

DOES PLANNING REALLY MATTER: THE IMPACT OF FOOD ALLERGY  
MANAGEMENT SYSTEMS IN EDUCATIONAL SETTINGS

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Doctor of Psychology

by  
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This dissertation by Nicole Thompson has been approved by the committee members, who recommend that it be accepted by the faculty of John F. Kennedy University, Pleasant Hill, California, in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

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## ABSTRACT

### DOES PLANNING REALLY MATTER: THE IMPACT OF FOOD ALLERGY MANAGEMENT SYSTEMS IN EDUCATIONAL SETTINGS

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There are 17 million people in the United States with a food allergy. Schools are not required to train faculty, staff, or students on food allergy safety, nor are they required to provide the lifesaving Epinephrine auto-injectors. There is no minimum food allergy standard concerning school meals or rules identifying a point person to be responsible for monitoring school cafeterias preparation and distribution of school meals; cleaning procedures; and avoiding cross contamination. There is little research on managing food allergies at schools. This dissertation reports data on current public and private school policies related to food allergies and their psychological impact on social development. Participants share effective strategies to maintaining the safety of students with food allergies and discuss the benefits and drawbacks associated with current standardized policies.

KEYWORDS: “Food Allergy”, “Quantitative Research”, “School”, “Policy”, “Management”

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## Table of Contents

	Page
Chapter I – Introduction.....	1
Rationale for the Study .....	3
Chapter II – Literature Review .....	5
Implications of Living with a Food Allergy .....	5
Demographic trends.....	5
Understanding food allergies.....	6
Physical implications.....	6
Financial implications.....	8
Parental Experience of having a Child with a Food Allergy .....	9
Spectrum of parental vigilance.....	12
Food Allergy Management at Different Stages of Development .....	14
Quality of life.....	17
Gender difference.....	18
Bullying.....	19
Food Allergy Policy and Procedures .....	20
Food Allergy Trends, Reactions, and Management in Schools.....	22
Food allergy training for nurses and school personnel.....	22
School lunch.....	24
Food allergy reactions and treatment in schools.....	25
Socioeconomic disparities in food allergy management.....	28
Food allergy policies and management plans.....	29

Chapter III – Methods.....	32
Choice of Method .....	32
Participants.....	32
Recruitment.....	33
Instruments.....	33
Data Collection .....	33
Data Analysis.....	34
Data Clearing Phase.....	34
Data Reduction.....	35
Chapter IV – Results.....	37
Demographic Characteristics of the Sample.....	37
Reliability.....	40
Notification .....	40
Qualitative responses to notification.....	41
Program Quality.....	42
Training.....	42
Qualitative responses to schools level of training.....	43
Policies to ensure safety.....	44
Qualitative responses to policies to ensure safety.....	47
Cross contamination.....	48
Qualitative responses to cross contamination.....	49
Medication.....	50
Qualitative responses to medication policy.....	52



Policy satisfaction.....	53
Relational Quality.....	55
Social exclusion.....	55
Parents qualitative responses to social exclusion.....	56
Knowledge.....	57
Parents' qualitative responses to lack of food allergy knowledge.....	58
Chapter V – Discussion.....	60
Policies to Ensure Safety.....	61
Cultural Demographics.....	63
Social Exclusion.....	65
Discrimination.....	66
Food Allergy Education.....	67
Resources for parents.....	68
Summary.....	68
Clinical and Systemic Implications.....	69
Limitations.....	72
Future Directions.....	73
References.....	76
Appendix A – Recruitment Social Media Post.....	89
Appendix B – Consent Form.....	90
Appendix C – Demographic Questionnaire.....	91
Appendix D – Parent Food Allergy Survey.....	94
Appendix E – Questions Loaded on Four Main Themes.....	106

## List of Figures

	Page
Figure 1. Illustrates the percentage of participants in each annual family income bracket .....	38
Figure 2. Illustrates the top eight reported food allergies .....	39
Figure 3. Illustrates the grade of the child with the food allergy .....	39
Figure 4. Individuals at the school who were notified of the student's food allergy.....	41
Figure 5. Percentages of school personnel that received food allergy training. ....	42
Figure 6. Percentage of types of meetings to discuss food allergy management.....	43
Figure 7. Percentage and types of food allergy management plans.....	44
Figure 8. Types of safety questions about food allergies during school registration .....	45
Figure 9. School food allergy policies. ....	46
Figure 10. Policies around food allergies within the classroom .....	47
Figure 11. Parents' perceived safety throughout the school day .....	48
Figure 12. Location of medication storage .....	51
Figure 13. Individuals responsible for administering medication during a food allergy reaction	52
Figure 14. Parents' satisfaction with school medication policies and procedures.....	54
Figure 15. Parents' rate of satisfaction with school policies regarding food allergies .....	54
Figure 16. Discrimination related to food allergies experienced by parents and their children ...	56
Figure 17. Highest and lowest food allergy knowledge scores as reported by parents .....	58
Figure 18. Program quality compared to parent's satisfaction with the policy .....	62

## Chapter I

### Introduction

Food allergies impact 8% of children in the United States (Gupta et al., 2011). While food allergies are a legally protected disability under the Americans with Disabilities Act (Sicherer & Mahr, 2010), and there are numerous free educational materials and food allergy management guidelines for schools (American Academy of Allergy, Asthma, and Immunology, 2010; Centers for Disease Control, 2013; Food Allergy Research & Education [FARE], 2017), studies show schools continue to be inconsistent in their approach and management of students with food allergies (Ercan, Ozen, Karatepe, Berber, & Cengizlier, 2012; Nowak-Wegrzyn, Conover-Walker, & Wood, 2001; Powers, Bergen, & Finnegan, 2007). As a result of this inconsistency, students with food allergies and their families experience a range of both emotional and potentially life-threatening experiences (Parnell, Schnur, & Green, 2016). Rates of bullying (Berendsen, 2015) and anxiety (Marks, 2017) are reported at higher rates in students with food allergies and as a result of poor school responses. Therefore, dissecting school policies and understanding parental perceptions of school responses to food allergy management policies needs greater attention by the field of psychology.

A food allergy occurs in individuals that have an adverse immune response to a specific food or food component (FARE, 2017). The adverse reactions can be mild, such as an itch in the mouth; or as severe as an anaphylactic reaction after skin contact, inhalation, or ingestion. A life-threatening food allergy is a food allergy that has been diagnosed by a physician for which epinephrine has been prescribed, to be administered in the event of an anaphylactic reaction (FARE, 2017). Epi-pen is one common brand of epinephrine auto injector prescribed to treat life threatening food allergies.

According to Food Allergy Research and Education (FARE; 2016), approximately fifteen million individuals in the United States have a food allergy. In addition, per the European Academy of Allergy and Clinical Immunology, seventeen million Europeans have a food allergy (as cited in FARE, 2016). The prevalence of food allergies in developing countries is as high as 10% (Prescott et al., 2013). Food allergies can hinder a child's daily activities (such as attending school), negatively impact their physical and psychological well-being, and decrease their quality of life (Bacal, 2013; Baiardini, Braido, Brandi, & Canonica, 2006).

Allergic reaction manifestations vary depending upon the organ or system they affect; some of the most severe reactions will affect multiple systems and result in death if not treated (Butt & MacDougall, 2008; Ebisawa, 2013). Food allergy-induced anaphylaxis results in approximately 200,000 emergency department visits, and 150 to 200 deaths per year (Avery, King, Knight, & Hourihane, 2003; FARE, 2016; Gupta et al., 2011). In fact, 16% to 18% of all children with food allergies had an allergic reaction while on a school campus (Young, Munoz-Furlong, & Sicherer, 2009).

With such a high prevalence of food allergies among children, it is important to monitor the management of food allergies in schools where children spend the majority of their days. According to previous studies (e.g., Sicherer, Furlong, DeSimone, & Sampson, 2001; Young et al., 2009), approximately 16% to 18% of all children with food allergies had an allergic reaction while on campus and 25% of children experienced their first reaction at school. Food allergy management in schools is handled differently among the states and have different labels, including but not limited to: food allergy management plan, 504 plan, IEP, health management plan, and food allergy emergency plan. Although there are federal guidelines, food allergy management within and among states is inconsistent. Prescott et al. (2013) conducted a global

survey and found “inequities in pediatric allergy services, availability of adrenaline auto-injectors and standardized National Anaphylaxis Action plans” (p.21). This further highlights the failure of systems of care to successfully address the needs of children with food allergies.

### **Rationale for the Study**

As a result of the limited research and the fact food allergies exist worldwide and cause significant psychological distress (Broom-Stone, 2012; Cummings, Knibb, King, & Lucas, 2010; Parnell et al., 2016), additional research is warranted. Research needs to understand the relationship between identifying distress and outside school environments (Parnell et al., 2016). School staff and administrators continue to be unaware of children’s food allergy needs (Parnell et al., 2016). Also, there is limited food allergy training for school personnel (Parnell et al., 2016). There are various national, state and private organizations guidelines for food allergy management in schools. However, food allergy management plans are not consistently created or followed, and some plans that are created do not meet Food Allergy and Anaphylaxis Network (FAAN) guidelines (Ercan et al., 2012; Nowak-Wegrzyn et al., 2001; Parnell et al., 2016; Powers et al., 2007).

Training school personnel and following FAAN allergy management plans may help reduce psychological distress of parents and children while at school (Parnell et al., 2016). Parents, not government policy, were the reason food allergy guidelines were implemented in schools (Lawlis, Bakonyi, & Williams, 2017). Parents’ perspectives of food allergy management in schools have been underrepresented (Parnell et al., 2016). Although research has shown food allergy management plans are not consistently implemented, there is limited research on the personal consequences to children with food allergies and their families.

Based on the prior research and discrepancies associated with implementation of food allergy plans, the present study sought to obtain a comprehensive understanding of the parents' experience of managing a food allergy, and identify current policies in the 2015-2016 school year. Specifically, this research examined the following areas:

1. To determine if states with food allergy management guidelines provided more food allergy management plans as compared to states without food allergy guidelines.
2. To determine the amount of food allergy management plans and 504 plans provided in schools.
3. To identify if family income was correlated with receiving a food allergy management plan and the amount of time to implement the plan.
4. To identify current food allergy school policies.
5. To identify parents' satisfaction with food allergy school policy.
6. To describe parents' experiences of managing their child's food allergy at school.

It is believed that understanding parental experiences of food allergies provides a framework to determine future actions steps for psychology and educational systems to take in providing effective services to children with food allergies. The experiences and insights provided from the participants may enable future development of resources and support that works for families with food allergies. This knowledge is also crucial for medical professionals, educational systems, mental health clinics, and other facilities serving families with food allergies.

## Chapter II

### Literature Review

#### Implications of Living with a Food Allergy

**Demographic trends.** Food allergies are a growing global health problem, especially for children (Ebisawa, 2013). In the United States, an estimated nine million adults (4%) and six million children (8%) have food allergies (Gupta et al., 2011). Additionally, 30.4% have multiple food allergies (Dyer & Gupta, 2013; Gupta et al., 2011). According to the Center for Disease Control and Prevention, between 1997 and 2011, the rate of food allergies in children rose 50% (Jackson, Howie, & Akinbami, 2013). Surprisingly, children from high-income families had higher rates of food allergies when compared to children from families below the poverty line (Jackson et al., 2013). There are currently no treatments or cure for food allergies. Food allergy management includes avoiding the allergen and treatment of symptoms, which is particularly important in schools where 16% to 18% of children had an allergic reaction, and 25% of these reactions were of people with an undiagnosed food allergy (Gupta et al., 2012; McIntyre, Sheetz, Carroll, & Young, 2005; Sicherer et al., 2001).

The most common food allergies in order of prevalence are: 25.2% peanut, 21.1% milk, 17.2% shellfish, 13.1% tree nut, 9.8% egg, 6.2% fin fish, 5% wheat, and 4.6% soy (Gupta et al., 2011). The prevalence of food allergies varies across geographic region when potential confounding variables, such as ethnicity, socioeconomic status, and latitude, were controlled (Gupta et al., 2012). According to Gupta et al. (2012), food allergies are 3.4% higher in urban areas than rural areas. There are several states where there is a food allergy prevalence of 9.5% or higher including: Alaska, Delaware, Florida, Georgia, Maryland, Nevada, and New Jersey. The states with the second highest prevalence of food allergies, 8.1% to 9.5%, are California,

Oregon, Texas, Arkansas, Louisiana, Mississippi, Alabama, Tennessee, North Carolina, New York, Maine, and the Hawaiian Islands. Gupta et al. (2012) hypothesized that food allergy rates are positively correlated with dense populations; however, there was no correlation with milk and soy allergies to geographic region.

**Understanding food allergies.** There have been waves of research to understand the causes of food allergies. Original food allergy theorists believed that food allergies were genetic, and the next wave was influenced by seasonal allergy research, followed by the hygiene hypothesis (Broome-Stone, 2012). Proponents of the hygiene hypothesis believed that an increase in allergies was directly related to an increase in hygiene, and fewer children per nuclear family unit, resulting in less secondary exposure to allergens (Broome-Stone, 2012). For example, a secondary exposure occurred when an older sibling came into contact with allergens and exposed their younger sibling to a smaller dose of that allergen, which caused the younger child to develop a tolerance. More recent research specifies that microbes in the environment, such as environmental exposure and urbanization, and the human microbiome (e.g., lifestyle, diet, and use of antibiotics), contribute to immune regulation (Bloomfield et al., 2016).

Children may present with numerous symptoms indicating a food allergy, such as urticaria or eczema, without being allergic to a particular specific food. This makes food allergy testing vital (Kelsay, 2003). Physicians often use skin prick testing, blood testing, or patient history to determine food allergens; however, these methods produce a high rate of error (Kelsay, 2003). The double-blind placebo controlled food challenge is the only reliable food allergy test, and must be performed in-patient at a specialty clinic due to potential anaphylaxis.

**Physical implications.** A food allergy is as an adverse health effect arising from a specific immune response, immunoglobulin E (IgE)-mediated or non-immunoglobulin E-



mediated reaction, that occurs reproducibly on exposure to a given food (Boyce et al., 2010; Dyer & Gupta, 2013). A food protein allergen is flagged by the immune system the first time the offending food is ingested. The body thinks the food protein is a foreign invader and proceeds to attack it. The immune system responds by producing antibodies and/or lymphocytes, which are specifically coded to that antigen. Mast cells are part of the immune system and reside within connective tissues of the body such as the skin, the stomach and intestine linings. When a mast cell is triggered by an antigen and antibody, it releases histamine, which causes the allergic reaction (Boyce et al., 2010; Dyer & Gupta, 2013).

There are two types of reactions. Type I Immunoglobulin E-mediated reactions produce symptoms within minutes of exposure when a food allergen is eaten or is absorbed through the skin, with the most severe reaction being anaphylaxis (Dyer & Gupta, 2013). Type II non-Immunoglobulin mediated reactions occur two to six hours after exposure and present less specific symptoms. Allergic reactions have varied manifestations dependent upon the organ or biological system they impact (Butt & MacDougall, 2008; Ebisawa, 2013). Skin reactions, for example, may include swelling (especially facial), hives, itching, and redness. Gastrointestinal reactions include palatal itching, swelling of the tongue, tingling, throat itching and tightness, colicky abdominal cramps, nausea, vomiting, and diarrhea (often bloody) (Butt & MacDougall, 2008). Reactions within the respiratory system include nasal itching and congestion, rhinorrhea (runny nose), hoarseness, stridor (a harsh vibrating sound heard during respiration when there is an obstruction), dry cough, dyspnea (shortness of breath), wheezing, and cyanosis (a blue or purplish discoloration in the skin from lack of oxygen). Cardiovascular reactions can result in hypotension, weak pulse, loss of consciousness, chest pain, tachycardia (rapid heartbeat), and generalized erythema (Butt & MacDougall, 2008). Some of the most severe reactions will affect

multiple systems such as dizziness, headache, metallic taste, urticarial rash (red, round welts that itch intensely that can happen inside or outside the body), circulatory collapse, anaphylaxis, coma, and even death (Butt & MacDougall, 2008; Ebisawa, 2013).

Anaphylaxis can be fatal because the throat, larynx, and bronchial tubes swell, the blood vessels collapse, and the body is without oxygen (Chasnoff, Ellis, & Fainman, 1987). Of all the ER visits for anaphylaxis in the USA, food allergy-induced anaphylaxis is the primary cause (Gupta et al., 2011). Almost 40% of children with food allergies have suffered severe or life-threatening reactions (FARE, 2016). The greatest number of deaths from anaphylaxis are caused by an allergy to peanuts (Avery et al., 2003). Food Allergy Research and Education (FARE, 2016) reported that about 50 deaths per year are due to an anaphylactic reaction to an insect sting. More dramatically, however, 150-200 deaths occur each year because of a food allergy anaphylactic reaction (FARE, 2016).

**Financial implications.** In the United States, the costs related to food-induced anaphylaxis for ambulance, emergency room care, hospitalization, and epinephrine treatments are approximately \$40 million per year, while the overall cost of managing a food allergy is estimated at \$25 billion per year (Cianferoni & Muraro, 2012; FARE, 2016). An estimated three quarters of that is for pediatric patients with food-induced anaphylaxis (Cianferoni & Muraro, 2012). Managing a food allergy is costly to the health care system and families with an estimated annual expense of \$4.3 billion for medical costs, \$5.5 billion for out-of-pocket expenses, and an economic cost of \$24.8 billion; which equates to roughly \$4,184 per family (Gupta et al., 2013). As well as being costly, food allergies also have an immense biopsychosocial impact.

Food allergies impact not only the individual with the allergy but also the person's family, social circle, and educational environment (Bacal, 2013). As a result, research advocates for physicians to take a biopsychosocial approach when making a food allergy diagnosis (Klennert & Robinson, 2008). A new diagnosis can leave parents feeling confused, isolated, and uncertain how to keep their child safe (Klennert & Robinson, 2008). Specifically, parents experience more anxiety if they leave the doctor's office with unanswered questions and with no food allergy education or preventative measures. Unfortunately, many families do not receive this information from doctors (Mandell, Curtis, Gold, & Hardie, 2002). Most parents reported they had not been given enough information when their child was diagnosed, particularly a lack of instruction for using an epinephrine pen (Mandell et al., 2002). However, through consultation and education, parents have less anxiety, and are better able to meet the needs of their children, which typically has a positive impact on the family's quality of life (Klennert & Robinson, 2008). More research is needed to examine the psychological, social, and familial impact of food allergies (Dyer & Gupta, 2013; Ebisawa, 2013).

### **Parental Experience of having a Child with a Food Allergy**

Raising a child with a food allergy impacts one's life in the same way as a parent managing a child's chronic illness (Broome-Stone, 2012; Sicherer, 2011; Sicherer et al., 2001). Several studies compared the demands on families and effects on health related quality of life when managing a child's chronic disease or food allergy (Bacal, 2013; Knibb & Stalker, 2012). Consistent with previous studies, results confirm a greater impact of emotional stress and poorer quality of daily life for families with children who have food allergies (Knibb & Stalker, 2012).

Managing a food allergy impacts parents emotionally, financially, socially, and in their daily routine (Broome-Stone, 2012; Klennert & Robinson, 2008; Kurnat & Moore, 1999).

Managing a food allergy requires a certain level of vigilance including reading labels and monitoring for cross-contamination from people and objects (CDC, 2013). Parents had difficulties managing medical issues, interfacing with school personnel, attending social functions, preparing meals, eating out, arranging child care, and planning trips (Cohen, Noone, Munoz-Furlong, & Sicherer 2004). Parents reported managing food allergies had the greatest impact on food preparation (70%), their social lives (60%), and their overall stress level (41%) (Bollinger et al., 2006). Stress related to managing a food allergy also affects the marital relationship and the ability to parent well (Kurnat & Moore, 1999).

Many parents experience increased anxiety due to the possibility of accidental ingestion of an allergen when they are not present (Broome-Stone, 2012; Kelsay, 2003). Accidental exposures were attributed to complex, incomplete, or mislabeled foods 33.6% of the time (Sheth et al., 2008). As many as 73% of products contain at least one of the top eight food allergens, and although there is high compliance with the Food Allergy Labeling and Consumer Protection Act (FALCPA), the advisory terms are not standardized and use technical terms (whey instead of milk), are ambiguous (may contain), incomplete (not identifying the type of gelatin or lecithin), and misleading (spices, natural flavors) to consumers (Chung, Pieretti, Pacenza, Slokin, & Sicherer, 2008; Sheth et al., 2008).

