrome are more willing to eat different foods and display more mature feeding skills when with peers or outside the home, this could represent an opportunity to promote exposure to different food textures in the childcare setting. This, in turn, could increase the development of oral-motor skills, facilitate parents feeling more comfortable offering different food textures at home, and increase child food acceptance at home.

Pre-school based interventions have shown success increasing fruit and vegetable consumption in 2-4-year-old typically developing children, with effects of changed eating behaviours shown to extend to other mealtimes, and not just the mealtime targeted during interventions (Horne et al., 2021). Additionally, social contextual factors such as peer modelling have an important influence on child food liking and

disliking (Hendy and Raudenbusch, 2000). It is not known how applicable eating interventions designed for typically developing children are to children with Down syndrome, but this represents a valuable topic for future exploration.

Child temperament was reported to have an important impact on eating behaviours and mealtimes. In particular, behaviours which mothers found difficult to manage during mealtimes such as throwing, refusal and negative affect were viewed as problematic. These behaviours exacerbated parental stress and made mothers anxious about addressing problematic eating routines, such as a reliance on easier food textures. This finding is consistent with the behavioural observations noted during video-recorded mealtimes carried out as part of the wider study (Chapters 3 to 5) whereby children with Down syndrome were coded to throw objects, refuse food and demonstrate negative affect at a higher frequency than typically developing children. Existing research has identified that children with Down syndrome display more challenging behaviours during mealtimes than typically developing children and this is a source of stress for parents (Brantley et al., 2023; Bhatia et al., 2005; van Dijk and Lipke-Steenbeek, 2018). Additionally, mothers of children with Down syndrome express a need for strategies which aim to improve stressful mealtime environments (Mengoni et al., 2023). However, it is not clear what support parents of children with Down syndrome typically receive around mealtime behaviour specifically in the UK, or to what extent existing feeding interventions consider the role of child temperament.

Child temperament is a factor which could affect the efficacy of interventions aiming to improve eating behaviours, as it has been demonstrated that parents adapt their feeding behaviours in response to child temperament, such as a lack of interest in food (Carnell et al., 2011; Holley et al., 2020). A key example reported by parents of children with

Down syndrome (within this study, and in other studies) is the use of screen time during meals for children who display difficult behaviours (Brantley et al., 2023). Mealtimes were viewed as an important part of family life for the mothers in the sample and sharing family mealtimes brought happiness and joy. This is consistent with previous reports which demonstrate that sharing family mealtimes is a clear goal for mothers of children with Down syndrome (Mengoni et al., 2023). Child temperament and challenging mealtime behaviours may present a barrier to mothers meeting these goals and so it is essential that they receive adequate support in managing this.

A strength of this study is that it adds to what is known about what high quality feeding support looks like for mothers of young children with Down syndrome. This is important for understanding how to improve services and reduce health inequalities moving forwards. High quality care started early, was multidisciplinary, integrated and easy to access. Mothers felt that support needed to be provided at a regular frequency (e.g. monthly speech and language therapy appointments) in order to see therapeutic benefit. A goal oriented, structured and progressive care plan which was straightforward to implement in the context of daily family life was valued.

Moreover, mothers benefitted from a ‘one-stop shop’ approach where they could access peer support, feeding and eating advice, as well as speech and language, occupational therapy and physiotherapy in one place, although this was not commonly available across the mothers in the sample. This draws similarities with the Sure Start programme, a universal UK scheme first introduced in 1999 which provided holistic support to families and children in the early years (Cattan et al., 2019). This had beneficial impacts on various elements of family life, child health and development

(Cattan et al., 2022). However, funding cuts since 2011 have led to widespread closures and reductions of services offered (Smith et al., 2018).

A limitation of this study is that interview participants were self-selected, and this may have influenced study findings. Participants were recruited from the wider longitudinal study outlined in Chapters 3 and 4, and they chose whether or not they would like to volunteer to participate in interviews. This approach to recruitment was taken in order to promote convenience and flexibility for study participants. However, individuals with particularly positive or negative experiences around child feeding may have been more motivated to take part in interviews and share their story, and study findings may reflect this. As such, it is difficult to ascertain how applicable study findings are to the wider Down syndrome community generally. Therefore, future research undertaken with a larger non-self-selected sample of parents of children with Down syndrome may able to capture experiences of a broader range of families, and confirm the findings of the present study.

6.4.1 Implications

There is a critical need for better support services for families of children with Down syndrome which are provided proactively. Policymakers should advocate for early, integrated support services that address the feeding and eating challenges of children with Down syndrome. This could involve multidisciplinary teams providing comprehensive care, similar to the Sure Start programme.

The study also indicates a clear need for interventions tailored to the specific needs of children with Down syndrome, for example to support parents to manage challenging mealtime behaviours. These interventions should be flexible enough to consider the

child's temperament and be designed to reduce parental stress and anxiety as well as including strategies to improve the mealtime environment. It is important that interventions are compatible with daily family routines and stressors, ensuring they are practical and achievable for parents to implement.

6.4.2 Conclusions

The findings of this study underscore the necessity of tailored support services for families of children with Down syndrome, particularly in managing mealtime challenges and improving overall family functioning. Challenging behaviours such as throwing and food refusal exacerbate parental stress, while positive traits like enjoyment of food facilitate a smoother feeding journey. Contextual factors, including the presence of peers and the setting of mealtimes (e.g., childcare versus home), play an influential role in food acceptance and self-feeding skills. A holistic, family-centered care approach is essential in addressing feeding issues, taking into account the daily stressors and practical realities of family life. There is a need for further studies which explore the bidirectional relationship between child temperament and parental feeding practices in children with Down syndrome, as well as the development of positive eating behaviours such as enjoyment of food.

Chapter 7. The experiences of new mothers accessing feeding support for infants with Down syndrome during the COVID-19 pandemic.

*This chapter has been published: Hielscher, L., Ludlow, A., Mengoni, S. E., Rogers, S., & Irvine, K. (2024). The experiences of new mothers accessing feeding support for infants with down syndrome during the COVID-19 pandemic. *International Journal of Developmental Disabilities*, *70*(3), 469-478. https://doi.org/10.1080/20473869.2022.2109000

Although the content of this chapter is largely the same as the published paper, some formatting changes for consistency of the thesis have been made.

7.1. Introduction

Research conducted in the UK before the pandemic highlighted that the breastfeeding support available for mothers of infants with Down syndrome was already inadequate (Cartwright and Boath, 2018) and families of infants with Down syndrome were more likely to report unmet health and social care needs (McGrath, 2011), including a need for more face-to-face contact (Sooben, 2010). Colon and colleagues (2009) found a third of mothers of infants with Down syndrome in their study reported receiving no feeding support and health professionals were unable to advise on specific feeding problems related to Down syndrome. Furthermore, where professionals lacked Down syndrome specific information, they were unable to refer mothers for guidance elsewhere (Cartwright et al., 2018).

As a result of the COVID-19 pandemic and subsequent lockdowns that occurred during this time, the provision of NHS feeding support services in the UK changed. This is not

unique to the UK, an international survey found that 74% of parents of children with intellectual and developmental disabilities reported that their child lost access to at least one therapy or education service, and 36% of respondents lost access to a healthcare provider (Jeste et al., 2020). In some regions, services were reduced and staff re-deployed to other areas, and some services were delivered in a new format (e.g. over the phone, video call) as opposed to the traditional face-to-face mode of delivery (Brown and Shenker, 2021).

Uncertainty remains over the effectiveness of feeding support delivered using a virtual format (Coxon et al., 2020), with the move to online support reported to have impacted maternal feeding experiences negatively (Vazquez et al., 2021). For example, Vazquez and colleagues found that 45% of mothers in the general population who gave birth during lockdown felt they had received inadequate support with feeding their infant. Additionally, 57% of mothers who had given birth prior to lockdown reported a reduction in the infant feeding support they consequently received during lockdown.

The emotional support that face-to-face interactions can facilitate is another important element of post-natal care (Schmied et al., 2001), with a lack of empathy from health professionals shown to increase new mothers' hesitancy to ask for practical support when needed (Fox et al., 2015). Importantly Brown and Shenker (2021) reported that 36% of participants they surveyed felt they had not received enough emotional support from health professionals during the pandemic. Moreover, 70.3% of these mothers cited the lack of available professional face-to-face feeding support as the main reason for stopping breastfeeding earlier than planned.

To date, there has been a paucity of research presenting mothers' voices and lived experiences of feeding infants with Down syndrome. Moreover, there is a need to examine how COVID-19-related changes to feeding support services have affected this group of mothers who reported struggling to access sufficient support prior to the pandemic. To address this need, mothers of infants with Down syndrome who gave birth shortly before and during lockdown took part in semi-structured interviews.

This study aimed to identify the needs and personal experiences of mothers accessing feeding support for their infants with Down syndrome and how this may have been impacted by the COVID-19 pandemic.

7.2. Methods

7.2.1 Study design

Of the little existing research which has examined feeding infants with Down syndrome, the vast majority has adopted a quantitative approach (Cartwright and Boath, 2018). Therefore, a qualitative approach was selected for the present study to allow exploration of mothers' experiences of accessing feeding support in rich detail. Participants took part in semi-structured interviews and reflexive thematic analysis (Braun and Clarke, 2006; 2019) was conducted to explore and identify common themes amongst the experiences of participants.

7.2.2 Participants

A purposive sampling method was used to recruit 13 mothers of infants with Down syndrome in the UK who gave birth either in the 12 months prior to the beginning of the first UK lockdown (23rd March 2020) or during lockdown. To be eligible for inclusion

in the study, mothers must have been at least 18 years of age, and able to speak fluent English, without assistance. It is worth noting that whilst the first UK lockdown began a phased ending from 4th July 2020, a variety of restrictions were still in place throughout the majority of 2020 and further lockdowns occurred in the latter part of 2020 and 2021. As such, women in the sample who gave birth after the first 'full' lockdown would have still been impacted by restrictions and social distancing measures related to COVID-19. Recruitment specifically focussed on mothers as opposed to parents because attendance at health settings was often restricted due to COVID safety measures. As a result, mothers may be likely to have had a greater number of experiences related to feeding and accessing feeding support, especially in the immediate post-natal period.

Table 7.1. *Sample characteristics*

	Maternal Characteristics	**Infant Characteristics**
Mean age	35.5 years, ***SD***= 3.9	11.8 months, ***SD***= 3.0
Age range	28-40 years	8-17 months
No. who gave birth before lockdown	3	
No. who gave birth after start of first lockdown	9	
No. of the sample that were first time mothers	6	
Postnatal hospital stay duration (range)	1-15	1-35
Postnatal hospital stay duration (mean)	6, ***SD***= 5.0	9.7, ***SD***= 9.9

Table 7.2. *Characteristics of individual participants and their infants.*

Participant Pseudonym	Age (years)	Country of residence	First time mother?	Child born before or after start of 1st UK lockdown	Mother's postnatal hospital stay duration (days)	Automatic referrals to relevant services[a] when leaving hospital?	Child age (months)	Infant's postnatal hospital stay duration (days)
Mother 1	39	England	Yes	Before	14	No	16	35
Mother 2	38	Scotland	No	After	4	No	11	4
Mother 3	28	England	Yes	After	12	No	8	12
Mother 4	34	England	No	After	1	No	9	1
Mother 5	34	England	Yes	Before	15	No	16	15
Mother 6	29	England	Yes	After	5	Yes	13	20
Mother 7	37	England	No	After	2	No	10	2
Mother 8	40	England	No	After	2	No	9	2
Mother 9	36	England	Yes	After	2	No	12	2
Mother 10	38	England	No	After	7	No	10	7
Mother 11	39	Northern Ireland	No	Before	6	Yes	17	6

Mother 12	34	England	Yes	After	2	Yes	11	10
Mother 13	-	England	No		-	No		-

Notes

[a]This encompasses all support services relevant to infants with Down syndrome e.g. Speech and Language, Occupational Therapy, Physiotherapy.

7.2.3 Health services questionnaire

To be able to consider the interview findings in the context of service-related changes, a questionnaire was first developed and distributed via email to various feeding support services in the local county and surrounding areas (Appendix C). This included hospital-based infant feeding and maternity units, health visitors, family centres and NHS community trusts. Around 20 services were contacted by email to distribute the survey. To encourage busy services to complete the questionnaire, they were provided with an overview of what the questionnaire aimed to explore and encouraged to select a relevant individual to complete the questionnaire, on behalf of the service. The questionnaire aimed to gather information about how feeding support delivery changed since the beginning of lockdown in March 2020, up until the time the questionnaire was distributed (June and July 2021). The questionnaire was not targeted at individuals with specific role titles. The questionnaire was shared with a variety of organisations whereby people with many different role titles had the opportunity to comment on its operation throughout the pandemic. Furthermore, throughout the pandemic, many health professionals were re-deployed to other departments and thus were working in environments that may have been incongruent with their official role title. A descriptive analysis of the closed-ended questions was conducted to determine how many services reported changes during the COVID-19 pandemic and to identify the nature of those changes. Responses to open-ended questions were also reviewed, and any relevant details regarding service modifications or feedback on these changes were extracted. The collated data is summarised in Table 7.3.

7.2.4 Interview schedule

The semi-structured interview schedule (Appendix D) aimed to explore mothers' experiences of feeding and feeding support both in hospital immediately after birth and in the community. To ensure that the interview schedule was suitably sensitive and appropriate, this was developed and then refined following discussions with the research team and a parent of a young person with Down syndrome who also has professional experience in health and education for young children with Down syndrome.

Key questions included:

- Can you describe your experience of feeding your baby shortly after birth?
- Can you describe the support you received with feeding your baby whilst in hospital?
- Has lockdown impacted your experience of feeding your child in any way?

Examples of follow-up questions and prompts include:

- How supported did you feel in overcoming the challenges you faced with feeding whilst in hospital?
- Did you change the way you fed your baby as a result of the support you received or didn't receive?
- Has lockdown impacted your experience of feeding your child in any positive ways?

7.2.5 Procedure

Approval was given by the University of Hertfordshire Ethics Committee (approved protocol number: LMS/PGT/UH/04532). Participants were provided with detailed information about the study to facilitate providing their informed consent. Participants were made aware that they would be recorded and how the recordings would be saved, stored and deleted upon transcription. Confidentiality was adhered to throughout the study. During transcription, all identifying details were removed. Participants were provided with a debrief sheet including supportive websites following the interview.

To recruit participants, information about the study was shared via websites and social media groups used by mothers of infants with Down syndrome. This included infant feeding and mother and baby support groups on social media. Information about the study was also shared via existing contacts with relevant local professional and support organisations and groups, and via word of mouth. Mothers were invited to contact the research team via email to volunteer to take part in the study. They were provided with a digital participant information sheet and consent form. Mothers provided their consent to participate by completing and signing the consent form and then emailing the digital document (or a scan of the hand completed version) back to the researcher.

Once mothers had provided their consent to participate in the study, a demographics questionnaire was completed and experiences were explored through interviews. Due to the social distancing measures in place at the time, video interviews were conducted between June 2021 and August 2021, through an online platform (Microsoft Teams). Following the interview, participants were given the opportunity to share further

information, thanked for their time and were given a debrief sheet. Recordings were made of each interview and were transcribed verbatim by the lead author.

7.2.6 Data Analysis

Reflexive thematic analysis was used to develop an understanding and interpretation of participants' subjective experiences, and identification of common themes amongst them (Braun and Clarke, 2006, 2022). The reporting of the data analysis process and resultant themes were guided by Braun and Clarke's Reflexive Thematic Analysis Reporting Guidelines (2024).

The lead author read and listened to the data several times to ensure familiarity; and then began line by line coding of the interview transcripts, utilising semantic (i.e. descriptions of events) and latent codes (e.g. reflections and interpretations of the emotional impact of challenges faced). Coding included noting potential themes, comments and interpretations. Themes were reviewed and developed in order to determine main themes and subthemes and were compared with direct quotes from the transcripts, to ensure they were supported by and rooted in the data. Themes were then further refined following discussions with the wider research team. Where disagreements occurred regarding themes, this was solved by discussion and comparison with direct source material from the interview transcripts. Theme outlines were then refined and shared with the research team again. This process was repeated until consensus was achieved regarding themes and the team was satisfied that the themes were strongly supported by the interview data. Themes were written up into a narrative account and continued to be refined throughout this stage. To ensure rigour

and credibility in the data, the final themes table with supporting quotes was developed through supervision; member checks were completed by giving all participants access to the finalised table for approval.

7.3. Results

In order to provide context for the results of the thematic analysis, the results of the questionnaire given to feeding support services are first presented (Table 7.1). Despite efforts to distribute the service questionnaire as widely as possible, response rates were very low. Eleven responses were received, but not all participants answered every question. Two responses were from NHS trusts and four were from family centres. Five respondents did not state their organisation.

Table 7.3. *Results from questionnaire distributed to professionals working in feeding services.*

Comments regarding changes to services during the pandemic	No. of services this change was reported by	Positive feedback from staff and their service users about feeding support services during the pandemic	Negative feedback from staff and service users about feeding support services during the pandemic
Feeding support services were stopped or changed during the pandemic, including peer support in hospital, drop-in breastfeeding clinics and face-to-face introduction to solids seminars at family centres. Some of these services remained available face-to-face but by appointment only instead of as a drop-in service and some sessions were offered via video call instead. Circumstances under which face-to-face appointments went ahead were where there were safeguarding concerns, where a full feeding assessment was required (e.g. in cases of a potential tongue tie), and if virtual consultations had not addressed parents' needs).	5	A switch to video and telephone appointments in some services meant that more service users could be contacted. Beneficial for staff to see where parents usually sit and feed baby at home. One service conducted an infant feeding survey and found that 93% of families surveyed were happy with the virtual drop-in service.	Two staff members from different organisations felt that feeding support availability at their service had reduced in this time. Some service users were unsure where to access feeding support. Staff confusion over service availability meant that staff were not referring service users to tongue tie clinics or Health Visiting specialist clinics, mistakenly thinking that they were not running anymore. Number of different options of support available to mothers was reduced. One service received feedback that mothers would like more universal drop in

			feeding groups that anyone could attend (which were available pre-pandemic), as opposed to specific groups for people with certain difficulties.
Some existing feeding support services increased throughout the pandemic.	3	One staff member felt that the overall quality of feeding support their service offered had improved throughout the pandemic.	
No feeding support services were increased throughout the pandemic.	3		
Introduced new 1:1 and group support sessions via telephone and video call e.g. new appointment at 3 months old	4	Being able to access support in service users' own homes was very positive. New systems were time effective. Video calls were beneficial for staff- allowed a closer view of baby's feeding than would have been possible from in-person appointment where a 2m distance would have been required. Service users were happy with extra contact at three months	

Analysis of thirteen semi-structured interviews with mothers produced three superordinate themes; 1) *Every baby with Down syndrome has a unique journey*, 2) *There's no point asking, they won't know*, and 3) *Lack of in-person support* (figure 7.1). Interviews lasted between 39:31 and 69:01 minutes (M= 54:55, SD= 8:50). Descriptive information about the overall sample is presented in Table 7.1 and characteristics of individual participants and their infants can be seen in Table 7.2. One participant (Mother 13) did not return the demographic details form (and so Table 7.2 does not include her data) but some demographic details were provided through her interview.

