# An Institutional Ethnography Inquiry into the Management of Anaphylaxis for Adolescents at-risk in Ontario Schools

by

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## **Author Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public

#### **Abstract**

In Ontario, Sabrina's Law mandates that all school boards have anaphylaxis policies in place to protect at-risk students. Despite this law research has shown that within schools, the management of anaphylactic allergies is still challenging and at-risk students report feelings of anxiety and risk of an allergic reaction. The purpose of this study is to explore how the everyday experiences of adolescents at risk of anaphylaxis is mediated and shaped by exterior forces (e.g. Sabrina's Law and school board policies) and secondarily to map how these forces shape and affect the everyday experiences of managing their allergies. The study employed Institutional Ethnography, a methodology that begins in the everyday experience of a particular standpoint (at risk adolescents) and then moves outwards to examine the social organization of anaphylaxis management in school settings. Data were collected through in-depth interviews with at-risk students and key informants, as well as through document analysis. Writing and mapping were used as analytical techniques to make visible the social organization of anaphylaxis management within school systems. Through this, the movement of institutional processes from their formation in the translocal and in the text, through their implementation in the local environment, to their effect on the everyday experience was explicated. Within this movement from the translocal down to the local, parts of the text are lost, unclear, or not implemented. Overall, translocal forces (Sabrina's Law and the School Board Anaphylaxis Policy) affected the student experience by shaping the environment students moved through. Students and families were separated from the institutional processes occurring around anaphylaxis management and unaware of the work done within the schools. Within student safety as it pertains to anaphylaxis management, there is a focus on an allergic reaction and the emergency response, removing the social and emotional needs of anaphylactic students. Anaphylaxis management has been split

into two concepts, Emergency Preparedness and Anaphylaxis Prevention, with Emergency Preparedness measures overshadowing preventative measures within the institutional processes. The results of this study support a need to incorporate Anaphylaxis Prevention back into the institutional processes, acknowledging the life experience of anaphylactic allergies, instead of focusing solely on the reaction.

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## **List of Abbreviations**

IE Institutional Ethnography

QoL Quality of Life

SBAP School Board Anaphylaxis Policy/Policies

## **Chapter 1: Overview**

With an estimated 6% to 8% of children in Canada affected by anaphylactic allergies (Ben-Shoshan, et al., 2010), this life-threatening condition is becoming a growing concern. There is presently no cure for anaphylactic allergies (Gillespie, et al., 2007), and the only long-term management available is complete avoidance of allergens (Bollinger, et al., 2006; Ben-Shoshan & Clarke, 2011; Gillespie, et al., 2007).

In Ontario, Sabrina's Law mandates that all school boards have anaphylaxis policies in place, which should contain strategies to reduce the risk of exposure to allergens, communication plans for the dissemination of information, and provide regular training for school personnel on how to manage and treat these reactions (Bill 3, 2005; Chipps, 2013). Principals are also mandated to create and maintain an individual plan for every at risk student, including their current treatment, copies of any prescriptions, instructions from the student's physician or nurse, and emergency contact information (Bill 3, 2005).

Research has shown that within schools, the management of anaphylactic allergies is difficult because of school personnel's lack of knowledge (Cicutto, et al., 2012), food sharing, cross contamination (Muñoz-Furlong, 2004), lack of written emergency plans, and inaccessible epinephrine (Rhim & McMorris, 2001). Other research found students with anaphylactic allergies also report feelings of anxiety and greater perceived risk for allergen exposure within high school environments compared to elementary schools (Fenton, et al., 2011; Fenton, et al., 2013). While there are anaphylactic policies in place, the intent of the policies is not experienced on the ground. Thus, this tension, a disjuncture (Smith, 2005; 2006) - contested area being experienced between "policy and actuality" (Ng, et al., 2012, p. 1) between the provincial policy,

school procedures, and the daily lives of adolescents at risk of anaphylaxis, is the focus of this study. Institutional Ethnography (IE) is employed to map the 'organization of work' (Ng, et al., 2012) from the standpoint (place of inquiry) of the everyday life of adolescents at-risk of anaphylaxis (Campbell & Manicom, 1995). IE is well suited for this inquiry as it focuses on extended chains of action (social relations) and looks for connections between complex practices and procedures, and can display how processes work together through text and by discourse (Grahame, 1998).

Specifically, this research examines the social organization of school-based anaphylaxis management policy as at-risk adolescents experience it, in order to better understand how the translocal or institutions occurring outside of or beyond the local experiences, shape the lives of the at-risk student population. Within this research, translocal forces included Sabrina's Law, School Board Anaphylaxis Policies (SBAP), and in some cases, the work done by the Schools around anaphylaxis management. Overall, translocal forces are text or institutions that control, coordinate and shape the everyday experience. Within this research, the experience of at-risk students was examined, along with other key informants identified by youth (educators, administrators etc.) to discover the "nature of connections" (Deveau, 2009, p. 15) between adolescent experiences of anaphylaxis management and the processes (text, discourse, resources) in place within the Schools and School Boards. Accordingly, this qualitative research study had the following objectives:

- To explore how the everyday experience of adolescents at risk of anaphylaxis is mediated and shaped by translocal forces (such as school policies and Sabrina's Law).
- 2. To map the work, text and resources connecting the everyday experience of anaphylactic adolescents managing their allergies to the translocal institutions

3. To assess the utility of Institutional Ethnography for examining the ruling relations involved in the management of anaphylaxis in adolescents.

The study design and methods are based on the social organization of knowledge, where institutional ethnography is located as a research strategy, and the conceptual framing of everyday experiences heard or read about, or observed, constitutes one of the distinctive features. A deeper understanding about the way the social organization of anaphylaxis management within school settings is put together, such that at-risk adolescents experience as they do, exposes the ruling practices affecting them. Making visible to further understand these translocal forces provides us information on: the links between knowledge and action within school settings, the processes and procedures that shape the experience of at-risk individuals, how anaphylaxis management occurs, and how these processes and social relations may prevent, or hinder, risk. It is anticipated that these findings will make substantial contributions to the anaphylaxis management literature as well as contribute methodologically to IE.

### **Chapter 2: Literature Review**

#### **Theoretical Approach: Social Organization and Social Relations**

With its roots in feminist theory, IE was developed as a methodology that examined social relations, without letting the everyday experience disappear. To situate IE is to understand its approach as an "explicit ontology of the social (shared with phenomenologists, ethnomethodologists and symbolic interactionists)" (McCoy, 1999, p.25). Similar to phenomenology, with its purpose to discover and describe the meaning or essence of lived experience, or knowledge as it appears to consciousness, to ethnomethodology, which focuses study on participant's perspectives of social order, assessment and explanation, to symbolic interaction in which the interactions between individual and context are seen to create knowledge and truth (Hayes & Singh, 2012); IE focuses, not on studying people or explaining people's behavior, but in understanding extended chains of action (social relations), mediated by documentary forms of knowledge, that share people's lives and circumstances (Grahame, 1998; Wallby, 2006).

Smith describes the shift in IE's methodological foundations as "turning the established enterprise on its head" (Smith, 1999 p 45). In the theoretical approach known as social organization of knowledge (where institutional ethnography is located as a research strategy), experience is the ground zero of the analysis (Smith, 1987, 1990a, 1990b, 2005). The objective of the analysis is to open up possibilities for people who live these experiences to have more room to move and act, on the basis of more knowledge about them (Campbell, 1998). Unlike other methodologies and sociologies, the goal of IE is not to explain people's behaviours, but to discover how the translocal shapes the lives and experiences of these people (Smith, 1999).

It is in understanding social organizations, and how work at the local setting is organized outside of that setting, which Smith (2005, 2006) and others have described as:

Social life is not chaotic but is instead organized to happen as it does. What Smith calls the social relations of everyday life actually organizes what goes on. People's own decisions and actions and how they are coordinated with outside events are part of social relations. It is the interplay of social relations, of people's ordinary activities being concerted and coordinated purposefully that constitutes "social organization" (Campbell & Gregor, 2008, p. 27).

Quinlan (2009) further suggests that social organization presents an understanding of the "sum of the experiences of everyday practice embedded in an institutional order, while simultaneously bringing into focus relations that are not particular to, but coordinate the experiences" (p. 629). IE is a study of "her or his doings, taken up relationally" (Smith, 2005, p.59).

IE uses ontology of the social (Smith, 2005), which involves the idea that people are real and in their body, and that the social is created through these people (Walby, 2005; Deveau, 2009; Smith, 2005). This understanding shifts the focus from trying to figure out "why things happen the way they do" to "how things happen the way they do" (Deveau, 2009 p 6). It is understood, then as coordination, "where-in-action is combined together, jointly arranges or planned" (Bisset & Barber, 2000, p.194) that the how of social relations are best understood. IE begins in people's everyday lives and looks beyond to examine how these experiences are shaped and coordinated by social relations (Smith, 2005; Smith, 2008; Walby, 2005). With the everyday experiences being considered local, these social relations and forces affecting the everyday are considered translocal-in other words, occurring outside of or beyond the local (Smith, 2008). Smith (2005, 2006) argues that social relations are actual practices and activities

through which people's lives are socially organized, which moves us from the idea of social construction towards social organization/relations. Clearly stated it is

something is actually connecting what happens here to what happens there, social relations are not done to people, nor do they just happen to people. Rather, people actively constitute social relations. People participate in social relations, often unknowingly, as they act competently and knowledgeably to concert and coordinate their own actions with professional standards or organizational rules. (Campbell & Gregor, 2008, p. 31)

Translocal forces, or ruling relations, organize and mediate the everyday lives of individuals (Deveau, 2009; Smith, 2005), and are made up by institutions. Smith (2005) describes these relations as "extraordinary yet ordinary complex of relations" (p 10). She explains this as:

instead of being ruled directly by individuals whom we've known (and perhaps hated) for years and who were known before us by our parents, we are ruled by people who are at work in corporations, government, professional settings and organizations, universities, public schools, hospitals and clinics, and so on and so on. Though they are, of course, individuals, their capacities to act derive from the originations and social relations that they both produce and are produced by. The relations and organization in which they are active are also those that organize our lives and in which we in various ways participate." (Smith, 2005 p 18)

Smith (2005) goes on to specify that the ruling relations do not refer to a form of domination, but a way of organizing society.

Overall, there are three assumptions that investigations using IE begin with:

First, people are experts in how they live their own lives. Second, subjects are located in sites throughout society (local setting). And third; powerful outside (translocal) forces shape how people live and experience their everyday lives (Deveau, 2009, p 3)

This allows researchers to explore individuals and their activities within the everyday world (Deveau, 2009). Through this, we are able to better understand, and change, the social forces that shape and transform the everyday world (Deveau, 2009). As Dorothy Smith argues, "anyone can get up on a soap box. But you are more likely to produce change if you get down, take a good look at what is actually happening, pointing to the problem and saying, 'that needs to change'" (personal communication, June 7<sup>th</sup>, 2014)

#### **Anaphylaxis: Presentation and Prevalence**

Anaphylaxis is an allergic reaction to specific proteins (allergens) that can involve the skin, the respiratory tract, the cardiovascular system and/or the gastrointestinal system. Symptoms can range from abdominal cramps, vomiting and diarrhea, to difficulty breathing, circulatory collapse, coma and death (Mandell, et al., 2005; Keet, 2011). These reactions are rapid in their onset, and the severity of the reaction can change during subsequent exposures to the allergen (Mandell, et al., 2005: Chipps, 2013). It is estimated that anaphylactic allergies affect 6% of children in North America (Branum & Lukacs, 2008; Sampson, 2004; Chipps, 2013), and 6% to 8% of children in Canada (Ben-Shoshan, et al., 2010).