Parents of children with life threatening allergies experienced continual fear and uncertainty (Gillespie, Woodgate, Chalmers, & Watson, 2007). Accidental ingestion, new information about potential risks, and the child entering a new level of independence and interacting with the medical community, schools, family, and friends increased parental stress (Broome-Stone, 2012; Kurnat & Moore, 1999; Mandell et al., 2002). The psychological impact on parents was reported as “sadness, worry about the future, helplessness, and general anxiety”

(Cohen et al., 2004, p. 1160). These burdens were exacerbated when the child had allergies to three or more foods and/or had a previous anaphylactic reaction (Cohen et al., 2004). The most significant correlation to increased anxiety was experiencing an emergency reaction and having to go to the hospital (King, Knibb, & Hourihane, 2009). Parent fear of a fatal anaphylactic reaction was positively correlated with the burden and psychological distress of managing their child's food allergy (Cohen et al., 2004).

Mothers reported more physical health concerns and higher chronic levels of anxiety than their husbands, and reported a lower quality of life than their child (King et al., 2009). This could be directly correlated to the allocation of responsibilities (King et al., 2009; Mandell et al., 2002). Mothers reported taking the lead in managing their child's allergy because they were more cognizant of all aspects of the allergy and therefore more capable than the child's father to monitor and manage safety. To be immediately available for their children, some mothers chose to not work (Mandell et al, 2002).

Based on these identified psychological stressors, parents appear to benefit from psychotherapy to assist them with the psychological impact of managing a food allergy (Klennert & Robinson, 2008). In fact, 70% of parents reported psychotherapy would have been beneficial; however, only 23% procured treatment (Annunziato et al., 2012). It is important to normalize the adjustment period for caregivers, and encourage them to find support and develop coping skills (Klennert & Robinson, 2008). Parents' anxiety levels decreased after their questions about the allergy were answered, a food allergy management plan was established, and they were familiarized with the epinephrine injector (Mandell et al., 2002). It was also noted that if a lot of time passed with no incidents, the family members began to be less guarded.

**Spectrum of parental vigilance.** Some parents have difficulty moderating anxiety and maintaining vigilance to ensure their child's safety; allowing for healthy development and family dynamics (Klennert & Robinson, 2008). While some anxiety can be productive, helping parents obtain education, and maintain food allergy management plans allows the parents and the child to feel more in control of their allergy; prolonged heightened anxiety leads to hyper vigilance where parents can become overly restrictive with maladaptive food allergy management strategies (Cohen et al., 2004; Kurnat & Moore, 1999; Mandell et al., 2002; Mandell et al., 2005). Some parents need psychoeducation, mental health support, and guidance to achieve effective food allergy management (Klennert & Robinson, 2008).

Parents who reported low levels of anxiety, burden, and fear of death tended to be overly lax in safety planning, such as not restricting diet (Eggsbo, Botten & Stigum, 2001), had limited strategies to avoid the allergen, and did not have injectable epinephrine on hand (Klennert & Robinson, 2008; Mandell et al., 2005). This was also true for parents of toddlers with milk allergies who underestimated the severity of allergic reactions and, were overly lax in safety planning, which resulted in exposure to the allergen (Boyano-Martinez et al., 2009). In fact, 40% of toddlers experienced allergic reactions 53 times, and most incidents occurred at home. Of those reactions, 15% were severe and researchers determined the severity and frequency to be ten times higher in children with asthma and very high levels of specific IgE cow's milk and casein (Boyano et al., 2009).

Prolonged heightened anxiety can also result in maladaptive food allergy management strategies (Cohen et al., 2004; Kurnat & Moore, 1999; Mandell et al., 2005). Parents who reported high levels of anxiety, burden, and fear of death, tended to have more restrictions on their children, especially social restrictions (Klennert & Robinson, 2008; Mandell et al., 2002;

Munoz-Furlong, 2003). Some parents did not allow their children to play at friends' houses, attend family functions, birthday parties, or school (Cohen et al., 2004). Social restrictions can prevent the child from being independent, which hinders normal social interaction; and when prolonged, language may be delayed along with stunted social and emotional development (Mandell et al., 2002). Parents can overly restrict the child's diet when the cause of ambiguous symptoms are unknown, which may lead to nutritional deficits and malnutrition (Eggesbo, Botten, & Stigum, 2001). Overly restricting a child's diet and social exposure can result in Failure to Thrive (FTT; Roesler, Barry, & Bock, 1994). Prolonged heightened anxiety and overly restrictive behaviors may decrease with effective food allergy management protocols and adaptive parental coping skills (Klennert & Robinson, 2008).

Although parents in the previous examples were too lax or overly restrictive, it is possible to safely manage a food allergy without being overly restrictive. This was achieved by parents who recognized that their child had the potential for a severe reaction, had detailed food allergy management procedures, were confident in their avoidant strategies, and were prepared in the event of a reaction (Mandell et al., 2002).

Developing optimal coping strategies after a child's diagnosis of anaphylaxis is crucial. It is best if all persons involved in the daily care of the child, especially caregivers, meet to get the doctor's medical instructions. These usually include written instructions, detailed information on avoiding all forms of the allergen, directions on how to administer an Epinephrine-pen, referrals to medical professionals, and information regarding support groups (Mandell et al., 2002). It is imperative that parents also learn about food labeling, vague or incorrect notations on restaurant menus, safe methods of food preparation, methods of avoiding cross contamination, and other risks for exposure. If parents do not get enough information from a doctor, they may have

difficulty getting accurate information from other sources. This increases the risk of accidental ingestion, which in turn causes stress to increase and the ability to properly manage the child's allergy to decrease (Mandell et al., 2002).

### **Food Allergy Management at Different Stages of Development**

There appear to be age specific trends in food allergy-related anxiety for children and their parents. Parents are solely responsible for managing food allergies in infants and young children, which includes ensuring child care settings are safe for their child (Houle, Leo & Clark, 2010). According to National Household Education Survey Program, 60.6% of children between the ages of three and six, not enrolled in kindergarten, received child care (U.S. Department of Education, National Center for Education Statistics, accessed 2017). According to Mandell et al. (2002), most food allergy diagnoses occur between the ages of two and eight when children are entering daycare, preschool, or elementary school. Identifying a food allergy reaction in young children is difficult when classic symptoms (i.e., hives, swelling of lips and face) are not present because common eating behaviors mimic a reaction, such as spitting out food, placing fingers in their mouth, and spitting up (Dunbar & Luyt, 1999). Also, young children can be especially susceptible to cross contamination because they frequently place their fingers and hands in their mouth (Sicherer et al., 2001).

Students at elementary schools are particularly vulnerable to having an allergic reaction, because that is when children are often exposed to new foods (Mandell et al., 2002). Most children enter first grade at the age of six, and they spend the majority of their week at school. This makes it important for parents to provide food allergy education to teachers and school staff (Mandell et al., 2002). At approximately age seven, children understand the risks associated with certain foods and also start to read labels (Bacal, 2013; Munoz-Furlong, 2003). This is also



the age when some children experience increased anxiety as they become aware of the risk from their allergy, especially severe anaphylactic reactions (Bacal, 2013; Munoz-Furlong, 2003). These children must be on guard to protect themselves from potentially fatal risks at school, parties, restaurants and playing with friends (Bacal, 2013).

School age children on the National School Lunch Program might encounter problems obtaining an allergen-free meal (Houle et al., 2010). Other potential complications for school age children include class field trips, the use of schools by community members, and the limited number of school nurses (Houle et al., 2012). Children eight years of age and younger are more capable of openly discussing their food allergy, rely on their parents to manage their food allergy, and are more confident in social situations (DunnGalvin, Gaffney & Hourihane, 2009). However, children nine years of age and older are gaining autonomy, yet tend to feel uncertain and anxious in social situations (DunnGalvin et al., 2009). Children nine to 11 years of age would discuss their food allergy with a “best friend” (DunnGalvin et al., 2009). Children aged six to eleven experience the highest levels of anxiety (Bacal, 2013; Munoz-Furlong, 2003). Having a restaurant that has provided allergen-free food and carrying an epinephrine pen were the two factors associated with increased feelings of safety for children with food allergies (Avery et al., 2003). Children who can manage their food allergy tend to experience less emotional distress (Klennert & Robinson, 2008).

For adolescents, a lack of understanding, social embarrassment, bullying, isolation, and feeling different contributed to not disclosing their food allergy, and in some cases delayed seeking help during a reaction (DunnGalvin et al., 2009; Houle et al., 2010). When adolescents experienced bullying, boys were more likely to minimize or reject their food allergy identity, whereas girls were more likely to avoid people and places (DunnGalvin et al., 2009).

Adolescents were also more likely to express the consequences of having a food allergy in regards to their peers' perception of their difference (DunnGalvin et al., 2009). Adolescents and young adults also engage in risky behaviors such as risking an allergic reaction by intentionally eating potentially unsafe food, partially to avoid social isolation, because the desire for social acceptance overrides the need for safety (DunnGalvin et al., 2009; Sampson, Munoz-Furlong, & Sicherer, 2006). The social representation theory would argue that a person's actions regarding safety are more influenced by social than rational cognitive factors (Joffe, 2002).

Fatalities due to food allergies are most common among adolescents and young adults (Bock, Munoz-Furlong, & Sampson, 2001; Sampson et al., 2006). Adolescents, ages 14 to 17 with nut allergies were twice as likely to have a severe reaction (Gupta et al., 2012). Bock et al. (2001) found in their study that 90% of fatalities were from anaphylactic reactions to a nut allergy. In all but one of these instances, the individual knew they had a nut allergy; however, none were carrying an epinephrine pen (Bock et al., 2001). Parents with children ages 12 to 18 were most vocal about reminding their child to carry their injectable epinephrine (Mandell et al., 2002). Adolescent boys spent the majority of time away from home and had higher rates of refusing to carry their auto injectable epinephrine (Munoz-Furlong, 2003). The risk of fatal reactions is even greater for those who also have asthma in this age group, who are unable to get an epinephrine injection quickly (FARE, 2013).

The perceived risk and social circumstances appeared to directly influence the risk-taking behaviors of adolescents and young adults (Sampson et al., 2006). Almost all participants would bring injectable epinephrine when traveling; however, approximately 50% did not bring their injectable epinephrine if participating in a sport activity or when wearing tight fitting clothing (Sampson et al., 2006). Though this behavior is very unsafe, this may be an attempt to avoid

being bullied. This data suggests there is a strong social component involved. This supports the social representation theory, that these adolescents are making decisions about their safety based on their social environment (Joffe, 2002). Having social support reduces psychological burden, which results in better coping skills and positively influences the illness (Sicherer, Noon, & Munoz-Furlong, 2001).

Across multiple age groups, there are some common experiences and behaviors. Parental perception of risk and level of anxiety greatly impacts their child's anxiety and perception of risk (DunnGalvin et al., 2009). Most children use adaptive avoidance strategies such as avoiding people and places that are not allergy friendly (DunnGalvin et al., 2009).

**Quality of life.** Receiving a food allergy diagnosis can dramatically affect the quality of life for the child diagnosed, as well as their family. Children with severe food allergies have a higher risk for experiencing anxiety, depression, and social isolation (Bacal, 2013). Children with a food allergy are more negatively affected by their allergy than a child with a chronic condition such as diabetes. More specifically, children with peanut allergies experienced more anxiety throughout the day, reported a lower quality of life, felt more restricted socially in their environment, in physical activities, and at restaurants than children with insulin-dependent diabetes (Avery et al., 2003).

There was no correlation between multiple food allergies and anxiety or lower quality of life scores (King et al., 2009). Children who had experienced an anaphylactic reaction and used their epinephrine injectors reported higher anxiety as well as higher physical concerns and poorer emotional functioning (King et al., 2009). An anaphylactic reaction can be fatal, and facing one's mortality is difficult for anyone, especially children. After a traumatic near death experience, increased anxiety seems a natural response.

The general public has limited food allergy knowledge in regard to prevalence, definition, and triggers, resulting in a common mistake such as cross contamination (Gupta, 2008). In fact, nearly half of fatal food allergy reactions are triggered by food consumed outside the home (Brock, Munoz-Furlong, & Sampson, 2007). It is not surprising that 16% of families with children with food allergies never eat out (Cohen et al., 2004).

Fear of accidental exposure to an allergen causes children and adolescents to limit their participation in activities, and refrain from socializing with other children, even in their own homes (Bacal, 2013; Dyer & Gupta, 2013; Kelsay, 2003). The stress of having a food allergy, especially experiencing anaphylaxis, can lead to PTSD and possibly Failure to Thrive (FTT) (Kelsay, 2003). These findings illustrate some of the psychological burdens due to food allergies, and the lowered quality of life experienced by children with a peanut allergy.

**Gender difference.** Data have suggested that there also appears to be a gender difference in the experience of living with a peanut allergy (King et al., 2009). These differences are first noted at birth. Girls are more likely to inherit an allergy from a mother with an atopic disease than boys (Johnson, Ownby, & Peterson, 1996; Liu et al., 2003). As children age, gender differences in emotional and psychosocial health are also apparent. Overall, children with a peanut allergy reported poorer emotional and psychosocial health when compared to their same sex sibling (King et al., 2009). Separation anxiety for the children with a peanut allergy was almost twice as high as their siblings. Both genders experienced the lowest quality of life at school, and girls had higher anxiety about their physical health at school (King et al., 2009).

Girls between the ages of eight and 12 are likely to be starting puberty, which may contribute to anxiety about their health, and experiencing lower quality of life at school.

Estrogen enhances antibody production causing more inflammation, which makes the allergic

reaction more severe (DunnGalvin et al., 2006). For adolescents and adults, there are 20% more women having severe allergic reactions than men (Lovik et al., 2003). It is reasonable that girls have more anxiety about their health and safety because their levels of estrogen put them at greater risk.

When children with a peanut allergy were compared, boys experienced less stress, anxiety and reported a higher quality of life than girls (King et al., 2009). An interesting finding that may affect family dynamics was the way in which a child with a peanut allergy views their siblings' quality of life (King et al., 2009). Both genders of children with a peanut allergy perceived their siblings as having a higher quality of life than reported by the sibling (King et al., 2009).

**Bullying.** Some schools segregate children with food allergies, such as having a nut free table, which hinders their ability to socialize (Bacal, 2013). This kind of segregation may be the precursor to bullying. Liberman, Weiss, Furlong, Sicherer, and Sicherer (2010) found that 31.5% of children with food allergies were bullied because of their food allergy. Some forms of bullying were potentially life threatening, such as waving the allergen in a child's face or smearing the allergen on the child's locker (Liberman et al., 2010; Munoz-Furlong, 2003). Disturbingly, 21% of the bullying was perpetrated by teachers and faculty (Liberman et al., 2010). Rates of bullying rose almost 4% over the next three years to 35.2% (Shemesh et al., 2013). As the incidents of bullying rise, so do the number of fatal incidences among those with food allergies. These studies fail to indicate methods for addressing food allergy bullying despite the fact these students are protected under multiple federal laws (Liberman et al., 2010; Shemesh et al., 2013).

## Food Allergy Policy and Procedures

The federal laws in place to protect the rights of children with food allergies include the Americans with Disabilities Act Amendments of 2008 (ADAAA), Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, the Food Safety Modernization Act of 2010 and the School Access to Emergency Act of 2013 (FARE,2017). Section 504 is the most commonly used federal law to protect the rights of children with food allergies. The majority of schools receive federal funding and are obligated to adhere to federal laws. Students who attend private schools that are not federally subsidized are covered under the Americans with Disabilities Act Amendments Act and a 504 could be set up (FARE, 2017).

In order to qualify for a 504 or Americans with Disabilities Act, schools require parents to submit documentation from a licensed health professional stating that the allergy is life-threatening (FARE, 2017). The school will then decide what changes, if any, are necessary to manage the food allergy. Children who qualify for an Individualized Education Program (IEP) would have their food allergy disability grouped with any other disability protected by IDEA rather than by Section 504. If a child with a food allergy does not qualify for a Section 504 or an IEP, they may qualify for an Individualized Health Plan (IHP or IHCP) to document the food allergy management plan. A student might need an IHP if their medical condition may interfere with their academics. It is recommended that schools that receive federal funding for meals have a written diet restriction form completed by a physician, so food service staff can make appropriate accommodations. The school food allergy management plan is coordinated with “school personnel (school administrators, 504 coordinators, licensed health care providers [e.g., registered nurse, physician], school health advisory council members, teachers, school nutrition staff, bus companies/drivers, after-school program personnel, etc.), students, families, and others

particularly affected by, or involved in, the implementation of the policy” (Budgen, Martinez, Green & Eig, 2012, p. 5).

The following states have published school food allergy management guidelines that were established in 2010: Arizona, Connecticut, Maryland, Massachusetts, Mississippi, New Jersey, New York, Tennessee, Vermont, Washington, and West Virginia. Illinois, Missouri, Pennsylvania, and Texas have school food allergy management guidelines that were established by 2013 (FARE, 2017).

A global survey identified inequity in standardized National Anaphylaxis Action plans (Prescott et al., 2013). Professional organizations, federal agencies, and patient advocacy groups worked together over a two-year period to develop guidelines for the diagnosis and management of food allergy in the United States (Boyce et al., 2010). A specific policies and procedures manual for responding to food allergies, created by the U.S. National School Board Association in 2010 (funded by the Centers for Disease Control), was made available to all schools with the intention of enabling schools to establish or upgrade their emergency response to life-threatening food allergies (Budgen et al., 2012). The Food Safety and Modernization Act of 2010 provides necessary information for public schools to create rules and procedures to protect children with life-threatening food allergies; however, the decision to implement is voluntary, and financial burden is on local school districts (Budgen et al. 2012). The protocol recommended by the National School Board Association includes:

- A. Identification of students with food allergies and provision of school health services;
- B. Individual written management plans;
- C. Medication protocols: storage, access, and administration;
- D. Healthy school environments: comprehensive and coordinated approach;

- E. Communication and confidentiality;
- F. Emergency response;
- G. Professional development and training for school personnel;
- H. Awareness education and resources for parents/caregivers; and
- I. Monitoring and evaluation.

### **Food Allergy Trends, Reactions, and Management in Schools**

While there are recommendations from the National School Board Association on managing food allergies, there are several factors that complicate food allergy management in schools. School districts often share nurses. In fact, 62% of school nurses reported being required to cover more than one school, and the average nurse-to-student ratio was one to six hundred fifty students (Carlisle et al., 2010). This often results in a nurse only being on school grounds once a week (Carlisle et al., 2010), and school staff are not competent in identifying and responding to allergic reactions (Ercan et al., 2012; Sharman, Mudd, & Acebal, 2010). Moreover, some schools do not have complete medical information for students, and they do not stock injectable epinephrine on campus or have an established anaphylaxis emergency plan. Additionally, food allergy management plans are inconsistently implemented and followed, and there are socioeconomic disparities in the treatment of food allergies (Carlisle et al., 2010; Powers et al., 2007; Pulcini, Marshall, & Naveed, 2011; Shah, Parker, & Davis, 2013; Sicherer & Mahr, 2010).

**Food allergy training for nurses and school personnel.** Part of creating a safe environment for food allergy management involves training the staff. School nurses may be the most attuned to student health care needs, and, based on self-reports, believe they need more food allergy education, as well as additional staff to better manage student health needs (Carlisle



et al., 2010). Sapien and Allen (2001) found that education on life-threatening allergies was not part of the course curriculum at the nursing schools in New York and Arkansas. Other studies noted that only 15% of nurses received food allergy training, whereas 35% were self-taught (Carlisle et al., 2010), and 74% developed their own food allergy training program (Weiss, Munoz-Furlong, Furlong, & Arbit, 2004). In fact, 40% of the school nurses requested food allergy training (Pulcini, Sease, & Marshall, 2010). The nurses reported low food allergy competency and requested education and training for themselves and school staff in emergency plan development (American Academy of Allergy, Asthma and Immunology, 1998). These studies support the need to provide standardized food allergy education.

The most common food allergy misconceptions held by school personnel and childcare staff included “incorrectly believing that a second dose of epinephrine could not safely be administered if symptoms persist (69%), epinephrine is an extremely dangerous drug with harmful side effects (63%), use of antibacterial hand sanitizer is recommended after eating (60%), and antihistamines should always be the first treatment for reactions (46%)” (Sharman et al., 2010, p. S1). While 47% of teachers knew foods could cause anaphylaxis, they misidentified the leading food allergies (Ercan et al., 2012). In the event of an anaphylactic reaction, 25% of teachers knew the symptoms, 10% knew injectable epinephrine was a treatment, 25% were willing to administer, but only 4% knew how to administer injectable epinephrine (Ercan et al., 2012). In Scotland schools, 58% of faculty and staff reported having adequate training to identify a food allergy reaction and administer medication (Clegg & Ritchi, 2001). These results clearly showed the need for food allergy education. Therefore, standardized food allergy training for teachers and childcare providers is necessary (CDC, 2013).