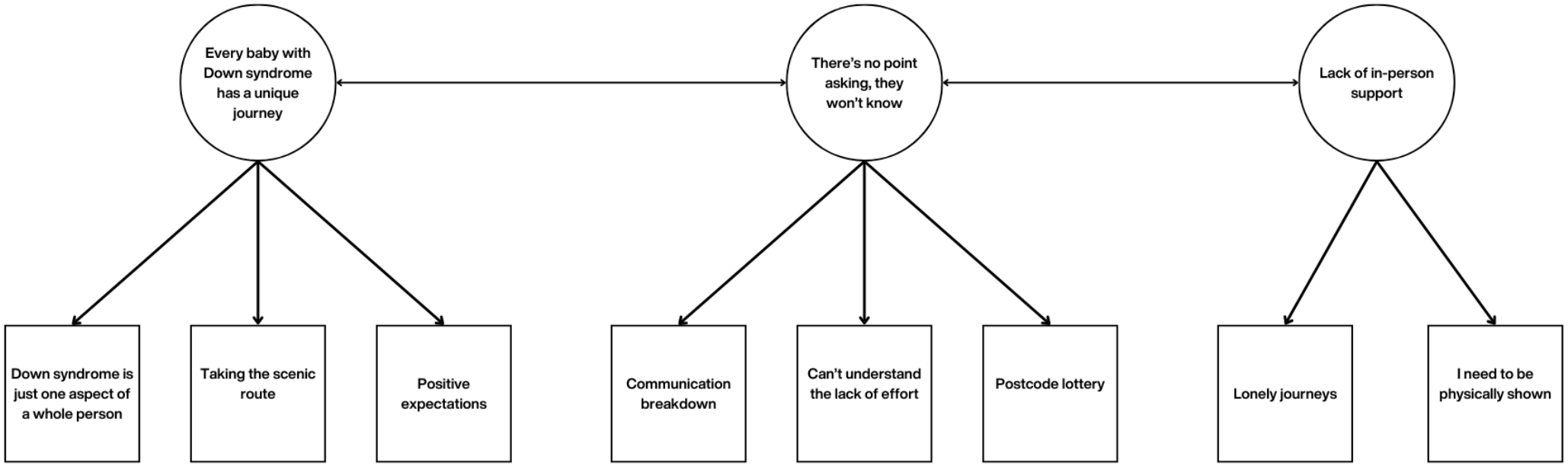

Figure 7.1. *Relationships between main themes and their sub-themes.*

7.3.1 Every baby with Down syndrome has a unique journey

This theme deals with the negative assumptions and expectations that can come with a diagnosis of Down syndrome, rather than acknowledgment that every infant with Down syndrome has unique needs and strengths.

7.3.1.1 Down syndrome is just one aspect of a whole person

Mothers commented that they didn't want health professionals to assume what their child's feeding abilities and developmental trajectory would be based on blanket assumptions about Down syndrome, as illustrated by Mother 4:

> *"So we had heart surgery and then obviously put an NG tube in because obviously that's how she needs to be fed because she's ventilated and everything else. But several nurses were like "oh, so she's tube fed at home?" Like it was an assumption that, well, she has to be tube fed because she's got Down syndrome. Whereas actually I was like no. She's bottle fed at home, and they were like, "really? I'm almost shocked and taken aback that she's bottle fed"."* (Mother 4)

Many mothers had a strong feeling that infants with Down syndrome have differing strengths and challenges despite having the same diagnosis and so infants should be treated as individuals and their own personal strengths and needs explored.

> *"What (child) can do physically, some of my friends' little ones can't, but they're way ahead of her in speech. You know, they're all so different and unique in their own little ways. They've all got some weaknesses as have we all, but I do think there is a*

lot of work to be done generally around information with feeding little ones with Down syndrome and there needs to be this sense of encouragement rather than this sense of I wouldn't even bother because they'll struggle." (Mother 5)

Mothers felt it was sometimes forgotten that their child is a baby first and foremost and that typically developing infants have feeding problems too. 'The Down syndrome' is not always the problem as illustrated by Mother 13, *"For me with (child), I never really felt that the Down syndrome affected his feeding, at least not his milk."*

There were mixed impressions regarding experiences with health care professionals with Mother 4 having a favourable impression: *"The first thing she was just like, oh, isn't she gorgeous."* Whereas Mother 2 has a very negative experience through this interaction.

"She (health visitor) wrote in that red book that (child) suffered from Down syndrome. And I was like no she doesn't. You know, just something like that. That seems so nothingy. It's just a massive thing. She doesn't suffer, people with Down syndrome don't suffer because they have Down syndrome". (Mother 2)

7.3.1.2 Taking the scenic route

Seven mothers in the sample reported feeling as if negative expectations were automatically placed on their child's feeding abilities as a result of their diagnosis.

"There were a couple of general midwives on the normal ward who actually said, I wouldn't even attempt to try and combi feed because it can be confusing for normal babies at the best of times. To which I thought OK. Normal babies, mine must be some kind of alien." (Mother 5)

However, many mothers felt that their infants would be just as able to reach a lot of the developmental milestones that typically developing infants do- they just may need different levels of support and time.

> *"I get ahead of myself and I start to get really stressed and worried about it and I'm like, oh, but he should be, you know, eating fish fingers by now or whatever and it's important for me to keep catching myself. He just needs a little bit more time."* (Mother 9)

> *"Just because she has Down syndrome, it shouldn't mean that she's held back from doing things. You know, it might take her a little longer and that's when, you know, they started describing things as taking the scenic route, which I think is quite a nice way of looking at it, really."* (Mother 5)

7.3.1.3 Positive expectations

Mothers noted how important it was to be given positive expectations of their child when coming to terms with a diagnosis or when struggling with feeding. Knowing it *was* possible for infants with Down syndrome to feed successfully helped them to better cope with challenges and to persevere.

> *"I think even just having that knowledge that just because it's hard doesn't mean it's impossible. It just means that it's taking longer, can massively impact how you feel when it's happening. Because, if you don't know that, and it's hard, it was so easy just to feel like, oh, that means it just can't happen and I failed, it's just not working and everything is awful."* (Mother 9)

This is especially pertinent because six mothers in the sample commented that the realities of breastfeeding were unexpected, as noted by Mother 3: *"I was so like, yes, I definitely want to breastfeed, it's been a lot more difficult than I thought."*

Three mothers also noted the impact that positive information about the lives, developmental trajectories and abilities of people with Down syndrome had on their ability to come to terms with the diagnosis and wishing they had this information at the hospital.

> *"I mean, it's not necessarily like they were negative. But everything that I've learned about how amazing their lives can be and what you know how fulfilling they can be. And like you say, they can do whatever they want to. They just might need a little bit of extra support to get there."* (Mother 9)

7.3.2 There's no point asking, they won't know

This theme addresses the relationship breakdown between mothers and health professionals resulting from a lack of trust.

7.3.2.1 Communication Breakdown

Several mothers felt disappointed and lost faith in health professionals working with them and became reluctant to seek their support.

> *"I think any trust with professionals had gone by that point. So I think I felt there's not much point trying to seek out anybody here, so we'll go online and find out what other people are doing."* (Mother 4)

Instead, many mothers cited online resources and charities such as Positive About Down Syndrome (PADS) and the Down's Syndrome Association (DSA) as a safety net in the face of their unmet needs, explaining that they didn't know how they would have coped without online resources which they often turned to instead of asking health professionals. As stated by Mother 3: *"You know there's all these things and like I said, everything I've learned about Down syndrome. I've learned online through my own doing, not from anyone."*

> *"I would use the internet, not any of the professionals that dealt with us, I would ask the woman who runs Positive about Down syndrome, and she's obviously just a volunteer."* (Mother 4)

Mothers who had breastfed before felt more prepared to deal with the challenges and could rely on their 'gut instinct' making them less vulnerable and reliant on health professionals.

> *"If I had been a first time mum I wouldn't have felt confident and I would have doubted my own ability. I would have probably gone straight over to formula; I would have just given up with the breastfeeding. But because I'd breastfed two babies before I knew."* (Mother 11)

7.3.2.2 Can't understand the lack of effort

It was commonly reported that health professionals lacked knowledge around various elements of feeding infants with Down syndrome, leaving mothers to try and seek necessary support elsewhere.

"Nobody that we spoke to knew much about Down syndrome. There was no specialist person to speak to who had knowledge around it, and so we were just left to flounder a little bit, we got sent home, told to Google." (Mother 4)

Mothers reported that health professionals couldn't signpost them to other services where they lacked knowledge of the issues themselves and questioned why the health professionals were not better informed about Down syndrome. This made mothers feel like health professionals didn't care about supporting them.

"Down syndrome isn't rare, they should have that knowledge there and actually when you're going into homes and working with mums that are trying to breastfeed babies or go into different appointments that they should know or they should be able to find out very quickly and easily to help you and support you and that was just never there." (Mother 2)

Three mothers found that professionals sometimes refused to acknowledge the diagnosis. For example, Mother 2 stated "*But you just think that because people don't understand or have a lot of knowledge so instead of asking they just don't ask and don't mention it."*

Mothers were unsure whether some of their feeding problems were directly a consequence of Down syndrome specifically and felt let down by professionals who shied away from mentioning it.

"I think probably if there had been some more information towards feeding with Down syndrome. Because I thought all the feeding was due to him being premature and it's not since I've come out and I've read obviously everyone else's stories online

that I realised things that I didn't necessarily realise at the time, I just thought he was so small." (Mother 3)

This sometimes presented as a reluctance to help and mothers such as Mother 5 and Mother 9 were left feeling let down and abandoned with their problems:

"I feel like they could have said yeah, that's the right position or just tweak it a little bit and move her around a bit more this way and you'll get it. That was all the advice that I was looking for... Why is it that Down syndrome conjures up such negative connotations in people's minds for them to think I don't think I can help this lady?" (Mother 5)

"Kindness and support, I think that was really lacking and not in all of the interactions. Some of the midwives in the hospital were amazing, but it needs to be all of them." (Mother 9)

In contrast, Mother 12 and Mother 7 showed how positive the experience could be when health professionals were there to provide needed support.

"They (NICU staff) were absolutely fantastic and I can't fault the level of support that we did get, even from the consultants- they were absolutely fantastic. It was a very supportive environment actually." (Mother 12)

"Having someone to talk through it with and someone who, that's their job. It felt a little bit more like, OK, I ***can*** *cope with this because at times, especially in the middle of the night, it did feel a little bit like I'm not sure I can cope."* (Mother 7)

7.3.2.3 Postcode Lottery

There was an overwhelming feeling amongst mothers that the ability to access the appropriate level of care for their child's needs shouldn't be down to luck and you should be able to access the same services- regardless of geographic location.

> *"It's a postcode lottery and that's wrong. It should be one service, it should be one size fits all…We know that a child with Trisomy 21 has development delays, so why wait until you see what those delays are?"* (Mother 11)

The level of support received by each mother differed considerably in terms of how much access they had to health professionals as they left hospital.

> *"Well, we were quite lucky. I've since realised in our area we just got referred to literally everybody the day we left hospital. So, our consultant's been brilliant and he just referred us to everyone, so he referred us straight to speech and language anyway."* (Mother 6)

Mothers were aware of the variability in care access and expressed a feeling of having been lucky in receiving good support.

> *"We could have easily gone home and not known that these are the type of people that need to be involved with her care, but they did it all for us and I couldn't be more thankful. I think it's unheard of, I don't think a lot of people get that."* (Mother 12).

"If I didn't have the speech and language therapist input, I probably wouldn't have known about the chewing (issue), I have to feel for parents that don't have that input." (Mother 11)

7.3.3 Lack of in-person support

This theme explores the unmet needs of the mothers in the sample which resulted from reduced in-person contact due to social distancing measures.

7.3.3.1 I Need to be Physically Shown

Mothers felt that the virtual feeding support offered in place of face-to-face appointments was not effective. Many mothers who expressed they lacked confidence with positioning were not completely reassured and worried that professionals hadn't been able to see what they were doing properly over video call.

"You know, reading stuff in books and being told what to do isn't as useful as being shown what to do and doing it in person, and so just having that face to face did help." (Mother 9)

First time mothers found it difficult to describe elements of feeding that they were new to and didn't understand to someone else as demonstrated by Mother 6:

"The breastfeeding people rang me and sort of discussed over the phone, which wasn't massively useful because they're sort of saying oh are you trying this and are you feeding him now and what's he doing? and I'm like, I don't know. He's latched,

maybe, I don't know. It's hard to describe something that you don't really know what you're doing down the phone to someone." (Mother 6)

Where feeding support services became exclusively virtual for some, eleven mothers expressed feelings of abandonment and helplessness.

"I ended up with post-natal depression because I just felt so low with it and overwhelmed and that feeling of well, if you're not gonna help me, and you're not gonna help me, who is there to help me kind of thing? And then obviously the lockdown hit and it made it 10 times worse." (Mother 5).

"I've had quite a lot of health professionals employed by different people, some of them could come into my home, some of them can't. Some of them still can't. Some of them can meet me outside, and so it varied massively. And I know across the country it's varied massively, so some people across the country would have had less support than other people as well, which isn't ideal." (Mother 6)

7.3.3.2 Lonely Journeys

Many mothers struggled with reduced peer support due to social distancing measures, and craved reassurance and encouragement and reflected on how much easier this would have made it to persevere in the face of feeding problems. For example, Mother 4 highlighted the lack of emotional support.

"There was never anybody to call when you're in a bit of a panic in the middle of the night or in the morning, I just thought we didn't really have a person to turn to." (Mother 4)

> *"It was almost moral support more than anything kind of practical advice. But I mean obviously practical advice would also have been really helpful, but having somebody there to be like don't worry, try again."* (Mother 5)

Eight mothers reported feeling lonely and isolated without the comfort of friends or breastfeeding clinics and expressed a deep desire to be around others who understood or were encountering similar challenges.

> *"I didn't realise first time around but what I needed was a support group and a group of women who were doing exactly the same as me and had the same issues and you know could give me advice. Or, you know, just people to talk to while you're feeding, even you know, kind of have a chat and a piece of cake or whatever. And that was amazingly useful for my mental health."* (Mother 7)

7.4. Discussion

The experiences of mothers of infants with Down syndrome who gave birth before and during the first UK lockdown were explored, to identify their personal experiences of feeding support and any resulting impact of COVID-19 pandemic. The findings highlighted mothers' desires for health professionals to view their child as an individual person, as opposed to just a diagnostic label, for the discourse about baby's feeding and development to be more positive and to be supported if/and when breast feeding concerns arose. The findings highlighted a lack of face-to-face support received during the pandemic, which had a negative impact on mothers' perception of the quality of support they received.

Mothers reported that too often the health professionals assessed their child's abilities based on blanket assumptions about Down syndrome, instead of acknowledging that all infants have unique abilities. These mothers expected their children to reach the same feeding milestones as typically developing children but recognised their journey to that point and support required along the way would look different. Therefore, there is a need for training of health professionals to highlight that although infants with Down syndrome may experience more difficulties breastfeeding, this should not rule it out as an option (Zhen et al., 2021). For example, Sooben (2012) acknowledges the importance of identifying individual feeding abilities and support requirements for both mother and child to promote successful breastfeeding. Where this is done effectively, infants with Down syndrome can go on to breastfeed successfully. Furthermore, feeling adequately supported can have a positive impact on the overall feeding experience and mental wellbeing of mothers as demonstrated by Mother 12, Mother 11 and Mother 7.

Mothers highlighted the variability across feeding services for Down syndrome, such as differences in levels of knowledge of Down syndrome that existed amongst health professionals, leading to a disparity in care being accessed. Many expressed the desire for all health professionals to be better informed to support parents (Douglas et al., 2016). Similar to the findings of Cartwright and Boath (2018), parents expressed frustration at health professionals who avoided giving advice (despite mothers asking for support) for fear of saying the incorrect thing, feeling that health professionals were 'out of their depth'. In the present study, this phenomenon left mothers feeling abandoned and also more heavily reliant on the internet as a source of information about feeding in Down syndrome.

Moreover, the online delivery of feeding services removed the opportunities for mothers to meet other new mothers, yet social support from other women at breastfeeding groups has

been reported to be more beneficial than professional feeding assistance by some mothers and can contribute to longer breastfeeding durations (Fox et al., 2015). Limiting face-to-face medical appointments in favour of virtual delivery can also inhibit the relationship that mothers develop with their midwives by preventing things like a comforting touch (Coxon et al., 2020). On the other hand, recent research suggests that virtual feeding support can be beneficial for many mothers and telehealth services can be more convenient and easily accessible than face to face support for some (Feinstein et al., 2021). This may be particularly applicable to those who may find it difficult to travel to in-person appointments or groups e.g. in the early postpartum period, or mothers with multiple children (Brown and Shenker, 2020). Some groups (for example first time mothers and/or mothers of infants with more feeding problems) may desire more face-to-face support and our research suggests that the provision of face-to-face support should be prioritised for these groups. It is important that mothers are given options regarding their care and the delivery of support services should be established on a case by case basis to suit the needs of individual mothers.

Findings from both the questionnaire given to feeding services and the mothers' interviews highlight the disparity in pandemic-related service provision. Whilst the low questionnaire response rate raises caution over the results' generalisability, it is interesting to note the level of variation across even a small number of services. A larger, UK-wide survey of hospital and community feeding support services would be required to better understand the wider patterns of change throughout the pandemic as well as both short- and long-term consequences of these. Furthermore, inconsistency in availability, accessibility and quality of feeding support services had been commonly reported amongst the literature pre-pandemic (Cartwright and Boath, 2018). As a result, it is difficult to estimate to what extent this gap in the services is related to the pandemic.

Better education of health professionals is needed because addressing health care staff assumptions about breastfeeding with adequate training has been shown to dramatically increase breastfeeding rates (Barbas and Kelleher, 2004). Moreover, a sense of encouragement and positivity about their infant's feeding is invaluable for mothers and can help them to persevere when encountering feeding difficulties. Health professionals should also be encouraged to ask questions and be willing to say when they are unsure about something, so that this may be used as an opportunity to develop understanding. Shying away from discussing Down syndrome out of fear of saying the wrong thing can have negative consequences.

It is interesting to note that the majority of mothers who participated in the study gave birth after the first lockdown. It is possible that more women who gave birth after lockdown volunteered to participate in the study because feeding support was a current or more recent concern and priority, given that their children were younger.

7.4.1 Implications

The findings highlight the need for a clearly defined, universal care pathway to reduce inequalities in service access and ensure all mothers of infants with Down syndrome have access to the same level of support. For example, referrals to appropriate services should be done automatically when mothers and infants leave hospital, and the services that children may need to access should be clearly set out to the parents early in the child's life to prevent parents feeling overwhelmed and underinformed.

7.4.2 Conclusions

Mothers of infants with Down syndrome faced significant challenges in accessing adequate feeding support during the COVID-19 pandemic. There were vast disparities in the knowledge and quality of support provided across different services, often leaving mothers feeling unsupported and relying on the internet for information. While virtual support can be convenient, the study findings suggest that in some cases, face-to-face interactions are more beneficial, especially for first-time mothers or those with more complex feeding issues. There is a need for better training of health professionals that support mothers of infants with Down syndrome, in order to improve breastfeeding rates and overall feeding support quality. Further investigation into the long-term impact of the pandemic on feeding support services is necessary.

Chapter 8. Parental experiences of nasogastric (NG) tube feeding for young children with Down syndrome.