Food is the most common cause of anaphylactic reactions (Chipps, 2013), and is defined as abnormal immunologic responses to food proteins (Bollinger, et al., 2006). Food has been estimated to cause approximately 33.2% to 56% of all cases of anaphylaxis (Ben-Shoshan & Clarke, 2011). Although food is a necessity of life, for people with anaphylactic food allergies, eating can be life-threatening if precautions are not taken. Food labels must be scrutinized for possible allergens, food preparers must be questioned, and cross contamination must be carefully avoided.

#### **Management of Anaphylaxis**

To date, much of the research on anaphylaxis management has focused at the acute level-the anaphylactic reaction (Kastner, Harada & Waserman, 2010). With no available cure (Gillespie, et al., 2007), the only form of long-term management is through complete avoidance of allergens (Bollinger, et al., 2006; Ben-Shoshan & Clarke, 2011; Gillespie, et al., 2007). However, removing all allergens from the diet and environment can be both difficult and time-consuming (Bollinger, et al., 2006) since allergens are not always visible or recognizable (Mandell, et al., 2005).

Research has acknowledged that anaphylaxis is often managed inadequately, regardless of setting (Pumphrey, 2000; Lieberman, 2008). Specifically, both immediate and long-term management are deemed inadequate due to factors such as: poor training of primary care physicians, lack of anaphylaxis preventative strategies, lack of access to both epinephrine autoinjectors and allergist specialist advice, and inefficient school-based support (Kastner, Harada & Waserman, 2010). These management issues raise significant concerns, particularly in the management of childhood anaphylaxis, since a child at risk is dependent upon others to both prevent and treat reactions (Kastner, Harada & Waserman, 2010). The Quality of Life (QoL) of patients at risk for anaphylaxis —as well as their caregivers—has been shown to be negatively affected by anaphylactic allergies (Kastner, Harada & Waserman, 2010). Avery, King, Knight and Hourihane (2003) compared children with peanut allergies to those with insulin-dependent diabetes mellitus using disease-specific QoL questionnaires. These results showed that children with peanut allergies have lower QoL overall, higher levels of anxiety toward eating, and greater fear of a reaction compared to children with diabetes (Avery, et al., 2003). These findings also revealed that while children with diabetes were unaware of the long-term consequences of their

disease, children with peanut allergies were acutely aware of possible consequential fatalities (Avery, et al., 2003). In addition, children with diabetes had a level of control over their condition, being able to manage it through eating properly, regular blood tests and insulin injections, as compared to children with peanut allergies, who had little control of the environment outside their homes and were constantly vigilant of their surroundings and the allergen hazards within it (Avery, et al., 2003). A decrease in QoL for children with anaphylactic allergies can also be attributed to restrictions and disruptions of social activities and interactions (Kastner, Harada & Waserman, 2010), for example, exclusions from such events as birthday parties, sleepovers, school trips and family social activities (Bollinger, et al., 2006; Fenton, et al., 2013).

#### **Adolescents and Anaphylaxis**

Research on adolescents and anaphylaxis has primarily focused on the transition from parental management to self-management, as well as risk taking. The entry into adolescence is often challenging, as children transition from parental management to more independent self-management of anaphylactic allergies (Gallagher, et al., 2012). Adolescents described this transition as involving more responsibilities for management, including being more independent, making more independent decisions and choices, taking more risks, and advocating for themselves (Fenton, et al., 2011; Fenton, et al., 2013). The most commonly cited responsibility developed from parent to adolescent was carrying medication (epinephrine auto-injectors, for example) and checking food labels for possible allergens (Gallagher, et al., 2012). Moreover, both parents and adolescents report that good management involves a balance between not letting allergies dominate lives and taking the risk of anaphylaxis seriously (Gallagher, et al., 2012).

Studies suggest that life transition and the impact of anaphylaxis on adolescents and their families is significant. Findings indicate that tensions around independence and risk taking is extremely challenging. In a qualitative study of food allergic adolescents and their parents, parental worry about increased risks remained present despite the preparation for selfmanagement and trust in adolescent abilities (Akeson, Worth & Sheikh, 2007). Adolescents, in the study, expressed different concerns around the burden of social restriction (Akeson, Worth & Sheikh, 2007). Akeson, Worth and Sheikh's research also revealed a paradox in the management of anaphylaxis. While adolescents respected their allergies and limited risk taking involving food, they often attached little importance to their allergies, describing them as 'no big deal' (Akeson, Worth & Sheikh, 2007). Research by Fenton and colleagues found that "adolescents who admitted to risk-taking behavior were less encumbered with fear, which enabled them to deal more independently within their social environment" (Fenton, et al., 2011, p 9). Monks and colleagues (2010) also found that the majority of adolescents reported reading food labels when consuming a new food or when unsure of a food item, and more than half of the teens admitted to trying foods that could potentially contain an allergen (Monks, et al., 2010), and viewed 'may contain' labels on foods as the manufacturer's way to 'cover their back' (Akeson, Worth & Sheikh, 2007, p. 1216). Anaphylactic adolescents approach to allergen avoidance depended upon the situation, with more risk-taking occurring in familiar situations, with people they knew, or when they had epinephrine auto-injectors with them (Monks, et al., 2010).

#### **Anaphylaxis and School Systems**

It is estimated that approximately half of a child's waking hours are spent at school or daycare, under the care of teachers and other school personnel (Bansal, et al., 2005). In the school setting, children eat lunch as well as multiple snacks. For children with anaphylactic food

allergies, this means multiple times a day that they may become exposed to allergens. In the United States, statistics show that accidental exposure does occur, with 25% of initial reactions occurring in the school setting (Sicherer, et al., 2001), as well as 16% to 18% of subsequent reactions (Sicherer & Mahr, 2010).

Research has shown that the management of anaphylaxis in school settings is difficult, for reasons including school personnel's lack of knowledge and skills in recognizing reactions (Cicutto, et al., 2012), food sharing between children, contamination of objects, such as desks (Muñoz-Furlong, 2004), lack of written emergency plans and inaccessible epinephrine (Rhim & McMorris, 2001). Fenton, et al. (2011; 2013) also found that high school environments posed greater perceived risk for allergen exposure compared to elementary schools, due to larger student populations, unmonitored eating areas, and increased class schedules.

In Canada, the provincial response to anaphylaxis in schools varies greatly - ranging from legislation mandating the development of anaphylaxis policies within schools (Ontario and British Columbia), to no guidelines (Saskatchewan, Northwest Territories and Nunavut). See Appendix A for a complete list of provincial responses to anaphylaxis management. The Canadian School Boards Association has also published *Anaphylaxis: A Handbook for School Boards*, which provides information on policy development, important elements within policies and division of responsibilities (Canadian School Board Association, 2001).

Ontario's Act to Protect Anaphylactic Pupils (also known as Sabrina's Law or Bill 3) was the first of its kind in the world. Sabrina's Law was enacted to support the protection of at-risk students within schools (Cicutto, et al., 2012). Sabrina's Law came into effect January 1, 2006, and specifically targeted all publicly funded school boards and schools in Ontario. The

legislation mandates that anaphylaxis procedures in all Ontario school boards contain strategies to reduce the risk of exposure to allergens in classrooms and common areas. The legislation also requires communication plans for disseminating information on life-threatening allergies to parents, pupils and employees, and regular training on how to react to these allergies for all employees and others in direct contact with students (Bill 3, 2005; Chipps, 2013). Additionally, school principals are required to create individual plans for students with anaphylactic allergy, and to maintain a file for each of these students (containing current treatment, copies of any prescriptions, instructions from the student's physician or nurse and current emergency contact list) (Bill 3, 2005). Sabrina's Law also protects Good Samaritans from legal action if they used epinephrine on a previously undiagnosed student experiencing an anaphylactic response (Cicutto, et al., 2012; Chipps, 2013). Contrary to other provinces, Ontario has created a mandatory policy to protect not only at-risk students, but also Good Samaritans.

Cicutto and colleagues (2012) found more consistency between school board level anaphylaxis-related policies and Canadian anaphylaxis guidelines in legislated school boards (such as those in Ontario) compared to unlegislated school boards. Legislated school boards were more likely to have policies pertaining to allergen avoidance; training and individual management plans for anaphylactic students (Cicutto, et al., 2012). Yet this study found that parents perceived a lack of awareness and training at school to place their child(ren) at risk (Cicutto, et al., 2012). Other research supports that food allergic children and adolescents continue to report feelings of anxiety and fear within schools (Fenton, et al., 2013; Fenton, et al., 2011). Even though Sabrina's Law is in place, students with anaphylactic allergies feel at risk, and unsafe. Arguably, a significant concern when laws are put into place is a lack of resources to implement and enforce them ("legal teeth") (Cicutto, et al., 2012, p 136). While Ontario is

leading the way in creating protective legislation, there is no enforcement body ensuring that this plan is assessed (Ciccuto, et al., 2012).

#### **Evaluation of Other School-Centered Legislation in Ontario**

The School Food and Beverage Policy (PPM 150) is another example of legislation in Ontario targeted at school boards that works to create a healthy environment for students. The legislation works by categorizing foods depending on their nutritional content, and regulating what foods can be sold within schools (PPM 150, 2010). Vine and colleagues have researched this legislation from government policy through implementation at school levels and students experience with the nutritional policies (Vine & Elliott, 2014a; Vine & Elliott, 2014b; Vine, Elliott & Raine, 2014). Within their research they found that 92% of the regional-level policies (school board) provided a link between nutrition and improved learning outcomes, however strategies on how nutritional education can be improved in both quality and amount at the school level were lacking. Looking more closely at specific school boards, all three were in compliance with PPM 150, however only 62% of school board policies provided information on the implementation and monitoring of nutrition policies at the school level (Vine & Elliott, 2014b).

At the school level, policy guidelines were seen as a barrier to food accessibility, with policy-compliant foods being higher in cost. While this concern was expressed across school boards, it was seen to be more of a problem within schools where there were higher percentages of low-income students. These higher priced foods caused some students to move off campus to purchase cheaper, unhealthy options, decreasing revenues of the cafeterias (Vine & Elliott, 2014a). These findings were echoed by secondary students who expressed concern over the high-cost and low-quality of PPM 150 compliant foods, and as a result bought food off campus

instead (Vine, Elliott, & Raine, 2014). Proximity to fast-food outlets was also seen as a barrier to policy implementation, with cheaper, unhealthy food options being easily accessible for students (Vine & Elliott, 2014a).

Some stakeholders expressed that the policy guidelines were too strict in nature, and that secondary school students should have opportunities to make their own food-related choices (Vine & Elliott, 2014a). Students also found that their voices were not heard in relation to school nutrition, and expressed a desire for input into what was provided in the cafeteria (Vine, Elliott & Raine, 2014).