Food allergy training has been shown to be effective. Food allergy knowledge for school nurses increased by 11.5% after one training session, and nurses were more confident and had improved attitudes towards food allergy management practices in schools (Alta, Patrick, & Wang, 2016). After training, teachers' scores increased from 24.6% to 34.6%, and they had a better understanding of allergens, signs of anaphylaxis, and treatment (Shah et al., 2013). This is a good indication that food allergy training for school personnel is effective. A national asthma education program for school personnel is in place and is effective; however, there are no standard national food allergy education programs even though there are effective training programs available (Alta et al., 2016; Zuniga et al., 2010).

**School lunch.** The most comprehensive study regarding school lunches and food allergens was conducted in Seoul, Korea (Yoon, Kwon, & Shim, 2012). More than half of the school lunches had at least one food allergen in them, and 75% of menu items contained multiple food allergens. Schools within Seoul had different approaches to managing food allergies: 1.9% did not serve any food allergens, 6.5% provided allergy free options, and 16.9% provided the ingredient list. The majority of schools (84.4%) had no food allergy management plans or procedures, and the responsibility of managing the food allergy was on the child. Not surprisingly, 46.8% of schools reported a food allergy reaction (Yoon et al., 2012). Schools need “policies on school-wide education, avoidance of food allergens, written emergency plans, access to epinephrine, and personnel in charge of administering epinephrine” (Yoon et al., 2012, p. 130).

According to the National Association of School Nurses (2013), banning foods is unrealistic and counterproductive to children (Thelen & Cameron, 2012). Another method segregates children with a food allergy to a specific section or table in the classroom or cafeteria,

which is discriminatory, and disregards psychological needs of children (Gaudreau, 2000). School is an important part of social and cognitive development, where children learn tools to help them navigate the world. Schools need to provide a safe environment while allowing children to learn to be their own advocate (NASN, 2013).

**Food allergy reactions and treatment in schools.** Carlisle et al. (2010) found that the greatest number of food allergic children in descending order were elementary, middle, and high school students. According to Mandell et al. (2002), most food allergy diagnoses occur between the ages of two and eight when children are entering daycare, preschool, and elementary school. The undiagnosed allergy can be the most dangerous. McIntyre et al. (2005) reported that 24% of the reactions occurred in individuals who were unaware they had a food allergy. This was consistent with a study by Sicherer et al. (2001) that reported that 25% of children experience their first reaction at school. Students at elementary schools are particularly vulnerable to having an allergic reaction, because that is when children are exposed to new foods. Children with food allergies have a high risk of having a reaction at school. In fact, 16% to 18% of all children with food allergies had an allergic reaction while on campus (Young et al., 2009). A study in Maryland reported 39% of schools had at least one food allergy reaction during a two-year period (Nowak-Wegrzyn et al., 2001). The National Peanut and Tree Nut Registry reported 84% of the children had a reaction at school and 15% had two reactions at school (Sicherer et al. 2001).

Causes of food allergy reactions in daycare and schools included ingestion (60%), skin contact/possible ingestion (24%), and inhalation or possible skin contact (16%) (Sicherer et al., 2001). Of these reactions, 44% were triggered by peanut butter craft projects in daycare and schools (Sicherer et al., 2001). Allergens are also found in art supplies such as finger paint, clay,

and paste; therefore, all teachers and daycare providers need to be properly trained to screen for allergen ingredients (CDC, 2013). Forty-eight Massachusetts school districts were followed for a two-year period. During that time, injectable epinephrine were administered to 111 children and four adult staff members (McIntyre et al., 2005). The majority of the reactions in Massachusetts schools were caused by ingestion of the allergen, and the onset of symptoms most frequently occurred in the classroom (46%) (McIntyre et al., 2005). Nowak-Wegrzyn et al. (2001) also found the majority of reactions occurred in the classroom (83%). Over the course of one year, 30% of schools reported one food allergy reaction, and 7% reported multiple food allergy reactions, which occurred in the cafeteria (50%) and in the classroom (43%) (Pulcini et al., 2010). It was also found that 19% of the reactions occurred outside the school building, indicating that epinephrine needs to be stored in multiple locations (McIntyre et al., 2005). These studies highlighted the importance of understanding student's food allergies and the screening supplies for allergens.

A large portion of South Carolina schools (86%) had a nurse and three additional staff members trained to administer injectable epinephrine; however, medication was only stored in the nurse's office at 60% of the schools (Pulcini et al., 2010). The majority of schools stored medication in the health office and, on average, epinephrine was administered 10 minutes after the onset of the reaction, with a range from zero to 75 minutes; and a nurse administered the injection 91% of the time (McIntyre et al., 2005). These findings were consistent with Nowak-Wegrzyn et al.'s (2001) findings, in that most medication was stored in the nurse's office, and reactions were treated primarily by the nurse within 10 minutes.

Another concerning issue highlighted was the delay in treatment (Sicherer et al., 2001). Several staff errors caused delay in providing treatment, including: lack of symptom awareness,

not following the emergency plan, calling parents before obeying emergency plan protocols, and no knowledge of how to give an epinephrine injection (Powers et al., 2007; Sicherer et al., 2001). Delayed treatment of anaphylaxis is a risk factor for death (Bock et al., 2007). When a child has a severe anaphylactic reaction, treatment must be administered within minutes (FARE, 2017). As many as one third of people have a secondary reaction, which is commonly not responsive to epinephrine and requires care only available at the hospital (McIntyre et al., 2005).

These studies by Sicherer et al. (2001) and McIntyre et al. (2005) further supported the recommendations that schools need an emergency procedure for anaphylactic reactions, and students with known allergies need a food allergy management plan in place. This plan needs to be strictly adhered to, and stocked injectable epinephrine needs to be available for those with known and unknown allergies. All staff needs food allergy training to prevent exposure, recognize symptoms, and administer medication in an emergency (McIntyre et al., 2005).

There is controversy over whether schools should have epinephrine pens at school, because some schools do not want the legal liability of failing to administer, or improperly administering epinephrine. For schools that choose to have epinephrine pens on hand, there is controversy over who should supply them. Stocking of unassigned epinephrine, that is, epinephrine that is not prescribed to a specific individual, is recommended to minimize treatment delay, but is not mandatory (Tsuang & Wang, 2016). Injectable epinephrine has a one-year expiration date, is very expensive, and not all families can afford the expense (FARE, 2013). The epinephrine must be administered within minutes of the reaction. Children do not have time to wait for an ambulance and with 25% of anaphylactic reactions happening for the first time at school, it is critical to have the epinephrine pens in stock (Sicherer et al., 2001).

Sampson, Mendelson, and Rosen (1992) conducted early research on fatal and near fatal food allergy reactions in schools, and found that the majority of the fatalities were due to delayed treatment. This continues to be the case as schools routinely lack adequate food allergy management plans, and faculty has little to no training on identifying symptoms and administering injectable epinephrine (FARE, 2017). Research is needed to examine school policy, or the lack thereof, in action. Identifying how schools communicate to parents their policy and procedures around food allergy treatment is important.

**Socioeconomic disparities in food allergy management.** The impact of socioeconomic status and ethnicity on asthma and food allergy diagnosis and management in Chicago public schools during the 2012/2013 school year were examined by Gupta et al. (2014). Students at Chicago public schools were primarily Latino and African American from families with lower socioeconomic status, and 84.9% of students were on the free/reduced lunch program. As mentioned above, eight percent of children have a food allergy and approximately 14% have asthma during childhood; however, rates of food allergies in minority children in Chicago public schools were much lower (Basche, 2010; Gupta et al., 2011; Gupta et al., 2014). African American and Latino students made up 85.4% of the student body population; however they had 0.96% and 0.79% of food allergy diagnoses respectively (Gupta et al., 2014). This was compared to Caucasian students, who made up 9% of the student population, but had 21.9% of food allergy diagnoses (Gupta et al., 2014). Earlier studies verified this disparity, and also reported that there is a significantly higher probability of food allergy in Asian and African American children compared to Caucasian children (Gupta, et al. 2011); however, physician verified diagnosed food allergies among minority groups was 3.4%, much lower than the national average (Taylor-Black & Wang, 2012).

As per Chicago public school policy, a physician must verify a diagnosis; only then is the diagnosis entered in the district database and a health management plan or 504 plan created. Health management plans were created for 24% of children with asthma and 51% of children with a food allergy (Gupta et al., 2014). Children that attended a school in the North-Northwest side, with a predominantly white population and annual household income over \$50,000, were significantly more likely to have a health management plan (Gupta et al., 2014). Gupta et al. (2014) noted that the “odds of having a school health management plan were significantly higher among students with both conditions, but the likelihood of having a plan on file was significantly lower among racial/ethnic minority and low-income students, regardless of medical condition” (p.729). Socioeconomic disparities were also found in treatment of food allergies as it relates to the cost of emergency room visits and hospitalizations due to a food allergy reaction; children with low family incomes were charged 2.5 times more than children with high family incomes (Gupta et al., 2014).

The use of injectable epinephrine in Chicago public schools during the 2012/2013 school year showed a similar trend to the allocation of health management plans. Of the 38 instances where injectable epinephrine was used, 36.8% were located on the North-Northwest Side of Chicago (DeSantiago-Cardenas et al., 2015). Also, of these 38 instances, 55% were for initial anaphylactic reactions (DeSantiago-Cardenas et al., 2015).

**Food allergy policies and management plans.** The American Academy of Allergy, Asthma and Immunology, the American Academy of Pediatrics and the National Association of School Nurses recommend emergency action plans that specify treatment for children with food allergies (Pulcini et al., 2010). One of the lowest rates of anaphylaxis management plans was 6% (Ercan, et al., 2012). Schools with at least one student with a food allergy were surveyed by

different researchers. In Michigan, only 16% of those diagnosed with a food allergy had written food allergy emergency plans (Rhim & McMorris, 2001). In South Carolina, 44% had emergency action plans (Pulcini et al., 2010). Of the schools that administered epinephrine to students in 48 Massachusetts school districts over a two year period, 63.9% had a food allergy management plan and 91% of schools had a policy that addressed life-threatening allergies (McIntyre et al., 2005). The National Peanut and Tree Nut Registry reported that 33% of schools had a food allergy emergency plan, which were followed 73% of the time (Sicherer et al. 2001). A representative sample of 844 schools in the US reported that 84% had children with food allergies; however, 69% reported using preventative measures and inconsistency in food allergy management (Verduin & Corbett, 2009). In Scotland schools, 35% of children had a food allergy emergency plan written by a physician (Clegg & Ritchi, 2001).

Powers et al. (2007) compared food allergy management plans to the Food Allergy and Anaphylaxis Network's (FAAN) Standard Plan. The FAAN has 32 criteria including: identifying data with a picture of the child, list of allergy/allergies, if the child has asthma, detailed warning signs of a reaction, emergency treatment protocol with contingencies and contact numbers including medical provider (Powers et al., 2007). Of the plans, only 15% were congruent with the current FAAN emergency plan, 35% were outdated FAAN plans, and 50% were not based on FAAN (Powers et al., 2007). Also, 30% of the plans did not warn that symptoms of the throat, lungs, and heart are life threatening (Powers et al., 2007). Effective treatment requires a distinction between nonfatal and fatal reaction. Children with asthma are at higher risk for an allergic reaction; however, only 57% of the plans noted this information. Powers et al. (2007) also found that only 18% of the plans alerted staff that inhalers are not a replacement for epinephrine, and 23% included which medication should be administered during an allergic



reaction. School nurses noted that schools were lacking procedures regarding field trips and emergency plans on campus (Carlisle et al., 2010).

Poor food allergy management in schools creates an unsafe environment and causes psychological distress to children (Parnell et al., 2016). Prescott et al. (2013) conducted a global survey and found “inequities in pediatric allergy services, availability of adrenaline auto-injectors and standardised National Anaphylaxis Action plans” (p.21). There are several factors contributing to unsafe schools environments: school staff and administrators continue to be unaware of children’s food allergy needs (Foster, & Bryant, 2004; Parnell et al., 2016); there is limited food allergy training for school personnel (Parnell et al., 2016); food allergy management plans are not consistently created or followed (Ercan et al., 2012; Pulcini et al., 2010; Rhim & McMorris, 2001); and some plans that were created did not meet Food Allergy and Anaphylaxis Network (FAAN) guidelines (Powers et al., 2007). Training school personnel and following FAAN allergy management plans may help reduce psychological distress of parents and children while at school (Parnell et al., 2016).

## Chapter III

### Methods

#### Choice of Method

This study examined parental perception of food allergy management by schools in the 2015-2016 school year. The purpose of this study was to inductively identify schools' food allergy management protocols and procedures. This study used both quantitative and qualitative research methods. A quantitative approach was used to objectively quantify responses to be used to improve food allergy management with schools. Qualitative analysis was used to gain a deeper understanding of the participants' experiences managing a food allergy in a school setting (Bloomberg & Volpe, 2012).

A quantitative approach was most suited for the variables within this study that were easily classified or quantified (Gliner, Morgan & Leech, 2009). The data in this study were analyzed to identify trends in individual schools. A quantitative research approach used a survey and gathered specific information about the accessibility of school assistance and policy. The descriptive statistics (frequencies) were tabulated to determine food allergy educational and policy management needed in schools. The researcher also examined the presumed effect of the attribute independent variables –socioeconomic status of family and if they lived in a state with food allergy guidelines. The researcher engaged in content analysis for the qualitative responses. Analysis of the qualitative data allowed the researcher to collect an in-depth explanation of parents' perception of school's food allergy management protocol.

#### Participants

Participants included caregivers of a child with a food allergy currently enrolled in school grades K-12. For consistency in data collection, all participants were fluent in reading English.

The caregiver with the most active involvement in managing the child's food allergy was asked to participate. Each participant electronically signed a consent form. Each participant was assigned a number to be used in place of identifying data. With a medium effect size and an alpha level of .05 and 80% power, the researcher needed 40 to 80 participants. This study gathered 151 participants.

### **Recruitment**

Parents of a child with a food allergy currently attending school in grades K-12 were asked to complete an anonymous online survey. Participants were recruited through social media, food allergy support groups, parent groups, and a food allergy summer camp (Appendix A).

### **Instruments**

All participants completed both a demographic questionnaire (Appendix C) and an online survey (see Appendix D). Questions were developed to address food allergy management in schools including program quality, policy satisfaction, relational quality, and knowledge of school personnel. Participants were also asked to answer short answer experiential questions and were able to leave comments.

### **Data Collection**

After the researcher obtained ethics approval to conduct the study from the National University Institutional Review Board, links to the survey were posted on social media, in food allergy support groups, in parent groups, and in the newsletter of a food allergy camp by the moderators of the sites. An introductory explanation about the researcher and the purpose of the study was provided prior to the start of the survey (Appendix B). The survey was managed

through Qualtrics, an online survey platform. Once started, participants were allowed to complete their survey during the course of one week.

### **Data Analysis**

This research utilized both quantitative and qualitative data. The quantitative data were analyzed using the Statistical Package for the Social Sciences (SPSS). Due to the fact that the data were ordinal and nominal, nonparametric statistics were used. Descriptive statistics, frequencies, and Spearman Rho correlations were calculated for data collected from the questionnaire.

Qualitative data were coded by theme and the themes were reviewed with other coders to ensure reliability. All the responses were reviewed by a blind reader who was asked to identify the major themes that emerged from the data. Their themes were compared to the themes identified by this researcher. The researcher, dissertation committee, and the blind reader had in depth discussions and any inconsistencies that arose were further explored.

### **Data Clearing Phase**

The questionnaire was produced and distributed using Qualtrics. All responses were stored on the Qualtrics website. The data from 171 participants were downloaded to an Excel spreadsheet. The responses were reviewed to ensure inclusion criteria were met. Twenty recorded responses ended up being dropped. Of those, six did not meet age related inclusion criteria, and eleven were not sufficiently complete to be includible. One person stopped responding at question 57, two stopped at question 41, and the rest stopped between questions 16 and 35. As per inclusion criteria, anyone who did not complete the full questionnaire was

excluded. Two were marked duplicate and one participant appeared to be completing the survey for two children. A total of 151 surveys were used in the study.

Before the data could be transferred to SPSS they had to be reformatted. The raw data were coded and all questions, excluding short answers and comments, were given a numerical value in preparation for SPSS. The survey questions were shortened to create identifiable titles that were compatible with SPSS. For example, “Question 8: In what grade is your child with food allergy/allergies?” was condensed to “Q8\_Grade.” This Excel spreadsheet was uploaded to SPSS. Descriptive statistics and frequencies were calculated.

### **Data Reduction**

At the onset of data analysis, it became apparent that the data were unmanageable when not grouped together. The researcher consulted with a statistics expert and it was determined the best course of action was to group questions by themes. Based on the 80 questions from the survey, the research team identified four major groupings. The four themes included: Program Quality, Policy Satisfaction, Relational Quality, and Knowledge (Appendix E). Program Quality was used to identify the quality of food allergy management program at the school based on the number of beneficial policies in place. Policy Satisfaction identified parents’ level of satisfaction with current policies. Relational Quality examined the interpersonal interactions in the school environment. Knowledge measured participants’ perception of the school personnel’s level of food allergy knowledge. Additionally, when the qualitative data were analyzed it was discovered that these categories were in line with the themes emerging from Program Quality, Policy Satisfaction, Relational Quality, and Knowledge.

Descriptive statistics, frequencies, and correlations were calculated for Program Quality, Policy Satisfaction, Relational Quality, and Knowledge. Cronbach’s  $\alpha$  was used to calculate the

inter-item reliability of each theme. When calculating Cronbach's  $\alpha$ , if data were missing in one question, the corresponding participant's data were dropped on all questions. For example, 30% of the children did not receive a food allergy management plan (question 49) and the follow up questions (50 and 51) were removed so as not to lose 30% of participants. Question 50 was removed from Program Quality and question 51 was removed from Policy Satisfaction. Question 48 appeared to be suppressing the usefulness of the category Program Quality and was removed to increase Cronbach's  $\alpha$ .

## Chapter IV

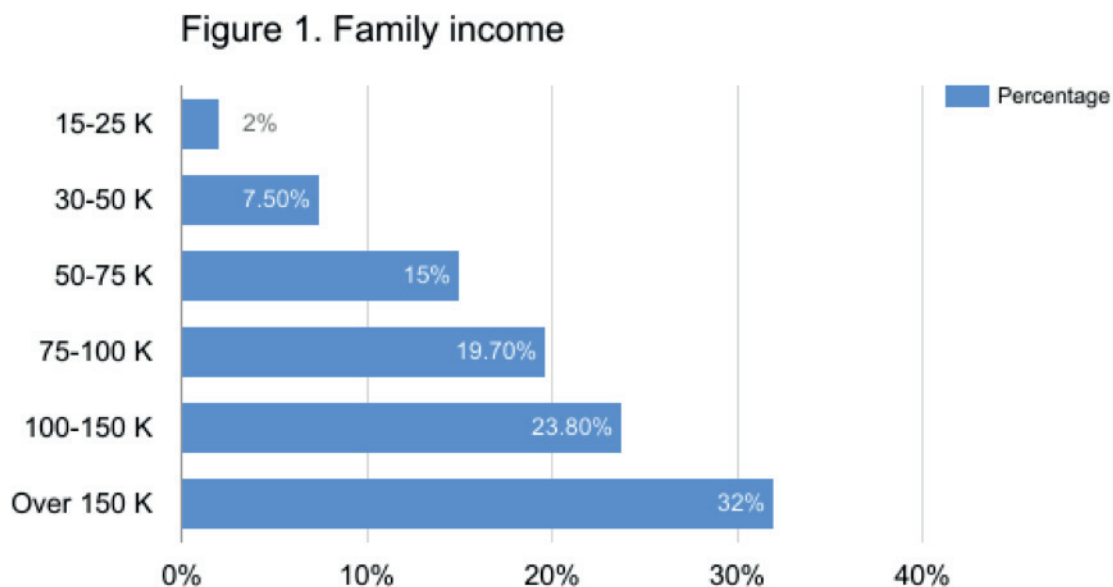
### Results

This study was designed to evaluate the parents' perspective for how schools approach food allergy management. Quantitative and qualitative analyses were completed on the collected data. The quantitative data were analyzed through SPSS while the qualitative data explored key thematic categories emphasized by parents of children with food allergies that were not adequately understood through quantitative statistics.