8.1. Introduction

Nasogastric (NG) tube feeding is the most common method of enteral nutrition (whereby nutrition is provided directly into the gastrointestinal tract) which is often used to ensure nutritional requirements are met for infants who are unable to eat or drink a sufficient amount (NICE, 2024). NG tubes are often used for infants that are born prematurely, or are unwell in early life (Bliss, 2024). Short-term NG tube feeding can provide vital nutritional benefits, prevent malnutrition and faltered growth for unwell infants, whilst minimising the energy expenditure needed to feed, for example in cases of congenital heart disease, prematurity, breathing and/or swallowing problems, liver disease, or renal failure (Bliss, 2024; Krom et al., 2019; Mason et al., 2005; NHS, 2024). It is estimated that between 13% and 50% of children with Down syndrome will need to be fed via NG tube in the first three months of life (Lewis and Kritzinger, 2004; Nordstrom et al., 2020, Williams et al., 2022). Some infants will require NG feeding for a short period of time, and others may leave hospital with an NG tube in place (NHS, 2024).

When an NG tube is placed, the tube enters through one nostril, is inserted down the back of the throat via the oesophagus and directly into the stomach (Oxford University Hospitals NHS Foundation Trust, 2024). The tube is secured to the face using medical tape. Before giving an NG feed, it is necessary to first check the tube is in the right place (the stomach and not the lungs) by drawing fluid up through the tube and testing the pH- this process is referred to as aspirating the NG tube (Oxford University Hospitals NHS Foundation Trust, 2024). Once complete, feeds may be delivered via the continuous or bolus method. Bolus feeding includes delivering a predetermined volume of feed into the NG tube via syringe over

a short period of time for a set number of times per day (Whittington Health NHS Trust, 2024). This method more closely simulates normal mealtimes. Alternatively, a continuous feeding pump may be used, which delivers a prescribed volume of feed steadily throughout the day (Whittington Health NHS Trust, 2024). A combination of bolus and continuous methods can be used. Fluids and medication can also be delivered via the NG tube (Sandwell and West Birmingham Hospitals NHS Trust, 2024).

Depending on the reasons for needing enteral nutrition, some infants are also able to attempt oral feeds whilst the NG tube is in place. Oral stimulation (e.g. non-nutritive sucking) is important in early life where sucking is largely reflexive and can improve transition from tube feeding to bottle feeding (Pinelli and Symington, 2005). Older babies (e.g. from roughly six months) who are introduced to oral feeds for the first time, or after a period of non-oral feeding, may not reflexively suck in response to oral stimulation as a younger infant would, and this can make establishing oral feeding very difficult (Mizuno and Ueda, 2001). Children who do not experience oral feeding early in life are more likely to experience feeding problems (Pados et al., 2019). Furthermore, early oral feeding attempts and stimulation are important as they allow infants to develop the oral motor and swallowing skills needed for feeding, later eating of solid foods and drinking liquids (e.g. effective lip seal and suck, co-ordination of suck, swallow and breathe, tongue control and movement). This is particularly important for children with Down syndrome, who are more likely to experience oral-motor delays and challenges with chewing and swallowing than children without Down syndrome (Anil et al., 2019; Ooka et al., 2012; Roccatello et al., 2021; Shaw et al., 2003; Spender et al., 1996).

Children with and without Down syndrome who are tube fed and introduced to solid food textures late may experience various feeding problems such as food refusal, vomiting and

chewing difficulties (Illingworth and Lister, 1964; Mason et al., 2005). The development of effective chewing skills is also dependent on experience. Without this, children will struggle to manage various food textures, thus further hindering eating development (Mason et al., 2005). Additionally, exposure to varying food textures and tastes within the first year of life is important for later food acceptance (Harris and Mason, 2017; Mason et al., 2005).

NG tubes are usually recommended for use in the short-term, and where a child is anticipated to require nutritional support in the long-term, it is recommended that percutaneous endoscopic gastronomy (PEG- whereby a surgical procedure is undertaken to insert a more permanent feeding tube directly into the stomach through the abdomen) is used instead (NICE, 2024). This is because PEG tubes are associated with increased quality of life, lower rates of tube feeding dependency and oral aversion in comparison to NG tubes (Tilyard et al., 2020). Furthermore, evidence suggests that children who are fed via NG tube for longer than 2-8 weeks may have difficulty re-establishing oral feeding once their initial illness has resolved, resulting in tube dependency (Dunitz-Scheer et al., 2009; Senez et al., 1996, Tilyard et al., 2020).

Research examining the use of NG feeding tubes in children with Down syndrome specifically is very sparse, but a 2022 report conducted by the charity Positive About Down Syndrome (PADS) highlighted preliminary concerns about high prevalence of NG tubes for children with Down syndrome, and a lack of structured support to stop NG tube use. Many studies have explored the use of NG tubes in other groups such as pre-term infants and have identified negative impacts that prolonged NG tube use may have on feeding development. For example, resistance to transition from tube feeding to oral feeding, food refusal, delayed development of oral-motor, chewing and swallowing abilities, and intolerance of a variety of

food textures and tastes (Mason et al., 2005; Strologo et al., 1997; Williams et al., 2019; Reilly et al., 1995).

NG tubes can cause unwanted side effects such as vomiting, gagging and reduced appetite (Krom et al., 2017). The presence of NG tubes can also make oral feeding more challenging- positioning whilst breastfeeding may be more difficult, and co-ordinating sucking, swallowing and breathing will be more challenging for infants as one nostril is obstructed (Koong Shiao et al., 1995). NG tubes may also become misplaced and enter the lungs, leading to respiratory problems, and they may be pulled out by young children (Williams et al., 2019). Inserting NG tubes can be very distressing for both infants and caregivers (Kristoffersen et al., 2011). Recurrent negative facial and oral experiences such as repeated tube insertion, choking, vomiting and gagging can lead to the development of oral aversions whereby infants refuse to have anything in or near the mouth, making feeding and eating very difficult to manage (Skuse et al., 1993; Hawdon et 2000). Where any oral aversions are present, prolonged need for NG tubes contributing to tube dependency are more likely.

Tube dependency is a particular concern for infants with Down syndrome because they are already more likely to have feeding problems than typically developing children, such as hypotonia, poor suck, swallow and latch, chewing and oral-motor delays, oral sensitivity, food refusal, and/or delayed introduction of solid foods (Agostini et al., 2021; Anil et al., 2019; Hielscher et al., 2023; Nordstrom et al., 2020). Therefore, prolonged use of feeding tubes in this group may be both a result of feeding problems and/or may also contribute to further difficulties with feeding.

Along with the direct impact on feeding, the use of NG tube feeding can also have significant negative psychosocial impacts on parents and families of infants fed this way. Parents worry

about their child becoming dependent on the NG tube and struggle to juggle the practical demands of NG tube feeding and tube weaning with family life (Dunitz-Scheer et al., 2009; Syrmis et al., 2018; Wright et al., 2024)

In order to promote positive outcomes and prevent prolonged use of NG tubes, it is recommended that exit plans are documented when NG tubes are first placed, in order to facilitate timely weaning from NG tubes (Tilyard et al., 2020). It is important that feeding goals are set and the necessity to use an NG tube is reviewed at regular intervals, with parents included in this process (Syrmis et al., 2019; Wilken, 2012; Remijn et al., 2022). However, there is evidence to suggest exit plans are not effectively and routinely used in health care settings. An Australian survey of health care professionals typically involved in tube feeding, conducted by Syrmis et al., (2020), found that only 18 of the 155 health professionals surveyed had received training on the process of weaning infants from tube feeding. An earlier international study by Syrmis et al., (2019) also identified a lack of guidance around weaning from feeding tubes and exit planning in information distributed to parents by the UK, New Zealand and Australian health services. This is of concern because children who are fed via NG tube longer than necessary are at risk of developing a feeding tube dependency and oral aversions (Tilyard et al., 2020).

Key stakeholders from within the Down syndrome community such as representatives from the charity Positive About Down Syndrome have expressed concern around the possible overuse of NG tube feeding among infants with Down syndrome and have suggested that this would be a valued topic for research. Given the scarcity of existing research on this particular topic, the present study aimed to further explore how NG feeding tubes are being used in the UK for young children with Down syndrome specifically, including exploring decision-making processes around NG tube use, exit-planning, and also the impact that parents feel

NG tubes have on feeding, eating, and drinking development. This study also aimed to identify any psychosocial impact and support needs of parents of children with Down syndrome who are fed via NG tube.

8.2. Method

8.2.1 Study design

Given the concerns expressed by Positive About Down Syndrome about NG tube use and the lack of existing research about NG tube feeding for infants and young children with Down syndrome specifically, a qualitative approach was undertaken. This would allow an understanding of how this group have been impacted, and to explore participants' experiences of NG tube use, their concerns and reflections. Semi-structured online interviews were conducted and analysed using reflexive thematic analysis (Braun and Clarke 2006) to identify common themes amongst participants' experiences.

8.2.2 Participants

A purposive sampling method was used to recruit 14 mothers of 15 children with Down syndrome (Mother 14 had two children with Down syndrome and spoke about her experiences with both children at interview). To be eligible for inclusion in the study, participants must have been UK based parents of a child with Down syndrome who was fed via an NG tube at some point between birth and five years old. The child may have been currently fed via NG tube, or the tube use may have occurred within the last five years. There was no minimum duration of NG tube feeding required to be eligible for study participation. Some mothers could not recall the exact duration their child was fed via NG tube, and in some cases, it was not possible to ascertain duration because the child's NG tube had been removed for a period of time and then re-introduced over a long period of time.

Parental gender was not specified, and parents could be biologically or non-biologically related to the child. However, all participants who volunteered to take part in the study identified as female and described themselves as the child's biological mother. Demographic details of mothers and children are shown in Tables 8.1 and 8.2. Seven of the 15 children with Down syndrome (47%) were born prematurely, at less than 37 weeks' gestation. Ten (67%) of the children had some kind of cardiac anomaly at birth.

Table 8.1. *Characteristics of individual participants and their children.*

Participant	Age (years)	Ethnicity	Location	First time mother?	Child gender	Child ethnicity	Child gestational age at birth (weeks)	Child weight at birth (kg)	Timing of Down syndrome diagnosis	Child age (months)	Co-morbid diagnoses of the child
Mother 1	45	White British	West Midlands	Yes	Male	White British	33	3.7	Pre-natal	57	Hypothyroidism Gastro-oesophageal reflux disease Unsafe swallow Chronic lung disease
Mother 2	41	Other White	East of England	No	Male	Other White	29	1.4	Post-natal	52	Congenital heart disease
Mother 3	35	White British	West Midlands	No	Female	White British	37	3.7	Pre-natal	30	Congenital heart disease Hirschsprung's disease Laryngomalacia
Mother 4	34	Mixed	South East England	No	Male	Mixed	22	2	Post-natal	18	Congenital Heart Disease Hypothyroidism Hypogonadism

Mother 5	42	Other White	South West England	No	Female	White British	38	2.6	Pre-natal	27	Congenital heart disease
Mother 6	30	White British	East Midlands	Yes	Male	White British	37	2.9	Pre-natal	59	Hirschprung's Disease Obstructive sleep apnoea
Mother 7	50	White British	Northern Ireland	No	Female	White British	33	2.5	Given high chance, confirmed post-natally	67	Congenital heart disease Global Developmental Delay Hypotonia Hearing loss
Mother 8	46	White British	Northern Ireland	Yes	Male	Mexican and British	34.5	1.9	Post-natal	60	
Mother 9	42	White British	South West England	No	Female	White British	41.9	3.3	Post-natal	37	Congenital heart disease Hypothyroidism Hypotonia
Mother 10	33	White British	Yorkshire and the Humber	No	Male	White British	39.9	3.2	Post-natal	31	Congenital heart disease

Mother 11	40	White British	South East England	No	Male	White British	33	2	Given high chance, confirmed post-natally	26	Congenital heart disease Adrenal insufficiency Infantile spasms Visual impairment Hearing impairment
Mother 12	31	White British	West Midlands	Yes	Female	White British	31	1.5	Pre-natal	7	Congenital heart disease
Mother 13	41	White British	East of England	Yes	Female	White British	39	3.3	Post-natal	67	
Mother 14	42	White British	East Midlands	Yes	Male	White British	42	3.5	Post-natal	55	Congenital heart disease Hearing impairment Visual impairment
Mother 14				No	Female	White British	39	2.7	Post-natal	19	Congenital heart disease Duodenal webbing repair

Table 8.2. *Sample characteristics.*

	Mean (SD)/ N (%)
Child's age	40.8 months (19.7 months)
Child age range	7-67 months
Mother's age	39.43 years (5.96 years)
Mother age range	30-50 years
Mother and child dyad ethnicity:	
White British	12 (80)
Other white	2 (13)
Mixed	1 (7)
First time mothers	6 (43)
Gestation at birth	35.23 weeks (19.71 weeks)
Gestation at birth range	22-42 weeks
Premature	7 (47)
Weight at birth	2.68 kg (0.78kg)
Weight at birth range	1.4-3.7 kg
Timing of Down syndrome diagnosis:	
Pre-natal	5 (33)
Post-natal	8 (53)
Given high chance then confirmed post-natally	2 (13)

8.2.3 Interview schedule

A semi-structured interview schedule was developed to explore parental experiences of NG tube feeding for their young child with Down syndrome (Appendix E). This included feeding in hospital shortly after birth, parents' goals for feeding, and support needs. Parents were also asked about challenges associated with NG tube use, perceived impact of NG tube use on later eating, speech and language development.

To ensure that the interview schedule was sensitive and appropriate, feedback was sought from key stakeholders within the Down syndrome community including the CEO of Positive About Down Syndrome and a parent of a young person with Down syndrome who also has professional experience in health and education for young children with Down syndrome. The interview schedule utilised both open ended questions as well as more specific prompts and follow up questions.

Key open-ended questions included the following:

- Can you tell me about when the NG tube was first introduced?
- What was it like for you during the time that your child was fed via NG tube?
- Can you tell me about your child's feeding after the removal of the tube?

Examples of follow-up questions and prompts include:

- What was the decision-making process like when the tube was first introduced?
- Did you have any concerns about the use of the NG tube?
- Was there anything about your experience with tube feeding that surprised you?

8.2.4 Procedure

Ethical approval to conduct the study was granted by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (approved protocol number: acLMS/PGT/UH/05175(1)). Given the potentially distressing nature of the interview topic, several considerations were made in order to minimise the risk to participants. Participants were provided with sufficient information before interviews to allow them to fully understand the nature of the interview, and the topics that discussions might include. Before interviews commenced, participants were informed that if at any point

they felt they wanted to pause or stop the interview, this was encouraged, and they need only to inform the interviewer. Debrief information which included signposting to relevant sources of support was provided to participants after interviews.

To recruit participants, a flyer was produced to advertise the study and information about the study was shared via websites and social media groups used by parents of children with Down syndrome. Information was also shared via existing contacts with professional organisations and key charities that support families of children with Down syndrome.

Parents were invited to contact the research team via email to express their interest in study participation, or to get further information. Parents were then sent a web link to access a digital participant information sheet, consent form and demographic questions (hosted by Qualtrics). Parents indicated their consent to participate in the study by clicking the corresponding response option. If parents selected that they would not like to take part in the study, they could not progress to the demographic questions, and no data was obtained from them. The researcher then contacted the participant to arrange a time and date to conduct the interview via Zoom. Interviews lasted between 42:21 minutes and 80:58 minutes (*M*=55:15 minutes, *SD*= 6:07 minutes). Interviews were audio recorded and then transcribed verbatim.

8.2.5 Data analysis

The data analysis process was informed by Braun and Clarke's (Braun and Clarke 2006, 2022) six-step process for conducting reflexive thematic analysis. The reporting of the data analysis process and resultant themes were guided by Braun and Clarke's Reflexive Thematic Analysis Reporting Guidelines (2024).

The lead author read transcripts and listened to interview audio recordings several times to ensure familiarity with the dataset. Coding of the transcripts was then carried out using Microsoft Word. Both semantic (e.g. descriptions of events) and latent (e.g. reflections on the emotional impact of challenges faced) codes were used, and comments and initial interpretations were also noted. Initial themes were then generated using the codes. Themes were reviewed and developed in order to determine main themes and subthemes and were compared with direct quotes from the transcripts, to ensure they were supported by and rooted in the data. Themes were then further refined following discussions with the wider research team. Where disagreements occurred regarding themes, this was solved by discussion and comparison with direct source material from the interview transcripts. Theme outlines were then refined and shared with the research team again. This process was repeated until consensus was achieved regarding themes and the team was satisfied that the themes were strongly supported by the interview data. Themes were written up into a narrative account and continued to be refined throughout this stage. Member checks were conducted to ensure rigour and credibility- all participants were given access to the finalised themes and supporting quotes and provided their approval.

8.3. Results

Analysis of 14 semi-structured interviews produced four main themes; (1) *Adjusted expectations*, (2) *The pervasive impact of the NG tube*, (3) *Finding our own way*, (4) *Feeding is inescapable and overwhelming* (Figure 8.1).

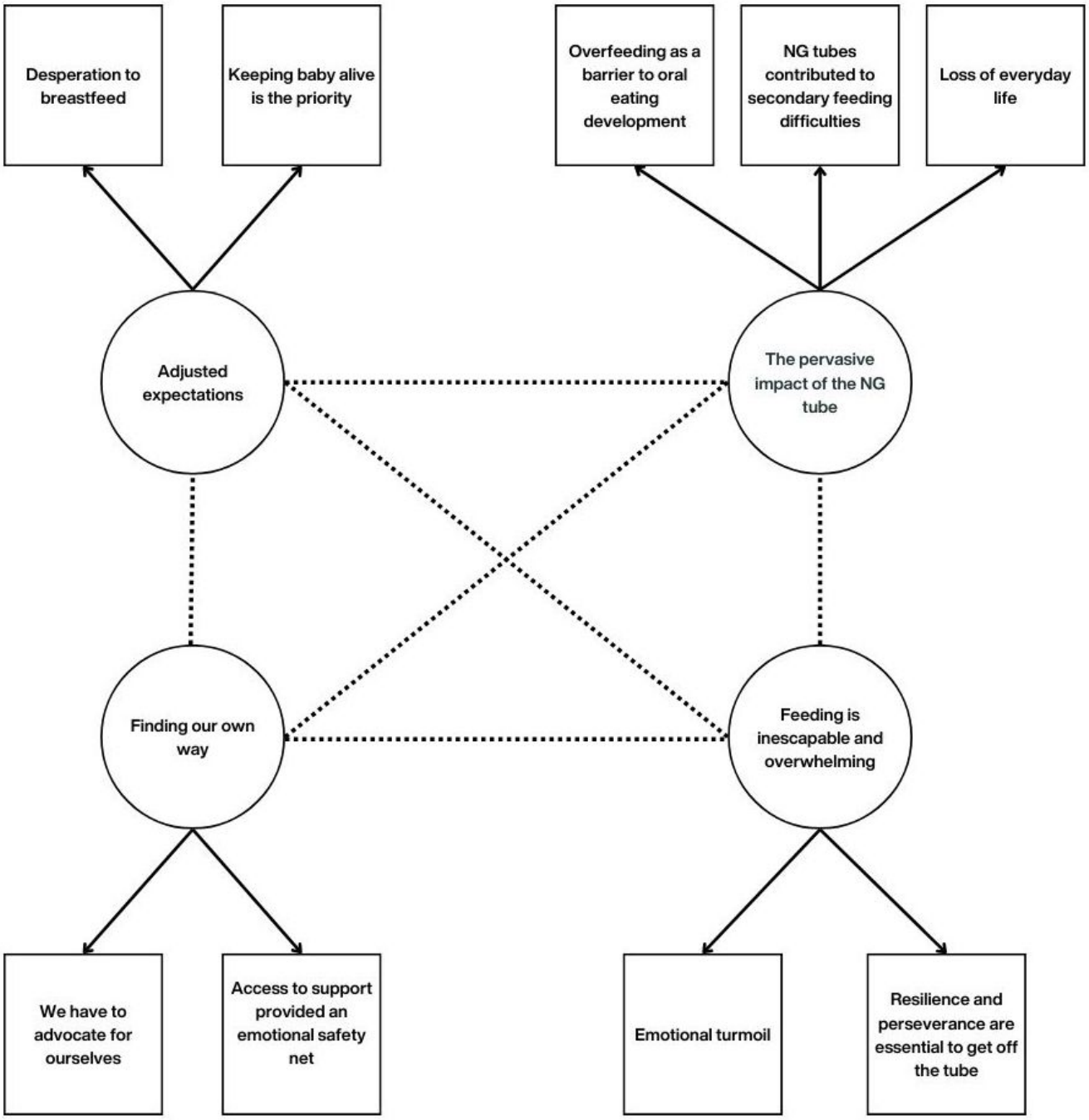

Figure 8.1. *Relationships between main themes and their sub-themes.*

8.3.1 Adjusted expectations

For many of the mothers, having a child who was very poorly in early life meant that there were unexpected ways in which family life and feeding differed from their initial expectations. Parents were required to shift their expectations and make sacrifices to manage competing priorities around baby's health needs, and their own desires for feeding.