Overall, it was seen as the collective responsibility of the community in the success of nutrition policies, with groups such as schools, parents and public health units being essential in the implementation of these policies. Consistent communication between these groups and all other stakeholders throughout policy implementation could help better its success (Vine & Elliott, 2014a).

#### The Use of IE within Research

A number of research groups ranging from legal systems and long-term care homes have utilized IE to explicate the social organization in ways that will help the people involved in them. The focus of this research examined how the institutional processes and social organizations shape and affect the people involved in them.

Rena Teary utilized her own experience of caring for her dying husband in her research examining the institutional processes around palliative care. Through this, she found that palliative interventions and the textual processes did not create her as a person interacting with

the palliative care process, but a problem to be managed by a professional (Campbell & Gregor, 2008).

Benjamin and colleagues' work focused on long-term care homes and personal support workers to gain understanding of how the organization affects the physical activity of the residents. They found that physical activity was considered an add-on activity, instead of a daily life activity, and that the standards in place disrupted the work of personal support workers, making it difficult for them to address the physical activity needs of the residents (Benjamin, et al., 2016).

Research by Ng and colleagues examined the work done by pediatric practitioners advocating for children with disabilities in schools. They found that advocacy work focused on two main topics, orienting special education for the child, and highlighting invisible disabilities. They also found that much of the advocacy work by pediatric practitioners was indirect, either through parents or through text, which lead to conflicts and inefficiencies (Ng, et al., 2015)

Research by Wilson and Pence focused on the US legal system and asking whether the interventions put in place for domestic assault cases are oriented in a way to benefit Indigenous women and their relationships and connections with the Indigenous communities (Smith, 2006). This research found that the institutional processes put in place to respond to domestic abuse cases focused on opposition and isolation, ignoring the familial and social connections that are important parts of Indigenous culture. The systems use of knowledge, for example using a professional's knowledge over the knowledge of a layperson, rendering these women powerless within the interventions. They suggested the development of a system that both protected the women who are abused, and held the offenders accountable to the women, children and their

community, with the system prioritizing the needs of the victim over the management needs of the institutional structure, and the acknowledgement and addressing of the women's experience, not focusing on the act of domestic violence (Smith, 2006).

Throughout these IE inquiries, there is a focus on helping those involved in the everyday experience, and working to find how the institutional processes that shape their lives can assist them. Whatever the focus of the research, IE researchers do this work to help individuals understand why their experiences are shaped the way there are, and highlight areas of improvement.

#### Helping or Hurting? Unintended Side Effects of School Policies

While policies and programs are implemented to assist and protect students at risk for anaphylaxis, research suggests that they can actually be harmful. Resnik (2013) argues that the weakness of such policies is they prioritize the good of anaphylactic students over the good of non-food allergic students. For example, allergen bans (complete removal of allergens such as eggs, milk, peanuts and nuts from the school setting), are unsupported by experts in the field (Sicherer & Mahr, 2010) due to school lunch monitoring difficulty (Resnik, 2013), and because it results in the removal of staple proteins from other students' lunches (Sicherer & Mahr, 2010; Behrmann, 2010). Resnik (2013) argues that undue hardship is at the heart of the issue.

In the development of policies and programs focused on protecting at-risk children, research underscores the importance that children not be separated or ostracized (Sicherer & Mahr, 2010; Behrmann, 2010). More recently, research has shown explicit rules and procedures in schools "tag" at-risk students as different (Fenton, et al., 2013, p 289). Other studies found that blatant discriminatory and unethical behaviours cause psychosocial stress for food allergic

children (Marklund, et al., 2007). For example, Marklund and colleagues (2007) found that atrisk children were segregated to a different location in the school for cafeteria food pick up (Marklund, et al., 2007; Behrmann, 2010). Food allergic students reported on the poor quality of the food provided to them (Marklund, et al., 2007; Behrmann, 2010). These procedures, while put in place to protect at-risk students, label them as different and separate them from other students, which has shown to cause stigmatization and discrimination (Behrmann, 2010; Marklund, et al., 2007; Fenton, et al., 2011; Fenton, et al., 2013; Dean, et al., 2015).

In summary, there are many inconsistencies in how anaphylaxis management policies are implemented that create difficulties for at-risk youth in schools. Even with policies such as Sabrina's Law in place, students with anaphylactic allergies still report feeling at risk and unsafe in school settings (Fenton, et al., 2011; Fenton, et al., 2013). This suggests that the intent of anaphylactic policies is not being seen in the local environment, or the everyday experience. Thus, the focus of investigation for this study is the tension between the provincial legislation, school board policies, school procedures, and their influence on the daily lives of adolescents atrisk of anaphylaxis. Therefore, the purpose will be to examine the social organization of schoolbased management policies from the standpoint of at-risk students. This will provide a better understanding of how the translocal affects and shapes adolescents' everyday experiences, and highlight possible disjunctures that prevent the good intentions of the legislative environment from positively affecting anaphylactic students' experiences within school systems. This will not only help us further our understanding of adolescents' experience within school systems, but may help move both legislation and policies in a direction to better provide a safe environment for students with life-threatening allergies. To the researcher's knowledge, this is the first time

that anaphylactic student experience and sociopolitical environment have been examined together, or within the framework of IE.

# Chapter 3: Institutional Ethnography as an Alternative Sociology and Methodology

This section provides an overview and "orienting discussion" (Mykhalovskiy & McCoy, 2002, p. 18) and key concepts provided by IE as the methodology used in this study's inquiry. *Institutional*, understood not as a particular organization, but rather as the work processes in place within translocal environments that coordinate actions within other sites (Smith, 2006) and *ethnography* as underscoring the importance of research methods that can explore the everyday experience, then move beyond it to understand how they are positioned within and coordinated by the translocal (Smith, 2005).

IE provides an approach for empirical investigation that begins in the everyday. It provides an understanding, for how a world is put together, through the work activities and actions of the actors (Rankin, 2004, p.4). Multiple terms guide the course for beginning research that uses insights from IE: begin in the work done in everyday experiences, identify a standpoint, and establish a problematic, coordinate talk and text as sources of data. What follows are key conceptual tools for "thinking and investigating" (Campbell & Gregor, 2008, p. 27) the everyday experience.

#### The Development of Institutional Ethnography as an Alternative Sociology

The development of IE began during the women's movement, with Dorothy Smith's realization that sociology and the research within it was not answering the questions that were arising within the movement. She found that:

"[t]he whole method of thinking, how social science addresses the world, creates a very peculiar relationship between women and our experience. Rather than beginning in our own actual situations and with our own good knowledge of the practicalities and

organization of our everyday and everynight worlds, social science's methods of writing its texts create a standpoint from which the reader reflects on her life as if she stood outside it, taking up the relevancies and focus built into the conceptual structure of the discourse. She becomes an object to herself... As a practical problem, we found in the women's movement that texts written in social scientific terms would not do the kind of job to which we were committed, which was to expand women's knowledge of what was going on from where they were in real, as contrasted with textual, life" (Smith, 1999, p. 30)

In continuing her work examining the established sociology of the time, Smith critiques the beginning of research within the text-mediated discourses and theories, which "operates selectively in assembling observations of the world that are ordered discursively" (Smith, 1999, p 4). Through this, the activities and people in question disappear from the research.

Through this work, Smith began to realize the need for an alternative sociology, one where a person is the expert knower of their life and the activities that go on within it, and that began in the everyday experience of this expert knower. Instead of working to explain these peoples' behaviors (separating them from their activities), the sociology needed to look upwards to explain how translocal forces (such as the economy, society, government and political processes), interact, affect and shape the lives of these knowers (Smith, 1999).

Within the development of the idea of the ruling relations, Smith was inspired by the thinking of Karl Marx on the development of the economy, relations of dependence, and capitalism. Marx describes the relations of dependence before capitalism as relations between specific people, for example the relationship between a lord and a villager or serf living on his land. With the movement towards capitalism, markets began displacing these relations of dependence, and "[p]eople's dependence on one another's work as members of a society

becomes unidimensional and abstract as it is objectified in the exchange of money and commodities" (Smith, 1999, p. 77). Smith utilized this thinking in the understanding and writing of the ruling relations, with the ruling relations (like the economy) being independent of the individuals (though individuals can participate within them), yet acting on and affecting their daily lives (Smith, 1999).

For the development of an alternative theory of knowledge (moving the role of the knower from the ruling relations and textual discourse to the individual), Smith pulls from the theoretical works of George Herbert Mead, Valentin I. Vološinov, and Mikhail B. Bakhtin. Mead's, Vološinov's, and Bakhtin's theories revolve around the location of self and language within the social processes of the everyday world. The three works complement each other, "rejecting the conceptions of language and ideology as systems independent of the local production of language and meaning" (Smith, 1999, p. 98). From these, Smith developed the idea of knowledge as being "essentially social and as an organization of social action among participating subjects" (Smith, 1999, p. 99). This acknowledges the individual as an expert of their lives, situated in the actualities of the everyday (instead of as a transcendent subject, separate and looking down at their lives) (Smith, 1999).

#### **Institutional Ethnography Research and its use of Theory**

While Smith pulled ideas and concepts from a number of different theories and research for the development of IE as a sociology, an IE *research project* should always begin within the everyday experience of the expert knower. For IE to be organized as an inquiry, it cannot begin by using an "exhaustively developed and comprehensive theory" (Smith, 1999, p. 12). These theories, and social science knowledge in general, are developed from and hold a standpoint

within the ruling relations. Instead, IE begins from the standpoint of the people, working to understand how their lives are affected by the ruling relations:

[T]he method of writing the social as a knowledge for people put forward in this book rejects the grand imaginary maps...which were held in suspension outside local practices of finding and recognizing. It rejects equally sociologies which give primacy to theory, whose phenomenal universe is constituted by abstractions and in which sequences of referring are completed entirely within discourse in returning to its own discursively constituted objects. Instead, it aims at knowing the social as people actually bring it into being (Smith, 1999, p. 129).

#### Moving from a Sociology to a Methodology

To solidify the movement of IE from the philosophical underpinnings around knowledge and ruling relations to its use in the development of research projects, it is helpful to consider it as two concepts; IE as an alternative sociology and IE as a methodology. IE as an alternative sociology involved moving the role of the knower from the ruling relations to the individual, and exploring the ruling relations and how they shape the everyday experience of said knower. IE as a methodology is informed by these philosophical underpinnings, but involves the development of a research project. This involves establishing a problematic or disjuncture to be explored, identifying a standpoint from which this will be done, and beginning in the everyday experience and the work involved in peoples' lives. Dorothy Smith developed IE as an alternative sociology because what she was trying to do within research (an early version of IE as a methodology) was not possible with the philosophical underpinnings of the sociology of the time.

#### The Work Done in Everyday Experiences

In its commitment to discovering how the local experience is put together, IE does not begin in theory, but in people's experience (Smith, 2006, p.1). From this start, in the everyday

life of the subject under investigation, the work of the researcher in undertaking IE is one of branching out and exploring "work" or the processes happening within the larger institutional context (DeVault, 2008, p. 5). In IE, "work" refers to any activity that "takes time and effort, that they intend to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about" (Smith, 2005 pp 151-152). This allows the actual doings of a person to be considered, what they are thinking and feeling, instead of simply what is listed as a part of the job description (Smith, 2005). This concept of 'work' orients the researcher to what people are actually doing in their everyday experiences, and the ways these experiences are coordinated by the ruling relations (Smith, 2005).