#### Demographic Characteristics of the Sample

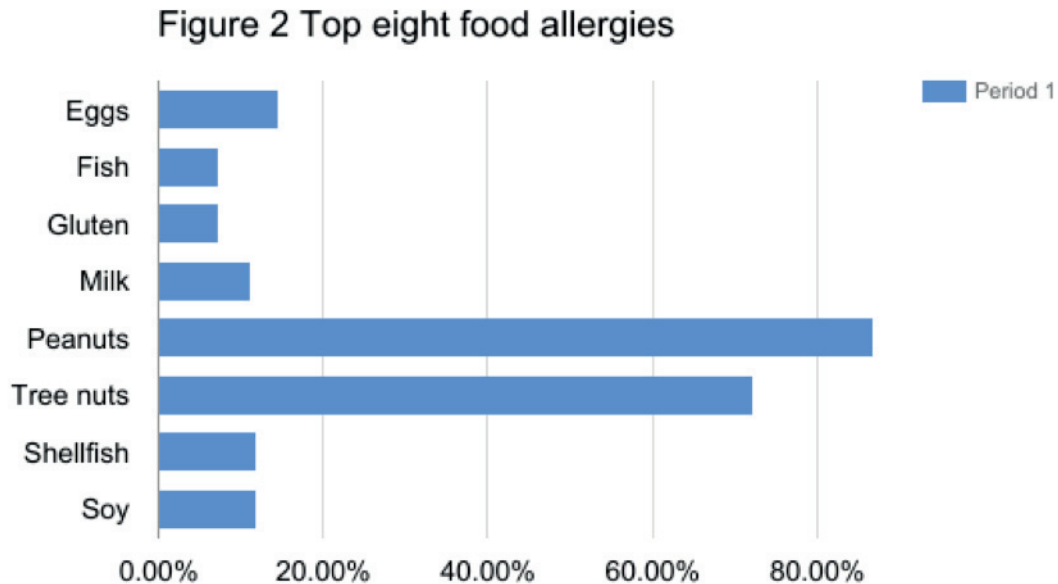
The survey was completed by parents of a child in kindergarten through twelfth grade with a food allergy. Of the 151 parents that completed the online survey, 149 (98.7%) were female. The children with the food allergy included 60 females (39.7%) and 91 males (60.3%). The majority of participants were Caucasian (78.1%), with a household income over \$100,000 (54.3%), and their children were enrolled in public schools (80.8%), mostly elementary schools (78.2%) (see figures 1 and 3). The age of food allergy diagnosis ranged from birth to 13 years old, with a mean age of 2.3 years old. The amount of food allergies each child had ranged from one to over five. The majority of children had two food allergies (37.1%), with the most common being peanut allergies (86.8%) (see figure 2). The children ranged in age from 4 years old to 18 years old, with the mean age 9 years old. Caregivers were asked about the length of time they had worked with their child's current school to manage their child's food allergy, and 53% had three or more years of experience. The participants were located in 32 different states in the United States, and there was one participant from Ireland and one participant from Canada. Some participants lived in a state with state food allergy guidelines (45.6%). During the 2015-

2016 school year, 20 (13.2%) of the children had a food allergy reaction at school, and five children had two reactions.

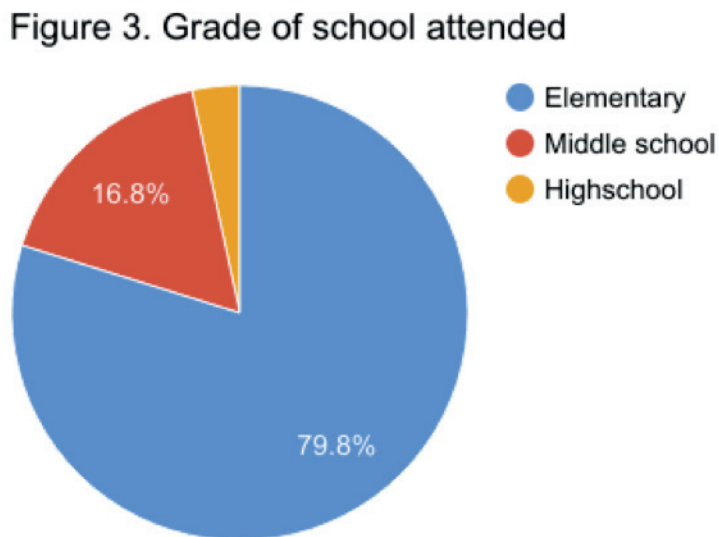


*Figure 1.* Illustrates the percentage of participants in each annual family income bracket.





*Figure 2.* Illustrates the top eight reported food allergies.



*Figure 3.* Illustrates the grade of the child with the food allergy.

## Reliability

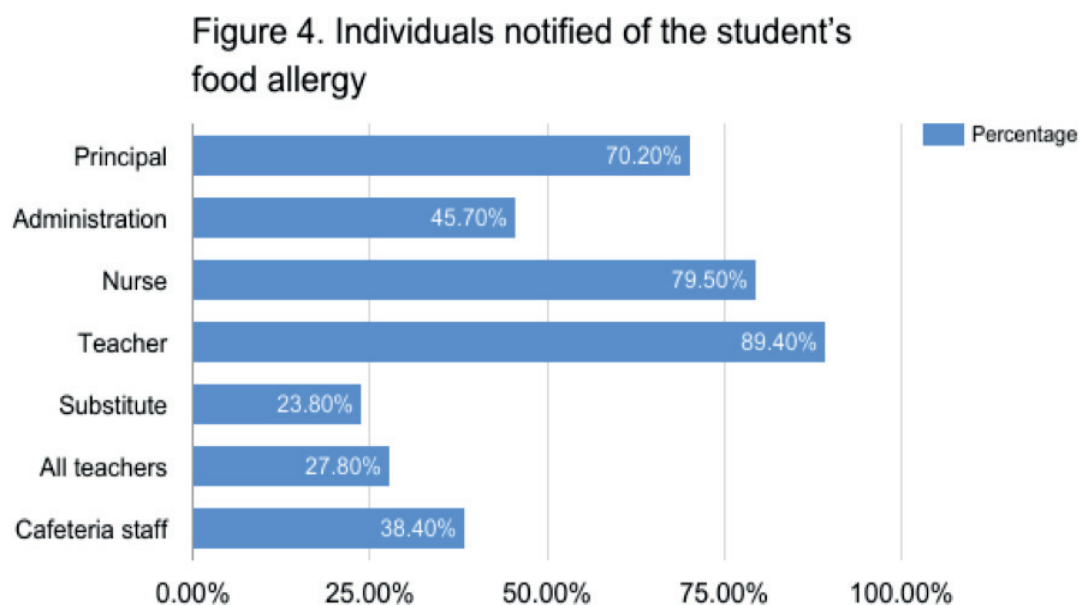
All survey questions in this index were answered using a Likert scale from extremely satisfied to extremely dissatisfied. Cronbach's  $\alpha$  was used to calculate the inter-item reliability of each category. Program Quality was used to identify the quality of school's food allergy management based on the number of beneficial policies in place. Program Quality revealed moderate inter-item reliability ( $\alpha = 0.767$ ) with a mean of 13.78 and standard deviation of 5.62. Policy Satisfaction identified parents' level of satisfaction with school policies. Policy Satisfaction revealed moderate inter-item reliability ( $\alpha = 0.776$ ) with a mean of 4.19 and standard deviation of 6.52. Relational Quality measured relational aspects of food allergy management at school. Relational Quality had poor inter-item reliability ( $\alpha = 0.560$ ) with a mean of 6.07 and standard deviation of 10.11. Knowledge included parent's assessment of the level of food allergy and the knowledge that school personnel had. Knowledge revealed strong inter-item reliability ( $\alpha = 0.881$ ), with a mean of 9.53 and standard deviation of 5.03. Descriptive statistics and frequencies were calculated for each revised category.

In addition to quantitative data, participants were invited to respond to five open-ended questions and were able to provide comments to six additional questions. Analysis of these data revealed five themes: policies to ensure safety, cross contamination, medication, social exclusion, and lack of education.

## Notification

When parents reported a food allergy for their child, they reported that the school contacted 113 (74.8%) of them within one month; however, 38 (17.9%) of parents never heard anything from the school. As seen in figure 4, the child's teacher (89.4%) and the school nurse

(79.5%) were the most likely to be notified of a student's food allergy. Nurses were reported at a higher rate (45%) for being the primary point of contact for managing their child's food allergy, as opposed to 31.1% of teachers.

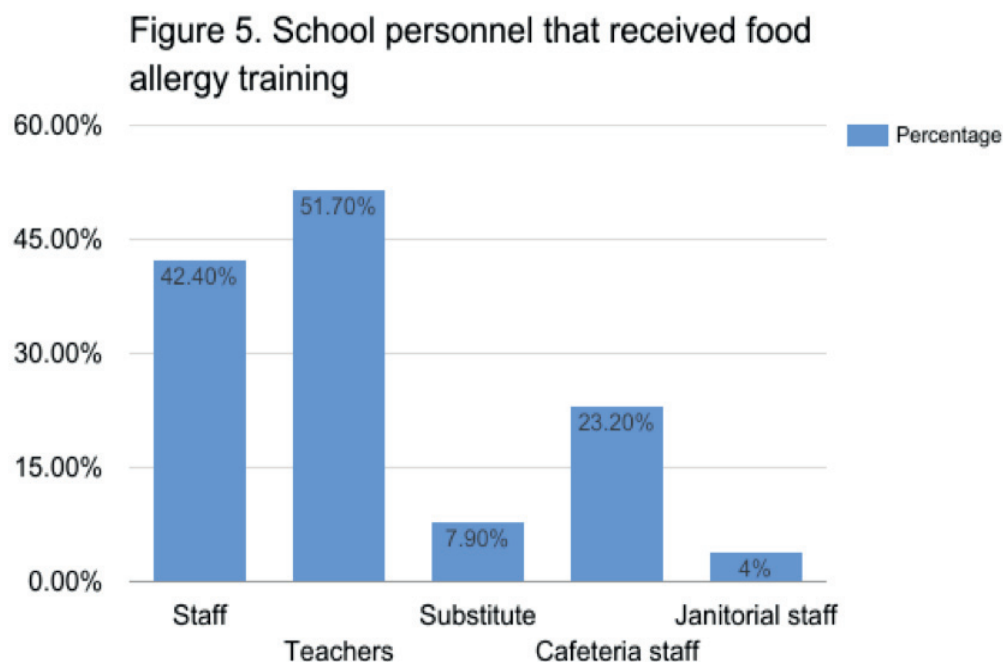


*Figure 4.* Individuals at the school who were notified of the student's food allergy.

**Qualitative responses to notification.** Parents that did not get a formal response from the school used different methods to address their child's needs. "I tried the nurse, admin staff and principal first, but learned no policy in place and indifferent. So focus now on working with the teacher." "We had to threaten legal action to get any response and allergy plan from the school."

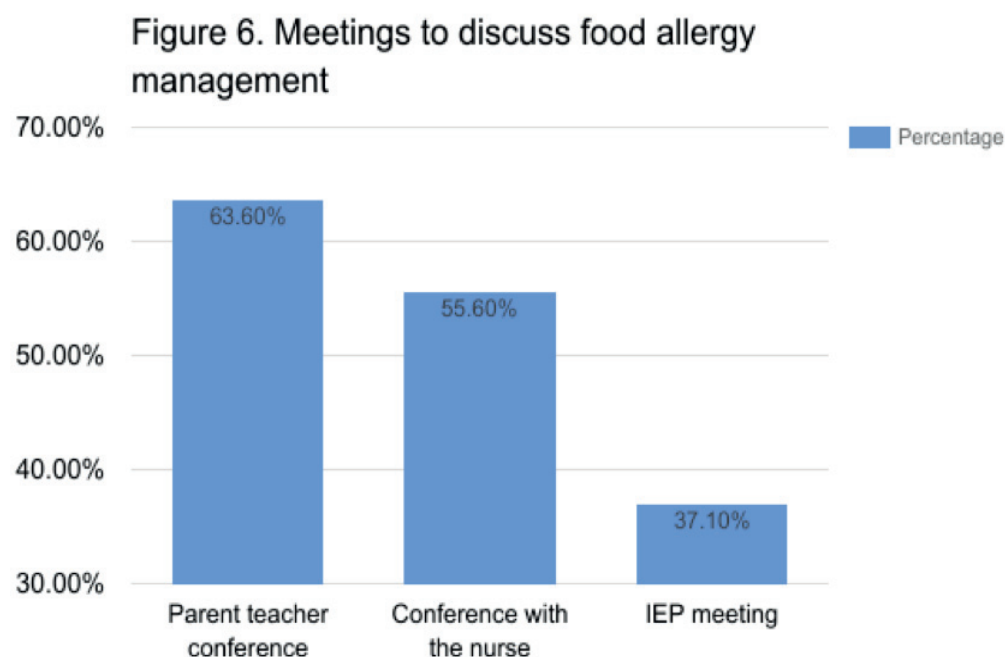
## Program Quality

**Training.** As seen in figure 5, parents reported that teachers were identified as being the most likely to receive food allergy training (51.7%), and that janitorial staff was least likely (4%) to receive training.



*Figure 5.* Percentages of school personnel that received food allergy training.

As figure 6 shows, parent-teacher conferences were the primary opportunities for food allergy meetings (63.6%) to occur. . Caregivers utilized various methods of education, the most common being providing medical forms (94%) and a letter from an allergist and/or pediatrician (76.8%).



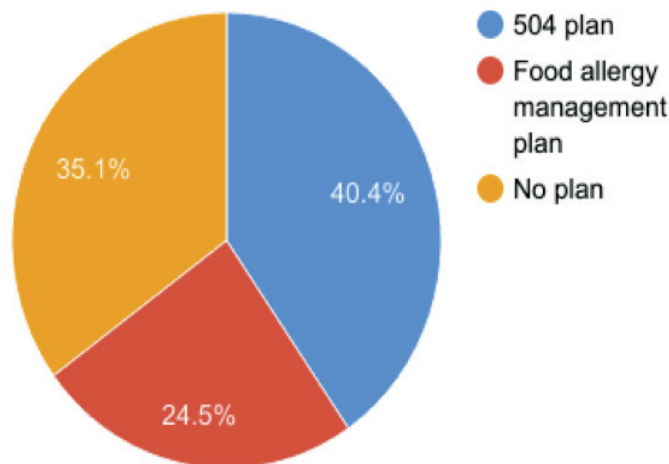
*Figure 6.* Percentage of types of meetings to discuss food allergy management.

***Qualitative responses to schools level of training.*** Within the qualitative responses that asked specifically about the level of training within schools, one participant summarized the lack of education by stating, “There is no training for the staff that supervises the children in the lunch area. No epi pen kept inside cafeteria.” Parents also identified the potential dangers related to lack of food allergy training. One parent said:

I feel the teacher is overly confident in dealing with food allergies. Her plan is to have all kids wash hands before and after eating. This is fine, but I had to point out to her that a teacher needed to turn on and off the tap, not the child who was covered in peanut butter. She has told me numerous times she had never thought of that. (This, after years of dealing with allergies in her class!) Plus, as a "job" in class, one of the kids suggested there should be a "peanut police" to make sure there were no stray peanuts/peanut butter left around the classroom after eating lunch. I thought that was a great idea, but incredibly the teacher has all kids, including those with peanut allergy, serve as "peanut police"... I am always terrified that some parent who thinks food allergies are not real will indirectly harm my child by bringing in something that is not safe for everyone.

**Policies to ensure safety.** Of the 151 children, 40.4% (61) had a 504 plan that addressed food allergy management (see figure 7). Of the 106 food allergy management and 504 plans that had been created, 79.2% (84) were implemented within one month. However, 35.1% of children had no 504 or food allergy management plan implemented. There was a weak correlation ( $RHO= 0.398$ ,  $p = 0.001$ ) between the amount of time to initial contact and the speed with which the food allergy management plan was created.

**Figure 7. Percentage of food allergy management plans**

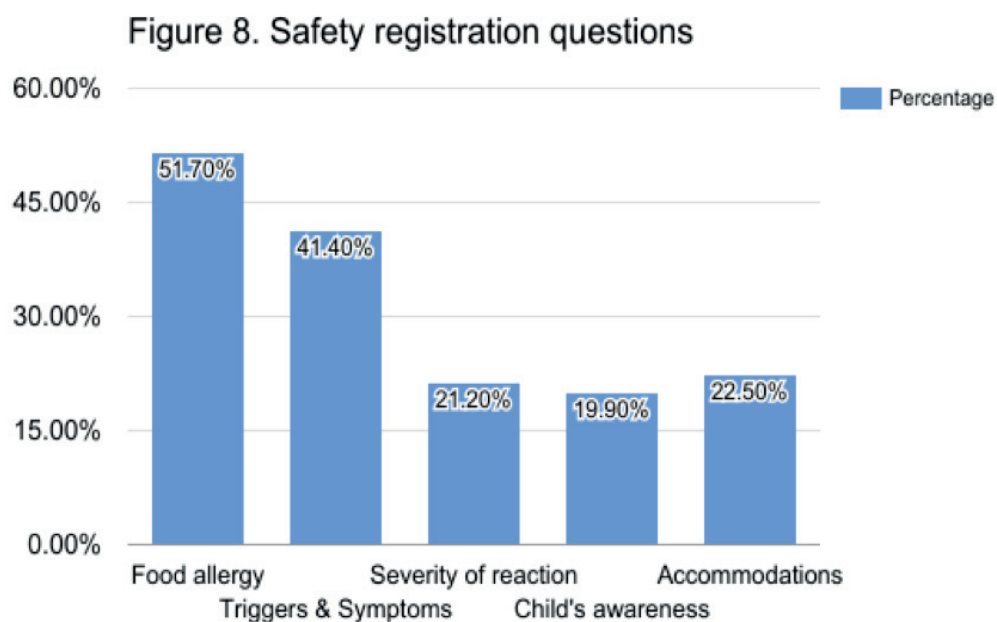


*Figure 7. Percentage and types of food allergy management plans.*

Living in a state with food allergy management guidelines was not significantly correlated with receiving a food allergy management plan, nor with the amount of time it took for the food allergy management plan to be implemented. Income was not significantly correlated to having a food allergy management plan created or implemented. The Chi Square could not be calculated due to missing or very low cell size in lower income brackets, in that

there were not enough people (five people needed to complete a Chi Square) that made under \$50,000 a year.

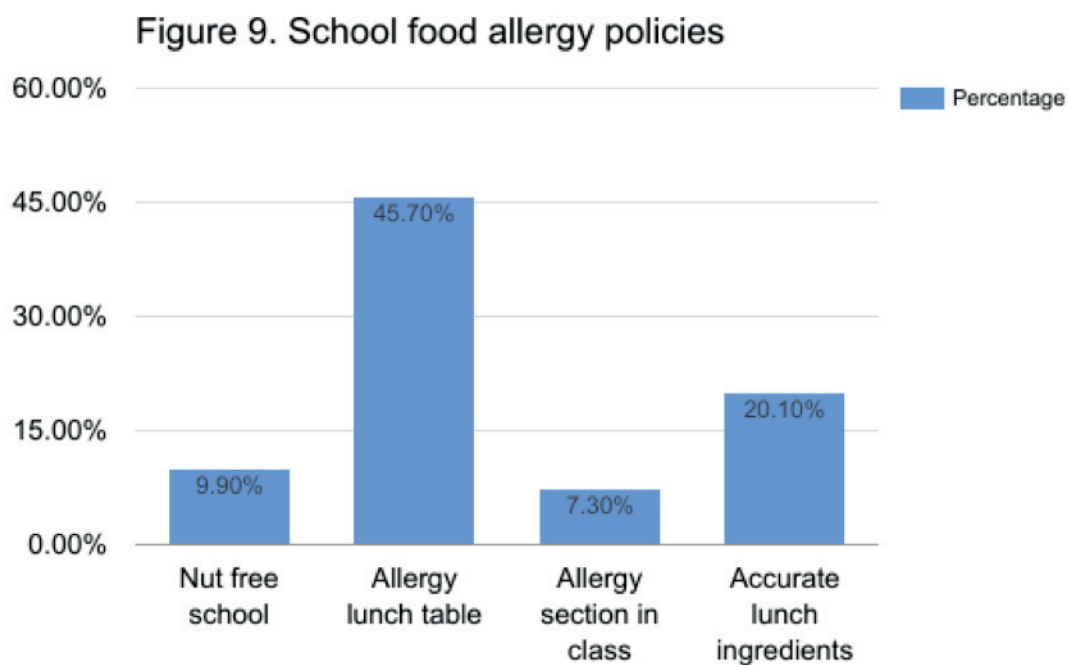
During school registration, 51.7% (78) of caregivers were asked if their child had a food allergy (see figure 8), along with additional information about the food allergy. However, few parents were asked about food allergy management plans.