8.3.1.1 Keeping baby alive is the priority

Mothers reported that despite having clear pre-natal feeding goals, feeding seemed insignificant and took a back seat when there were serious medical concerns in the early days of their child's life. *"We just wanted her to survive. We just wanted her to live. We were just willing her to live. My brain wasn't on feeding her."* (Mother 3)

There was often no discussion regarding the initial insertion of the NG tube, it was something which just appeared. Mothers put their own desires around how they'd like to feed their child aside, and they put their faith in the decision-making of the health professionals who were supporting them. *"They didn't tell me they put it (NG tube) in, but it was obviously done for the right reasons." (Mother 6)*

Mothers described feeling like they had no control over their child's care, and no choice but to accept the decisions of health professionals:

> *"That was the experience with all their care really in the neonatal unit, it didn't feel like there was any real choice. They would just do stuff and then tell you about it or not tell you about it, and then you'd have to ask."* (Mother 14)

Sometimes the lack of input and control around feeding decisions was very emotionally challenging.

> *"He had actually had a little bit of a breastfeed before he went down to the neonatal unit. So to then go down and find that he was having to be fed via a tube and being told that he was going to have to have formula instead of breast milk…Yeah, it was very distressing."* (Mother 14)

Mothers accepted the necessity of the NG tube and made difficult compromises around their feeding goals. It was often expected that the NG tube would only be necessary in the short-term, and that breast or bottle feeding was something they could work towards when baby's health was more stable: *"He needs to be the weight for his operation so NG feed until the operation and then we'll focus on feeding."* (Mother 10). Mothers' feeding goals were still incredibly important to them, but their belief that this was something they would be able to work on once the acute phase of their child's illness had passed allowed them to make what they believed were short-term, difficult concessions.

However, for some mothers, their child's NG tube ended up being in place for far longer than they could have anticipated when it first appeared: *"We sort of thought it (NG tube) would come out after the surgery but she became dependent on it very quickly, if I'm honest, and she eventually lost her suck, and because then she lost that, when we were putting anything in her mouth then she didn't know what to do with it."* (Mother 7)

In some cases, participants' children breastfed successfully after birth and so they couldn't initially understand why their child needed to be fed via NG tube instead: *"That private*

speech and language (therapist) basically just said you need to just keep going with the tube and it felt like nobody believed that he could eat or he could drink orally and that really, really frustrated me given that the first eight weeks of his life he had fed orally." (Mother 4)

Mothers had to adjust their expectations around baby's feeding when the NG tube was first inserted, and continually throughout the journey that followed. Ultimately, despite its importance to mothers, preferences around feeding were put aside and concessions made, because mothers prioritised their child's acute medical needs: *"When he was first born the main thing was to keep him alive."* (Mother 2).

8.3.1.2 Desperation to breastfeed

Mothers often commented on how important it was to them to be able to breastfeed their child:

> *"Not long after birth she was already trying to suck, she was hungry, trying to sort of root and things. With my other children I breast fed them so, immediately I was like oh can I feed her, she's hungry, and concerned about when she could feed, and they were just like no, not yet. We need to do echoes on her heart see where we're at."* (Mother 3)

Where there were initial struggles establishing breastfeeding, (e.g. due to challenges around baby's suck and swallow, or very tired, floppy babies) mothers were proactive and persevered to eventually establish breastfeeding. *"I guess as she got stronger, trying to offer her the boob each time and then top up with the NG and I mean, I was clear that I intended to exclusively breast feed, I felt quite strongly about it." (Mother 13)*

Mothers reported concerns about baby losing their ability to suck or latch effectively as a result of not feeding orally, and were desperate to do all they could to promote this and therefore increase their chances of eventually being able to breastfeed their child: *"Once I knew I was going home, I asked to speak to a speech and language therapist to assess her orally and her sucking so that's what I wanted to get the advice on about going home, about what I can do next to help her not lose her sucking reflex and help her latch."* (Mother 3)

Often mothers poured their energy into expressing breastmilk, hoping that this could be given to their child via NG tube or bottle. Expressing breast milk served as a coping mechanism, a small thing they could control during an uncertain and scary period: "*I couldn't do anything else for her apart from express, as much milk as I could, knowing we could save it and hoping she gets it one day."* (Mother 3). However, for some, expressing was incredibly challenging, as highlighted by Mother 12 when asked about whether she would consider trying to breastfeed again in the future:

> *"It's at that point now where I don't know if I've got it in me because I think back to all the pumping and everything that I did, it was really difficult… I don't know if I'm strong enough to go back and try again."* (Mother 12)

Concerns around milk supply when expressing could be devastating and emotional support and encouragement were vital to manage this.

> *"You get one mil at the beginning and I was just like, oh, I'm gonna cry, is that it? And the girl was like 'Oh wow, you're brilliant, that's amazing, that is gold.' And then she came back three hours later, we got two mils and I was like, oh my goodness this is a nightmare and she was just so over the moon and I was like has she*

lost her marbles, you know? But she's like, oh you're doing brilliant…She was so encouraging and then, within a few days the milk started to come." (Mother 8)

Some mothers were able to initiate breastfeeding their child, but health concerns and subsequent NG insertion meant that they were pressured to stop, against their wishes.

"His cardiologist was concerned, he obviously needs to reach his optimum weight for his operation and the sooner he reaches that weight, the sooner he can have his operation and the better that will be for him. They wanted to put him on a feeding plan, and told me basically you can't breastfeed him anymore… I was like, but why? He's established it and they were like, well, he's using too much energy to breastfeed.. but he doesn't seem overly tired after a feed. And actually, one of the nurses supported me in that because she said, when she was aspirating for his feeds, there's more milk in his tummy after a feed when he's breastfed than when he's had a measured (NG) feed. I felt quite pressured to not breastfeed him." (Mother 10)

Sometimes, health professionals discouraged mothers' desires to breastfeed, and held very negative assumptions about the child's ability to establish oral feeding. Mothers felt that such assumptions were false, and they wanted hope and positive expectations of baby's feeding capabilities. Mothers felt vindicated when their perseverance with oral feeding had meant baby exceeded health professionals' expectations.

"A consultant sat down with me and he told me I needed to not stress about breastfeeding, it would probably never happen for us. (Child) was a very poorly boy and I shouldn't really expect him ever to breastfeed or probably ever feed normally…I

do make a point of breastfeeding (child) in front of him (because they still see the same Consultant)*."* (Mother 11)

One mother was surprised by how much she wanted to breastfeed her baby, despite previously not having strong preferences regarding feeding modality.

> *"Oddly, I had said to myself and to my midwife that I'd like to try breastfeeding, but if it doesn't work, it doesn't work. I'm not bothered, but then it turned out I really was bothered. I think it's because obviously when they do latch and they're there, you get that rush of hormones, don't you, an emotion? As soon as I got that, I was like, yeah, I wanna do this. It's lovely. And then I just never really got through." (Mother 12)*

Where mothers had wanted to breastfeed, but this ultimately did not happen for them, they reported a feeling of mourning and loss which stayed with them long after. This was particularly felt by Mothers 3 and 13: *"(I was) devastated after everything I'd tried, and it just felt like I'd lost the little timeframe I had to try and keep her latch and her suck, I'd lost that now."* (Mother 3). *"I wanted to breastfeed, it never happened. I'm still sad about that."* (Mother 12)

Ultimately, for many mothers breastfeeding felt incredibly important. Their breastfeeding journey did not always match their pre-natal expectations and mothers had to adapt to this and navigate an unknown path.

8.3.2 The pervasive impact of the NG tube

Having an NG tube significantly impacted many aspects of life for these families and they were not always prepared for or equipped to deal with this. Challenges associated with

having the NG were far reaching and affected themselves, their child and family life as whole.

8.3.2.1 Overfeeding as a barrier to oral eating development

For many mothers, the regular NG feeding schedule and their child's resulting constant satiety hindered the development of their child's oral feeding. Where tube feeds were given at regular, frequent intervals, children were not experiencing physical sensations of hunger. Parents felt strongly that attempting to orally feed a child who was not hungry was akin to fighting a losing battle. ***"****I feel like she was always overfed, so why would she make the effort for anything else when she was full up all the time?"* (Mother 9). Mothers struggled to motivate their child to eat orally*: "I think she felt she was getting what she needed through the tube. It was almost like she knew, you know? Well, I don't need to do that because this is happening, so why bother?"* (Mother 7). As such, children experienced delays developing the oral motor skills needed for safe oral milk feeds, eating of solid foods and drinking, which in turn meant that their child needed to remain on the NG tube for longer. *"One of the other things that we needed to try was to try and get him moving stuff around his mouth because he just didn't have the control, the oral skills to eat because he'd never had to do it."* (Mother 1)

Many mothers felt that health professionals prioritised weight goals which felt arbitrary, and that encouraging development of their child's feeding skills should take priority over this. *"You definitely felt that the emphasis was just on getting the calories in rather than giving her exposure to encourage her to feed."* (Mother 9). It was important to mothers for their child to become familiar with their innate hunger cues, but this often conflicted with health professionals' advice. *"I wanted him to get used to knowing when he needed food and without being force fed. That felt more of a priority than getting him to some arbitrarily chosen weight."* (Mother 14)

In some cases, mothers felt that their child was pushed to a higher than necessary weight in order to have cardiac surgery in early life. It was felt that this hindered other developmental milestones such as gross motor skills.

> *"I think he was overfed…he was just on these eight feeds a day…and he was just a little roly poly, bless him. And I know that that will have impacted his development as well. I feel like because of the weight that he gained, he had to be on his back, he had to be not moving (after surgery) and then he's just taking in all these calories and not exerting them in any way. I feel like that delayed him then in a lot of his physical milestones because he was showing the readiness and the willingness for it. But I think he was just such a little chunk, bless him, he couldn't if he wanted to."* (Mother 10)

8.3.2.2 NG tubes contributed to secondary feeding difficulties

The presence of the NG tube had a wider impact on the children's feeding than just hunger. Mothers commented that their child developed oral aversions and would refuse anything in their mouth. This impacted both milk feeding *("It got to a point when he was about 7 weeks old where he just started gagging. Like any time that the bottle teat would be near his mouth, he would just start gagging.*" Mother 10) and also eating of solid foods: ***"****I desperately wanted to spoon (feed) anything. It could be out of a jar, I did not care. I wanted her to eat and she just didn't want to do it."* (Mother 9)

Furthermore, having the NG tube in place caused significant difficulties with reflux and vomiting. *"They explained to us that because the tube is inserted, the channel is always open, so reflux can happen much more and be much worse in babies with the NG tube inserted. So*

it was really, really difficult." (Mother 5). Vomiting made it very challenging for mothers to ensure their children were reaching nutrition goals. "*She started vomiting a lot. It got to the point where she would vomit on every NG feed."* (Mother 14). Mothers did their best to minimise problems with vomiting after feeds, but for some, mealtimes felt overwhelming.

> *"His reflux was horrendous. So, we would tube feed him, then we would have to keep him upright for half an hour, he couldn't go on his belly. Any kind of movement he would projectile vomit it up and then it would be awful because it would be like, OK, well, that's a tube feed that we didn't want to do and now the milk's come back up. So, we're gonna have to top up the tube again and it just, yeah, it was horrendous." (Mother 4)*

8.3.2.3 Loss of everyday life

The presence of the NG tube placed many practical limitations upon everyday life. When first bringing their child home from the hospital with the NG tube in situ, many mothers wondered how they would cope with the requirements of tube feeding their child. *"I felt at one point that it was going to be quite impossible when we came home."* (Mother 1). As a result, parents often felt they were confined to their home in the early days. **"***We kind of certainly for the first few months felt like we were stuck in the house because trying to tube feed when you are new to it and taking all the stuff you need."* (Mother 9). Even once they became more familiar with the NG tube, typical family experiences such as holidays included extra challenges.

> *"It really is difficult when you're going anywhere to make sure that everything's there and then fighting with airports because you have to bring this milk and they see all this medical equipment and you need an extra suitcase that you're not going to pay*

for because it's medical and you've all these arguments depending on what airport you're going through, some of them are fine and some of them are a nightmare." (Mother 7)

Additionally, constant fears around their child pulling out their NG tube made it very difficult for mothers to do day-to-day things with their child, such as driving in the car.

"He was constantly ripping it out. I don't know how I didn't crash the car, really. Driving around with him in the car, in his car seat, in the back. I think I used to watch (child) through the rearview mirror and not watch what I was doing driving most of the time. And I used to see him reach up and I'd just slam the brakes on and I'd have to stop the car to try and stop him pulling his tube out." (Mother 1)

Reports of children regularly pulling their NG tube out were very common during interviews. This often meant having to attend hospital to have it reinserted or mothers inserting it themselves at home. *"She was always pulling the tube out, we were going to the hospital several times a week (to have the tube reinserted)."* (Mother 5). Many mothers were reluctant to insert their child's NG tube themselves as they did not want to be the person doing something unpleasant to their child. Even when health professionals were inserting the NG tube, mothers found the thought of this very difficult to bear. "*She was really small still, so watching them do that to such a small person just seemed really barbaric because they literally, you know, two nurses would have to hold her to put it in because one would stop her struggling and the other one would put it in."* (Mother 7). The process of inserting the tube created significant distress for the children too.

> *"We were constantly going to the hospital. Inserting the tube was horrible, horrible. When she gets stressed, she gets stress spots on her face. She was covered constantly. Plus, the feeding was going really, really badly… we were thinking what's the point of this? This is making everyone's life hell."* (Mother 5)

The presence of the NG tube complicated vital aspects of family life, such as sibling relationships.

> *"And for her sister…one of my phrases that's out my mouth all the time is 'watch her tube'… because even though it's tucked down her back, the feeding port is quite bulky, still loose, if it presses against her skin or anything she ends up with a bruise when they're wrestling around." (Mother 9)*

Furthermore, typical experiences which should be enjoyable for a young child can instead be fraught with worry and distress.

> *"We've been in soft play, the last time it happened, the little girl, I would say she was around four and she pulled it right off her face. And the duoderm that holds that on literally it takes a layer of skin off. It was horrific, the screams of her was awful…. And it was kind of bleeding a wee bit." (Mother 7)*

Simultaneously, mothers worried about their child's social integration amongst their peers. They were aware that the NG tube made their child look different and struggled explaining it to younger children. *"The sticker is really obvious and it is the one thing little kids ask me about. 'Why has he got a plaster on his face? What has happened to (child)'s face?'"* (Mother 11). Parents worried about their child feeling othered, and sometimes PEG was

considered instead of NG as it is less visible. **"***Speech and language and the dietitian felt that once she started school, an NG tube would make her stand out more from other children, which I can understand… She's on the list to have a PEG tube now and I don't want to have it done because I think she's got the ability to get there in her own time*." (Mother 9)

Mothers aspired towards eating and drinking experiences that they considered to be 'normal', such as family mealtimes. *"It was always the goal to get her eating food with the family just the same way any other kids do."* (Mother 7). Eating and drinking orally were seen as universal, enjoyable experiences that they did not want their child to miss out on. As a result, mothers were desperate to persevere, and have the opportunity to work towards this goal.

> *"I want her to enjoy life and enjoy eating and drinking. I don't want her to rely on having top ups. So then I think that made us more determined… We're going to keep going as long as we can until the point of someone saying look she really needs a PEG." (Mother 3)*

8.3.3 Finding our own way

This theme highlights the inconsistency in feeding support access across the sample, and how mothers responded to this. A lack of feeding support and access to health professionals with specialist training/knowledge created unmet needs. Access to appropriate support was vital and where this was available, it provided a buffer for mothers during a very difficult time. Where it was not available, it created even further complications on their tube feeding journey.

8.3.3.1 We have to advocate for ourselves

It was felt that the NG tube was sometimes used as a 'sticking plaster' for children with Down syndrome who had complex feeding difficulties. In particular, Mothers 4 and 5 felt as if inserting an NG tube was a default, automatic choice for children with Down syndrome and that their child's individual cases were not fully considered when health professionals made decisions regarding their care. *"I just felt like we weren't properly informed and it was a little bit like she has Down syndrome, she has a heart problem, it's the same for everyone."* (Mother 5). Sometimes, mothers felt that assumptions were made about their child's feeding due to the Down syndrome diagnosis, and that health professionals were not fully understanding of parents' priorities concerning their child's feeding.

> *"So yeah, I felt like it was just 'ohh he's complex, he needs the tube' rather than anyone giving us solid tips on how to progress him…. I couldn't see a valid reason, either developmentally or medically, that he needed the tube. It was just that we couldn't find the support to get him off it."* (Mother 4)

It was also felt that health professionals did not fully inform parents about the use of the NG tube, the process involved and the risks associated with it.

> *"We weren't properly informed about everything that is involved with the entire tube, all the risks. We were never told about the aversion, for example. And then I learned more about that because I was on very high alert because she stopped having the bottles. And when I started looking, Googling about how do I remove an NG tube? Is it safe? All that and a lot of stuff were coming up about children then having oral aversions and that was a big concern."* (Mother 5)

Once NG tubes were in situ, it was important to mothers to have a structured plan they could work towards in order to eventually move their child away from the tube. Many were shocked that this information and support was not available. *"But there's just no obvious pathway…there doesn't seem to be any NHS process that we're aware of that weans a child from a tube."* (Mother 9). Mothers tried everything they could to develop their child's oral feeding in order to move away from needing the tube, but without a structured and progressive plan, this sometimes hindered more than helped. *"I think we tried so many things because we were desperate, and he then gradually got more aversive. So actually, I think if we'd have had like a structured approach to trying different things, yeah, maybe he would have come off it quicker."* (Mother 11). Where mothers could not access structured support to wean their child from the NG tube via the NHS, they sometimes sought out expensive overseas programmes that specialised in this. *"We started researching private programs that we could get to, and so we found Graz and we found one in the US called Growing Independent Eaters."* (Mother 4)

When mothers were able to access support from health professionals, they were frustrated by the inconsistency in the advice given to them by different individuals.