#### **Identify a Standpoint**

Smith (2005) suggests the standpoint is a starting point for the problematic that provides a guiding perspective or experience - an entry point into the social and a place from which to look (Campbell & Manicom, 1995) that helps guide researchers within the problematic to the direction of inquiry (Smith, 2005). Beginning in a standpoint and working to understand peoples experience, helps reinforce the idea that there may be differing ways of knowing the social relations and organizations within a person's life (Smith, 2005). This differing in realities is for IE called disjuncture, an issue of two differing forms of reality (Smith, 2005).

#### **Establish a Problematic**

One of the defining characteristics of IE is how inquiry begins. In many other methodologies, inquiry begins at a problem statement or concern, with hypotheses being formed (Smith, 2005). For IE, inquiry begins in a problematic, a misleading term since it does not refer

to a problem or a research question (Deveau, 2009). The problematic is a term used in IE to identify the place where the study inquiry begins to discover a puzzle, a situation that someone in that world is living in, knowing it from the inside – or how the researchers will orient the inquiry.

#### Coordinate Talk and Text as Sources of Data

Smith (2005) argues that language is integral to the investigation of the social (p.70). Language, either spoken or as text, creates new dimensions of organization as the coordinator of other activities (Smith, 2005). For example, language, which encompasses both talk and text, comes into being when it causes the same response in both speaker and listener (Smith, 2005). It is the response to the language that is learned and remembered from past experiences; these experiences being socially organized (Smith, 2005). It is through language that institutions and ruling relations are able to coordinate and mediate the everyday experience of people.

In IE, text refers to words, sounds or images that are in a definite material form. More specifically, they are replicable in a way that allows anyone from anywhere else to interact with these same words, sounds or images (Smith, 2005; Smith, 2006). People interact with these replicable texts at a local and observable level, but at the same time they are being hooked into translocal relations (Smith, 2006). By interacting with a text, a person's everyday experience is mediated by the translocal institutions, and these translocal institutions coordinate their consciousness of the text with others (Smith, 2006). Smith (2005) argues that these institutional relations are essentially text mediated. In other words, IE recognizes text (and discourses) in people's activities and experiences as they are mediated and coordinated through ruling relations (Smith, 2005; Smith, 2006; Walby, 2005).

For instance, a text left on a bookshelf does not have an effect on the local experience of people. It is by looking it up and "activating" it that the text can affect their local experience (Smith, 1999 p 146). In IE, this is described as a conversation between the text and the reader (Smith, 2005). It is this activation of the text by the reader that allows the text's message to be included in the local (Smith, 2005). Yet, this text-reader conversation is two-sided, with the reader providing both sides (Smith, 2005). The reader has a conversation with the text by not only activating it (reading) but also by responding to it (Smith, 1999; Smith, 2005). They may agree or disagree with the text. So while they are reading the text, they are also responding to it, creating a two-sided conversation.

#### Mapping as an Analytic Technique- Making Visible Work and Text

Turner (2006) talks about mapping as a way of extending beyond an ethnography, or people's experiences, and to look at the work and text that connect the institutional processes to these experiences. In this study, mapping as an analytical technique tracks and visually displays the institutional processes, or the everyday text-based work and local discourses of the institutional anaphylaxis management processes (Smith, 2006). Mapping visually displays observable work of people and the text that mediates their everyday lives and the institution and ruling relations that produce them (Smith, 2006; Walby, 2005). Mapping provides the ability to track these translocal institutional processes and to develop an understanding of how they act on, coordinate, and shape the everyday experience (Turner, 2006). The power of mapping is that it reveals the dynamic forms of institutional action, and opens up pathways for interventions. For instance, IE is commonly used to examine policy implementation and action, and their disconnections and gaps from the lived experience (Ng, et al., 2013). Smith (2005) argues IE is

an invaluable methodology that enables researchers to look inside at the workings of the institution, to reveal the inefficient or even harmful work processes within it, which creates possibilities for change.

# **Chapter 4: Methods**

Institutional Ethnography (IE) was employed to map the organization of work from the standpoint of adolescents at-risk of anaphylaxis, while concurrently connecting these to the overarching translocal environments. Thus, this study utilized three main methods: interviews; document and Boss Text analysis; and mapping as an analytic technique. Finally, this section concludes with a discussion on methodological trustworthiness and the researcher's role in IE.

Using IE as an approach, the following strategies and approaches were used to address the key research questions:

- 1. To explore how the everyday experience of adolescents at risk of anaphylaxis is mediated and shaped by translocal forces (such as School Board policies and Sabrina's Law).
  - In-depth interviews using a semi-structured interview guide (Charmaz, 2006), informal interviews, observations, and document (text) analysis (Bowen, 2009) were used to understand the role that documents (text) play in anaphylaxis management policies/strategies for at-risk adolescents. Adolescent interviewees and parents were purposefully recruited from local schools. Additional key informants (educators, administrators, etc.) emerged during the initial data collection stage. The collection of key documents (text) that guided the implementation of anaphylaxis management strategies/policies occurred simultaneously. Documents were identified through dialogue and connections made with adolescents, key informants, and other documents in understanding the everyday experiences of navigating regulated processes.
- 2. To map the work, text and resources connecting the everyday experience of anaphylactic adolescents managing their allergies to the translocal institutions
  - Interview data and key document analysis were used to generate maps that track and visually display institutional processes (Turner, 2006, 2008b). The mapping rendered

actual work processes, document based work, and local discourse patterns that shaped the experiences of managing anaphylaxis at-risk adolescents in school settings.

3. To assess the utility of Institutional Ethnography for examining the ruling relations involved in the management of anaphylaxis in adolescents

Utilizing IE, research findings from this pilot study provide important insights into how and why regulated school-based processes shape adolescent experiences; specifically, a) the mechanisms that link knowledge to action in school based settings; b) how processes and procedures shape the experiences of at-risk adolescents; c) how anaphylaxis management support happens as it does; and, d) how processes and social relations impact anaphylaxis management to either hinder or prevent risk.

In this study, the problematic was the disjuncture between the provincial legislation (Sabrina's Law), school procedures and the daily lives of adolescents at-risk of anaphylaxis. The standpoint of an adolescent with anaphylactic allergies acted as the entry point for inquiry in order to better understand the broader sociopolitical institutional organization.

### Recruitment

The study was conducted in the Waterloo region, within a local School Board. The Kitchener-Waterloo region was an ideal region as recent media attention (2012) surrounding anaphylaxis management and child safety are paramount (McCarthy, 2012); thus, it will become increasingly important to understand how the everyday experience of managing anaphylactic allergies occurs, and how the school environments translocal forces shape them.

After ethics approval was received from the University of Waterloo Research Ethics Board (REB), research approval was sought from School Board A. School Board A then rejected the research project on the basis that it appeared the research had been completed previously.

However, while examining the proposal and holding discussions with an individual from the Office of Research Ethics, it was found that the School Board may have seen the research as unbeneficial to the institution, and concerns about the school being "put under the microscope", since there was initially only one School Board involved in the project. The proposal was then reframed to make it clear that this was one part of a larger research agenda, and that future studies would develop from it. It was also stressed that the project did not intend to evaluate Schools or School boards, and that the goals of the research were to help make the management of anaphylaxis more effective for students, schools and school boards. We then applied and gained research approval to School Board B.

Schools were then individually approached for approval to conduct research within their institution and student population. Schools were recruited purposively to provide a diversity of socio-economic status. Past literature has examined barriers for low-income families around anaphylaxis management and preparedness, such as costs of medication, costs and stress related to obtaining allergen-free foods, and misinformation around social support programs (Minaker, Elliott, Clarke, 2014). Given these socio-economic factors, it was important to consider low-income status within the selection of schools, as income could affect anaphylaxis management within the school environment. With 10.2% of the Waterloo Region population living below the Low Income Cut-Off (Region of Waterloo Public Health, 2011), it was important to consider the possible effect of low-income populations on students and the school environment. Therefore, schools were chosen based on their proximity to higher and lower Neighborhood Economic Security Index areas, as reported in the 2011 Waterloo Region Community Assessment Report. Neighborhood Economic Security Index is calculated based on six economic indicators:

unemployment rate, low income families, education level, family structure, rental housing and home spending (Region of Waterloo Public Health, 2011).

The Neighborhood Economic Security Index was utilized instead of asking the School Board or Schools directly about the economic status of their students for a number of reasons. We wanted the School Board to see this research project as beneficial to the institutions and people involved, not as a comparison between Schools with higher or lower income families. We felt that by asking the School Board to offer Schools within these groups, it would negatively affect their view of the project and their willingness to allow the research to continue. Asking Schools about the economic security of their student population was also seen as sub-optimal option, since this would have had to be determined before gaining permission from the School to conduct the research within their institution (guaranteeing we had a range of Schools). We believed that asking Schools about the economic security of the student population before any form of rapport was formed would be seen as intrusive, and negatively affect the School's opinion of the research. This could have greatly affected whether the Schools would have allowed the research to take place within their institution, especially if they saw this as a comparative research project where they could be seen in a negative light because of the economic standings of their students and families. To prevent this, the economic standing of the student population was estimated by the proximity of the school to areas of higher or lower economic security, with the reasoning that these would be the areas that the school would "pull" students from. Two Schools were then chosen with one located closer to areas of lower economic security and one to areas of higher economic security.

The two Schools were then approached, and approval was provided to conduct the research within the School. Information sheets about the research and parental consent forms

were sent home to the families of students with anaphylactic allergies. Within one of the Schools, the first recruitment attempt was unsuccessful, and the School rejected any further recruiting. Because of this, a third School was approached within a similar economic region and approval was gained to conduct the research. Recruitment attempts were then successful at the third School, and a total of two schools participated in the research project. Of these two Schools, one was in an area of higher economic security, one in a lower area. One was a midsized School with ~1300 students, the other was the largest School in the School Board with ~1700 students.

The selection criteria for the adolescents included – 13-18 years old; diversity of gender; clinical diagnosis of life-threatening food allergy; and attendance at publicly funded high school (private school and homeschooled students were excluded). Five parents expressed interest in the project, and signed consent forms for the student researcher to interview their six children. Parents were asked general questions about their children to assist with recruitment (age/grade, gender, allergy, whether they were involved in extracurricular activities, and whether they had a reaction within the last 3 years). Because the purpose of the research was to start with adolescents' experiences of managing anaphylaxis within their school environment, it was important to recruit participants who engage in a range of different settings at school (for example, extracurricular activities, grade levels). If there were high interest in the research project, purposeful sampling would have been utilized to include as diverse an array of experiences possible. When only five families approached the student researcher, they were all included for interviewing. Key informant participants were identified by at-risk adolescents and through the researcher's interactions and conversations while in school environments. Key informants met the following criteria:

having necessary knowledge, information and experience on the topic being researched, is capable of reflecting on that knowledge and experience, has time to be involved in the study, is willing the be involved in the study, and indeed, can provide access to other informants (Morse, 1995, p.228).