*Figure 8.* Types of safety questions about food allergies during school registration.

The majority of parents (90%) identified safety concerns as their primary challenge in managing their child's food allergy. Of those, 25.8% (39) specifically identified safety concerns at school. Parents were asked about aspects of the school environment as it related to their child's food allergy. The majority of parents, 74.2% (112), reported that their child's food allergy impacts their day at school. Parents identified 9.9% (15) schools as nut free, 7.3% (11) classes with a designated food allergy section, 45.7% (69) lunch sections with a designated food allergy

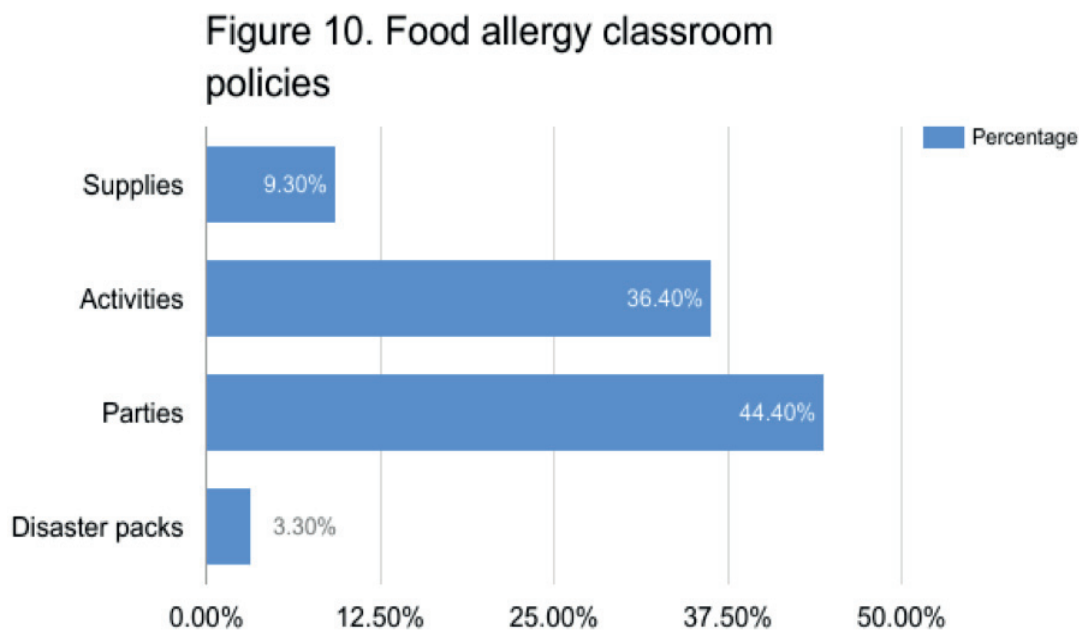
section, and 20.1% provided up-to-date ingredients for lunches (see figure 9).



*Figure 9.* School food allergy policies.

As seen in figure 10, schools were most likely to have food allergy policies regarding class parties and school events that have food (44.4%), while a minority (9.3%) looked at food allergy concerns with the class supplies.





*Figure 10.* Policies around food allergies within the classroom.

***Qualitative responses to policies to ensure safety.*** The majority of caregivers were satisfied with their child’s food allergy management plan. One parent said, “We have a solid 504 plan which has made all the difference. The school often turns to me for resources, advice and information. Plus, I know my child's rights so I am able to advocate effectively.”

Caregivers spoke to the lack of consistency related to school policies and food allergies. For example, as one parent said, “every teacher decides how to deal with allergies in their classroom. So, each year, it's different. In my daughter's current class, there are no bans of any common allergens. She sits side-by-side with students eating peanut butter.” Another parent reported, “Everything you do is a great challenge.” Some parents reported that school policies were too lax, including this parent, who wrote,

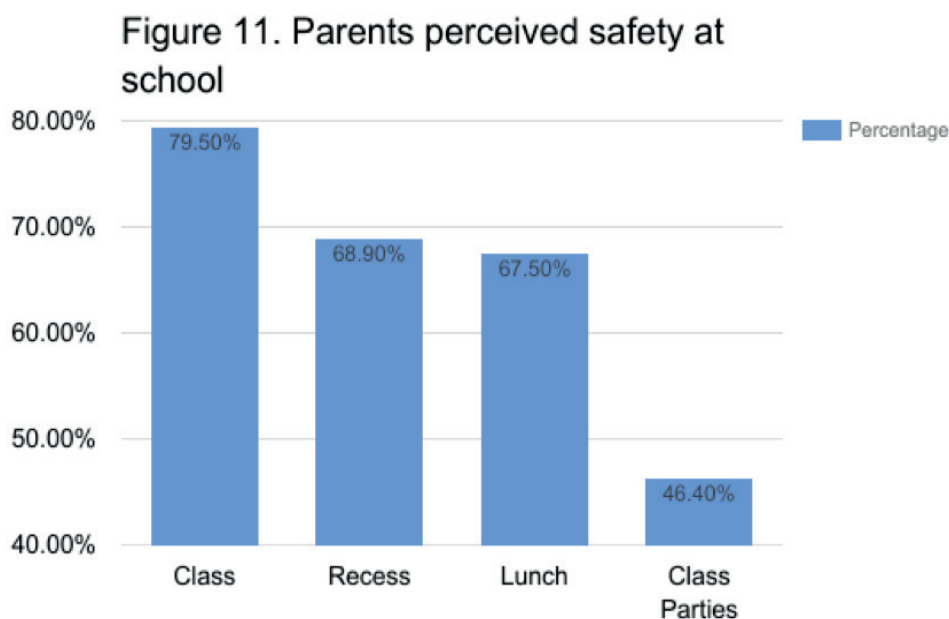
I find that school officials are still reluctant to place the SAFEST possible policies in place in regards to food allergies. The school district nurse made a comment

about how she understands why parents would want to send peanut butter to school, even if a child's life is at stake.

One parent reported that their child was unable to participate in extracurricular activities because, “Many after school activities, summer camps do not have the skills or controls in place to keep our son safe.” Some parents ultimately left their child’s school, including this parent who said, “We left a private school due to my son's safety risk and started at a public school, which has been great,” and another parent who wrote,

We had to leave public school beginning in Kindergarten due to the lack of understanding by the staff and parents of other children. We got the 504 but still felt that the district wasn't doing enough to keep him safe and manage his anxiety.

**Cross contamination.** As it relates to their food allergy, parents were asked if their child was safe during different times of the school day (see figure 11). Parents reported that their child was safest in class (79.5%), but least safe during class parties with food (46.4%).



*Figure 11.* Parents’ perceived safety throughout the school day.

***Qualitative responses to cross contamination.*** Caregivers reported challenges avoiding cross contamination (20.1%). One parent wrote, “checking foods to make sure that there is not a chance of any nut product contained and getting people to understand that nuts can hide in many foods that do not ‘contain’ nuts.” Avoiding allergens can be difficult for caregivers with experience, and some of this difficulty is related to poor labeling laws. One parent shared, “there are no laws for foods being labeled for cross contamination so unless we already know the company and their practices we have to avoid new foods.” As a result, labels need to be checked every time food is purchased because manufacturers can change ingredients. A parent said:

Labels and ingredients change on a weekly basis so NOTHING can be eaten without reading the label EVERY TIME and/or contacting the manufacturer to check for cross-contamination issues (labeling for cross contact is voluntary and not required by the FDA).

Caregivers provided examples of cross contamination risks: “Fear of cross contaminated food and objects in the classroom;” “kids made projects out of recycled materials for earth day and there were boxes donated that had contained peanuts, nutter butters, etc. The dust/contamination from that can trigger a reaction;” “My son has told me the tables are sometimes cleaned with the same sponges so peanut allergens could be spread to the ‘allergy free’ table.”

One parent commented that one of the most difficult things to manage within the school setting is when fellow parents bring food into the class for parties.

I would like the teacher to be more insistent with other parents about not bringing in home-baked goods and other non-safe items. She cannot take their word for it that it is safe. She can recommend safe alternatives. There is a snack rotation and I provide alternative snacks for him, but it isn't that hard to make other parents stick to an approved safe list.

Parents noted concern for their child when they were not present (20.8%) due to events such as; “after school program snacks often have dairy and they sometimes forget my son shouldn't have it and give it to him.” Two parents talked about the food allergy management problems that were present even after their 504 was established. One parent wrote:

Teachers don't comply with 504 and have an emergency meeting and in a few days it's right back to the same thing. Passing out food in the classrooms with no warning, teachers eating nuts at their desk not washing hands.

Another parent said:

Our teacher refuses to acknowledge our sons allergies. Even after a 504 meeting and providing her with facts, she still doesn't believe allergies exist. Or at least she acts as though we're all making this up. She has violated our 504 at least once and tried the 2nd time.

**Medication.** Of the 151 participants, 94% of children (142) required full time access to their food allergy medication; however, of those, only 42.3% had their medication with them. As seen in figure 12, schools most frequently stored epinephrine auto injectors in the nurses' office (68.9%) and the classroom (45%), and were less likely to have medication in the cafeteria (7.3%). Only 22.5% (34) of the schools paid for epinephrine auto injectors.

Figure 12. Storage of medication

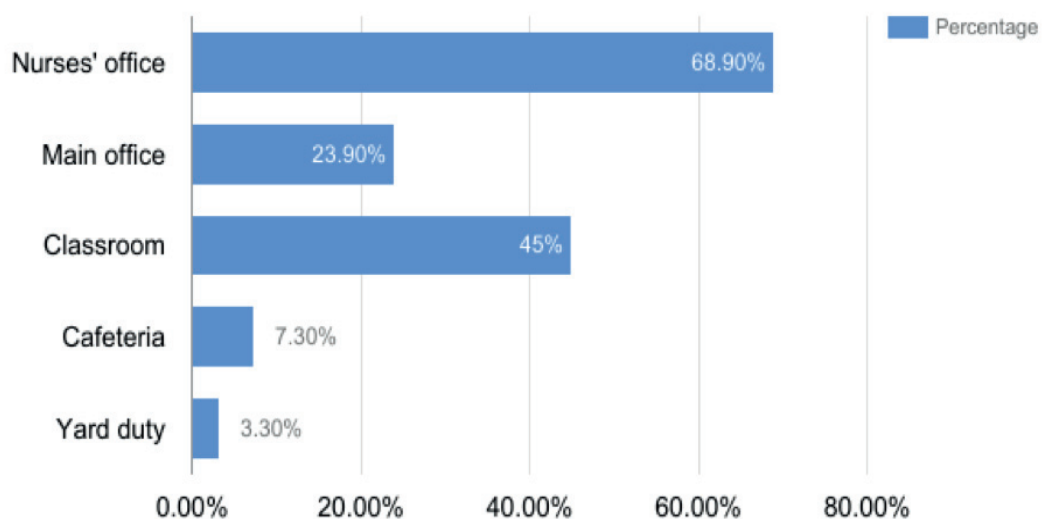
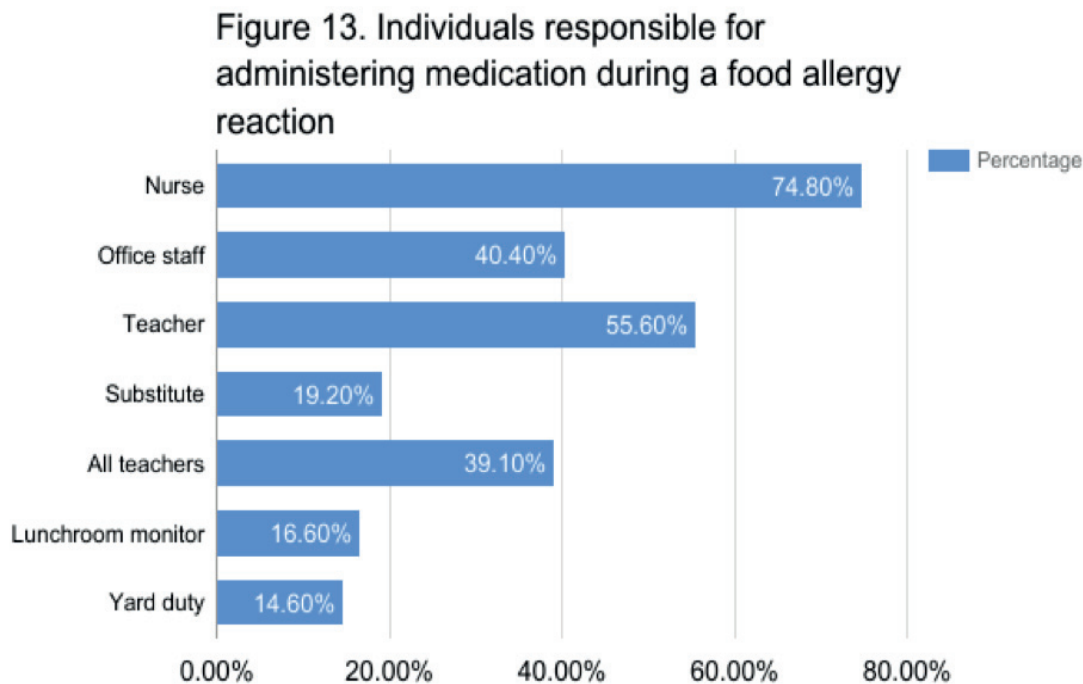


Figure 12. Location of medication storage.

As seen in figure 13, nurses were identified as the individual for administering medication 74.8% of the time, while teachers were identified as administering medication 55.6% of the time. Lunchroom monitors were identified as administering the medication 16.6% of the time.



*Figure 13.* Individuals responsible for administering medication during a food allergy reaction.

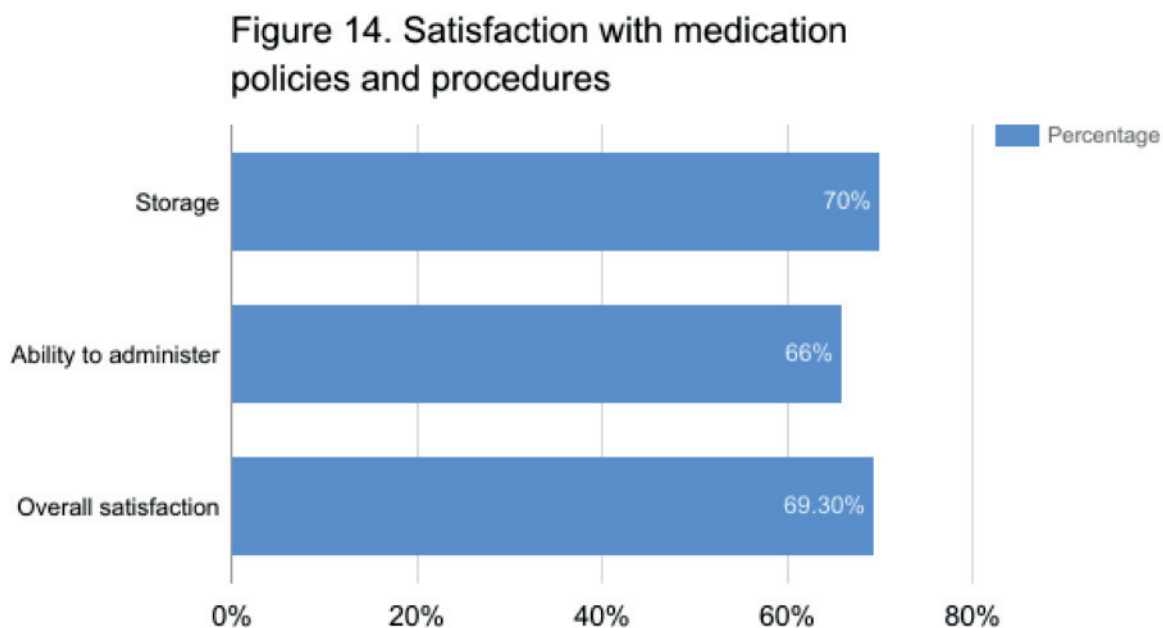
***Qualitative responses to medication policy.*** Some parents commented about potential delays in treatment based on each school’s medication policy and who had access to the child’s allergy medication. One person wrote, “Front desk staff keeps a key to pad locked cabinet in nurse station. Hope cabinet is better organized now because when I was shown the storage area, the staff could not locate my son's medication quickly.” Another parent reported, “Our school recently lost some of our medicine. They have withheld some from her and that led to meetings with the staff and principal.” One parent shared,

The Epi pens are kept locked in the nurse's office? How long will it take to find the nurse, open cabinet, run it down to my child and administer? What if the nurse has stepped away? I have fought for epi pens to be available in the classroom and on my child, but everything is a battle. Everything.

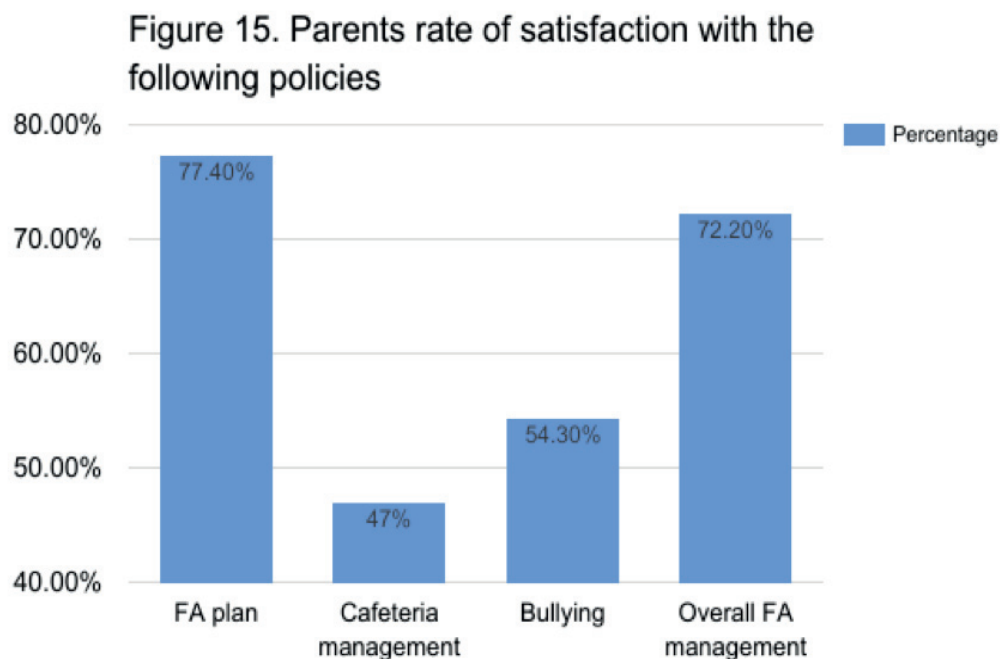
An example of clear medication administration policy for a school was shared by one parent, who shared: “In our district, ALL personnel is authorized to administer the meds under vocal directions thru a 911 call. Conversely, ALL staff are encouraged to call 911 asap and follow their direction if call can be made without delays.” Other parents reported a lack of policy regarding a reaction, with one parent writing, “The principal told me the firehouse is just around the corner and they should arrive in minutes....” and another parent saying,

They don't have a policy, nor have they discussed this. They said that the volunteers can choose whether or not they want to be trained on proper use of an epi pen, but it isn't their protocol to bring it up to them on their own.

**Policy satisfaction.** As seen in figure 14, parents reported similar satisfaction rates for the storage of medication, the ability of the person administering medication and overall satisfaction with medication policies and procedures. Parents were less satisfied with food allergy management in the cafeteria (47%) and with their school’s bullying policy (54.3%), as seen in figure 15. The majority of those who received a food allergy management plan were satisfied with the plan (77.4%), and overall food allergy management satisfaction was 72.2%.



*Figure 14.* Parents' satisfaction with school medication policies and procedures.