> *"I had some conflicting advice within the same hospital on the same ward from a couple of different nurses. Obviously we were in a stressful situation anyway, very heightened emotions… I hated that because I just didn't know what to do. And I wanted to look towards the medical professionals for advice and when they're conflicting it just didn't help."* (Mother 12)

The quality of healthcare and feeding support also varied significantly across Trusts, which meant that children's feeding development and outcomes could be determined by a postcode lottery.

> *"He got sent to (different hospital) and there the team were horrified that he was still on the NG tube and they were basically like if you lived in (different city), this wouldn't have happened. And that obviously is just super frustrating. It was reassuring for us to kind of be a little bit vindicated in that I knew he didn't need it."* (Mother 4)

Accessing healthcare was reported to be a complex battle. Whether this was specialist feeding support, speech and language, occupational or physiotherapy, simply trying to access appropriate support was a huge burden on parents who were already managing a very challenging situation.

> *"The majority of parents that have a child, not just with Down syndrome, but with any type of disability, the chasing around that you have to do. The following up because they've (health professionals) not done this, they haven't done that. They've not referred you to this person. It's just huge. It's a full-time job. Yeah, I call myself (child)'s personal assistant because that's basically what I am."* (Mother 1)

When mothers could access support, it was rarely available in a frequency that would be effective and meet their needs. *"I don't think he saw speech and language until he was six months old. There was nothing in the early months at all*." (Mother 14)

> *"The SALT team came and saw us…they came round maybe once a week and I really would have liked to have seen them maybe twice a week, if not more often. I do*

understand that they were busy and they had other wards that they had to go and see. But really when you're trying every two hours and seeing them once a week seems like a very small percentage of the amount of time that you're trying to try." (Mother 11)

Furthermore, mothers spoke of the necessity of specialist advice from professionals who had expertise regarding feeding problems in children with Down syndrome, and could not understand why this was so challenging to find.

"I think it might have been nice to speak to someone who actually was an expert in kids with Down syndrome and their feeding as opposed to well-meaning but uninformed general hospital staff…this is the most common chromosomal difference, why are there not loads of experts? It's really not that unusual and we all (parents) feel like we know more than them. it's a really frustrating place to be." (Mother 13)

Mothers had to adapt to insufficient support in order to meet their own needs. As a result, they became very proactive. In many cases, they stopped relying on health professionals for their advice regarding how to develop their child's feeding and move away from the NG tube. Where they felt they weren't listened to, or that health professionals did not understand their priorities, mothers sometimes went against the advice of health professionals, or stopped seeking their advice altogether. For example, when their child pulled their tube out, mothers chose not to replace the tube straight away, instead opting to see how their child might manage without it. They often did this without informing their dietician, and instead informed them after the fact.

"So, I sort of thought to myself, I'm going to take control of this now, so I felt very confident to do that, and to manage it myself. So, if she pulled it out, I'd maybe, I

started off by giving her a few hours without it and seeing and then put a little bit of juice in a cup, and try and get her to taste, taste it like that, and then I'd be like right. She hasn't had that much now, I'm going to put another tube in." (Mother 3)

As such, there was often no specific plan or clinical decision-making which guided the removal of their child's NG tube. Their child pulled the tube out and the mothers wanted to give their child an opportunity to cope without it, and this is what led to their child moving away from the NG tube, and to eating completely orally.

Ultimately, mothers often felt alone and had to rely on themselves to navigate a very challenging and unique journey. It was commonly reported that they had to work with their child and find their own way through, given the absence of adequate and specific advice or support.

"I know he has Down syndrome, I know his swallow is different, but it is very good. But then you realize, OK, all the advice you're getting from my friends whose kids don't have a disability, I just had to take it with a pinch of salt. So. thank you, but knew I wouldn't be doing it, and just found my own path." (Mother 8)

8.3.3.2 Access to support provided an emotional safety net

Conversely, when mothers' support needs were met, the impact it had on them was akin to having a safety net whilst navigating this unexpected world. Some mothers spoke positively of elements of their care and support. Where this was the case, they were less anxious and so could take more risks and try things to aid feeding development, knowing they could access

support should anything go wrong. For example, Mother 6 described a conversation had with a nurse after she called to notify them her child had pulled his NG tube out:

> *"She was like, to be honest, I don't think there's any point putting it back in for now… there's always someone on hand 24/7 if you need somebody, just ring the team and we'll come and put it back in. If you think it's not right for him. But you know, we'll book in an appointment for a week and I'll see how he's getting on? And that was perfect."* (Mother 6)

Furthermore, mothers spoke very highly of healthcare professionals who they felt understood their feeding goals and were actively supporting them to achieve this.

> *"The nurses were brilliant, they were really amazing, very promotive of trying to breastfeed. So, although they really helped me with the bottle feeding, because they knew I wanted to breastfeed and they wanted to support that, I think he was 5 weeks old, and we introduced trying to let him suck as well. So, he was nasogastric and bottle and breast (fed) at one point."* (Mother 8)

During long hospital stays mothers often struggled to get information about what would be required to get baby home. They were desperate to establish some sort of family life and move towards normality. When mothers felt listened to and as if health professionals prioritised this too, it gave them hope.

> *"A different doctor came… and I remember him being on the rounds one day and usually they just sort of sit there and talk over my head and he was the first person to look at us and say 'what is keeping this baby here?'…I remember that so vividly, this*

is the first person who's ever mentioned getting us out of here and no one could answer his question….The road to home happened so suddenly, and I credit it all to this doctor…He was amazing." (Mother 12)

Additionally, mothers highlighted the value of having access to vital information regarding feeding and NG tube use. This empowered them and meant that they were less reliant on health professionals.

"When we arrived, we were given a folder which had all the information that we could ever want in it, and it had all the information on NG tubes and oxygen and everything so that if we didn't want to go and ask someone, it was in there which was fantastic." (Mother 12)

Beyond this, being given information which set positive expectations about their child's life and feeding capabilities was invaluable.

"There was a lady who gave me a really ancient photocopy of an Australian article. It was the first sort of really positive material that I'd read that that you know, it really could happen and it would be fine. So that was a useful moth-eaten piece of literature that was inspiring." (Mother 13)

Furthermore, where mothers struggled to access support from healthcare professionals in-person, they relied on online support groups, charities and other parents within the Down syndrome community. Mother 7 wondered how she would have coped were this not available to her: *"I think I would have been at a real loss, I probably got more advice from them than I did from health professionals."*

8.3.4 Feeding is inescapable and overwhelming

This theme captures the un-relenting nature of feeding challenges and the emotional distress that came with them. There was no getting away from feeding and associated issues- either practically or mentally and when challenges occurred this bled into many areas of life and became all-encompassing. Many elements around feeding were described like going to war- an arduous process full of uncertainties and a lack of control.

> *"I just think it's really opaque and difficult to find out where to get help and feeding is so relentless with a baby. (Child) has had many different medical issues and the feeding has been the most stressful by far because it's every three hours, every day. You can't forget about it, or you can't get around it."* (Mother 4)

8.3.4.1 Emotional turmoil

Mothers experienced a vast array of challenging emotions during their tube feeding journey. During the interviews, many participants became very upset when reflecting on their experiences, even if they felt their child was eating very well currently. In particular, mothers experienced immense emotional difficulty when their child struggled with vomiting as a result of the NG tube. "*The tube went in and she was awful on it initially, was very, very sick. She vomited all the time, wasn't tolerating the feeds, and it was just awful, but they insisted it needed to stay in and it needed to keep going. I was very distressed over it, to be honest."* (Mother 7)

Additionally, before mothers could begin an NG feed, they had to aspirate and test the pH level of fluid produced, to ensure that the tube was correctly placed in the stomach. This

process was often problematic and could hold up feeds. Mothers found this incredibly overwhelming.

> *"Particularly during the night, I'd have to get up at least half an hour before the feed was due so that I gave myself enough time to be able to test the tube because, you know, you'd, you'd have to put her in different positions and try lots of different things before you could get an aspirate potentially. And I wanted to be able to feed her on time so I'd get up early to do that. And then the actual feed itself would take ages because I'd have to do it really slowly because of the vomiting and then often she would vomit anyway. So then you'd have to change the sheets and change her. And so often you might only get an hour, half an hour sleep in between feeds."* (Mother 14)

Regarding oral feeding and eating, mothers experienced hypervigilance and anxiety. They worried about their child choking and found mealtimes stressful.

> *"Meal times are still an anxious time because actually one of the chokes in particular was really serious... I'm a nurse and I've got all my first aid kind of training up to date, but I just couldn't dislodge it and I ended up calling an ambulance and she started to kind of go limp and lose colour and it was really terrifying."* (Mother 13)

Fears around choking sometimes lead to mothers limiting the types of food they offered their children, which could in turn hinder the development of their child's eating skills. *"Initially those kinds of things he choked on and I just couldn't cope. I couldn't just try it again."* (Mother 8)

> *"I'm gonna ask for a swallow study to be done because I said there's part of me that thinks I've always been a bit hesitant in feeding her because she's never had the opportunity to develop the oral skill she needs to feed, and nobody's ever really tested her swallow."* (Mother 9)

Parents often had complicated, conflicting feelings about the use of the NG tube. It caused vast distress but when it was gone there were new challenges to reckon with such as giving medication and water.

> *"When you've got the tube, you hate the tube, but then when you haven't got the tube, you wish you've got the tube because medication. You know, before we would just shove the medication down the tube, but now we're faced with a child that doesn't even like eating chocolate that you've gotta give him medication."* (Mother 1)

Mothers were desperate to get rid of the NG tube but sometimes felt guilty about this and feared that their child's wellbeing may take a backwards step if it was gone. *"Do you want to push the tube away when it's actually helping her grow? I'm confident she can eat for Britain, but it's just I don't want it to go wrong."* (Mother 9)

Mothers also felt threatened by the prospect of potentially needing a PEG if their child's oral feeding and eating did not improve. Whilst they found the NG tube difficult, they preferred the idea of this temporary measure to a more permanent PEG.

"I remember this one conversation (with the dietician) and she said right I think I'll refer you to a gastroenterologist now because she's not getting rid of the tube and to think about maybe getting a PEG tube. But I just thought no, I don't really want that for her. I want her to

enjoy life and enjoy eating and drinking. I don't want her to rely on having top ups. So then I think that made us more determined then to No, we're not going to agree to any of this. We're going to keep going as long as we can until the point of someone saying look she really needs a PEG." (Mother 3)

8.3.4.2 Resilience and perseverance are essential to get off the tube

Working towards completely oral eating and drinking to allow removal of the NG tube was a long process with many steps forwards and backwards. *"It was a process, it took months. I'm not sure exactly how many months, but it definitely took months of encouragement and perseverance every day of going through everything to see what does she really like?"* (Mother 7) This process could take a long time, and sometimes it felt as if things would never improve. "*To be honest, feeding is still the hardest part*." (Mother 5).

Mothers commented on the pressure they put on themselves to get their child off of the NG tube, and how difficult it was to persevere when things were not going according to plan.

> *"I remember speaking to the neonatal dietician. Once I got home, she called me to follow up on something and she made some comment about, we would have expected him to be off of the NG by now. But because he's not, I've got to transfer you to the community dietitian service and that really upset me. I felt like I'd failed because I hadn't managed to get him off the NG tube."* (Mother 14)

The journey to weaning their child off the NG tube was full of unpredictability. Mothers struggled to find foods they could rely on their child always eating, and this complicated the process. *"It was a real difficulty, I couldn't go out anywhere because you could never tell*

whether he was going to eat anything. It was just an absolute nightmare." (Mother 6). As a result of this unpredictability, mothers could not completely control the process and so had to let go somewhat and follow their child's lead. *"I honestly spent an absolute fortune for those months trying to find the right thing that would make her eat and eventually I just stopped because I knew it wasn't going to make any difference. She will do it in her own time."* (Mother 7).

Mothers also had to adapt to feeding problems such as a refusal to chew, textural sensitivities and oral aversion, in order to progress their child's eating abilities and meet their nutritional requirements. *"He won't chew meat. He'll just spit it back out. So, we have to blend that in so we can get some protein."* (Mother 1)

It was difficult for mothers to manage the practical challenges that came with trying to progress their child's eating such as mess and long mealtimes, particularly when they had other young children at home. *"She cannot have anything on her tray, because everything that's on the tray goes on the floor. So that's in a way difficult, because she's not going to feed herself if she cannot have food in front of her."* (Mother 5)

Illness could also interrupt very positive eating and drinking progress, which made it often seem as if mothers took one step forwards, and two steps back.

> *"She would take softer things in her hand and eat it and she was doing brilliantly well and drinking loads of milk, which was the main thing that was keeping the weight on her. And then the sickness started and once the sickness started, that was just awful and she just got a bug and just got really unwell and was vomiting and from it we just have not been able to do anything with her at all."* (Mother 7)

Furthermore, mothers commented that whilst their child's eating was no longer problematic, it was concern around drinking liquids and taking medication which kept the child's NG tube in situ.

"He's on movicol (laxative)*…but movicol needs dissolving in 65 to 70 mil of water. So, I can't really stop tube feeding until I know that he can have 70 mil and over a relatively short period of time...We want so badly for him to drink from a cup. I'd take the bottle right now, I'd take anything. You so badly want him to drink from something normal so you can get rid of this tube"* (Mother 11)

For some mothers, the journey towards removal of the NG tube was often not straightforward and required remarkable levels of perseverance. Conversely, for others the NG tube was removed very quickly, but this could also be difficult.

> *"It came out very quickly, so I think it was a lot of stress about him just choking on the bottle. Could he manage it?or did he need the tube back in again? Had they taken the tube out a bit too early?"* (Mother 8)

8.4. Discussion

The findings of this study portray the extremely difficult and usually unexpected journey experienced by parents of young children with Down syndrome who are fed via NG tube. Mothers often did not feel included or heard regarding their child's feeding and were not always supported to meet breastfeeding goals which were very important to them. Mothers worried about their child becoming dependent on the NG tube, and felt the tube hindered the development of oral eating skills but struggled to access support to address this. When at

home, juggling the practicalities of NG tube feeding with the demands of everyday life was a challenge which many were not prepared for. The process of working towards weaning from NG feeding tubes was a very emotionally challenging and tumultuous journey requiring significant resilience.

For the majority of mothers, NG insertion was not discussed with them beforehand, and it was something which suddenly appeared when first visiting their baby in NICU shortly after birth. There is a lack of available research examining communication between parents and health professionals about the decision to introduce NG tubes and the impact of this. Future research is required to better understand whether this lack of communication is common for all infants that are fed via NG tubes, and how communication can be improved.

The introduction of NG tubes usually occurred against a backdrop of serious neonatal illness and so mothers often did not question their use. Feeding became insignificant as they prioritised their baby's survival above all else. It was typically assumed that NG tubes would only be used in the short-term and it was very important to mothers to prioritise working towards establishing breastfeeding. This is consistent with existing research whereby families of children who were dependent on tube feeding describe feeling grateful for the beneficial impact of the feeding tube but remain hopeful for their child to transition to oral feeding and drinking (Forbes and Grover, 2015; Syrmis et al., 2018). Where mothers did not receive adequate support to meet breastfeeding goals, they mourned the loss of their opportunity to do so and felt they missed out on important emotional bonding that comes with breastfeeding.

The importance of establishing successful breastfeeding for mothers of infants with Down syndrome has been well established throughout existing literature (Cartwright and Boath, 2018; Hielscher et al., 2022, Mengoni et al., 2023). Mothers of infants with Down syndrome

who wish to breastfeed should be supported to do so wherever possible and prolonged breastfeeding can have protective effects against various health conditions of which infants with Down syndrome are at an increased risk, such as type 1 diabetes and coeliac disease (Williams et al., 2022). Where mothers of infants with Down syndrome are provided with timely and effective breastfeeding support, breastfeeding rates are comparable with that of typically developing children (Sooben et al., 2012, Zhen et al., 2021). Mothers express a desire for breastfeeding support and information that is specific to the feeding challenges faced by children with Down syndrome (Hielscher et al., 2022; Mengoni et al., 2023; Williams et al., 2022). Unfortunately, research conducted both before, during and after the COVID-19 pandemic demonstrates that breastfeeding support quality and access for mothers of infants with Down syndrome is highly variable, does not always meet mothers' needs, and has worsened since the pandemic (Brown and Shenker, 2021; Cartwright and Boath, 2018; Colon et al., 2009; Hielscher et al., 2022; Vazquez-Vazquez et al., 2021). There is a considerable negative psychosocial impact on mothers who are unable to meet their breastfeeding goals, and who do not receive adequate practical and emotional support to do so (Brown and Shenker, 2021, Chaput et al., 2016). Where mothers wish to breastfeed but are not able to meet their goals, they report experiencing feelings of grief, anger and loss (Brown, 2018). This can be especially pertinent where infants are born premature, or are unwell at birth, as mothers feel that breastfeeding is a way that they can protect their infants, as described by the mothers in this study (Brown, 2018, Lööf-Johanson et al., 2013; Marshall et al., 2007).The findings of the present study highlight the importance of quality breastfeeding support that is targeted specifically for mothers of infants with Down syndrome and in particular addresses challenges faced by those whose child is fed via NG tube.

There was a lack of transparency and structured decision-making processes by health professionals right from initial insertion through to eventual removal of NG tubes. Mothers

did not feel included or informed about decisions around their child's feeding. Additionally, mothers reported not being informed by health professionals about potential negative impacts of NG tube feeding such as the development of oral aversions and oral motor delays even though the link between NG tube feeding and such negative outcomes is well documented (Steward et al., 2020; Syrmis et al., 2020). The findings of the present study are consistent with previous research which highlighted that information given to parents about NG tube feeding did not consider various important topics such as risk of oral aversion and the psychosocial impact upon parent and child of NG tube feeding (Syrmis et al., 2018).

Often, mothers felt that the priorities of healthcare professionals did not align with their own. This is consistent with existing research whereby mothers of infants with Down syndrome reported that health professionals have different priorities to their own in regard to oral feeding (Cartwright and Boath, 2018). In the present study, it was particularly important to mothers to work towards oral feeding and NG tube removal, but it was felt that NG tubes were kept in place based on a need to reach weight goals set by dieticians which often felt arbitrary and inappropriately high. Mothers instead wanted to prioritise helping their child to recognise hunger cues and develop the oral eating and drinking skills necessary for NG tube removal. Tensions arose between mothers and healthcare providers, as mothers felt that reducing NG feeds was necessary to develop feeding skills, as their child would not be motivated to eat orally when already full. Similarly, research conducted by Wright et al., (2023) highlights that parents of children fed by NG feeding tubes report feeling as if they are on different pages with healthcare providers regarding their child's care. There is evidence to suggest that in some cases, fear of weight loss should not be used to prolong weaning from NG tubes, and that even where there are nutritional concerns, oral nutrition can have better outcomes (Dunitz-Scheer et al., 2009). Furthermore, it has been established that the presence of hunger is essential for effective tube weaning, to allow infants to recognise hunger and to

learn that eating is the solution to hunger (Dunitz-Scheer et al., 2009, Mason et al., 2005; Senez et al., 1996).