### **Data Collection: Interviews with At-Risk Adolescents**

Six at-risk adolescents participated in in-depth semi structured interviews (Charmaz, 2006). The purpose of these interviews focused on understanding their experiences of managing anaphylaxis – exploring how it happened within school environment. This investigation did not study adolescent perspectives per se, but rather explored the activities and how they were organized, in relations crystallized in texts (Campbell & Gregor, 2008, p.57). Interviews with adolescents lasted approximately 45-90 minutes in length and were in person. Parents were able to choose the location of the interview; five adolescent interviews occurred in their homes and one occurred at the University. The interviews focused on who was involved in helping them navigate their anaphylaxis management experience, as well as identified text(s) involved (information pamphlets, provincial policy, school policy, classroom rules, etc.) that mediate this process. An interview guide (see Appendix B) was used to guide conversations to explore the understanding of the social organization of anaphylaxis management, with questions and probes exploring participants practice, knowledge transfer, documents, and discourses. Questions in general focused on: background/demographics, experience/behaviors, opinion/knowledge, and sensory questions (Patton, 1990). Questions were pilot tested with both a fellow student researcher as well as a university student with severe food allergies. The interviews were digitally audio-recorded and transcribed verbatim for subsequent analysis and mapping.

From the adolescents interviewed, entry-level data was collected. Entry-level data is generated from the participants whose experience represents the problematic under investigation (Deveau, 2009). This information furthered our understanding of the problematic and the exterior forces involved, and directed us to other key informants involved in the problematic, but not at an experiential level (Deveau, 2009).

## **Data Collection: Interviews with Key Informants**

Key informants, as identified by adolescent interviews and through interactions and conversations within Schools, were then asked to participate in in-depth, semi-structured interviews or informal interviews. The style of interview was determined by the interaction and the time available for the participant. In total, 20 key informants were included in this research, including five parents, one Vice-Principal, four secretaries, seven teachers, one supply teacher, one guidance counselor, and one School Administrative Secretary. All key informants that were approached consented and were very interested in being interviewed. This "discovery" of informants is what leads IE to be an emergent methodology. Parents and students were given the opportunity to participate in the interviews together. The purpose of these interviews was to gain an understanding of the work and text involved in supporting the management of anaphylaxis. Questions were shaped as open-ended inquiry, oriented to sequences of interconnected activities with the purpose to learn "how things work" (DeVault & McCoy, 2006). It was from these individuals that level-two data was collected, providing us with an understanding of the key informants and their role in the system of anaphylaxis management within the school setting (Deveau, 2009). This additional data further contributed to our understanding of the sociopolitical dimensions or ruling relations involved within the problematic (Deveau, 2009).

### **Data Collection: Document Collection**

The collection of key documents (text) that guide the implementation of anaphylaxis management strategies/policies occurred simultaneously with interviews. Various documents were identified through dialogue and connections made with adolescents and key informants in understanding the everyday experiences of navigating regulated processes, as well as through identification by other documents. Documents and important text were also identified through observations around the school environment (for example, signage). Example of documents included Sabrina's Law (Appendix D), SBAP (Appendix E), and school level medical forms. The incorporation of documents, or text, into the inquiry allows us to look beyond the local and observable (the experience of an anaphylactic student) towards the translocal social relations and organizations that control the local (Smith, 2006).

## **Analysis: Writing as an Analytical Approach**

While there are ample resources on the theory and development of IE, there is a paucity in the literature on how the analysis within an IE is *actually* done. However, Campbell and Gregor (2008) published a primer in IE that provides accessible information on how to proceed with an IE analysis, which and is drawn upon extensively to articulate the analytic approach used in this study.

Instead of working towards examining and describing an everyday experience, IE works to explicate it (Campbell & Gregor, 2008). By learning not only about the everyday experience of managing anaphylaxis, but also the work, text and people involved in the process, allows us to look deeper into the experience. Instead of understanding just what it is like, we can learn about

what shapes these experiences. Campbell and Gregor suggests early analysis begins through storytelling:

find someone with whom you can talk about what you are learning from your data. Begin to try to explain to someone else what you now see. Listen to their questions and try to answer comprehensively. Watch yourself draw on what your informants have told you, or what you learned in your observations, or from textual materials that you have gathered from the setting you studied. As you talk, make notes to yourself about what chunks of data illuminate the stories you are able to tell. (Campbell & Gregor, 2008, p. 92)

This informal storytelling assists in data analysis in two main ways. First, it helps in determining what elements or aspects of the data to include within the writing of the story. Second, it can also help in understanding and clarifying where the data boundaries exist. Understanding the questions your data can and cannot answer prepares you for writing the story (Campbell & Gregor, 2008).

Within this research project, informal story telling was undertaken with my supervisor (Dr. Fenton), a committee member (Dr. Dean), as well as others both inside and outside of the University. This wide range of experiences provided me the opportunity to not only gain different perspectives and identify different types of questions raised about the data, but also provided me the opportunity to go back and discuss the data multiple times.

After informal storytelling, analysis through writing begins. Throughout the process of writing, it is important to constantly be asking the question, what is actually happening in the setting I am examining? This explication of the actualities and the social relations in play is key in the analytical practices of IE (Campbell & Gregor, 2008).

Through reflecting upon the collected data, and keeping close consideration of the problematic that you are trying to explore, a story begins to form, "just as you can 'tell a story' to a listener, now in writing you are telling a story about what you learned to the reader. You can use 'the point' that you saw in your storytelling, to make an analytic point in your writing" (Campbell & Gregor, 2008, p 93). Throughout this process, it is important to keep the original problematic in mind. This will help in sifting through the data and in understanding what pieces to include that help to increase our understanding of the problematic (Campbell & Gregor, 2008). For this step in analysis, I utilized notes from informal storytelling, interview transcripts, pictures taken around the School, text and documents collected, and observations during data collection to begin piecing together the story of what is happening within this problematic, or the disjuncture between students' everyday experience of managing allergies in Schools, School procedures, and the legislative environment. I began in the everyday experience of adolescents with anaphylactic food allergies, using interviews with students and their parents to build their story. This included what they do in their lives, how they manage their allergies, how the two intersect, and what their experiences had been at school. Next, I looked beyond the local experience of the adolescents and began building an account of the institutional processes, activities and work done in schools around anaphylaxis management. Finally, I looked beyond the School environment to the legislative and policy environments that the school operates within, developing an understanding of where these texts come from, the actions that they cause, and the power that they hold within the institutional processes. Throughout the data analysis, and specifically with text, questions were asked to help uncover the work-text-work processes and social relations at play within the institutional processes:

• What does activating the text lead to?

- What outside factors cause peoples' activities, and what are the effects of them?
- What social relations can be seen in the everyday activities?
- How do these social relations play into and create institutional processes? (Campbell & Gregor, 2008)

Throughout the analysis, interpretations are developed that look at and explicate the "linkages that are lived, and brought into existence in time and space by actual people doing actual things" (Campbell & Gregor, 2008, p 98). Through this, the institutional processes and ruling relations are exposed.

Within this analysis, I also conducted specific analysis of the Boss Texts - Sabrina's Law and the SBAP. Boss Texts are text created within the ruling relations that create further institutional processes, and coordinates the work, text and environments below it in the hierarchy (Smith & Turner, 2014). Boss Text analysis involved not only the analysis steps described above, but also approaching the Boss Text with the mindset of someone who needed to utilize the text, for example, a staff member who was unfamiliar with anaphylaxis management in schools. To do this, I read (activated) the text multiple times, using it as the text instructed me to (for example, moving to a specified appendix when directed to in the text). This approach helped me further understand the work-text-work processes that the text set up. It also helped me develop an understanding of the gaps within the text, identify missing information, text, or direction, which prevents readers from being able to participate in work-text-work processes.

# **Analysis: Mapping Work Processes as an Analytic Approach**

Mapping was accomplished by utilizing the data from adolescent and key informant interviews and assembling these different sets of knowledge together to create a visual account of the institutional processes at play in this situation (Smith, 2005). This account is used to create

a map, representing the people, the work and the text that shape and affect the at-risk students' everyday experiences managing anaphylaxis.

The mapping depicts the actual work processes, document-based work, and local discourse patterns that shape at-risk students experience of managing anaphylaxis in school settings. Visual maps assist in understanding how school-based anaphylaxis management policies are implemented to support (or not) adolescents at risk. Descriptive mapping can include: documents; specific language used in documents; documents linked to other text (local processes); wording in documents; and, sequences of text-talk-action (Turner, 2006)

Interview data and key documents were analyzed to generate a map, which works to visually display institutional processes (Turner, 2008a). Throughout this process, five elements were utilized to support the map development:

- Documents (text) that comes into play in people's work that operate in their routine work knowledge and activities;
- Specific language used in the documents (text) to focus language and discourse;
- Documents (text) linked with other text (e.g., behind-the-scene documents (text) – manuals, legislation);
- Wording in documents (text) that is changed in their move from one setting to next; and
- Sequences of text talk action with their resulting consequences. (Turner, 2008b)

I began the map development process by physically drawing the map, working through data one interview at a time. This process started at the students' experiences, then branched out to their experience of the involvement of their School in the management of

their allergies. I then went to the interviews with School Staff in order to build the work and processes involved at the School level around anaphylaxis management. At this point, I began inputting the map into Creately (a diagraming application) and breaking the map down into smaller subunits for accessibility and readability. I then moved to the legislation and polices around anaphylaxis in schools, mapping the institutions involved in their creation, the texts and work created by them, and the actions and effects they intended to have. These working maps were then utilized for further analysis.

Within this processes, sections of working maps that showed a break in the knowledge to action pathway (disjunctures) were highlighted. This was where institutional processes put in place by the ruling relations were not implemented on the ground, for reasons such as:

- Incorrect or incomplete knowledge
- Unclear intended action (institutional process)
- Redundancies across text

These disjunctures were then included in the writing as analysis process. Because of sizing concerns, portions of the working maps were chosen to further illustrate salient topics within the results. Examples of larger working maps are available, by contacting the student researcher (Leah Graystone, leahgraystone@yahoo.com)

### **Ensuring Methodological Trustworthiness**

There are four traditional criteria in which both qualitative and quantitative research are judged for rigor: truth value, applicability, consistency and neutrality. Specifically, for qualitative research, these are referred to as credibility, transferability, dependability and

confirmability (Guba & Lincoln, 1982). Strategies for trustworthiness were used throughout the research project, not only on the outcomes of the research (Morse, et al., 2002)

Credibility has been described as the ability of the results to properly represent the realities of the respondents (Guba & Lincoln, 1982). Strategies for ensuring credibility in the results will include triangulation, member checking, peer debriefing, and reflexivity (Creswell & Miller, 2000; Guba & Lincoln, 1982; Lincoln & Guba, 1986). Triangulation involves the researcher looking for similarities or convergence between different sources of data (Creswell & Miller, 2000; Guba & Lincoln, 1982; Lincoln & Guba, 1986; Stiles, 1993). Member checking involves the researchers going back to the respondents and sharing data and interpretations. This acts as a way of confirming that the results are representative of the actual experience (Creswell & Miller, 2000; Guba & Lincoln, 1982; Lincoln & Guba, 1986). Peer debriefing involves someone familiar with the research or the topic reviewing the data and results. This allows them to question and challenge the researcher's results in a constructive way (Creswell & Miller, 2000; Guba & Lincoln, 1982; Lincoln & Guba, 1986; Stiles, 1993). Reflexivity involves the researcher disclosing their assumptions, beliefs and biases that may affect the inquiry, allowing readers to understand their position (Creswell & Miller, 2000; Guba & Lincoln, 1982; Stiles, 1993). These strategies will be used in this inquiry to ensure credibility.