*Figure 15.* Parents' rate of satisfaction with school policies regarding food allergies.

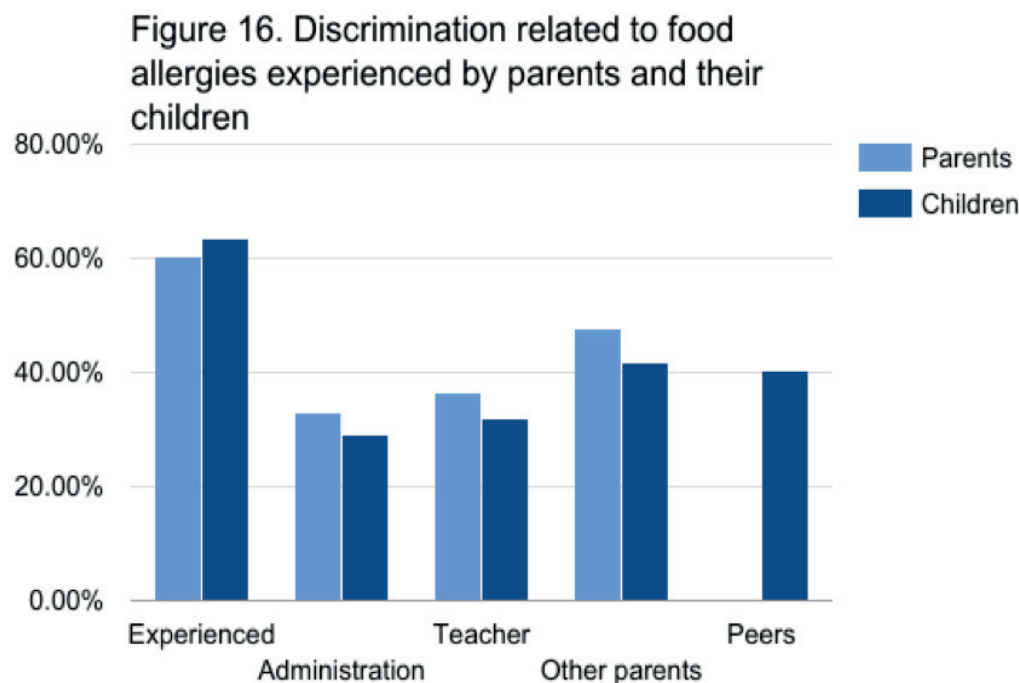


The overall satisfaction with food allergy management was most strongly correlated Policy Satisfaction (sig. (2-tailed) .000, correlation -.645). Multiple regression indicated that 40.2% of overall satisfaction with food allergy management is explained by Policy Satisfaction. An additional 4.6% is explained by Knowledge.

### **Relational Quality**

**Social exclusion.** The third major theme reported by participants was the experience of exclusion based on their child's food allergy. The participants reported that 2% of teachers were allowed to refuse to have a child in their classroom due to their food allergies. Additionally, 15.9% (24) of caregivers felt that their child's food allergy negatively affected their relationship with their child's teacher.

Participants also reported encountering disrespectful interactions by peers (10.6%) and by other parents (29.8%). Figure 16 depicts the amount of discrimination experienced in the represented sample. Discrimination was experienced by 60.3% of parents and 63.6% of children. The majority of discrimination was from fellow parents. Of the children who experienced discrimination, 65.6% was from other parents, 63.5% was from peers, 53.3% was from teachers, and 45.8% was from school administration. The majority of parents (80.2%) were satisfied with the teacher's willingness to accommodate their child's food allergy needs.



*Figure 16.* Discrimination related to food allergies experienced by parents and their children.

Caregivers reported difficulty eating outside the home (29.3%), and the additional planning required for daily life, social events, and travel added to their difficulty. In an attempt to address safety issues, 45.7% of caregivers stated their schools segregated children with food allergies by having them sit at a special table.

***Parents' qualitative responses to social exclusion.*** One of the main themes from the qualitative data that the participants identified was social exclusion (26%). Managing a food allergy can be restricting to the family, and, as one participant wrote, “requires good planning, preparing, research, there is no spontaneity, no easy task with a food allergic child because food is everywhere.” Another participant shared, “traveling is especially difficult because ‘safe’ food is hard to find on the road! We always have to stay somewhere with a kitchen so we can cook for ourselves.”

Some parents reported that they needed to be available for their child's extracurricular activities, as one parent summarized here:

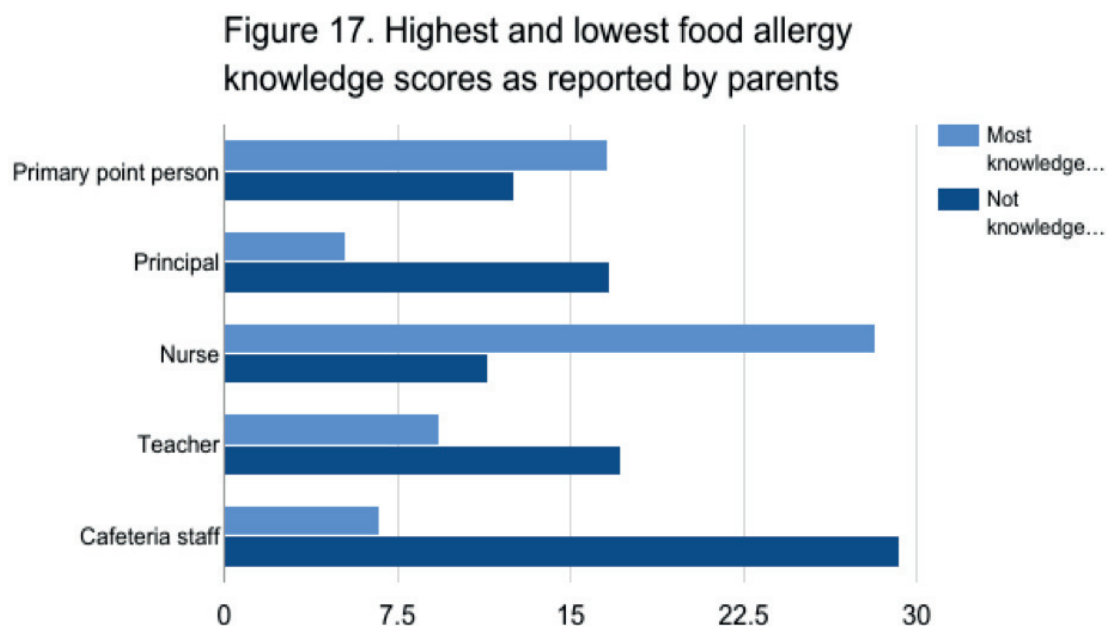
When his school band goes away on weekend trips, I [his mom] always have to go too so I can supply him with food, because he can't eat at the restaurants they take the kids to. It's also upsetting because people assume we're being overprotective, because they don't understand the real danger of consuming even trace amounts of an allergen.

Some parents talked specifically about the challenges related to attitudes. One participant said: "Some parents and adults lack of compassion and empathy is biggest challenge. Seems to be a widespread American attitude of 'why should we be inconvenienced by YOUR kids allergy'... regardless if they are speaking about keeping a child alive."

Parents' provided examples of their child being excluded from social activities that involve food, such as: "making them sit at a table all alone during lunch;" "my daughter is singled out and currently eats alone which is ruining her self-confidence;" and "my kids are always out to the side separated from their class when celebrating with food."

### **Knowledge**

As seen in figure 17, teachers were rated moderately to extremely knowledgeable about food allergies by 55.6% of parents. Parents reported the school nurse as being most knowledgeable (78.1%) and the cafeteria staff the least knowledgeable (47.7%).



*Figure 17.* Highest and lowest food allergy knowledge scores as reported by parents.

**Parents’ qualitative responses to lack of food allergy knowledge.** The second major theme identified by 37.3% (56) of parents was lack of food allergy knowledge. Underestimating the seriousness of food allergies was identified by caregivers. One participant said, “getting others to understand that it is a life-threatening condition and reducing the possibility of accidental exposure is key to managing the allergy.” Another one shared, “I do not believe she truly understands the severity of his allergy. He has been at risk in the classroom a few times. I have spoken to her numerous times and had to have his 504 reworded,” and “even with a 504 in place, the teacher still brings allergen into the classroom.” One parent reported concerns that others would not be able to identify and treat a reaction and said, “[I am] not feeling confident people know how to spot a reaction and give epinephrine quickly.”

As a result of schools lacking knowledge, 8.1% of parents engaged in advocacy efforts to improve the climate for their child. Advocacy was identified by many parents as a response method for the lack of education about and experience with food allergies in the school system. For example, one caregiver spoke to the importance of additional training by writing, “Advocating for her school and extracurricular activities that her 504 is applicable and the lack of food allergy management/training of school staff....often complete ignorance.” It was necessary for one parent to use a professional advocate; “We have spent thousands of dollars with an educational advocate to get us to an acceptable level. It's constant and ongoing. We cannot stop using the advocate or things deteriorate.” One parent reported that they had to become an advocate to address poor food allergy management at their school, “I founded a non-profit and advocated at the district level to change policy.”

## Chapter V

### Discussion

Food allergy management in schools is a global issue, and consistent quality food allergy management is not in place (Cummings et al., 2010; Lawlis et al., 2017; Parnell et al., 2016; Tsuang & Wang, 2016; Wang, Young, & Nowak-Wegrzyn, 2014). The current study sought to gain an in depth understanding of the policies and procedures implemented by schools and determine whether or not families found them useful. Previous food allergy management studies focused on a geographic region, whereas the current study had participants from thirty-two states (Gupta et al., 2014; Pulcini et al., 2010). The findings of this study were grouped in four main categories: Program Quality, Policy Satisfaction, Relational Quality, and Knowledge. This study enhanced prior research on food allergy management in schools, and the psychological impact of food allergies from the parent's perspective.

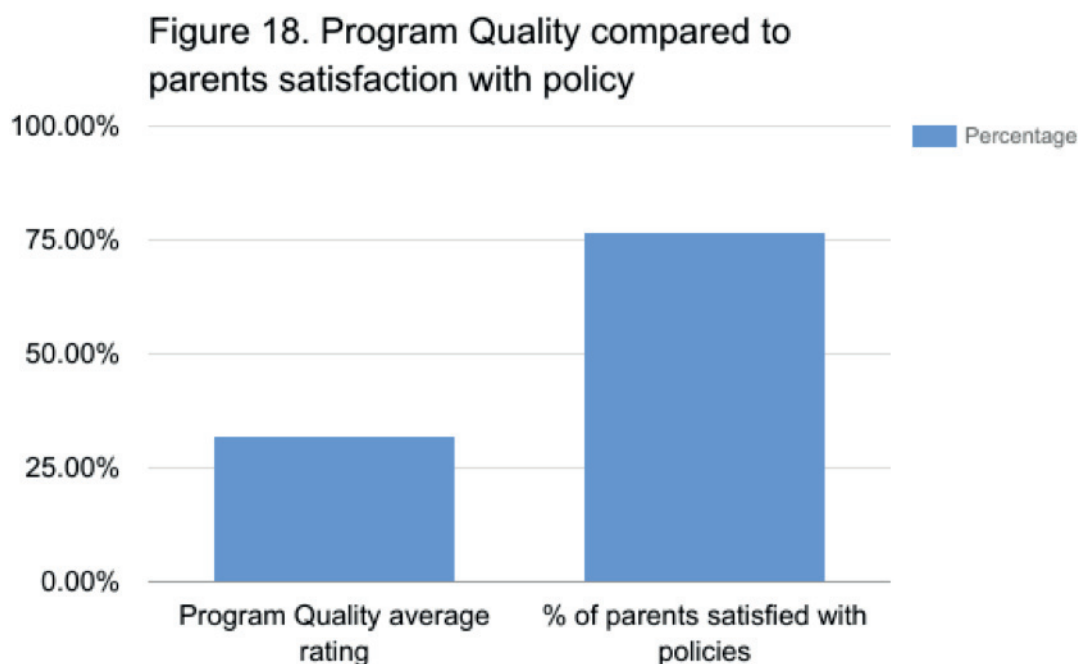
Previous research (e.g., Broom-Stone, 2012; Cummings et al., 2010; LeBovidge et al., 2006; Lyons & Forde, 2004; Parnell et al., 2016) determined that life-threatening food allergies causes significant psychological distress, some of which is related to unsafe school environments. Data from this study further confirms safety as a primary concern when it comes to food allergies, with (90.6%) reporting safety as their primary concern, and 26% of those participants specifically reported safety concerns at school. These findings corresponded with previous research that parents experience increased anxiety due to the possibility of accidental ingestion at school (Broome-Stone, 2012; Kelsay, 2003). As previously stated, schools are not meeting the standard of care set forth in national and state guidelines (Boyce et al., 2010; Budgen et al. 2012) which is consistent with the findings of this study.

The need for food allergy education has been well documented (Clegg & Ritchie, 2001; Lawlis et al., 2017; Parnell et al., 2016; Tsuang & Wang 2016) and was also demonstrated in this study. Data from this study also revealed no significant differences between states with or without state guidelines. A study by Cicutto and colleagues (2012) examined the compliance of food allergy action plans and anaphylaxis in region with and without guidelines and legislative power. They found that there was significantly greater compliance in regions with legislative power (Cicutto et al., 2012). This further supports a need for more standardized food allergy laws (Lawlis et al., 2017).

### **Policies to Ensure Safety**

The federal laws that protect children with life-threatening food allergies include the Americans with Disabilities Act (ADA), as well as section 504 of the Rehabilitation Act which provides accommodations to ensure they have access to the learning environment (Sicherer & Mahr, 2010; Walton, 2015). In this study, 40.4% of participants had a 504 plan, and 24.5% had an active food allergy management plan, which was higher than previously reported rates (6% to 69%) (Ercan et al., 2012; Gupta et al., 2014; Pulcini et al., 2010; Rhim & McMorris, 2001; Sicherer et al. 2001; Verduin & Corbett, 2009). The majority of schools in this study had no policies to ensure the safety of children with food allergies, nor did they allow children to have their medication with them. Pulcini et al. (2010) noted that 25% of schools made no accommodations for children with food allergies, and that only 14% of children had medication with them. National guidelines recommend schools have stock epinephrine and train multiple staff members to recognize a reaction and administer medication; however, most states do not require schools to carry stock epinephrine, nor is there adequate training (Parnell et al., 2016; Sicherer et al., 2010; Tsuang & Wang, 2016).

The population in the current study had a slightly higher life-threatening reaction rate (55.6%) than the national average of 40% reported by FARE (2017). In this study, however, 13.2% of children had a food allergy reaction at school, lower than the 16-18% previously reported (Gupta et al., 2012; McIntyre et al., 2005; Sicherer et al., 2001; Young et al., 2009). This sample contained higher rates of food allergy management plans which led to children who had fewer food allergy reactions at school. This further supports implementation of food allergy policies within school settings.



*Figure 18.* Program quality compared to parent’s satisfaction with the policy.

As seen in figure 18, parents’ reported high levels of policy satisfaction, but also that many recommendations highlighted in previous studies (e.g., Gupta et al., 2012; Sicherer & Mahr, 2010) were not utilized. Although schools had minimal beneficial policies and procedures, parents tended to report higher levels of satisfaction. It is hypothesized that although schools had limited food allergy policies, there was a high number of food allergy management



plans that were followed, which may have increased satisfaction. Adherence to food allergy management plans may have compensated for the lack of school policies.

Another contributing factor to reported satisfaction of policies is the amount of experience. The majority of caregivers in the sample (81.5%) had previous experience working with the school to manage their child's food allergy. This may have contributed to high overall satisfaction rates. As parents become more experienced in dealing with their child's food allergies, they learn effective strategies to work with their child's school and thus have a more positive experience. Lawlis et al. (2017) reported that parents are the primary reason food allergy guidelines are implemented, which may be the case in this study. Caregivers with less experience managing food allergies may have had different response trends. It is also unknown if the participants would have answered questions in a similar fashion if they had been asked at the start of their food allergy management journey.

### **Cultural Demographics**

While the national childhood food allergy rate is 8%, research on food allergies is predominantly completed by Caucasian participants (FARE, 2017). In the current study, the researcher attempted to seek a more diverse participant pool. Nevertheless, 78.1% of participants were Caucasian. This lack of participation from Asian and African-American families is concerning, especially in light of the research reporting these ethnic groups are at a higher risk for developing food allergies (Gupta et al., 2011). Additionally, individuals from ethnic minorities are less likely to receive a medical diagnosis (Taylor-Black & Wang, 2012). The data from this study provided support for this argument because in order to participate in this study, the parents were required to have a child with a medical diagnosis.

Socioeconomic status continues to be a confounding variable in food allergy research. In this study, 78.1% of children were Caucasian, with health insurance (96.7%) and under the care of an allergist (87.4%). The majority of this sample (75.8%) had an annual family income over \$75K, and 64.9% had a food allergy management plan. The majority of participants in this study had financial resources, time, and experience advocating for their child. These findings parallel the findings of Jackson et al. (2013), who reported that children from high-income families were more likely to have a food allergy diagnosis and food allergy management plans at school when compared to children from families below the poverty line. Higher rates of diagnosis among affluent families may be directly related to their access to health care. It is possible that parents with less access to resources are less aware of their child's rights, making it very difficult to successfully advocate for their child.

To be covered under the ADA and eligible for a 504 plan, the child needs a medical diagnosis of a life-threatening food allergy (Sicherer & Mahr, 2010; Walton, 2015). In this respect, the medical model is problematic because it operates under the assumption that all families have equal access to allergy testing. This disconnect between policy and those who use the policy has yet to be addressed. Policies need to include the marginalized groups that do not have equal access to health care. More studies are needed to examine the socioeconomic disparities in food allergy management in schools, and access to health care (Bilaver et al., 2016; DeSantiago-Cardenas et al., 2015; Gupta et al., 2014). Children with a food allergy who are raised in an economically privileged family and community appear to access services at a higher rate and thus are likely to experience less psychological distress (Evans, Broido, Brown, & Wilke, 2017). Fatal anaphylaxis was significantly associated with African Americans (Jerschow, Lin, Scaperotti, & McGinn, 2014). Schools in districts with more low-income families were less

likely to have medication at school (Frost & Chalin, 2005). Another economic disparity may be for children who rely on the National School Lunch Program. In this study only 20.1% of schools provide accurate up-to-date ingredients and food allergy information. The number of children with food allergies currently on the National School Lunch Program was not found in previous research, which may indicate that more research on this topic is needed. Future studies need to target lower socioeconomic populations, as well as marginalized ethnic groups. Future research needs to explore the differences that might arise for children with food allergies who grow up with inadequate financial resources.

However unintentional, all of these inequalities create a form of oppression that exists at the personal, institutional, and cultural levels. Currently, policies are being created through a legal lens driven by a medical model rather than a social justice model. Most of the policies are being formulated and implemented by people who do not have that disability and who may even have limited knowledge of the disability, creating further potential for oppression. The medical model views an individual with a disability as the problem, whereas the social justice model views the barriers in one's environment and seeks accommodations (Evans, Broido, Brown, & Wilke, 2017). Thus, more appropriate and equitable legislation is needed.

### **Social Exclusion**

The number one form of oppression identified in past research and supported by this research is the experience of social exclusion. According to Jaffe Food Allergy institute “avoidance measures should minimize separation of children with food allergies from their peers (Egan & Sicherer, 2016). In the current study, 45.7% of the schools had a designated food allergy section in the cafeteria. Segregating children with a food allergy to a specific section is discriminatory, disregards psychological needs of children, and produces negative psychological

consequences (Gaudreau, 2000). Moreover, segregation might not even be an effective strategy to avoid cross contamination.

Additionally, this kind of segregation makes children socially vulnerable and may be the precursor to bullying (Bacal, 2013). Peers may become resentful when they are not allowed to bring certain foods to school, or feel the child with a food allergy receives special treatment, and these negative feelings may lead to bullying (Thelen & Cameron, 2012). In the current sample, 40.4% of children experienced bullying related to their food allergy, which is a slightly higher rate of bullying than found previously (31.5%) by Liberman et al. (2010). Data from this study confirms that schools focus on an exclusionary model emphasizing the focus on singling out children with food allergies rather than an inclusionary model, which would designate tables for children who bring food containing allergens.