Various strategies have been suggested to promote oral feeding in NG tube fed children, such as only offering continuous feeds at night, and smaller bolus feeds during the day (whereby food and/or non-nutritive oral stimulation is offered before and during tube feeds), and giving bolus feeds at the approximate volume and timing of typical mealtimes throughout the day, in order to create periods of hunger (Dunitz-Scheer et al., 2009, Mason et al.,Senez et al., 1996). It is important that mothers' concerns about the development of their child's hunger and feeding are considered in conjunction with weight goals set by dieticians. This would allow for individualisation of care plans and NG tube feeding schedules that promote optimal developmental outcomes for infants with Down syndrome.

When an infant is first given an NG tube, exit planning is of vital importance. However, in the present study mothers reported a lack of exit planning regarding NG tube removal. It has been recommended that a date to review the need for the NG tube should be documented upon insertion, and the decision should be regularly reviewed on an ongoing basis by a multidisciplinary team (Dunitz- Scheer et al., 2009; Tilyard et al., 2020; Trabi et al., 2010). This is in order to ensure that infants who are able to eat orally are given the opportunity to do so as soon as possible, and to prevent tube dependency (Syrmis et al., 2018). Additionally, individualised and specific goal setting is essential. This should encompass weight goals, the practicalities of tube feeding (e.g. times of day, method, duration) and factors necessary for tube weaning (Dunitz-Scheer et al., 2009; Krom et al., 2017; Wilken, et al., 2013; Wright, 2013). The documentation of NG tube exit plans have been associated with better clinical outcomes such as reduced hospital stay duration (Tilyard et al., 2020). Where possible, NG tubes should be inserted as late as possible to prevent disruption of sensitive periods of oral-

motor and feeding development, which are thought to occur in the first year or life (Strologo et al., 1996; Pados et al., 2019; Steward et al., 2020). Furthermore, whilst the NG tube is in situ, oral stimulation is necessary to prevent the development of oral aversion and subsequent tube dependency (Senez et al., 1996). Importantly, infants who do not receive oral nutrition or stimulation in the first three months of life have been shown to have reduced tolerance to oral sensations (Scarborough, 2006). In the present study, some mothers were not aware of the need for oral stimulation, and so did not offer it, which they felt led to further feeding complications. Infants and children who are primarily fed via NG tube for longer than eight weeks are at an increased risk of tube dependency, and so it is important that structured exit planning is in place to ensure that NG tube use is not unnecessarily prolonged, and to promote optimal feeding and eating development (Dunitz-Scheer et al., 2009). Despite this, there is evidence to suggest that NG tube feeding exit planning is often not undertaken in practice (Syrmis et al., 2020; Tilyard et al., 2020).

Working towards oral feeding and subsequent NG tube removal was a priority for mothers and they were shocked to find that there was no structured framework to guide this process. Mothers wanted a step by step programme they could follow to address feeding concerns and establish oral eating and drinking, to allow safe removal of the NG tube. Where there is an absence of concrete plan for tube weaning, parents' concerns about their child becoming dependent on the feeding tube long-term are exacerbated, but education and targeted tube weaning goals have been shown to reduce parental anxiety regarding tube feeding dependency (Slater et al., 2021; Wright et al., 2023).

It was felt that NG tube use profoundly hindered the development of feeding and eating skills. Mothers reported that children who had not fed orally early in life missed out on the development of oral muscle strength and oral motor control. This is of particular consequence

to this group, as children with Down syndrome are more likely to experience low muscle tone and oral-motor delays than typically developing children. As such, children struggled to establish effective sucking, chewing and swallowing and speech skills. This in turn limited the types of food and drink their child could safely consume. Additionally, fears regarding an unsafe swallow limited the types and textures of food that mothers offered their child, which may hinder the development of eating skills further due to a lack of exposure to challenging food textures (Cochran et al., 2021; Reilly et al., 1995)

Furthermore, NG tube use contributed to problems with vomiting and gagging. Other adverse oral experiences such as the traumatic insertion of NG tubes combined with a lack of oral stimulation during the period of NG tube feeding were felt to contribute to oral aversions, which hindered eating development and prolonged the use of NG tubes. Mothers wanted proactive and preventative support to avoid the development of problems such as oral aversions, but in many cases found that support was instead offered responsively after the development of problems, which left mothers feeling dissatisfied (Mengoni et al., 2023).

The period of NG tube use was seen to have a significant negative psychosocial impact on participants. For example, mothers struggled with the practical demands of NG tube feeding, which made day to day life feel complicated and impossible. Challenges aspirating NG tubes created immense feelings of distress. Furthermore, NG insertion itself was found to be incredibly traumatic, whether this was done by mothers themselves or by health professionals. Taken together with existing research, this demonstrates the need for thorough in-hospital education and training to ensure that parents are equipped to manage NG tube feeding when leaving hospital, and the impact it may have on their day-to-day lives (Syrmis et al., 2018; Wright et al., 2023).

It is important to note that when parents are given information handouts about NG tube feeding, this does not consider the significant social or emotional challenges that may arise, despite the established need for such information (Craig, 2013; Fereday et al., 2009; Townsley and Robinson, 1999; Syrmis et al., 2018). In the present study, mothers struggled to manage the uncertainty and unpredictability that came with feeding problems, NG tube use and weaning. Mothers worried about whether and what their child would eat, whether they would vomit the NG feed up, constant worry about weight loss, illness, choking risks and fear that the tube may be pulled out. Mothers became hypervigilant and felt a huge emotional strain. The results of this study are consistent with existing research which has demonstrated the need for integrated mental health support for parents of infants and children who are experiencing feeding difficulties or fed by NG tube (Woolf-King et al., 2017; Wright et al., 2023).

This study was one of the first to explore parental experiences of NG tube feeding for young children with Down syndrome. Despite this there are a few limitations to note. While participant recruitment was not restricted to either mothers or fathers, only mothers volunteered to participate in the study- a phenomenon previously documented within parenting and feeding research (Docherty and Dimond, 2018; Mengoni et al., 2023). As such, the findings of the present study do not represent the paternal experience regarding NG tube use for young children with Down syndrome. Further research which explores the unique paternal experience would be of value, particularly given that whole family dynamics are impacted when a child leaves hospital with an NG tube (Wright et al., 2023). Moreover, within the participant sample, the majority of mothers described their ethnicity as White British, so the sample was not diverse. As a result, the study findings may not accurately represent the experiences of individuals from minority groups, who have been reported to face additional barriers when accessing quality maternity care (Obionu et al., 2023).

However, the participant sample was varied in terms of geographic location, reflecting NHS services all throughout the UK.

During interviews, mothers referenced overseas specialist programmes which delivered structured tube-weaning protocols that they could not access within NHS services. Mother 4 in particular recalled how her child very quickly transitioned from being fully NG tube-fed, to fully orally fed in a matter of weeks after engaging these services. Examples of existing programmes include the Graz tube-weaning protocol which aims to reduce tube feeding volume and increase oral eating over a period of three weeks (Dunitz-Scheer et al., 2009). Future research could explore the suitability of existing tube-weaning protocols for use with infants and children with Down syndrome specifically, and the feasibility of employing them within NHS services. Additionally, preventive factors aiming to reduce rates of tube dependency have been explored in other populations (Dunitz-Scheer et al., 2009; Krom et al., 2017). An investigation of preventive practices that reduce tube dependency and promote positive eating outcomes for children with Down syndrome specifically is necessary in order to inform and improve future practice.

8.4.1 Implications

Parents wish to be involved in decision-making processes around eating and the use of the NG tube, to be informed of what is happening and why. Access to information about NG feeding tubes was highly desired, and this should be both informative and holistic- taking into consideration risks associated with NG tube use, practicalities of tube use and potential psychosocial impact. Structured NG tube exit planning is necessary to reduce parental anxieties and prevent feeding tube dependency but is not being carried out in practice. Exit

plans should encompass specific timelines and goals where possible, including preventive action that aims to avoid loss of sucking reflex and development of oral aversions.

Additionally, a multidisciplinary co-ordinated care pathway offering structured guidelines and advice regarding NG tube weaning was desired. This should enable step-by-step, practical advice about how to address feeding problems which may be preventing the removal of the NG tube, such as oral aversions or chewing delays. This should also take into consideration challenges around drinking and consumption of medication, which can prolong NG tube use.

Anxieties around choking were a significant issue for parents and they wanted reassurance about the safety of their child's swallow. Early video fluoroscopy swallow studies and observation of their child's eating of solid foods by a Speech and Language Therapist were proposed as ways to address this.

8.4.1 Conclusions

The results of this study highlight several unmet support needs for parents of children with Down syndrome that are fed via NG tube. Breastfeeding was a high priority, and mothers want specialist practical support that is targeted to children with Down syndrome, in order to prioritise attempts at oral feeding where possible. Furthermore, emotional support and encouragement was vital for parents of children with Down syndrome whose child was fed via NG tube. Ongoing mental health support should be offered to parents whose child is leaving hospital with an NG tube.

Chapter 9. Discussion

This thesis aimed to explore factors related to feeding problems and weight, and to identify parental support needs throughout the early years (birth to five years old) for children with Down syndrome. To achieve this, a mixed-methods approach was taken which encompassed a scoping literature review, longitudinal research, parent interviews, questionnaires and mealtime observations.

9.1 Challenges assessing feeding problems

Before discussing feeding problems, their impact and potential interventions, it is important to first consider how they are assessed in research and in practice. The triangulation of research methods used in the longitudinal study (presented in Chapters 3-6) revealed challenges regarding accurate measurement of child feeding problems. Parents of children with Down syndrome reported difficulties with food texture sensitivity, eating and mealtimes during interviews (Chapter 6) regardless of whether their child was classed as having feeding problems according to questionnaire data. Furthermore, mealtime observations (Chapter 5) showed behavioural differences and more eating challenges for children with Down syndrome compared to TD children, even though very few of the children with Down syndrome had feeding problems according to questionnaire data. Taken together, these findings indicate that quantitative screening tools which produce a binary classification of 'feeding problems' or 'no feeding problems' may not be an accurate way to assess challenges with feeding and eating if used in isolation. Given the heterogenous and complex nature of feeding problems, it is unsurprising that one quantitative measure alone may be insufficient to accurately capture them (Estrem et al., 2017).

This has implications for the assessment of feeding problems in both future research and clinical practice. The importance of utilising different methods to gain a holistic and thorough understanding of child feeding and eating challenges is evident. Consistent with this, previous research utilising both parent report questionnaires and mealtime observations identified discrepancies between findings of each data collection method (van Dijk and Lipke-Steenbeek, 2018). The findings of the longitudinal study suggests that in clinical practice, relying on quantitative screening tools to assess feeding problems, may result in several mothers being left without support, as these measures show their child's feeding to be unproblematic. Recent evidence conducted with occupational therapists and speech and language therapists mirrors this, with professionals reporting many issues with current assessment methods and that no single assessment tool is adequate to understand feeding problems when used in isolation (Rabaey et al., 2023).

Based on this thesis's findings, clinicians and researchers should use a range of methods to assess feeding problems. This includes observation techniques and parent consultations alongside quantitative assessment and screening tools. This approach ensures that parents' concerns about feeding difficulties are addressed, even when these issues are not detected by standard screening tools. Additionally, observational methods provide insight into aspects of mealtimes, such as interactions, that parents might not be aware of.

9.2 Feeding problems and weight are influenced by complex interrelated factors

The composite findings of this programme of research clearly demonstrate a strong need for early intervention related to feeding, eating and weight that is both holistic and integrated. The development and maintenance of feeding problems and weight outcomes were due to a complex interrelation of contributory factors such as food texture sensitivity, underlying

health issues, motor delays, sensory problems, child eating behaviours, and parental feeding practices. Chapters 3 and 4 indicated that these factors were all present by around two years of age, highlighting the necessity of early support. If these factors are not addressed early, then secondary feeding problems (such as oral aversions) can emerge, as seen in Chapters 2, 5 and 8. Additionally, we found that mothers face significant barriers addressing feeding problems and weight concerns, particularly when unaddressed motor, behavioural, and sensory challenges impede their ability to advance their child's eating habits (see Chapters 5 and 8). Taken together, these findings demonstrate that to promote optimal feeding and eating development and weight for children with Down syndrome, parents must be supported regarding *all* factors which could impact eating, and this should be delivered pro-actively rather than episodically, after problems have already developed (Mengoni et al., 2023).

Further evidence for the complex interrelated nature of feeding problems, and importance of early intervention was evident during the mealtime observations (see Chapter 5). Children with Down syndrome were less likely to be given foods requiring co-ordination of gross motor and active biting skills such as sandwiches and wraps than TD children and were frequently offered finger foods that they could munch or foods requiring utensils during their meal. The difference in food choice may have been influenced by the child's biting and chewing abilities. This would be in line with the finding that children with Down syndrome who struggle with biting and chewing tend to consume challenging food textures, (such as meat, raw vegetables, and fruit) less often and prefer easier-to-eat food textures (Hopman et al., 1998; Roccatello et al., 2023) as observed in Chapter 2. In support of this, during the mealtime observations children with Down syndrome showed more difficulty actively biting foods and often displayed a munching chewing pattern, as reported by Kumin and Bahr (1999) and Ross et al., (2022).

9.3 A complex dynamic systems approach to considering feeding problems

The findings of this thesis highlight the necessity of taking a complex dynamic systems approach to the understanding and treatment of feeding problems in early childhood for children with Down syndrome (van Dijk, 2021). This approach posits that the development of feeding problems is the result of several interacting factors such as broader biological, social and psychological factors, but also complex intra-individual factors related to the child, caregiver, environment etc. The relationships between these factors are non-linear, and this approach considers a series of cause and effect feedback loops which operate within the system. For example, a child with oral-motor difficulties may eat slowly or gag/choke due to poor chewing, leading to child distress. Child distress and choking may in turn increase caregiver stress, which the caregiver may respond to by adapting their feeding practices, for example by limiting the difficulty of food textures they offer their child (consistent with findings of chapters 2, 5 and 8). This can in-turn hinder the development of skills needed to safely eat more difficult food textures, and lead to increases in caregiver and child stress. Van Dijk (2021) illustrates how such factors can operate within a specific child-caregiver dyad, and this diagram is included at the end of subsection 9.1 for clarity (see Figure 9.1). This approach also makes room for meal to meal variability, and subsequent unpredictability, and the non-linear 'two steps forward, one step back' feeding experience which mothers frequently reported throughout the qualitative studies within this thesis. This approach has important implications for clinical practice relating to feeding problems, as it emphasises the need to understand the complex interactions between a multitude of factors which impact the development and maintenance of feeding problems, as opposed to identifying and treating a single 'main problem' or cause (van Dijk 2021).

A demonstration of these complex processes which can play out during mealtimes was described by Mother 13 in the interview study outlined in Chapter 6. She commented that

mealtimes could last a long time because her child with Down syndrome would refuse a bite unless it was very small. She speculated that this could be the result of sensory problems and the child was trying to avoid food touching the lips/face if the spoon is overloaded, as this caused the child distress. As a result, more bites were required to consume a smaller amount of food. This may be particularly challenging to manage for parents of children with Down syndrome who are already anxious about their child consuming enough food at mealtimes, and could then exacerbate caregiver stress (Brantley et al., 2023). The mother also went on to explain that the long duration of mealtimes sometimes meant that she would prefer to spoon feed the child in an attempt to speed up mealtimes, but this in turn meant that the child's opportunity to practice and develop self-feeding skills were limited.

Applied to clinical practice, this highlights the potential value of a biopsychosocial case formulation approach to understanding and treating feeding problems for children with Down syndrome and their families, similar to what is commonly undertaken in clinical health psychology. Case formulations aim to develop an integrative and individualised model of factors which influence the development and maintenance of client problems. This is achieved by incorporating psychological theory with idiosyncratic information specific to the client (Johnstone and Dallos, 2014). Applied to feeding, this approach would take into account the myriad interacting factors relating to parent and child that can lead to the development and maintenance of feeding problems, as outlined above.

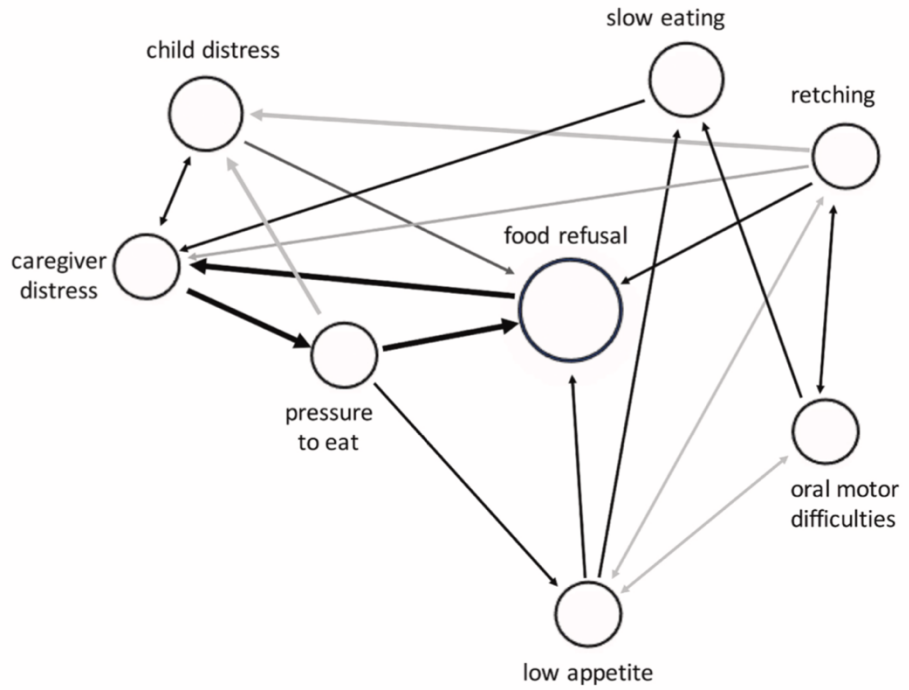

Fig. 1. Illustration of a network of interacting symptoms in a (hypothetical) specific child-caregiver dyad (emergent-causality approach).

Figure 9.1. *A worked illustration of a complex dynamical systems approach to feeding interactions and feeding problems by Van Dijk (2021).*

Notes

Taken from van Dijk, M. (2021). A complex dynamical systems approach to the development of feeding problems in early childhood. In *Appetite* (Vol. 157). Academic Press. https://doi.org/10.1016/j.appet.2020.104982

9.4 Impact of feeding problems for health and weight outcomes

Feeding problems in children with Down syndrome can lead to significant health and weight issues, including malnutrition, growth delays, and obesity. These challenges can exacerbate developmental delays, increase the risk of infections, and contribute to long-term chronic conditions like cardiovascular disease, coeliac disease, chronic constipation and diabetes, which children with Down syndrome are already at increased risk of (Bergholdt et al., 2006; Bermudez et al., 2019; Oliveira et al., 2010; Pavlovic et al., 2017).

Where children with Down syndrome struggle with food refusal, limited diet or chewing difficulties, there can be important implications for dietary intake, and consequently, health and weight outcomes. For example, parents frequently described relying on pre-prepared shop-bought food pouches for their child. They reported preferring to offer home-cooked foods, but over time as their children refused home-cooked foods, mothers increasingly relied on smooth pouches as they were more likely to be accepted due to either taste or textural sensitivities because of their lack of lumps (see Chapter 6). Reliance on lower textured smooth pouches could be problematic for children with Down syndrome, as it may occur as a result of oral food processing challenges, but also may exacerbate such challenges, as the development of chewing abilities is reliant on practice with challenging food textures (Forde and Tournier, 2023).