Transferability involves the ability to show that the data was collected from a sample that is representative of the population (Guba & Lincoln, 1982). This can be achieved through theoretical or purposive sampling and thick descriptions (Guba & Lincoln, 1982). Theoretical or purposive sampling is used to maximize the range of information collected (Guba & Lincoln, 1982; Morse, et al., 2002). Within this research, steps to allow for purposive sampling were done (basic information was collected from parents of at-risk adolescents before interviews).

However, given the small number of diversity within the sample, all adolescents were included in the research. Thick descriptions are used in two ways: allowing the reader to feel as if they have experienced the situation in question, as well as making decisions on whether the hypothesis may be transferable to other contexts (Guba & Lincoln, 1982; Lincoln & Guba, 1986).

A note must be made in regards to transferability (commonly known as generalizability) specific to IE inquiries. While there may be questions on the transferability of the findings at the *local* level, it must be considered that "the local is penetrated with the extra- or translocal relations that are generalized across particular settings" (Smith, 2005, p 42). The processes and relations being examined and made visible in the ruling relations are transferable beyond the specific local environment they are being examined within (Smith, 2005).

Dependability refers to the replicability of the study; if the same study was to be repeated, the same results would be found (Guba & Lincoln, 1982). However, this criterion must be taken with a grain of salt, as IE is an emergent methodology and the exact replication of the study can be difficult (Guba & Lincoln, 1982). As with transferability, with the research looking upward into the ruling relations, this can be found in other sites (Smith, 2005). Dependability can be reached through the use of overlapping methods, stepwise replication and dependability audits (Guba & Lincoln, 1982). Dependability audits was used in this work, and involved the primary researcher keeping a journal of all methodological steps and decision points, as well as keeping all raw data on file. This will allow exterior researchers to examine all steps to the final results (Guba & Lincoln, 1982; Lincoln & Guba, 1986).

Confirmability looks specifically at the data and whether the results can be confirmed by another researcher using the raw data. This involves triangulation, reflexivity and confirmability audits (Guba & Lincoln, 1982). Triangulation and reflexivity are as described above.

Confirmability audits can be seen as the counterpart to dependability audits, and involves the tracing of each result back through to the raw data (Guba & Lincoln, 1982; Lincoln & Guba, 1986). These strategies will assist in the confirmability of the data.

#### The Researcher's Role in IE

Institutional ethnography (IE) is a methodology that I was first introduced to by Nancy Fenton. She was very excited about it, and thought it would be perfect fit for the project we had been talking about. At first I was excited, IE sounded new and exotic. I withdrew four of Dorothy Smith's (the creator of IE) books from the library, thinking I would be able to read them in a few weeks. Two weeks later, after spending countless hours curled up in my desk chair, a dictionary on one side and my computer on the other, I got through 50 pages of the first book. I learned through experience about the shift with IE. Not just a small one, but a shift ontologically and epistemologically. Everything I had recently learned in my Qualitative Methods course (which was enough of a shift then) had to be untangled. There was a complete change in how to think about a problem, how inquiry was done, how analysis was conducted. There were very few threads of recognition to try to grab onto.

Then, I was able to attend a course on IE where I met and learnt from Dorothy Smith. At the seminar, I had the opportunity to try my hand at mapping, an analytical technique used in IE. I took to it like a fish to water. It was like a puzzle, trying to figure out how things happen. After

the seminar, the books started making more sense. By being able to sit down with Dorothy Smith and have a conversation with her, things became much clearer.

IE is a methodology that involves the immersion of the researcher into the everyday world they are examining. For me, this everyday experience of at-risk students is completely foreign. I do not have food allergies, and neither does anyone in my family. I will be entering this research and asking these respondents to tell me what their life is, what their job is, and to teach me everything involved. Even the small introduction I had to this, by listening to parents of anaphylactic children at Anaphylaxis Canada/Food Allergy Canada Conference, was eye opening. There is something very distant about reading a paper or study on anaphylactic allergies. To have someone in front of you, talking about it, is a very different experience. It will be through these close encounters that I hope to piece together the "how" of these experiences and, with luck, be able to help affect change.

# **Chapter 5: Results**

The problematic of the research is the disjuncture between the legislative environments, school procedures and the daily lives of adolescents with anaphylactic allergies, and the standpoint is of an adolescent with anaphylactic allergies.

In the results chapter, we present four sections: The Legislative Environment – Sabrina's Law, The School Board Anaphylaxis Policy (SBAP), The Work of School Systems in Anaphylaxis Management, and Anaphylactic Students Experience within School Environments. Through this, we will begin in the Boss Text and work from there down to the everyday experience. The first results section involves a policy analysis of Sabrina's Law and an examination of anaphylactic families within it. The second results section is an analysis of the SBAP highlighting how Sabrina's Law affects this next Boss Text. In the third section, we focus on the school environment providing an exploration of how the Boss Text shapes the institutional processes within this environment. Finally, in the fourth section, we move to the everyday experience of an anaphylactic student in schools, and connect the Boss Text and institutional processes to these experiences.

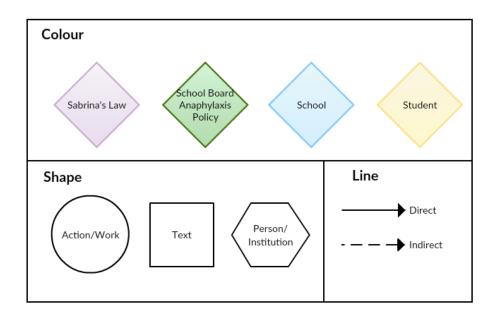


Figure 1: Legend

Table 1: Glossary of IE Terminology

Term	Definition
Boss Text	Developed and authorized through institutional processes
	within the ruling relations, these are text that create further
	institutional processes, coordinating work, text and
	environments. Sabrina's Law is an example of a Boss Text,
	created by the institutional processes within the Ontario
	Government, and creates further institutional processes at
	School Board levels by mandating the formation of
	anaphylaxis policies.
Institutional Processes	Activities, work and text within the ruling relations that allow
	for the coordination of the everyday experience.
Ruling Relations	Groups of institutions that organize and mediate the everyday
	experience of individuals. Examples can include: legal
	systems, health care organizations, and government
	organizations.
Text	Refers to words, sounds or images that are in definite material
	form and are replicable, allowing anyone from anywhere else
	to interact with the same words, sounds or images.
Translocal	Occurring outside of or beyond the local (everyday)

	experience. For example, the planning of construction on a
	busy bridge occurs in the translocal (within and by institutions
	in the ruling relation), which then affects the local experience
	(by affecting individuals commute to and from work).
Work	The idea of work in IE extends beyond what person is paid to
	do, and includes anything that an individual does that takes
	time, effort and intent
Work-text-work processes	Processes describing what people do with text, how they use it,
	what outcomes happen because of it

# The Legislative Environment - Sabrina's Law

A visual depiction of Sabrina's Law can be seen in Figure 2. As a law being set out by the Ontario Government, it holds the power and authority of this institutional body behind it.

This creates a sense of power behind the text, setting it as a text that must be followed and adhered to.

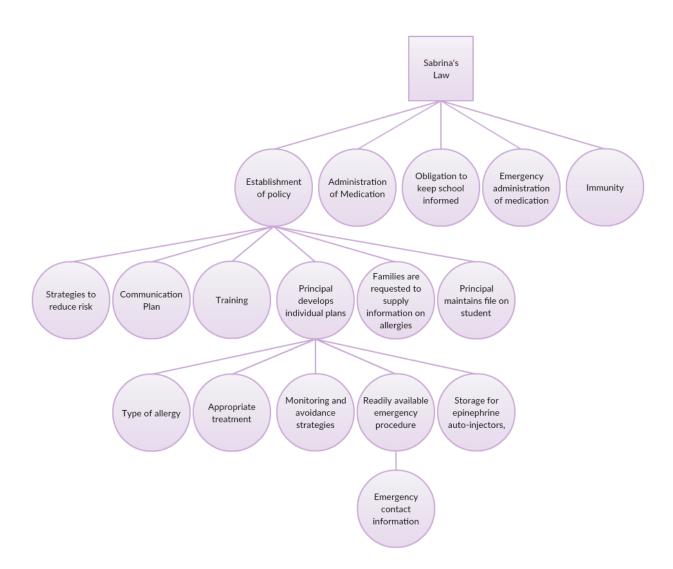


Figure 2: Visual depiction of Sabrina's Law

On the Ontario Ministry of Education website, the statement of purpose for Sabrina's Law's (a Boss Text) states, "this law ensures all school boards have policies or procedures in place to address anaphylaxis in schools, which includes providing instruction to staff and guidance on the administration of medication" (Ontario Ministry of Education, 2016). The intent of the legislation extends to the School Board, and no further. There is no mention of the local environment or the intent of the legislation on anaphylactic students and families. While we will later see how Sabrina's Law extends down to the local environment, it does not directly affect

the everyday experience. Instead, Sabrina's Law affects the everyday experience indirectly, by coordinating the development of the SBAP, which in turn affects the everyday (Figure 3).

Because the intent of the policy ends at the School Board, it is through the text at the School Board level that Sabrina's Law is able to coordinate the everyday experience.

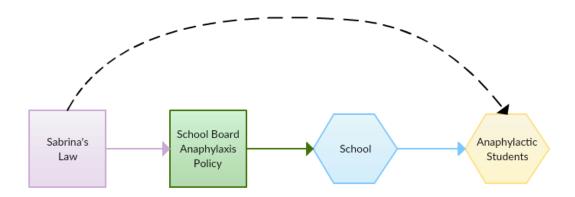


Figure 3: The direct and indirect actions of Sabrina's Law

Within Sabrina's Law, there are five main sections: 1) the development and maintenance of School Board anaphylaxis policies; 2) the preauthorization of employees to administer medication; 3) the obligation of parent/guardian/pupil to keep information up-to-date; 4) the ability of employees to administer auto-injectors without preauthorization in an emergency; and, 5) the protection of employees from legal action if they act in good faith. While the last four topics stand alone, the anaphylaxis policy is further broken down into different procedures and actions that must be included within these policies.

One of the first things to take note of within this legislation is the lack of specific text being identified. Sabrina's Law states actions, procedures, and information that must be included in the text, however it does not provide specific text that can be used by School Boards within their anaphylaxis policy or their schools. The text that is utilized (for example: forms, information sheets, etc.) is left to the discretion of the School Boards, as long as they are in

accordance with the legislative requirements. It is through text that the ruling relations coordinate and control the local environment. Yet this Boss Text, created by an institution within the ruling relations, provides no further text to be used by School Boards or schools. Other text (forms, information sheets, etc.) being brought into or created by other institutions may differ between different groups (School Boards, schools, etc.). Since they must be in accordance with Sabrina's Law, the specific outcome within the institution (for example, a school) may be the same. However, the process of getting to the outcome, and how it affects the local environment, may be different.