### **Discrimination**

In this sample, 60% of parents and 64% of children experienced discrimination at school by other parents, peers, teachers and school administration. Perceived discrimination is highly correlated with depression, anxiety, chronic stress, posttraumatic stress disorder, and low self-esteem (Cooke, Bowie, & Carrere, 2014). Experiencing discrimination, social exclusion, and unfair treatment can negatively impact child development (Cooke et al., 2014; Oxman-Martinez et al., 2012). Although the literature has indicated that most discrimination comes from teachers and staff, the results of the current study suggest that parents of classmates were the worst perpetrators. Additionally, 38.1% of children in the current study experienced discrimination from teachers. Although it is illegal to refuse to have a child in their class because of disability, 2% of teachers did. As Oxman-Martinez et al. (2012) wrote, “Perceived discrimination by teachers was found to predict lower sense of social competence in peer relationships, lower self-

esteem, and less sense of academic competence” (pp. 383-384). School principals and teachers are less knowledgeable about social and emotional issues related to food allergies; in fact, 37.2% were aware of emotional consequences and 10.2% knew about social difficulties (Polloni, Lazzaroto, Toniolo, Duocolin, & Murano, 2013).

Since the data confirms this high level of discrimination, it is recommended that systems of care pay particular attention to how children with food allergies cope with discrimination. Specifically, it is recommended that school psychologists to screen for discrimination. Food allergy education needs to include emotional concerns as well as safety measures (Parnell et al., 2016). School personnel, especially teachers, need to be made aware of the potential psychological distress children can experience as well as concrete examples of ways teachers have discriminated children with food allergies in the past. Further research needs to dissect the impact this discrimination has on or influences self-esteem, anxiety, and depression.

### **Food Allergy Education**

Previous studies noted food allergy education regarding allergy avoidance, recognizing a reaction, and treating a reaction (Parnell, et al., 2016; Polloni et al., 2013; Polloni et al., 2016). In this study, parents reported that a small percentage of school personnel were extremely knowledgeable about food allergies including the nurse (28.2%), primary point person (16.6%), and teacher (9.3%). Participants in this study reported a general lack of understanding and empathy. There are several organizations that offer effective food allergy education programs (Alta et al., 2016; Shah et al., 2013). The national asthma education program for school personnel is in place and effective; however, there is no national food allergy education program (Alta et al., 2016; Zuniga, et al., 2010). Food allergy education could also foster a school culture of inclusion rather than isolation. Food allergy education for faculty, parents and students could

decrease stigma for children with food allergies, which may increase empathy and decrease bullying.

**Resources for parents.** Many parents reported that they did not receive enough information when their child was diagnosed, with a particular lack of instruction for using an epinephrine pen (Mandell et al. 2002). A new diagnosis can leave parents feeling confused, isolated, and uncertain how to keep their child safe (Klennert & Robinson, 2008). Resources and education for parents needs to address the developmental stage of their child. For example, a parent who is new to food allergies needs safety tips on reading labels, learning to identify a reaction, and how to treat a reaction. Parents of school age children with more experience prefer practical advice from other food allergy parents (Gillespie, Ross, & Becker, 2014). Interacting with school personnel can be difficult and stressful (Broome-Stone, 2012; Cohen et al. 2004; Kurnat & Moore, 1999). Parents with school age children benefit from practical information such as the process to establish a 504 and discussing food allergy needs with school personnel (Gillespie et al., 2014).

**Summary.** Although most states have some form of food allergy guidelines, they are inconsistently followed in schools. These tend to be medically driven guidelines that do not address social justice issues or take into account the negative psychological impact of having a food allergy. Children with food allergies are at higher risk of negative mental health symptoms. A high number of children with food allergies experience social exclusion and various forms of discrimination, which are correlated with negative mental health symptoms. There appears to be economic disparities in the diagnosis, management and psychological impact of having a food allergy. There is also a general lack of food allergy training and knowledge, which may contribute to negative interactions and experiences of social isolation and discrimination.

## Clinical and Systemic Implications

When examining the current legislation, there are inconsistent reports on which states adopted guidelines and which did not. It is important to identify the current state guidelines compared to national guidelines before determining which policies are being followed in schools. Considering the majority of food allergy reactions at school occur in the cafeteria and classroom, schools need to have epinephrine in both locations, in addition to revising their policies on using food as rewards and for activities. An initial step is to clearly identify what policies exist in the school, and whether or not they are being implemented. Policies need to address safety, psychological health, and be inclusive to marginalized groups. Parents reported having more perceived safety when multiple people in the school knew proper protocol; thus schools need to consider identifying multiple people to be knowledgeable of food allergy procedures.

There are socioeconomic disparities in food allergy diagnosis that may be related to access to health care. With the current political landscape and the health care systems in place, these issues are becoming more significant. It appears that policies need to be revised to include input from families currently managing a food allergy. Current food allergy policies are not inclusive for low income families. For example, families who do not have insurance plans that cover allergy testing and treatment may not be able to afford the out of pocket expenses related to proper monitoring and care of their child with a food allergy. National food allergy policies need to address this gap in access to health care.

Currently, children are required to have a diagnosis of a life-threatening food allergy to receive accommodations at school, which may be cost prohibitive for some families. The current policy may exclude children from families with the least amount of resources. Even though

families with more means are more likely to receive food allergy treatment, 504 plans, and food allergy management plans, food allergy management in schools is not consistent. Clear, consistent policies that are enforced are needed to ensure all children receive quality food allergy management at school (Lawlis et al., 2017). When a consistent level of care is achieved, it may be easier to identify any needed policy changes. The true effectiveness of policy can only be evaluated once it is in effect. Therefore, it may also be necessary to compare written school policies with the working policies.

Additionally, there are trends in food allergy management related to ethnic group and socioeconomic status. Children from middle to upper class families are more likely to have a food allergy management plan, and are less likely to experience negative mental health symptoms. This may be related to access to resources. For example, children with financial means do not rely on the National School Lunch Program (NSLP) and do not need to be concerned that the majority of schools do not provide allergen information. The NSLP needs to ensure that schools provide ingredients to parents and children, as well as provide allergen free options. As the NSLP uses the Dietary Guidelines for Americans, these guidelines need to address food allergies.

While schools are increasing policies, they need to keep in mind the intent versus the impact of the policy. For example, the intent of a food allergy section in the cafeteria might be to keep children safe, but the impact might be that children feel isolated. This can lead to the perceived experiences of discrimination. Schools need to consider the psychological implications of their policies. Schools may need to directly address discriminatory behaviors, including those from non-food allergy parents.



In this study, 7.3% of lunchrooms had epinephrine in the same area, and 16.6% of the time, the lunchroom monitor was responsible for administering the medication. Bullying often occurs in the cafeteria; therefore, if the lunchroom is where children experience the most fear and bullying, there needs to be a better policy to create a safer environment. Policies need to consider how to create environments that lower anxiety and increase safety.

In this study, the majority of discrimination was from other parents. Also, there was an 8.9% increase in reported bullying from Liberman et al.'s (2010 study to the current study. Educating fellow parents about the negative mental health and safety risks may decrease negative interactions and discrimination. If the school's culture celebrated diversity and fostered inclusiveness, there may be a decrease in negative interactions. This can be achieved by food allergy education and active information on inclusive environments during registration, PTA meetings, and back to school night. Schools need to explore ways to create an inclusive education environment.

Clinicians need to be aware of the increased mental health risks for children with food allergies and screen for negative mental health symptoms, while being prepared to discuss social exclusion and discrimination. If a clinician has a client with a food allergy, it would be helpful to research the experience of having a food allergy in an attempt to limit microaggressions in session. Clinicians also need to be prepared to help families new to food allergy management by providing resources such as: support groups, an educational advocate, educational organizations such as FARE, and social resources, as well as help them understand the possible mental health risks. School counselors in particular could form a support group for children with food allergies in the school itself.

## Limitations

One major limitation in this study is the similarity of participants. The majority of participants identified as female (99%), Caucasian (78.1%) caregivers of a child in public (80.8%) elementary school (78.2%), with a family income over \$75,000 (73.5%). Allergy prevalence in the sample was different from the national trends. In this sample, the top three food allergies were peanuts (86.8%), tree nuts (72.2%), and eggs (14.6%), as compared to the national averages, where the top three food allergies are peanuts (25.2%), milk (21.1%), and shellfish (17.2%) (Gupta et al., 2011). A large portion of respondents were from a parent group specific to nut allergies and it is likely that this skewed the sample. The participants also had good access to health care, as 96.7% of them had health insurance. These caregivers likely had better access to resources and may have had more available time to participate in food allergy management.

The study also had a high dropout rate, possibly due to the length of the questionnaire. A pre-existing standardized measure for food allergy management in schools was not available, so this researcher had to create one. In this study, Cronbach's  $\alpha$  for the Policy Satisfaction Index was .776, and for the Program Quality Index it was 0.767. Cronbach's  $\alpha$  in this range indicate preliminary evidence that an index measuring program quality and policy satisfaction is possible. Further research will help to refine items that most accurately measure program quality and policy satisfaction. Cronbach's  $\alpha$  for the Relational Quality Index in this study was .560. Nothing in the item analysis indicated that removing one question would increase Cronbach's  $\alpha$ , indicating there was too much variability among questions. It may be prudent to further divide components of relational quality to increase inter item reliability.

A standardized measure to evaluate food allergy management along with concrete experiential questions would provide a more complete picture of food allergy management in schools. A standard measure may need different scales for elementary and high school children given the difference in daily routine and the level of a child's independence. A standardized measure may have had a faster completion time and proven effectiveness in identifying important issues related to food allergy management in schools.

The results of this study may not be applicable for high school students. Only 3.3% of participants had a child with a food allergy in high school. Adolescents may assume more responsibility in managing their food allergy; however, they are an increased risk. Adolescents typically spend more time away from home, may be bullied, and may attempt to hide their food allergy diagnosis. Future studies may further examine allergy management in high school, with specific attention to policies and procedures taking into account that the schools may be larger, students may be able to each off campus for lunch, and that there are multiple teachers throughout the day. It is hoped that a greater number of high schools allow students to self-carry their medication.

### **Future Directions**

More research is needed to examine the economic disparities in food allergy diagnosis and management. Research is also needed to better understand the relationship between financial resources and the psychological impact of having a food allergy, such as discrimination, microaggressions, social exclusion and the possible compounding effects of food allergy, such as financial resources and ethnic group membership. A better understanding of what reduces the psychological burden of having a food allergy can influence policy and move away from the ableist perspective of food allergy management. Although previous research has

focused on discrimination from teachers, more research is needed to identify the current prevalence of discrimination from peers and fellow students' parents.

Research is needed to address multiple issues related to school lunches including: if schools make lunch ingredients available to parents; the amount of children with food allergies on the national lunch program; and the amount and quality of allergen free options. In this sample, parents expressed the desire to have their children eat school lunches; however, they do not feel confident there were allergen free options. Research is needed to identify what steps are necessary for schools to provide allergen free options. Additionally, it may be helpful to research school districts that successfully manage food allergies, and see what has and has not worked for them.

More research is needed on how parents are getting their information. It is unclear how many parents know that children with a life-threatening food allergy are covered under the ADA and are entitled to a 504 plan. Understand where parents go for information may be a great way to fill the gap. Many parents feel that they have to reinvent the wheel. It may also be helpful to provide tips such as how to talk to other parents and teachers about food allergies.

Since this study did not ask about specific recommendations to decrease anxiety, future studies need to explore this specific area in greater detail. A safe school environment may decrease psychological distress for children and parents, which can be achieved by adherence to existing national guidelines (Parnell et al., 2016).

Clinicians need to be cognizant that children with food allergies can experience multiple forms of discrimination ranging from overt to indirect microaggressions. Experiencing microaggressions are correlated with negative mental health symptoms such as depression,

anxiety, and negative affect (Nadal, Griffin, Wong, Hamit, & Rasmus, 2014). Further research is needed to better understand the ways in which children with food allergies experience microaggressions. It is likely that children with food allergies experience similar reactions to food allergy microaggressions. Studies on microaggressions may be used to develop a food allergy microaggression scale. While studies have examined individual factors, more research is needed to explore the compounding effects of experiencing multiple forms of discrimination related to food allergy, ethnicity, and socioeconomic status.

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## Appendix A

### Recruitment Social Media Post

Hello,

I am a doctoral student at JFK University investigating the experiences of parents and caregivers of children with food allergies with regard to how the needs of these children are managed in schools. Using an anonymous survey, I hope to gain an understanding of the parents' experiences in order to make recommendations as to how schools might improve their management policies and practices.

I am asking parents/caregivers of children in K-12 with a food allergy to complete an anonymous survey. The results will be reported in a dissertation that I will complete as a requirement of my graduate program.

Thank you for helping me in the pursuit of making schools safer for children with food allergies. Please share!

## Appendix B

### Consent Form

Hello,

My name is Nicole Thompson and I am a student in the Doctor of Psychology program at John F. Kennedy University. I am conducting a study on caregiver experience of food allergy management by schools. I hope to obtain a rich, in-depth understanding of this experience in order to make recommendations as to how schools might improve their management policies and practices. If you are a parent/caregiver of a child with a food allergy in K-12 please complete this anonymous survey.

The anonymous survey includes demographic information and questions that ask you to describe your experience and rate your satisfaction with school staff, policies and procedures. There are also comment sections to allow you to share any information about your experience. It will take on average 30-40 minutes.

To qualify for this study, you must be over the age of 18 and be the parent/caregiver of a child with a food allergy enrolled in school (K-12).

Your participation in the study is voluntary. If you decide to participate, your responses will be anonymous – that is, recorded without any identifying information that is linked to you. The results will be reported in a dissertation that I will complete as a requirement of my graduate program. If you have any questions regarding this survey or, please contact me at [nthompson@email.jfku.edu](mailto:nthompson@email.jfku.edu).

If you have any questions regarding your rights as a human subject and participation in this study, or to report research-related problems, you may call the Institutional Review Board at NU for information at (858) 642-8384, or [irb@nu.edu](mailto:irb@nu.edu).

Thank you for helping me in the pursuit of making schools safer for children with food allergies!

Nicole Thompson  
Psy. D student  
John F. Kennedy University  
[nthompson@email.jfku.edu](mailto:nthompson@email.jfku.edu)

## Appendix C

### Demographic Questionnaire

1. Gender of child with food allergy
  - a. Female
  - b. Male
  - c. Transgender
  - d. other \_\_\_\_\_
  
2. Please check all that apply to your child's ethnicity
  - a.  African American
  - b.  Asian
  - c.  Caucasian
  - d.  East Indian
  - e.  Latino
  - f.  Native American
  - g.  Middle Eastern
  - h.  Pacific Islander
  - i.  Other
  
3. Age of child with food allergy: \_\_\_\_\_
  
4. When was your child diagnosed with a food allergy?
  - a. Age
  - b. Year
  - c. My child has not been diagnosed with a food allergy by a doctor
  
5. What food allergy/allergies does your child have (Please check all that apply)
  - a.  Eggs
  - b.  Fish
  - c.  Crustacean shellfish (crab, lobster, shrimp)
  - d.  Milk/ dairy
  - e.  Peanuts
  - f.  Tree nuts
  - g.  Soybeans
  - h.  Wheat (gluten)
  - i.  other please list
  
6. In what grade is your child with food allergy/allergies? \_\_\_\_\_
  
7. Please indicate if your child's school is:
  - a. Public
  - b. Private
  - c. Charter

8. In which state is your child's school?
9. In which school district is your child's school?
10. Does your child have a 504? (If no, skip to question 13)
  - a. Yes
  - b. No
11. Please indicate if your child's 504 includes accommodations for: (Please check all that apply)
  - a. Learning disabilities
  - b. Behavioral management
  - c. Physical access
  - d. Food allergy management
  - e. Other medical condition
12. Has your child ever had an anaphylactic reaction?
  - a. Yes
  - b. No
13. How many times has your child had an anaphylactic reaction?
  - a. 1
  - b. 2-3
  - c. 4-5
  - d. 6-7
  - e. 8+
14. Does your family have health insurance?
  - a. Yes
  - b. No
15. Does your insurance cover all needs corresponding to your child's food allergy diagnosis?
  - a. Yes
  - b. No
16. Is your child under the care of an allergist?
  - a. Yes
  - b. No

#### Caregiver Information

17. Please identify your gender
  - a. Female
  - b. Male
  - c. Transgender
  - d. Other

18. What is the household income?

- a. Under \$10,000
- b. \$10,000 - \$15,000
- c. \$15,000 - \$25,000
- d. \$25,000 - \$30,000
- e. \$30,000 - \$50,000
- f. \$50,000 - \$75,000
- g. \$75,000 - \$100,000
- h. \$100,000 - \$150,000
- i. Over \$150,000

## Appendix D

### Parent Food Allergy Survey

19. What is your greatest challenge with regard to your child's food allergy/allergies?

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20. What is your child's greatest challenge with regard to their food allergy/allergies?

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21. Please answer the following questions regarding your school's registration process

22. Which medical conditions were specifically asked about on the school registration form?  
(Please check all that apply)

- a. Allergies
- b. Asthma
- c. Diabetes
- d. Epilepsy
- e. Food Allergy
- f. Heart Condition
- g. None
- h. Other \_\_\_\_\_

23. Prior to school starting: (Please check all that apply)

- a. The school asked if my child has an allergy
- b. The school asked about my child's triggers and symptoms
- c. The school asked about the length of time to the onset of the reaction
- d. The school asked when and the severity of the last food allergy reaction
- e. The school asked about medical treatment for my child's food allergy
- f. The school asked if my child is aware of the signs and symptoms of an allergic reaction
- g. The school asked if my child requires medication
- h. The school asked about accommodations for my child

24. Comments

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25. Please rate your level of agreement with the following statements as it relates to your child's current school and their response to his/her food allergy.
26. How long have you been working with the current school to manage your child's food allergy?
- Less than 1 year
  - 1-2 years
  - 2-3 years
  - 3-4 years
  - Other: \_\_\_\_\_
27. How many times has the principal changed while your child has attended this school?
- Principal has not changed
  - Principal changed once
  - Principal changed twice
  - Other: \_\_\_\_\_
28. My child's food allergy/allergies impacts his/her day at school?
- Strongly disagree
  - Disagree
  - Somewhat disagree
  - Neither agree or disagree
  - Somewhat agree
  - Agree
  - Strongly agree
29. If yes, please comment how your child's food allergy/allergies impacts his/her day at school.
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
30. My child's school is a welcoming environment for my child.
- Strongly disagree
  - Disagree
  - Somewhat disagree
  - Neither agree nor disagree
  - Somewhat agree
  - Agree
  - Strongly agree
31. My child's school is a welcoming environment for me.
- Strongly disagree
  - Disagree

- c. Somewhat disagree  
 d. Neither agree or disagree  
 e. Somewhat agree  
 f. Agree  
 g. Strongly agree
32. My child's classmates are respectful of my child's food allergy needs/food allergy management plan.
- a. Strongly disagree  
 b. Disagree  
 c. Somewhat disagree  
 d. Neither agree nor disagree  
 e. Somewhat agree  
 f. Agree  
 g. Strongly agree
33. Fellow parents in my child's class are respectful of my child's food allergy needs/food allergy management plan.
- a. Strongly disagree  
 b. Disagree  
 c. Somewhat disagree  
 d. Neither agree nor disagree  
 e. Somewhat agree  
 f. Agree  
 g. Strongly agree
34. As it relates to their food allergy, my child is safe:

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
at recess	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
during lunch	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
during class parties that have food	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

35. I have experienced discrimination related to my child's food allergy from:

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
other parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
teachers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
school administration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

36. How many times have you experienced discrimination at your child's school?

- 0
- 1
- 2
- 3
- 4
- 5 or more

37. My child has experienced discrimination related to their food allergy from:

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
peers/classmates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
other parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
teachers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
school admin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

38. How many times has discrimination occurred, for you or your child, at their school?

- 0
- 1
- 2
- 3
- 4
- 5 or more

## 39. Comments

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Please answer the following questions about your impression of your child's school's knowledge and practices regarding students with food allergies.