Amongst the general population, mothers' preference for giving their children home-cooked food is widely reported amongst the literature but can be undermined by uncertainties around the practicalities of child feeding such as food safety, timing of food introduction and ideal food consistencies (Neve et al., 2024). Commercial child food products can offer many benefits for parents, such as convenience and time efficiency (Isaacs et al., 2022). However, many commercial child foods such as pouches and purees exceed recommended sugar intake levels and are commonly ultra-processed foods (Neve et al., 2024). Intake of ultra-processed foods has been linked to a variety of negative health outcomes such as inadequate dietary nutrient intake, increased energy intake and their consumption can negatively shape later taste preferences and eating habits (Childs and Sibson, 2023). For children with Down syndrome who are already more likely to have excess weight and experience health challenges (as set out in Chapter 1), this is particularly concerning.

In general, difficulties with food acceptance and chewing can have a limiting effect on the diet of children with Down syndrome, and this effect can be long lasting, even into adulthood (Canizares-Prado et al., 2022). This can have important implications for later child weight, making it more challenging for children to maintain a healthy weight, which is already a concern for children and adults with Down syndrome (Nordstrom et al., 2020). Although, evidence for this hypothesis is limited, and future research which assesses relationships between oral motor skills, food selectivity and preferences, dietary quality and weight throughout childhood and adulthood for people with Down syndrome would be valuable.

9.5 Interventions for feeding problems and weight

To effectively address the complex factors underlying feeding problems and weight in children with Down syndrome, an integrated approach to intervention is necessary. For example, applying a biopsychosocial case formulation approach (as outlined above) would allow for the development of holistic treatment plans which consider the broad system in which feeding problems develop and operate. As a result, this would address the unmet needs associated with separate, component-based care as reported in Chapters 2, 5, 7 and 8. Where interventions which aim to address feeding problems concentrate on individual components as opposed to wider dynamic processes and systems, interventions may be of limited utility for parents of children with Down syndrome. For example, Mother 12 recalls therapists frequently advising messy play with food to improve self-feeding skills, address picky eating and food refusal. However, she expresses frustration that her child still does not bring food to their mouth to eat it, and that this type of intervention is not effective. Her description of events also highlights the impact of the wider family context (e.g. financial considerations) and the role this can play within addressing problematic feeding and eating: "*He doesn't eat any snacks and I forever get told, 'put snacks in front of him, Mommy, and just let him play'. Okay, how much food am I supposed to waste here? I don't have a money tree for a child that*

is unwilling to eat or bring food to their mouth." (see Chapter 6). This highlights the necessity of holistic support relating to feeding problems for children with Down syndrome.

In support of this, Overland (2011) advocates for a sensory-motor approach to feeding therapy, asserting that oral sensitivity and oral-motor challenges are interconnected, and so it is necessary to address both in conjunction. Similarly, Aswathy et al., (2016) outline a multifaceted therapeutic approach to addressing oral sensory problems for autistic children, which includes several components such as oral motor exercise, oral sensory exercises, systematic desensitisation and progressively working through a food texture transition hierarchy. A need for routine screening for feeding and sensory processing challenges has already been established for young children with intellectual disabilities due to the interrelation between the two (Engel-Yeger et al., 2015), but it is not currently clear to what extent this happens in practice, or what support UK parents of young children with Down syndrome currently receive regarding oral-sensory challenges and eating. It is also not known whether interventions designed for other populations (e.g., autistic children) are effective for children with Down syndrome, or when the optimal period for early intervention may be. Essential further research is needed to establish this, and to guide better practice.

The findings of the mealtime observations (Chapter 5) and Time 2 parent interviews detailed in Chapter 6 indicate that another important area of concern for parents of children with Down syndrome is behavioural difficulties during mealtimes. In mealtime recordings children with Down syndrome were seen to throw food and utensils more often, and to demonstrate negative affect more frequently than TD children. During interviews, parents highlighted such behaviours as particularly difficult to manage, with some describing seeking support specifically to address this, and identifying it as a barrier to progressing their child's eating. In other research, parents of children with Down syndrome have reported using

distraction techniques, such as playing music or allowing screen time, to cope with challenging mealtime behaviours (Brantley et al., 2023). However, during the Time 2 interviews (Chapter 6), parents mentioned that they did not want to have to rely on screen time and distractions during mealtimes. As such, access to interventions which aim to address problematic mealtime behaviour is important for families of children with Down syndrome.

Family-centred positive behaviour support approaches have been shown to improve mealtime behaviours such as food refusal in children with other developmental disabilities (e.g. autism, Chu, 2012, McDowell et al., 2015). Currently, little research has explored the effectiveness of positive behaviour support for reducing challenging mealtime behaviours in children with Down syndrome, and this could be a valuable topic for future research.

Throughout this thesis, key time points also emerged in which the provision of interventions and feeding support are particularly important such as early initiation of breastfeeding, and introduction of complementary foods. Additionally, where children with Down syndrome experienced acute medical challenges in early life, they were more likely to be fed via NG tube, and mothers were less likely to meet their feeding goals (see Chapter 8). Understandably, feeding was not a priority during periods of acute illness, but a lack of support once baby's health started to improve often meant that feeding challenges and subsequent concerns about poor weight gain could persist (Edwards et al., 2015). For example, mothers worried about the efficacy and safety of their child's swallow, as a result of a period of NG tube feeding where baby was not required to do so. Existing research has shown that infants who are fed via NG tube can lose their swallowing skills even if they've previously developed them via oral feeding (Morris et al., 1989). Where concerns about swallow safety were not addressed, mothers approached feeding with caution and this made it challenging to progress their child's eating because they were worried about choking when

giving their child more challenging food textures. Furthermore, we found that recurrent periods of illness (e.g. respiratory infections) could set eating back significantly and mothers found it very difficult to overcome this. Evidently, where there are periods of acute illness, these are key time points in which intervention and feeding support is vitally important, in order to prevent the risk of long-term feeding challenges emerging as a result. Therefore, this should be factored into care plans but unfortunately, our findings suggest that this currently does not happen for mothers of children with Down syndrome.

9.6 Difficulties accessing quality feeding support

Early multidisciplinary intervention such as advice from speech and language therapists, as well as occupational therapists, is crucial for children with Down syndrome (Brantley et al., 2023). These interventions should aim to address and prevent oral motor delays as early as possible to promote the development of optimal chewing and biting skills. Additionally, early support which targets increasing food acceptance and addressing food-related sensory challenges in children with food selectivity is necessary. Such support would facilitate timely exposure to a variety of food tastes and textures, and consumption of a nutritionally balanced diet.

However, a common finding throughout this programme of research is the psychological and emotional difficulties that mothers face when there are challenges feeding their children with Down syndrome. This was reported regarding breastfeeding and early milk feeding (Chapter 7), NG tube feeding (Chapter 8), introducing first solid foods and food texture progression (Chapters 2 and 5). Where feeding and eating is not straightforward, mothers find feeding to be inescapable, unpredictable and overwhelming. It is clear that timely access to high quality support is imperative for this group. However, it was unfortunately observed throughout this

thesis that many mothers lack access to adequate support relating to feeding. Where intervention was available, it was frequently not available early enough. Early, holistic intervention is not consistently happening in reality for mothers of children with Down syndrome. This has been a common theme amongst the interview studies reported in Chapters 6, 7 and 8. Parents frequently lament the poor availability of services, long waitlists, and report that in some trusts NHS speech and language therapy services are only available after two years of age, which they feel is too late (Hielscher et al., 2022; Mengoni et al., 2023). This is problematic for eating, as it is recommended that solid foods are first introduced at six months old (WHO, 2024). This also has implications for promoting healthy weight outcomes, as in Chapter 5 it was seen that children with Down syndrome were more likely to be overweight than TD children, and that factors predicting weight outcomes were already in place by around two years of age.

Additionally, mothers repeatedly described a need for feeding information that is specific to the challenges faced by infants and children with Down syndrome, and they often found that health professionals could not provide what they needed. The need for Down syndrome-specific information about feeding was confirmed in Chapters 3 and 4, whereby significant and lasting differences in factors relating to feeding and weight were observed for children with Down syndrome compared to TD children.

Parents described accessing support services as a complex battle, but even when they are able to access support, appointments were not offered frequently or regularly enough to address the feeding challenges that mothers faced. Additionally, it was felt that there was an overreliance on virtual appointments since COVID-19, whereas mothers felt that they needed a health professional present in order to fully benefit from their support. Similarly, during Time 2 interviews mothers reported feeling that health professionals needed to observe their

child eating in-person in order to understand feeding challenges, and that phone consultations were not sufficient. There was a lack of person-centered, individualised care which left mothers with many unmet needs. Mothers tried to cope with these unmet needs by relying on online charities and peer-support groups, receiving support and advice from other parents of children with Down syndrome (Hielscher et al., 2022). Some had no choice but to seek out costly private healthcare in order to address their unmet needs where this could not be accessed via the NHS. A lack of adequate feeding support created and exacerbated significant caregiver stress.

9.6.1 Implications of financial disadvantages and inequalities in the context of feeding problems and weight

Throughout this thesis, a common underlying factor which was interlinked with feeding problems and weight was families' economic resources. Having a child with feeding problems came with challenging financial implications, but also access to financial resources impacted the types of support and resources they could utilise to address their child's problematic feeding.

Throughout all of the qualitative studies, mothers frequently described desperately buying multiple types of bottles, spoons, cups, high chairs and other equipment in the hopes that it may be the thing that finally helps their child's eating. Food waste was a common concern and meant that mothers sometimes found it costly to employ intervention strategies advised by health professionals like repeated offerings and messy play. This research highlights the difficult financial implications for parents when their child has feeding problems, and parents of children with Down syndrome may be disproportionately affected by this due to the increased incidence of feeding problems in this population. This is problematic because

evidence indicates that children with developmental disabilities are more likely to grow up in poverty than non-disabled peers (Blackburn et al., 2010; Shahtahmasebi et al., 2011).

It was also observed that mothers' access to financial resources could lead to better support and feeding outcomes. During interviews conducted to explore experiences of feeding support during COVID (Chapter 7), some mothers described seeking private lactation support, reflecting that for others who are unable to access this, they did not know how they could cope. Similarly, Mother 7 described that her child's eating progress was largely due to the short waiting lists and regular appointment frequency of private speech and language therapy and wider healthcare. Mother 4 (Chapter 8) remarked that had she not been able to afford a private nasogastric (NG) tube weaning programme, her child would likely still be reliant on an NG tube. These findings suggest that those who could afford private healthcare could offset the negative impact of poor access to NHS services. This aligns with existing research which has identified an association between economic deprivation and unmet early support needs for families of children with developmental disabilities in the UK (Sapiets et al., 2024).

9.7 Landscape of support services and recommendations for the future

The results of this programme of research emphasise the value of early intervention for mothers of children with Down syndrome, but that this was not always available is perhaps sadly unsurprising. This is set against a backdrop of severely underfunded early intervention, health and education services for children. Between 2010-11 and 2017-18 local authority spending on early intervention services for children and young people reduced by 49% across the UK, despite early intervention proving to be cost effective in the long term (Karoly et al.,

2005; Williams & Franklin, 2021). There is an urgent need for early, connected child services which are co-produced with families (Child of the North, 2023).

Currently, many child health and education services operate very separately. Hogg (2024) emphasises the potential value of connected health visiting and early education services, whereby health visitors and early years workers operate within a unified team. This approach offers many benefits to parents and ensures that children with additional needs receive joined up support in both their childcare setting, and their home (Hogg, 2024). A further benefit of this is that it facilitates better parental support during the establishment of Education, Health and Care Plans, which can be a difficult and stressful process for parents (Keville et al., 2024). This is consistent with comments made by Mother 11 in Chapter 6 who emphasised the value of having early years workers which would visit her child in their nursery. She commented that the joined up, holistic support received made her feel confident that her child was supported to have the best possible start in life.

Throughout this thesis, there are also some examples of positive experiences regarding support reported by mothers. The inconsistency of support access and quality was repeatedly seen throughout all qualitative studies and is reflective of a general postcode lottery regarding healthcare for UK parents of children with Down syndrome (Hielscher et al., 2022; Mengoni et al., 2023). Parents whose support needs were met frequently described themselves as ‘very lucky’. There are some NHS trusts and local authorities throughout the UK that have extensive care pathways in place for families of people with Down syndrome. For example, the Humber and North Yorkshire Health and Care Partnership (2023) offer a specific Down syndrome care pathway which has been co-produced with parents, carers, health professionals, people with Down syndrome, and charities that support families of people with Down syndrome. Within the plan, there are several elements which would address unmet

needs reported by mothers during our research. For example, parents are connected with a Down syndrome Champion Health Visitor very shortly after birth. Infant feeding co-ordinators are notified and linked in with the families' care as soon as possible. This could be during pregnancy if a high likelihood of Down syndrome is detected, or post-natally if the diagnosis was unexpected. This means that parents are educated about potential feeding challenges but supported to meet any breastfeeding goals as early as possible. We found that mothers struggled with a lack of informed support around breastfeeding and were devastated when this meant that their breastfeeding goals could not be met. They were unnecessarily given poor expectations of their child's feeding and found feeding problems very stressful. The provision of early education around feeding and specialist support, as well as the important impact of a Down syndrome Champion could prevent or help parents to manage the challenges described in these chapters, thus improving their care quality and feeding outcomes. Furthermore, throughout every step of the care pathway, from initial screening to post-birth, referrals to Down syndrome support charities are offered and specific Down syndrome related information and resources are provided. This pathway also dictates that parents must be supported to begin Education, Health and Care plans as soon as possible, and certainly before the child reaches two years of age. This means that children with Down syndrome should have an extensive multidisciplinary package of support available very early, within any pre-school childcare setting. This is important, because parents of children with special educational needs frequently report many challenges obtaining an EHCP and find it to be a very difficult and stressful process (Keville et al., 2024).

A further example of an existing Down syndrome care pathway is provided by Islington NHS trust (2024). A particularly relevant tenet of this pathway is that parents will be provided with early information about introducing solid foods to their child with Down syndrome, and challenges which may occur when the child is around four months of age. This early

education regarding solid foods addresses the need identified in Chapters 3, 4 and 8. Early information and education around challenges with solid foods can help parents to manage expectations, and to reduce distress when feeding problems do occur (Usman et al., 2023). During this programme of research, parents reported introducing solid foods and progressing food textures more cautiously due to anxieties around choking. However, early education around solid foods also provides opportunities for parents to seek support around such anxieties and could enable them to introduce varying solid food textures at an appropriate rate, thereby promoting eating development (Cochran et al., 2022; Hielscher et al., 2023).

A further important need identified throughout this thesis is access to mental health support for mothers of children with Down syndrome. This need is particularly important where there are feeding problems whether this is in relation to breastfeeding and milk feeding, fears around weight loss, managing NG tube feeding outside of hospital, or around the introduction of solid foods and texture progression (as seen in Chapters 2, 3, 4, 8). The need for encouragement and support to persevere with difficulties around feeding was frequently observed. Where there were challenges relating to feeding and eating, or organising care relating to this, mothers' mental wellbeing was significantly impacted. It is important that mothers receive adequate emotional support, but for many participants in this programme of research, this was not accounted for in their care. Family centred care pathways offer provision for this. For example, the Humber and North Yorkshire Health and Care Partnership (2023) Down syndrome care pathway includes access to a community team which offer psychology services for people with learning disabilities and their families/carers. Support available includes access to talking therapies, help with anxiety management and mood problems.

Given that extensive co-produced care pathways exist within specific trusts and local authorities throughout the UK, it is disappointing that such provision is not available more

widely in the UK (as reported by mothers in Chapters 6, 7 and 8). There already exists a blueprint of what 'good' care looks like, but access to this is inconsistent throughout the Down syndrome community, and many are left without necessary support. The Down Syndrome Act (2022) offers some hope in addressing this. The Act seeks to establish universal guidance from the Department of Health and Social Care for how local authorities can better meet the needs of people with Down syndrome and their families. It is hoped that the act will reduce health inequalities and improve access to healthcare support services throughout the UK (Department of Health and Social Care, 2022). Following a call for evidence, guidance is still being developed at present, but this provides cause for optimism for future feeding support and health outcomes for children with Down syndrome and their families.

9.8 Strengths and limitations

A strength of this programme of research is that it strives to place the voice and priorities of mothers of children with Down syndrome, and the wider Down syndrome community, at its heart. Existing research which has explored feeding for children with Down syndrome is relatively sparse compared to other populations e.g. autistic children. What does exist more frequently focusses on breastfeeding or weight only, rather than the broader feeding journey throughout the early years which is explored in this thesis. This was highlighted by the small number of studies which were eligible for inclusion in the scoping review undertaken in Chapter 2. Within the existing small pool of research, a large proportion of this is quantitative research which on its own does not illuminate the lived experience of this community (Cartwright and Boath, 2018). The qualitative studies undertaken within this thesis aimed to give a voice to a community which frequently describes feeling unheard, to shed light on the barriers they face, and the impact unmet needs have on the lives of the individuals and their families. Effort was taken to engage with the Down syndrome community in order to

understand their priorities and factor this into the design of the studies and research materials within this research. This included attending local Down syndrome support groups, consulting with key charities such as Positive About Down Syndrome and the Downs Syndrome Association, and also attending an international meeting of healthcare professionals with specific expertise in supporting families of people with Down syndrome (the Down Syndrome Medical Interest Group). This required a willingness to listen and understand, which may have contributed to the generous honesty and vulnerability shared by mothers in the qualitative chapters of this thesis, and the 98% participant retention rate seen in the longitudinal study outlined in Chapters 3 and 4.

Whilst opportunities were taken to consult with the Down syndrome community regarding this programme of research, this could be taken further in future by co-producing research with people with Down syndrome and their families. The interview study which explored experiences of NG tube feeding (Chapter 8) was specifically added as a result of concerns expressed by people with lived experience, in an attempt to respond to the needs of the community. As such, this study was designed in consultation with the charity Positive About Down Syndrome. Representatives from Positive About Down Syndrome expressed concerns about high usage rates of NG feeding tubes for infants with Down syndrome and a lack of support to move children away from tube feeding and towards oral eating once tubes were in situ. The charity and the parents they represented shared concerns that NG tube use may be having negative impacts on eating, speech and language development. Given the lack of existing research on this particular topic, the interview study outlined in Chapter 8 aimed to respond to these concerns by exploring parental experiences of NG tube use, as well as support needs. However, this approach could be built upon in future. Directly including the voices of people with Down syndrome would facilitate the design of research that reflects what they feel is important about food and eating.

Additionally, many of the studies reported within this thesis reflected on the impact of health professionals on the care of families of children with Down syndrome, but the voices of health professionals were not included. The inclusion of health professionals that support families of children with Down syndrome, either as research participants or via co-production would strengthen this programme of research. Recent examples of work which has done this (Cochran et al., 2022; Mengoni et al., 2023) highlight challenges faced by health professionals, and offer a nuanced perspective on the care of families of children with Down syndrome.