Through the activation (or reading) of Sabrina's Law, some of the work-text-work processes and the players within them begin to emerge, making visible how institutional processes are shaped by Boss Text. For example, in the section of Sabrina's Law focusing on Administration of Medication, it states that "employees may be preauthorized to administer medication or supervise a pupil while he or she takes medication in response to an anaphylactic reaction, if the school has up to date treatment information and the consent of the parent, guardian or pupil, as applicable." This statement shows that there must be the formation (action) of a textual process of authorization that allows for the action of administrating medication to occur (see map in Figure 4). This statement has provided enough information for people or institutions to activate this text, know what is intended by it, and to then create the procedures it deems necessary.

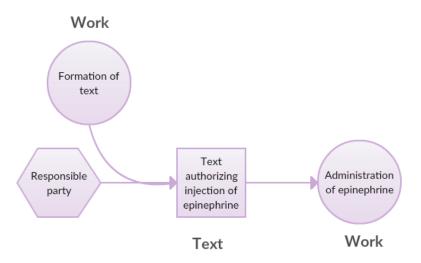


Figure 4: Formation of preauthorizing text for use in school environment

The legislation also provides information on actions that should be completed by specific people. For example, under Contents of Anaphylactic Policy, Sabrina's Law states that policies must contain "a requirement that every school principal maintain a file for each anaphylactic pupil of current treatment and other information, including a copy of any prescriptions and instructions from the pupil's physician or nurse and a current emergency contact list." This creates a work-text-work processes that must be in School Board policies, specifically for the responsibility of principals in the schools. The policy (text) must state that principals must collect (work) the information required to create a file (text) (see map in Figure 5). This statement creates a specific institutional process that must be in place within every School Board and every school within Ontario, coordinating the actions of the principals across the province in accordance with this legislation.

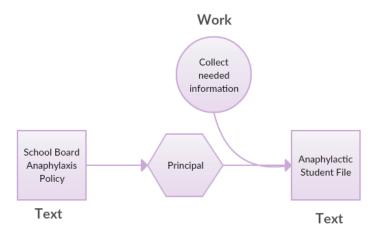


Figure 5: Development of Anaphylactic Student Files by Principals

The legislation does, however, include less information for other topics. For example, the Contents of Anaphylactic Policy states that the policy must include "strategies that reduce the risk of exposure to anaphylactic causative agents in classrooms and common school areas." While this statement will lead to institutional processes for risk reduction being included in anaphylactic policies, it does not provide information on what types of strategies this would entail, whether they must be evidence informed risk reduction strategies, and how they may differ at different levels of schools (for example, between elementary and high schools). Risk reduction procedures such as promoting hand washing, discouraging food sharing and teaching students about anaphylactic allergies could be used to achieve this requirement. However, a school that has only banned peanuts and nuts is also in accordance with this policy. Thus, creating space for interpretation at the level of the School Board may lead to confusion over what the legislation actually entails, and introduce differences at the local environment.

This lack of information can also be seen when examining training; School Board policies include, "regular training on dealing with life-threatening allergies for all employees and others who are in direct contact with pupils on a regular basis." This statement, though important

in ensuring that teachers are prepared to assist anaphylactic students in schools, does not provide specific information requirements. For example, there is no information about how often this training must occur or what is to be included in this training. To "deal with" allergies is such a broad topic that it cannot be determined if this is intended to focus on the daily management or the emergency management of these allergies. Leaving training open to interpretation may mean the information that school staff are provided and trained on can differ greatly between School Boards, which may create unsafe environments for students if staff are not properly prepared.

#### Students and Families in Sabrina's Law

The intention of the legislation on the School Board can be seen more clearly when the role of the families is examined. Throughout the legislation, the anaphylactic students and their families are passive participants in school management. Outside of supplying information about anaphylactic allergies and keeping information on file up to date, everything involving anaphylaxis management is happening *to them*. Information is disseminated to them, files are created about them, staff is trained on how to deal with their allergies, staff are authorized to administer medication to them. Students and families are created in the text as passive individuals, with all the procedural work of managing anaphylaxis happening around them. Based on this analysis, there appears to no place for input from the people who know best how these allergies are managed. Instead of being seen as valuable resources for information on how to manage anaphylactic allergies, something they live with every day, they are created as something that anaphylaxis management moves around.

### The School Board Anaphylaxis Policy

The next Boss Text is the School Board Anaphylaxis Policy (SBAP). The policy itself is titled an Administrative Procedures Memorandum, creating the policy as something that happens within the school's background administrative processes. In this study, I have named these policies "filing cabinet policies", procedures and actions that occur within the school and by staff members yet are hidden from view at the local level. The listed purpose of the SBAP is, "in accordance with Sabrina's Law 2005 – An Act to Protect Anaphylactic Pupils, it is the policy of the [School Board] to establish and maintain a policy for students diagnosed with anaphylactic allergies." While it is clear that this policy was developed because of Sabrina's Law (a work-text-work process), it provides little information about the outcomes that the policy intends to have on the school environment and the students. It is a policy "for students diagnosed with anaphylactic allergies", but its intended effect on these students (whether it is to create a safe environment for them within schools, to provide support as they move through environments, or to create overhead processes around anaphylaxis management) is unclear.

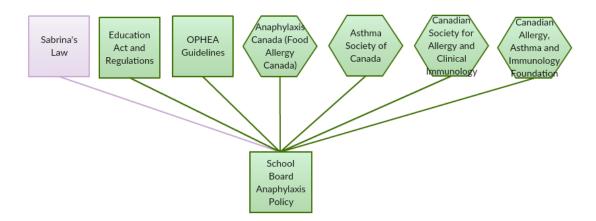


Figure 6: Institutional powers behind the School Board Anaphylaxis Policy

The power of this Boss Text comes from two main areas: First, the policy is introduced into the system from the Director of Education, the person responsible for the running of the School Board. By having this policy seen as coming from not only the School Board, but the Director of Education, it holds the authority of the institution and the title. Second, the SBAP lists a number of texts and organizations as references (seen in Figure 6), which suggests that information was used and incorporated from references in the formation of the policy. However, it does not specify *what* information was utilized. Even without proper citation of information from these sources, listing these institutions and text as references utilizes their power and authority. It creates the text as something that is evidence-informed and in accordance with the present legislation. Despite the power that the text holds, the majority of the policy is listed as "Comments and Guidelines," which sets the policy up as voluntary actions that schools *could* do, but are not required or mandated to do.

### School Anaphylactic Management Plan

Within the SBAP, it stresses the need for a reduction in risk, stating that, "avoidance of a specific allergen is the cornerstone of management in preventing anaphylaxis." It also explains that measures can be taken to reduce the risk of exposure, but cannot be completely eliminated. It then states that, "while schools cannot guarantee that an environment is completely safe, the School Anaphylactic Management Plan will include necessary measures and procedures to reduce the risk of anaphylactic reactions and assist in making the school as "allergen-free" as possible." While the formation of the School Anaphylactic Management Plan appears to be an important element of school-level anaphylaxis management, there is no further information on the measures and procedures that should be included in such a plan. Furthermore, the term "School Anaphylactic Management Plan" is never mentioned in the policy again. As a result, this

absence of definition and detail creates a dead end in the work-text-work processes within the local environment whereby the formation of a text is mentioned without specific information and guidelines on what information is needed, what actions should occur, or what the outcomes should be. These dead-end processes can be seen as a form of disconnect within a single text. This omission creates a gap between what the policy intends schools to do, and what schools actually do in regards to this text, as schools try their best to follow instructions that are lacking in clarity.

### *Risk Reduction – Roles and Responsibilities*

The next section within the policy is "Risk Reduction – Roles and Responsibilities", which is divided into three main groups: Parents/Guardians, School Principals, and Classroom Teachers. With only six responsibilities, the role of the parent/guardian is the least involved role. Within these responsibilities there is a focus on the daily management of anaphylaxis. With responsibilities such as filling out paperwork, supplying two auto-injectors, a Medic-Alert® bracelet, and helping their children develop appropriate coping skills, the parent/guardian is left to work on individual management. There is no place for the parent or guardian to supply advice or suggestions on how to better protect students in schools.

Within these responsibilities, we also see the formation of the work-text-work processes that the text pulls the parents into. For example, parents are responsible for completing the "Medical Information" form and then returning it to the school (see map in Figure 7). However, the language used to describe these work-text-work processes is not consistent. While this section says that the form is called "Medical Information", there is no form with such a title. Instead, a form that is provided (and, assumingly, the one the policy intends for parents to complete) is called the "Critical Medical Alert Form". This disjuncture between languages used

to name different forms could cause difficulties at the school level, as schools may interpret this information differently.

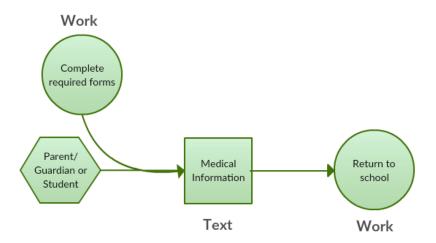


Figure 7: Work-text-work processes for parents/guardians within the School Board Anaphylaxis Policy

We then move from the parental responsibilities to the responsibilities of the School Principal. Within this list, we see an expected transition from the individual management to group management of anaphylactic allergies, with more overhead procedures and actions taking place. We also begin to see the development of specific work-text-work processes; for example, using health forms to identify students with anaphylactic allergies (see map in Figure 8), or in ensuring that parents and guardians participate in their own work-text-work processes (completing health forms). However, we also see gaps in the processes and actions that this text lays out. The first gap is that the language used by the text is very broad and does not provide the Principal with enough information on what their actions or work should be. For instance, one of the Principal's responsibilities is to share and review anaphylactic procedures for students with staff, supply teachers, bus drivers, and others who come in contact with anaphylactic students (see map in Figure 9). While some of the text that is to be shared with different staff members is

specified (for example, with supply staff and bus drivers), what these anaphylactic procedures should entail is not explained. As with the School Anaphylactic Management Plan, the term "anaphylactic procedures" is not mentioned again in the policy. By not providing further information on what actions are required by the text (the policy), the absence of information leaves schools open to interpret what institutional processes may be formed around the text. This may negatively affect the intended coordinating actions of the text, with different schools instituting different procedures.