40. My child's school has the following policies: (Please check all that apply)
- Food allergies are addressed in the student handbook
  - Food policy for classroom activities (i.e. food as reward, counting food items, using food for arts and crafts)
  - Policy regarding materials/supplies addresses allergens (requiring soap, glue, paint etc. to be allergen free)
  - Policy for class parties and school events that include food
  - My child's school is nut free
  - Disaster backpacks include a safe food item for my child
  - Children with food allergies are required to sit in a designated area in the classroom
  - Children with food allergies are required to sit in a designated area in the lunchroom
  - Teachers are allowed to refuse to have a child with a food allergy in their class
41. My child's school has the following food allergy training: (Please check all that apply)
- Staff have food allergy training
  - Teachers have food allergy training
  - Substitute teachers have food allergy training
  - Cafeteria staff have food allergy training
  - Janitorial staff have food allergy training
42. The following people at my child's school were notified about my child's food allergy/allergies (Please check all that apply)
- Principal
  - Teacher
  - Substitute teacher
  - Teacher's aid
  - School nurse
  - Cafeteria staff
  - Admin/support staff
  - Resource teacher

43. Please indicate the primary point of contact for managing your child's food allergy/allergies at school.
- Principal
  - Teacher
  - Substitute teacher
  - Teacher's aid
  - School nurse
  - Cafeteria staff
  - Admin/support staff
44. Once you notified the school of your child's food allergy/allergies, how long did it take for a response from the school?
- Within 1 month
  - 2 - 3 months
  - 4 - 6 months
  - 7 - 9 months
  - The school never formally responded/contacted me
45. Was a food allergy management plan created? (If no, skip to question 30)
- No
  - Yes
46. How long did it take for the food allergy management plan to be implemented?
- Within 1 month
  - 2 - 3 months
  - 4 - 6 months
  - 7 - 9 months
  - The school did not implement a food allergy plan
47. How satisfied are you with the food allergy management plan?
- Extremely satisfied
  - Moderately satisfied
  - Slightly satisfied
  - Neither satisfied nor dissatisfied
  - Slightly dissatisfied
  - Moderately dissatisfied
  - Extremely dissatisfied

48. When your child started school, how knowledgeable were the following people regarding food allergies?

	Extremely knowledgeable	Very knowledgeable	Moderately knowledgeable	Slightly knowledgeable	Somewhat knowledgeable	Not knowledgeable at all
Primary point person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
principal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
school nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child's teacher	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cafeteria staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

49. Check all methods of education you utilized when working with the school to manage your child's food allergy/allergies

- Completing medical forms
- Provided a letter from Pediatrician or Allergist
- Parent teacher conference
- IEP/504 meeting
- A conference with the school nurse
- Provided verbal information/education
- Provided written information/education
- Provided video information/education
- Provided verbal, written or video information for other parents
- Providing education was unnecessary

50. How knowledgeable was your child's teacher after you provided education?

- Extremely knowledgeable
- Very knowledgeable
- Moderately knowledgeable
- Slightly knowledgeable
- Not knowledgeable at all

51. How satisfied are you with your teachers' willingness to accommodate your child's food allergy needs?

- Extremely satisfied
- Moderately satisfied
- Slightly satisfied
- Neither satisfied nor dissatisfied
- Slightly dissatisfied

- f. Moderately dissatisfied
  - g. Extremely dissatisfied
52. How satisfied are you discussing academic issues with your child's teacher?
- a. Extremely satisfied
  - b. Moderately satisfied
  - c. Slightly satisfied
  - d. Neither satisfied nor dissatisfied
  - e. Slightly dissatisfied
  - f. Moderately dissatisfied
  - g. Extremely dissatisfied
53. Has your child's food allergy affected your relationship with the teacher?
- a. Very positively affected
  - b. Positively affected
  - c. Somewhat positively affected
  - d. The relationship was not affected
  - e. Somewhat negatively affected
  - f. Negatively affected
  - g. Very negatively affected

54. Comments

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Please answer the following questions related to lunchtime procedures.

55. Where does your child eat lunch?
- a. With his/her class
  - b. In the cafeteria with supervision
  - c. In the cafeteria without supervision
  - d. In a designated food allergy section
  - e. On campus without supervision
  - f. Students are allowed to leave campus for lunch
  - g. Other \_\_\_\_\_
56. Does your cafeteria provide ingredients and food allergen information?
- a. They never provide ingredients and food allergen information
  - b. They provide incomplete or inaccurate ingredients and food allergen information
  - c. They sometimes provide accurate and up-to-date ingredients and food allergen information

- d. They always provide accurate and up-to-date ingredients and food allergen information
57. How satisfied are you with food allergy management in your child's school cafeteria?
- Extremely satisfied
  - Moderately satisfied
  - Slightly satisfied
  - Neither satisfied nor dissatisfied
  - Slightly dissatisfied
  - Moderately dissatisfied
  - Extremely dissatisfied
58. Comments

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The following questions are related to medication and food allergy reactions at school.

59. My child's school has the following: (Please check all that apply)
- Epinephrine auto injectors are kept in the teacher's emergency backpack
  - Epinephrine auto injectors are kept in the classroom
  - Epinephrine auto injectors are kept in the cafeteria
  - Epinephrine auto injectors are kept in the nurse's office
  - Epinephrine auto injectors are kept with my child
  - Epinephrine auto injectors are kept in the main school office
  - Epinephrine auto injectors are kept with the yard duty
  - The school has a supply of epinephrine auto injectors (supplied/aid for by the
60. How satisfied are you with the school's storage of medication?
- Extremely satisfied
  - Moderately satisfied
  - Slightly satisfied
  - Neither satisfied nor dissatisfied
  - Slightly dissatisfied
  - Moderately dissatisfied
  - Extremely dissatisfied
61. Who is authorized to administer medication
- School nurse
  - My child's teacher
  - Substitute teacher
  - All teachers
  - My child
  - Yard duty



- g. Office staff/ Admin  
 h. Lunchroom monitor  
 i. Other: \_\_\_\_\_
62. How satisfied are you with the ability of person/persons responsible to administer medication during a reaction?  
 a. Extremely satisfied  
 b. Moderately satisfied  
 c. Slightly satisfied  
 d. Neither satisfied nor dissatisfied  
 e. Slightly dissatisfied  
 f. Moderately dissatisfied  
 g. Extremely dissatisfied
63. What is the procedure if no one authorized to administer the medication is present during a reaction:  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
- 
64. Please rate your overall level of satisfaction regarding medication policies and procedures.  
 a. Extremely satisfied  
 b. Moderately satisfied  
 c. Slightly satisfied  
 d. Neither satisfied nor dissatisfied  
 e. Slightly dissatisfied  
 f. Moderately dissatisfied  
 g. Extremely dissatisfied
65. Who is responsible for assisting your child if they have a food allergy reaction at school?  
 a. School nurse  
 b. My child's teacher  
 c. Substitute teacher  
 d. All teachers  
 e. My child  
 f. Yard Duty  
 g. Office staff/Admin  
 h. Lunchroom monitor  
 i. Other \_\_\_\_\_

66. Does your child's Food Allergy require them to have full-time access to medication (i.e. an Epinephrine auto injector, Benadryl, other)
- Yes
  - No
67. This school year, how many times has your child had a food allergy reaction while at school?
- 0
  - 1
  - 2
  - 3
  - 4
  - Other \_\_\_\_\_

68. Comments

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Please answer the following questions related to bullying.

69. If your child has been bullied, how many times have been directly related to his or her food allergy?
- 0
  - 1 - 2
  - 3 - 5
  - 6 - 8
  - 9+
70. In general, how does the school intervene when bullying occurs? (Please check all that apply.)
- The school does not intervene
  - Meeting with children involved
  - Meeting with children involved and their parents
  - Children may be suspended for bullying
  - Children may be expelled for bullying
  - Other \_\_\_\_\_
71. How satisfied are you with the way the school handles bullying?
- Extremely satisfied
  - Moderately satisfied
  - Slightly satisfied
  - Neither satisfied nor dissatisfied
  - Slightly dissatisfied
  - Moderately dissatisfied

g. Extremely dissatisfied

72. Comments

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73. Please rate your overall level of satisfaction with how your child's current school has addressed his/her food allergy/allergies.

- a. Extremely satisfied
- b. Moderately satisfied
- c. Slightly satisfied
- d. Neither satisfied nor dissatisfied
- e. Slightly dissatisfied
- f. Moderately dissatisfied
- g. Extremely dissatisfied

74. What if anything, do you feel needs to be done to improve the management of food allergies at your child's school?

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## Appendix E

### Questions Loaded on Four Main Themes

#### Program Quality

Question 26	<p>Prior to school starting, the school asked: (Please check all that apply)</p> <ul style="list-style-type: none"> <li><input type="radio"/> If my child has an allergy</li> <li><input type="radio"/> About my child's triggers and symptoms</li> <li><input type="radio"/> About the length of time to the onset of the reaction</li> <li><input type="radio"/> When and the severity of the last food allergy reaction</li> <li><input type="radio"/> If my child is aware of the signs and symptoms of an allergic reaction</li> <li><input type="radio"/> If my child requires medication</li> <li><input type="radio"/> About accommodations for my child</li> </ul>
Question 44	<p>My child's school has the following policies: (Please check all that apply)</p> <ul style="list-style-type: none"> <li><input type="radio"/> Food allergies are addressed in the student handbook</li> <li><input type="radio"/> Food policy for classroom activities (i.e. food as reward, counting food items, using food for arts and crafts)</li> <li><input type="radio"/> Policy regarding materials/supplies address allergens (requiring soap, glue, paint etc. to be allergen free)</li> <li><input type="radio"/> Policy for class parties and school events that involve food</li> <li><input type="radio"/> My child's school is nut free</li> <li><input type="radio"/> Disaster back packs include a safe food item for my child</li> <li><input type="radio"/> Children with food allergies are required to sit in a designated area in the classroom</li> <li><input type="radio"/> Children with food allergies are required to sit in a designated area in the lunchroom</li> <li><input type="radio"/> Teachers are allowed to refuse to have a child with a food allergy in their class</li> </ul>
Question 45	<p>My child's school has the following food allergy training: (Please check all that apply)</p>

	<ul style="list-style-type: none"> <li>○ Staff have food allergy training</li> <li>○ Teachers have food allergy training</li> <li>○ Substitute teachers have food allergy training</li> <li>○ Cafeteria staff have food allergy training</li> <li>○ Janitorial staff have food allergy training</li> </ul>
Question 48	<p>Once you notified the school of your child's food allergy/allergies, how long did it take for the 'primary point of contact' to respond to you?</p> <ul style="list-style-type: none"> <li>○ Within 1 month</li> <li>○ 2 – 3 months</li> <li>○ 4 – 6 months</li> <li>○ 7 – 9 months</li> <li>○ the school never formally responded / contacted me</li> </ul>
Question 49	<p>Was a food allergy management plan created</p> <ul style="list-style-type: none"> <li>○ Yes</li> <li>○ No</li> </ul>
Question 50	<p>How long did it take for the food allergy management plan to be implemented?</p> <ul style="list-style-type: none"> <li>○ Within 1 month</li> <li>○ 2 – 3 months</li> <li>○ 4 – 6 months</li> <li>○ 7 – 9 months</li> <li>○ the school did not implement the food allergy plan</li> </ul>
Question 61	<p>Does your cafeteria provide ingredients and food allergen information?</p> <ul style="list-style-type: none"> <li>○ They never provide ingredients and food allergen information</li> <li>○ They provide incomplete or inaccurate ingredients and food allergen information</li> <li>○ They sometimes provide accurate and up-to-date ingredients and food allergen information</li> </ul>

	<ul style="list-style-type: none"> <li>○ They always provide accurate and up-to-date ingredients and food allergen information</li> </ul>
Question 65	<p>My child's school has the following (Please check all that apply)</p> <ul style="list-style-type: none"> <li>○ Epinephrine auto injectors are kept in the teacher's emergency backpack</li> <li>○ Epinephrine auto injectors are kept in the classroom</li> <li>○ Epinephrine auto injectors are kept in the cafeteria</li> <li>○ Epinephrine auto injectors are kept in the nurses office</li> <li>○ Epinephrine auto injectors are kept with my child</li> <li>○ Epinephrine auto injectors are kept in the main school office</li> <li>○ Epinephrine auto injectors are kept with the yard duty</li> <li>○ The school has a supply of epinephrine auto injectors (supplied/paid for by the school)</li> <li>○ Other</li> </ul>
Question 67	<p>Who is authorized to administer medication? (Please check all that apply)</p> <ul style="list-style-type: none"> <li>○ School nurse</li> <li>○ My child's teacher</li> <li>○ Substitute teacher</li> <li>○ All teachers</li> <li>○ My child</li> <li>○ Yard duty</li> <li>○ Office staff/admin</li> <li>○ Lunch-room monitor</li> </ul>

### Policy Satisfaction

Question 62	<p>How satisfied are you with food allergy management in your child's school cafeteria?</p> <ul style="list-style-type: none"> <li>○ Extremely satisfied</li> <li>○ Moderately satisfied</li> <li>○ Slightly satisfied</li> <li>○ Neither satisfied nor dissatisfied</li> </ul>
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	<ul style="list-style-type: none"> <li><input type="radio"/> Slightly dissatisfied</li> <li><input type="radio"/> Moderately dissatisfied</li> <li><input type="radio"/> Extremely dissatisfied</li> </ul>
Question 66	<p>How satisfied are you with the school's storage of medication?</p> <ul style="list-style-type: none"> <li><input type="radio"/> Extremely satisfied</li> <li><input type="radio"/> Moderately satisfied</li> <li><input type="radio"/> Slightly satisfied</li> <li><input type="radio"/> Neither satisfied nor dissatisfied</li> <li><input type="radio"/> Slightly dissatisfied</li> <li><input type="radio"/> Moderately dissatisfied</li> <li><input type="radio"/> Extremely dissatisfied</li> </ul>
Question 68	<p>How satisfied are you with the ability of the person/ persons responsible to administer medication during a reaction?</p> <ul style="list-style-type: none"> <li><input type="radio"/> Extremely satisfied</li> <li><input type="radio"/> Moderately satisfied</li> <li><input type="radio"/> Slightly satisfied</li> <li><input type="radio"/> Neither satisfied nor dissatisfied</li> <li><input type="radio"/> Slightly dissatisfied</li> <li><input type="radio"/> Moderately dissatisfied</li> <li><input type="radio"/> Extremely dissatisfied</li> </ul>
Question 70	<p>Please rate your overall satisfaction regarding medication policies and procedures.</p> <ul style="list-style-type: none"> <li><input type="radio"/> Extremely satisfied</li> <li><input type="radio"/> Moderately satisfied</li> <li><input type="radio"/> Slightly satisfied</li> <li><input type="radio"/> Neither satisfied nor dissatisfied</li> <li><input type="radio"/> Slightly dissatisfied</li> <li><input type="radio"/> Moderately dissatisfied</li> <li><input type="radio"/> Extremely dissatisfied</li> </ul>
Question 78	<p>How satisfied are you with the way the school handles bullying?</p> <ul style="list-style-type: none"> <li><input type="radio"/> Extremely satisfied</li> <li><input type="radio"/> Moderately satisfied</li> <li><input type="radio"/> Slightly satisfied</li> </ul>

	<input type="radio"/> Neither satisfied nor dissatisfied <input type="radio"/> Slightly dissatisfied <input type="radio"/> Moderately dissatisfied <input type="radio"/> Extremely dissatisfied
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	Extremely knowledgeable	Very knowledgeable	Moderately knowledgeable	Slightly knowledgeable	Somewhat knowledgeable	Not knowledgeable at all
Primary point person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Principal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child's teacher	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cafeteria staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Knowledge

Question 52	When your child started school, how knowledgeable were the following people regarding food allergies?
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	Extremely knowledgeable	Very knowledgeable	Moderately knowledgeable	Slightly knowledgeable	Somewhat knowledgeable	Not knowledgeable at all
Primary point person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
principal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
school nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child's teacher	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Cafeteria  
staff

## Relational Quality

Question 33	<p>My child's school is a welcoming environment for my child.</p> <ul style="list-style-type: none"> <li><input type="radio"/> Strongly disagree</li> <li><input type="radio"/> Disagree</li> <li><input type="radio"/> Somewhat disagree</li> <li><input type="radio"/> Neither agree nor disagree</li> <li><input type="radio"/> Somewhat agree</li> <li><input type="radio"/> Agree</li> <li><input type="radio"/> Strongly agree</li> </ul>
Question 34	<p>My child's school is a welcoming environment for me.</p> <ul style="list-style-type: none"> <li><input type="radio"/> Strongly disagree</li> <li><input type="radio"/> Disagree</li> <li><input type="radio"/> Somewhat disagree</li> <li><input type="radio"/> Neither agree nor disagree</li> <li><input type="radio"/> Somewhat agree</li> <li><input type="radio"/> Agree</li> <li><input type="radio"/> Strongly agree</li> </ul>
Question 35	<p>My child's classmates are respectful of my child's food allergy needs/ food allergy management plan.</p> <ul style="list-style-type: none"> <li><input type="radio"/> Strongly disagree</li> <li><input type="radio"/> Disagree</li> <li><input type="radio"/> Somewhat disagree</li> <li><input type="radio"/> Neither agree nor disagree</li> <li><input type="radio"/> Somewhat agree</li> <li><input type="radio"/> Agree</li> <li><input type="radio"/> Strongly agree</li> </ul>

Question 36	<p>Fellow parents in my child's class are respectful of my child's food allergy needs/ food allergy management plan.</p> <ul style="list-style-type: none"> <li><input type="radio"/> Strongly disagree</li> <li><input type="radio"/> Disagree</li> <li><input type="radio"/> Somewhat disagree</li> <li><input type="radio"/> Neither agree nor disagree</li> <li><input type="radio"/> Somewhat agree</li> <li><input type="radio"/> Agree</li> <li><input type="radio"/> Strongly agree</li> </ul>																																								
Question 37	<p>As it relates to their food allergy, my child is safe:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 30%;"></th> <th style="width: 12.5%;">Strongly disagree</th> <th style="width: 12.5%;">Disagree</th> <th style="width: 12.5%;">Somewhat disagree</th> <th style="width: 12.5%;">Neither agree nor disagree</th> <th style="width: 12.5%;">Somewhat agree</th> <th style="width: 12.5%;">Agree</th> <th style="width: 12.5%;">Strongly agree</th> </tr> </thead> <tbody> <tr> <td>in class</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>at recess</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>during lunch</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>during class parties that have food</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> </tbody> </table>		Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree	in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	at recess	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	during lunch	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	during class parties that have food	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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during lunch	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>																																		
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Question 38	<p>I have experienced discrimination related to my child's food allergy from:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 30%;"></th> <th style="width: 12.5%;">Strongly disagree</th> <th style="width: 12.5%;">Disagree</th> <th style="width: 12.5%;">Somewhat disagree</th> <th style="width: 12.5%;">Neither agree nor disagree</th> <th style="width: 12.5%;">Somewhat agree</th> <th style="width: 12.5%;">Agree</th> <th style="width: 12.5%;">Strongly agree</th> </tr> </thead> <tbody> <tr> <td>other parents</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>teachers</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> <tr> <td>school administration</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> </tbody> </table>		Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree	other parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	teachers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	school administration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>								
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Question 40	<p>My child has experienced discrimination related to their food allergy from:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 30%;"></th> <th style="width: 12.5%;">Strongly disagree</th> <th style="width: 12.5%;">Disagree</th> <th style="width: 12.5%;">Somewhat disagree</th> <th style="width: 12.5%;">Neither agree nor disagree</th> <th style="width: 12.5%;">Somewhat agree</th> <th style="width: 12.5%;">Agree</th> <th style="width: 12.5%;">Strongly agree</th> </tr> </thead> <tbody> <tr> <td>peers/classmates</td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> <td><input type="radio"/></td> </tr> </tbody> </table>		Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree	peers/classmates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>																								
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	teachers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	school admin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Question 55	<p>How satisfied are you with you teacher's willingness to accommodate your child's food allergy needs?</p> <ul style="list-style-type: none"> <li><input type="radio"/> Extremely satisfied</li> <li><input type="radio"/> Moderately satisfied</li> <li><input type="radio"/> Slightly satisfied</li> <li><input type="radio"/> Neither satisfied nor dissatisfied</li> <li><input type="radio"/> Slightly dissatisfied</li> <li><input type="radio"/> Moderately dissatisfied</li> <li><input type="radio"/> Extremely dissatisfied</li> </ul>							
Question 57	<p>Has your child's food allergy affected your relationship with the teacher?</p> <ul style="list-style-type: none"> <li><input type="radio"/> Very positively affected</li> <li><input type="radio"/> Positively affected</li> <li><input type="radio"/> Somewhat positively affected</li> <li><input type="radio"/> The relationship was not affected</li> <li><input type="radio"/> Somewhat negatively affected</li> <li><input type="radio"/> Negatively affected</li> <li><input type="radio"/> Very negatively affected</li> </ul>							