Furthermore, across the studies within this thesis, all participants were mothers, meaning that study findings are not necessarily applicable to fathers of children with Down syndrome. Whilst this is a relatively common phenomenon within child feeding research (Docherty and Dimond, 2018; Mengoni et al., 2023), this is problematic as a growing body of literature indicates that fathers play an influential role in the development of child eating behaviours (Litchfield et al., 2020). For example, paternal feeding styles have been shown to moderate relationships between child eating behaviours and child BMI (Vollmer et al., 2015). Existing research also indicates that fathers display different mealtime behaviours in relation to fussy eating compared to mothers, use more pressuring feeding practices and are less likely to monitor child food intake than mothers (Khandpur et al., 2014). Fathers' presence at mealtimes can also potentially impact mothers' feeding practices (Haycraft and Blissett, 2008). A qualitative metasynthesis conducted by Campbell et al., (2022) identified a lack of collaboration between mothers and fathers during mothers' attempts to improve the dietary quality of their children by offering new or healthier foods at mealtimes. Where fathers are resistant to mothers' attempts, mothers report being more likely to avoid trying to improve child dietary quality in future (Campbell et al., 2022). To address this limitation, future

studies should specifically aim to recruit both mothers and fathers to research about child feeding. Additionally, future research could include questions about the division of child feeding responsibilities within the household, and mothers could be asked to reflect on the impact of fathers on their own feeding practices, child eating behaviours and family mealtime experiences. This would provide some contextual information about parent feeding even in cases where fathers are less represented within the participant sample.

9.9 Conclusions

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For children with Down syndrome, feeding problems and weight are often influenced by a complex mix of factors, including food texture sensitivity, underlying health issues, motor delays, sensory problems, child eating behaviours, and parental feeding practices. Feeding and eating behaviours should be a routine part of developmental assessments for young children with Down syndrome, as if early feeding challenges are not addressed, secondary problems (e.g. oral aversions) can develop. As such, there is a critical need for early, holistic and integrated interventions related to feeding, eating and weight. Mothers require access to specialists with expertise in Down syndrome, and support should be provided proactively and continuously, particularly at crux points in feeding journeys e.g. early initiation of breastfeeding and introduction of complementary foods. Currently, mothers of children with Down syndrome face several barriers accessing support and addressing feeding problems, which can cause significant distress. Child healthcare plans must be family-centred and include provision of mental health support for mothers of children with Down syndrome who are experiencing feeding problems. The findings of this programme of research suggest a need for policy changes and increased funding to support early intervention programmes, promote consistency of feeding support quality and reduce the current postcode lottery faced by families of children with Down syndrome across the UK.

9.10 Future directions

Moving forwards, research priorities should include longitudinal studies which track the impact of feeding problems on developmental outcomes, diet and weight into adulthood. There is also a need for further research that explores which interventions are effective for children with Down syndrome who experience feeding problems, and when critical periods for intervention are. Additionally, the financial implications of feeding problems for families of children with Down syndrome should be explored further. Specifically, the impact of socioeconomic status on access to care, intervention effectiveness and long-term outcomes should be studied. This could highlight disparities in care and inform policies aimed at making interventions more accessible to underprivileged groups.

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Appendices

***Appendix A**: The adapted mealtime coding scheme used in Chapter 5.*

Code	Description
Child behaviour	
Reject	Instances where the child rejected food or drink offered (either verbal or physical refusal).
Negative affect	Display of negative emotions or behaviours during mealtime, such as frustration, anger or distress.
Drink	When the child drank from a cup, bottle, or any other drinking utensil.
Self-feed	When the child independently fed themselves without assistance from the caregiver.
Use utensils	When the child used utensils (e.g., fork, spoon) to take bites of food.
Throw	Instances of throwing food, utensils, or cups during the mealtime.
Tongue thrust	Noting when the child displayed tongue protrusion during the mealtime.
Coughing/choking	Instances of coughing or choking during the meal, which could signal feeding problems or unsafe eating behaviour.
Parent behaviour	
Instruction	General instructions given by the caregiver, such as “sit down” or “eat nicely.”
Offer (verbal or physical)	Specific offers of food or drink by the caregiver, either verbal or physical (e.g., “Would you like some apple?” or physically offering food).

The original coding scheme used by van Dijk and Lipke-Steenbeek (2018**):**

Taken from van Dijk, M., & Lipke-Steenbeek, W. (2018). Measuring feeding difficulties in toddlers with Down syndrome. *Appetite*, *126*, 61–65.

https://doi.org/10.1016/j.appet.2018.03.018

Coding scheme used for the quantification of feeding and interaction behavior.

Eating and feeding
G: Give (event): caregiver brings food towards the mouth of the child ('Cleaning' is not seen as a Give, only when the food is subsequently put into the mouth.) **A:** Accept (event): food goes into the mouth **X:** Refuse (event): child refuses usually by not opening the mouth (Note: all Gives that are not accepted are refused.) **S:** Self-feeding (event): each action by the child to bring food into the mouth (If a child is chewing on a larger piece of food, each action of bringing the food *into* the mouth is coded separately.) **T:** Tongue protrusion (event): each time the tongue visibly pushes food out of the mouth.
Interaction behavior
I: Instructions caregiver (event): all parental verbal interaction that tells the child to eat (e.g. "have a bite"), the tone does not matter (includes coaxing and giving directives) **N:** negative affect infant (event): all instances of starting to cry, whine or fuss, choking, rough physical behavior by the infant (includes pushing away or pulling spoon)

Appendix B: *Interview Schedule (Semi-Structured)- Longitudinal predictors of feeding problems and weight for children with Down syndrome- Time 2 interviews*

Introduction:

- Revisit information contained within the Participant Information Sheet.
- Give participant time to ask any questions.
- Review aim of the interview- to understand feeding experience and how parents perceive feeding problems, potential determining factors, consequences and support needed.
- Highlight that some questions may seem similar to those in the questionnaires
- Encourage participant to be as open as they feel comfortable being when answering questions.
- Advise that I may be relatively quiet throughout the interview and this is because I am trying to listen and understand the participant's views.
- Encourage participant to take time to pause and think where required.

Questions:

1. **Can you start by telling me a little bit about your family?**
- How old is (name of child)?
- Who lives with them?
- Do they have any siblings?
- If so, how old are they?

2. **When you were pregnant, how did you plan on feeding (name of child) milk?**
E.g. breast, expressing, formula, combi-feeding.
- Did your feeding plan change once you knew (name of child) had Down syndrome? (for group with Down syndrome)
- Were you told about the Down syndrome pre or post-natally? (for group with Down syndrome)

3. **Can you tell me a bit more about how milk feeding went for you?**
- How did you find it?
- Were there any difficulties at all?
- Did you need any feeding support during this period?
- Were you able to access this if so?

4. **Could you tell me about when you started to introduce (name of child) to solid food?**
- How old was (name of child)?
- What method of weaning did you use? *(e.g. traditional weaning methods, baby led weaning, a combination).*
- How prepared did you feel to start introducing solid foods?
- Did you have any worries or concerns before introducing solid foods to (name of child)?
- What kind of foods did you start with when you started introducing solids to (name of child)?
- What went well?
- What did you enjoy about this process?
- Were there any difficulties regarding the introduction of solid food?
- Did (name of child) experience any preferences regarding flavours when introducing solids?
- Did (name of child) experience any preferences regarding texture when introducing solids?
- Does (name of child) experience any preferences or problems with flavour or texture of foods now? If yes, what type of preferences/problems, how do you manage this?
- What type of drinks does your child have?
- Has your child had any issues regarding drinking?
- If problems with eating/drinking are reported, then prompt regarding type of problems and any potential causes/contributors e.g. muscle tone, oral motor skills, gross/fine motor skills, sensory issues

- What helped with introducing solid food? E.g. modelling food (parent/sibling), type of food, method of weaning, support, particular cutlery, equipment

5. **What support have you received regarding introduction of solid foods to (name of child), if any?**

- Did this meet your needs?
- How easy was it to access feeding support?
- Where did you find feeding support?
- How do you feel about the support received?
- Were there any situations where you would have liked more information or support with feeding?
- If so, what would you have liked?

6. **What has feeding/mealtimes been like since moving (name of child) onto solid foods?**

- How do you feel about feeding and mealtimes now?

Debrief:

- Thank the participant for their time.
- Ensure wellbeing- ask how participant found the interview and how they're feeling now.
- Describe what will happen to results.
- Advise that participant can contact me with any further questions and that contact details will be listed on the debrief sheet which will be emailed.
- Ask whether participant would be interested in being contacted about the findings of the study or participation in future studies in a similar research area. If yes, send additional consent form along with debrief sheet.

Appendix C: *Questionnaire for local infant feeding support services- Hospital and Community Services*

This survey aims to explore how infant feeding support services have changed as a result of the COVID-19 pandemic and subsequent lockdowns. Please answer all questions that apply.

1. **Have any feeding support services been stopped during the pandemic?**
   If yes, what services were stopped and between what dates were they stopped?
   If yes, was any feedback received from staff or service users about the services that had been stopped? Please provide details of feedback received.
   If yes, were service users signposted to other services or charities where they could access this type of support? Please provide details.

2. **Have any feeding support services been reduced during the pandemic (e.g. no new referrals being made but service still running)?**
   If yes, what services were reduced and between what dates were they reduced?
   If yes, was any feedback received from staff or service users about the services that had been reduced? Please provide details of feedback received.
   If yes, were service users signposted to other services or charities where they could access this type of support? Please provide details.

3. **Have any feeding support services been increased during the pandemic?**
   If yes, what services increased and between what dates were they increased?
   If yes, was any feedback received from staff or service users about the services that were increased? Please provide details of feedback received.

4. **Have any new feeding support services been introduced during the pandemic?**
   If yes, what services were introduced and between what dates did they go ahead?
   If yes, will these services continue to be offered post-pandemic?
   If yes, was any feedback received from staff or service users about the new services that were introduced? Please provide details of feedback received.

5. **Have any face to face appointments still gone ahead during the pandemic?**
   If these were stopped, when did they stop and when did they resume?
   If these were reduced, during what time period was appointment availability reduced?
   If these were reduced, under what circumstances would face to face appointments have been offered?
   Were any changes made to how face to face appointments were carried out e.g. only one parent allowed to attend appointment? If yes, please provide details of changes.
   Did the way service users arrange accessing face to face support change? For example, from drop-in sessions to pre-bookable one to one appointments? If yes, please provide details of changes.

6. **Has there been a change to delivery of individual appointments during the pandemic? (e.g. from face to face to virtual, over the phone, in patient's home)**
   If yes, how were they previously delivered and how has this changed?

7. **Have group breastfeeding support clinics still gone ahead?**
   Have these been delivered in a different way during the pandemic? Please provide details of how they were previously delivered and how this has changed?
   Were service users required to book attendance in advance before the pandemic?

Will service users be required to book attendance in advance post-pandemic?

8. Have Introducing Solids sessions been running during the pandemic?

If these where stopped, during what period were they stopped?

If yes, in what format were these sessions delivered? E.g. virtually, face to face.

Is this different to pre-pandemic and if so, how?

If no, how did parents get information on breastfeeding and introducing solids during the pandemic?

9. Have any staff been redeployed elsewhere during the pandemic?

If yes, how has this affected feeding support available to service users?

10. Has the capacity of your service changed during the pandemic? E.g. Has the number of appointments available changed throughout the pandemic?

If yes, in what way was capacity different?

If yes, during what period was capacity different?

11. Has the quality of feeding support the service is able to deliver changed during the pandemic? If yes, please provide details.

If yes, was any feedback received from staff or service users about the quality of services during the pandemic? Please provide details of feedback received.

12. Please use this space to provide any other comments you think may be relevant.

***Appendix D**: Interview Schedule (Semi-Structured)- The experiences of new mothers accessing feeding support for infants with Down syndrome during the COVID-19 pandemic.*

Introduction:

- Revisit information contained within the Participant Information Sheet.
- Give participant time to ask any questions.
- Review aim of the interview- to gain an in-depth understanding of participants' experience of feeding support services during the COVID-19 pandemic.
- Explain that I am interested in exploring subjective thoughts, feelings, perceptions and reflections.
- Encourage participant to be as open as they feel comfortable being when answering questions.
- Advise that I may be relatively quiet throughout the interview and this is because I am trying to listen and understand the participant's views.
- Encourage participant to take time to pause and think where required.

Questions:

1. **Can you describe your experience of feeding your baby shortly after birth?**

- How long did you stay in hospital after giving birth?
- Was baby with you, or did baby have to stay on the NICU (Neonatal Intensive Care Unit)?
- Did you experience any challenges feeding your baby?
- What were these challenges?
- How long did you experience these challenges?
- (if yes) how supported did you feel in overcoming these challenges?
- Did baby need an NGT at all?

2. **Can you describe the support you received with feeding your baby whilst in hospital?**

- How supported did you feel in overcoming the challenges you faced with feeding whilst in hospital?
- What other support would you have liked to receive?

3. **Can you tell me what it was like feeding your baby once you left hospital?**

- Did you encounter any problems or challenges?
- What challenges or problems did you face?
- When did these begin?
- How long did these problems last?
- *If relevant- were thickeners used?*

4. **Can you tell me about your experience finding support with feeding after you left hospital?**

- Did you face any challenges when trying to find support?
- Where did you look for support with feeding?
- Who did you contact for support with feeding?

5. **Can you tell me about the support you received with feeding your child?**
- In what format was feeding support delivered to you?
- How does this compare to any feeding support accessed before lockdown?
- Did you feel like your needs were fully met?
- (if no) What do you feel was missing?
- What other support would you have liked to receive?

6. **Can you tell me how able you felt to fully communicate your needs and concerns to health care professionals?**
- Did you feel that your needs were understood by health care professionals?
- Did this differ according to which health professional you spoke to?
- How? Why?
- What impact do you feel this had on you?
- Did you change the way you fed your baby as a result of the support you received or didn't receive?
- In what way did you change the way you fed your baby? (Method or duration?)
- Did you *want* to change the way you fed your baby?
- (if no) did changing the way you fed your baby affect you? How?

7. **Can you tell me how you think lockdown has impacted your experience of feeding your child?**
- How in control of feeding choices did you feel?
- Method of feeding in line with initial plans/wishes?
- Has lockdown impacted your experience of feeding your child in any positive ways?

8. **Can you tell me how you think lockdown has affected the quality of feeding support available to mothers of children with Down syndrome?**

Debrief:

- Thank the participant for their time.
- Ensure wellbeing- ask how participant found the interview and how they're feeling now.
- Describe what will happen to results.
- Advise that participant can contact me with any further questions and that contact details will be listed on the debrief sheet which will be sent virtually.
- Ask whether participant would be interested in being contacted about participation in future studies in a similar research area. If yes, send additional consent form along with debrief sheet.

Appendix E: *Interview Schedule (Semi-Structured): Parental experiences of nasogastric tube feeding for young children with Down syndrome*

Introduction:

- Revisit information contained within the Participant Information Sheet.
- Give participant time to ask any questions.
- Review aim of the interview- to gain an in-depth understanding of participants' experience around NG tube use for their child.
- Explain that I am interested in exploring subjective thoughts, feelings, perceptions and reflections.
- Encourage participant to be as open as they feel comfortable being when answering questions.
- Advise that I may be relatively quiet throughout the interview and this is because I am trying to listen and understand the participant's views.
- Encourage participant to take time to pause and think where required.

Interview Questions:

9. Can you tell me about your child's feeding shortly after birth?
- How long did your child stay in hospital after birth?
- Did your child have any health complications shortly after birth?
- How did you initially plan to feed your child?
- Did you experience any challenges feeding your child?
- What were these challenges?
- How long did you experience these challenges?
- (if yes) how supported did you feel in overcoming these challenges?

10. Can you tell me about when the NG tube was first introduced?
- What led to the NG tube being necessary?
- What was the decision-making process like when the tube was first introduced? And who was involved in this process?
- Were alternatives to an NG tube discussed with you? (e.g. G-tube/PEG/waiting and monitoring)
- Did you have any concerns about the use of the NG tube?
- Do you feel that your thoughts and concerns were heard and listened to during the decision-making process?
- How informed did you feel about the decision to use an NG tube?
- Were any other interventions attempted before the decision was made to use the tube?
- How did you feel when the NG tube was introduced?
- Were you given any indication about how long the tube may be used for/ under what circumstances it may be able to be removed?
- Were you given any information about when the decision to use the tube will be reviewed?
- Was the feeding tube used for one period of time, or multiple periods?

11. What was it like for you during the time that your child was fed via NG tube?
- Did you encounter any challenges using the NG tube?
- (if applicable) How supported were you to overcome these challenges?
- (if applicable) where did this support come from?
- Were you encouraged to attempt any oral feeds during the time that your child was using the NG tube?

- (If yes) how did you do this?
- (if yes) how supported did you feel with this?
- (if applicable) Were you encouraged to express breastmilk during the period that your child was fed via NG tube?
- (if yes) How supported did you feel with this?
- Do you think the use of the tube had any impact on family life?
- Do you feel that there was any impact on your emotional or mental wellbeing during this time?

12. Can you tell me about when the decision to remove the NG tube was made (if appropriate)?
- How often was the decision to use or remove the NG tube reviewed? And who was involved in this process?
- Was there a plan in place to work towards tube removal?
- Were you supported to work towards being able to remove the tube?
- Who was involved in the decision to remove the tube?
- Who was involved in your child's care during this time? E.g. paediatrician, SLT, dietician, OT etc.

13. How did you feel when the NG tube was removed (if appropriate)?
- How informed did you feel about feeding after its' removal?
- Did you have any worries/concerns around the removal of the tube?
- How able to express your concerns did you feel?
- Is there any support you didn't have that you would have liked at the time?

14. Can you tell me about your child's feeding after the removal of the tube (if appropriate)?
- How did you plan to feed your child after the tube was removed?
- Did you experience any challenges feeding your child after the tube was removed?
- (if yes) how supported did you feel in overcoming these challenges?
- Where did you look for support?

15. What were your initial expectations around tube feeding?
- Were your expectations met?
- Did tube feeding differ from what you expected in any way?
- Was there anything about your experience with tube feeding that surprised you?

16. Can you tell me about how your child eats now?
- Have you introduced solid foods?
- (if yes) At what age did you first introduce solid foods?
- (if yes) How did you find this process?
- Did you experience any challenges introducing solid foods to your child?
- Did you seek any advice/support regarding introducing solid foods to your child?
- Does your child have any issues with eating at the moment? *E.g. difficulties with texture, food fussiness, chewing, swallowing.*
- Does your child have any issues with drinking at the moment?
- (if yes) Have you sought support for any issues with your child's eating or drinking?
- (if yes) what support did you receive?
- Did the support you receive meet your needs?

17. **Do you think that the NG tube impacted your child's feeding development in any way?**
- Do you have any concerns about this?
- Are you currently/have you previously been supported to address these concerns?

18. **Do you think that the NG tube impacted your child's speech and language development in any way?**
- Do you have any concerns about this?
- Are you currently/have you previously been supported to address these concerns?
- Can you tell me about any input you have had from speech and language therapists? E.g. safe swallow assessment, support with encouraging oral-motor skill development.
- Is there any specific support you would have liked to receive (or would like to receive in future) regarding speech and language?

Debrief:

- Thank the participant for their time.
- Ensure wellbeing- ask how participant found the interview and how they're feeling now.
- Describe what will happen to results.
- Advise that participant can contact me with any further questions and that contact details will be listed on the debrief sheet which will be sent virtually.
- Ask whether participant would be interested in being contacted about participation in future studies in a similar research area. If yes, send additional consent form along with debrief sheet.