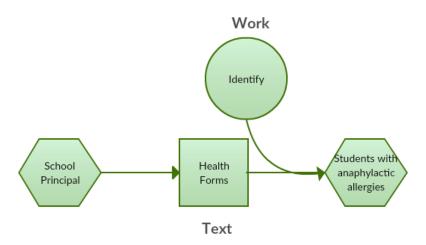


Figure 8: Work-text-work processes for identification of anaphylactic students within the School Board Anaphylaxis Policy

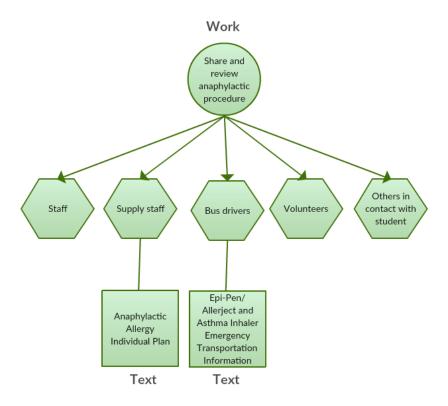


Figure 9: Work-text-work processes around sharing and reviewing of anaphylactic procedures

There are also some actions required that could be harmful for students involved. One of the Principal's responsibilities is to "post Anaphylaxis Alert forms in the office, staff room, cafeteria and other common areas and ensure that all staff could identify these students."

However, by posting this information in cafeterias and common areas within the school, this allows other students to access this information, which could have harmful or create stigmatizing effects (see Behrmann, 2010; Dean, et al., 2015)

One interesting thing to note is that one of the responsibilities of the Principal is to convene a meeting with the parents or guardians of students with anaphylaxis to develop an Anaphylactic Allergy Individual Plan (see map in Figure 10). However, within the parent/guardian responsibilities, there is no mention of any involvement in the development of this plan. Even though both parties are supposed to be involved in the development of these

plans, it is primarily the Principal's responsibility. This divide in responsibility creates a space where the Principal is moving through the institutional processes, and the parents/guardians are involved as bystanders, as someone who the institutional processes are happening to, instead of as active participants within them. Yet again, this creates a space where there is no required input from the parents/guardians into the school-level management of their child's allergies.

Anaphylactic students and their families are there to provide the information that is needed by the Principal for the institutional processes, not to participate in these processes and create change that may be needed by them.

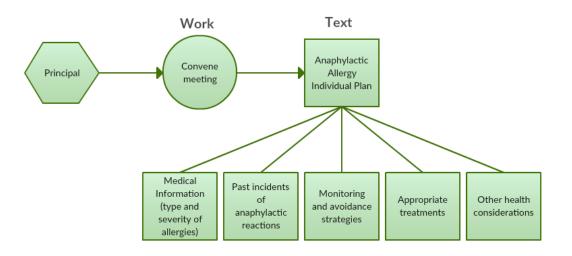


Figure 10: Development of Anaphylactic Allergy Individual Plan

While there is still a focus on risk reduction, we begin to see the inclusion of emergency management within this section. For example, the Principal is required to train an Emergency Response team on how to "handle an anaphylactic reaction". This process, while important in the school-level management of anaphylaxis, does not fall under the category of risk reduction. It involves the emergency management of anaphylaxis, yet it is still under Reducing Risk, a topic that suggests more preventative measures. Furthermore, this listed responsibility does not provide enough information on *what* the response team should be taught. Being able to "handle a

reaction" could entail being able to identify different severities of anaphylactic reactions, provide necessary emergency treatment (including using an auto-injector), and call emergency services.

Or it could involve only knowing how to inject an auto-injector, when required. This lack in specificity of what training an Emergency Response team needs again leaves room for interpretation at the school level, which may cause issues at the local level. If Emergency Response teams are not properly prepared to respond to an anaphylactic reaction, this could create an unsafe environment for students with anaphylaxis.

The final list is the role of the Classroom Teacher. One of the first things to notice in this section is that these responsibilities are "as age appropriate for the student". This is the first time within this policy that differences in the management of anaphylaxis within different age groups is acknowledged. This suggests that despite there being large changes as a student transitions from a child to an adolescent, and transitions from parental management to self-management, the majority of the policy is supposed to apply across all age groups. This lack of information in what a student actually needs across different age ranges can lead to the feeling that schools are "hovering" too much at the high school level, with procedures that are designed to benefit younger age groups.

As we begin reading through these responsibilities, more connections to the parents/guardians and anaphylactic students can be seen, as well as the general student population. The Classroom Teacher is responsible for communicating anaphylaxis avoidance procedures (another term where there is no further information provided, and is used only once) with anaphylactic students and their families, as well as communicating to all parents and students the need for an allergen-free classroom and avoiding food sharing. Where the Principal's responsibilities had more of a focus on the administrative side of anaphylaxis

management, Classroom Teachers' responsibilities focus on the more personal side of management, working on both the individual management (through communication with anaphylactic students and families) and the group management levels (through communication to all students and families).

#### Risk Reduction- Peanut Butter Substitute

The next section in the SBAP involves peanuts, nuts and peanut better substitutes in schools. It explains that School Board policy states, "The CEO shall not cause or allow conditions, procedures, actions, or decisions that are unsafe or unhealthy." It goes on to say that since exposure to peanuts and nuts can be harmful or fatal to some students, "peanut butter and all products containing nuts of any kind are not permitted in [schools]", and that peanut butter substitutes will be dealt with in the same manner as peanut butter. It then states, "despite its best efforts to limit the presence of nut-containing food products [,] parents of anaphylactic children should be aware that the [School Board] cannot and does not guarantee schools are allergen free."

An interesting note from this section is that it is the first and only time throughout either of the Boss Texts that any specific allergen is named, or special procedures put in place because of it. It is also important to note that the SBAP and School Board policy could be used as grounds for the banning of *any* allergen, yet in this case it is used specifically for peanuts, nuts, and peanut butter substitutes.

### Emergency Plan

The next section of the SBAP Boss Text is entitled "Emergency Plan", which explains that reactions may still occur within a school, and it is essential that there is an emergency plan

in place and staff are appropriately trained. However, instead of providing readers information on the text and institutional processes that should be included in a school wide emergency plan, it goes on to explain the Anaphylactic Allergy Individual Plan and what should be contained within each student's file (Figure 11).

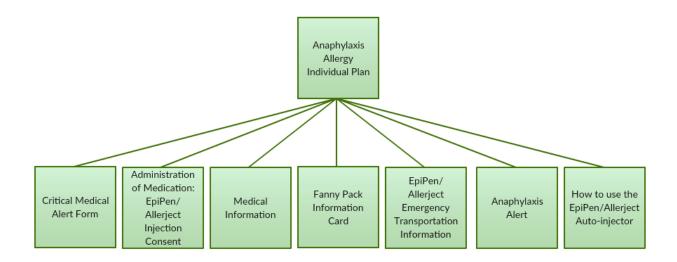


Figure 11: Contents of the Anaphylactic Allergy Individual Plan

While it may appear that this is a thorough and understandable list of text to include in the file, there are still two questionable areas. First, this list calls for both the Critical Medical Alert form and Medical Information to be included, and it was discussed previously that there was no form entitled "Medical Information". It is possible that, as in the parental responsibilities, the phrase Medical Information is being used to describe the Critical Medical Alert Form. If this is the case, this would mean that the same form is being referred to twice in the listed contents of the Anaphylaxis Allergy Individual Plan, leading to redundancies within the Plan.

## Sabrina's Law Grants Immunity to Non-Health Care Staff

The final section of the SBAP Boss Text focuses on the Immunity section of Sabrina's Law, and the importance of acting quickly in an event of a possible reaction. In this we can see

the work-text-work processes being created by Sabrina's Law. Because of the previous Boss Text (Sabrina's Law), information on staff member immunity from legal action has been included in the SBAP. However, there is an issue with the language used in the policy. Sabrina's Law grants immunity to *all* employees, which according to the definitions within the legislation, is "an employee of a board who regularly works at the school, in the case of a school operated by the board" (Bill 3, 2005). Whereas the SBAP specifies that non-health care staff are granted immunity. This difference in language use between employee and non-health care staff could raise concerns for individuals who have previous health care experience, or who work as nurses within the School Board.

Forms Provided by the School Board Anaphylaxis Policy

As we begin to examine the forms provided by the SBAP (Figure 12), more disconnects emerge. The first form, the Critical Medical Alert Form, involves all medical perils, which includes asthma, diabetes, and epilepsy. It requires parents/guardians to provide information on recommended emergency response, medications prescribed for the condition, and emergency contacts. Specific to anaphylactic allergies, it asks about the triggers for a reaction, and whether the student and office have auto-injectors. Finally, it contains an Authorization for Administration of Epinephrine Injection, giving permission for the Principal or a designate(s) to administer epinephrine in the event of an emergency, and states that the parent/guardian will not hold that person, any other staff or the School Board accountable for actions that may occur because of the injection. Nowhere on the form does it ask about the symptoms or severity of an anaphylactic reaction. A completed copy of this form is then to be included in the school's Medical Emergency file, the Ontario Student Record, and send to transportation services (as requested).

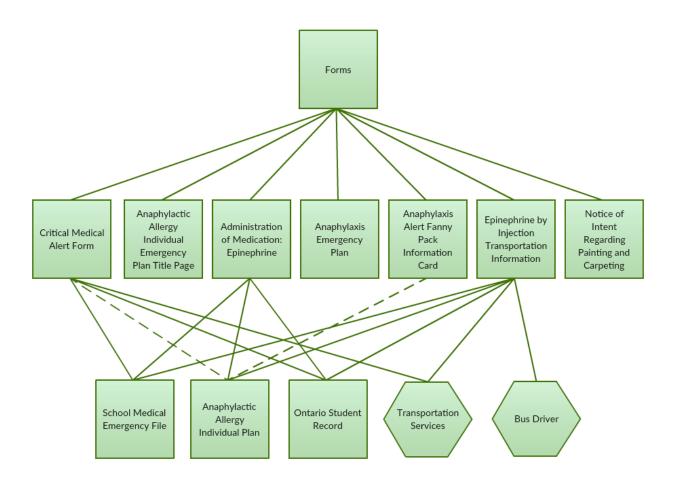


Figure 12: Forms provided by the School Board Anaphylaxis Policy, and their respective locations

Throughout this form, there is a focus on emergency management including information on "triggers" and what to do in the case of a reaction. Information on daily management or input from the parent/guardian or student is not included. The sole intent of the form is to collect emergency information in preparation for an emergency. Yet, there is no room on the form that includes information about a student's life, or how they live with allergies, therefore removing the student experience from the text.

The second form provided is the Administration of Medication: Epinephrine Injection.

Throughout the SBAP, this form is referred to as the Administration of Medication:

EpiPen®/Allerject<sup>TM</sup> Form. Within this form, it asks for the symptoms of an allergic reaction,

and authorization for the Principal or a designate to administer epinephrine in the event of an emergency. A copy of this form is required to be included in the Anaphylactic Allergy Individual Plan file, the School Medical Emergency File, and the Ontario Student Record. The wording in the authorization is the same between this form and the Critical Medical Alert Form. However, this form does not ask about what the student is allergic to, or the proper emergency procedures. These two forms are redundant to each other, yet cannot stand without the other.

The third form is entitled "Anaphylaxis Emergency Plan" form, which appears to be a form describing how an anaphylactic reaction will be treated. The first third of the form asks for the student's information, their medical details, a photo, emergency contacts, and the location of their auto-injector. The second third describes possible symptoms of an anaphylactic reaction. The final third of the form describes the emergency procedures in the event of a reaction. However, besides the first third of the form on student information, the remainder of the form is pre-printed. Even though this appears to be an emergency plan for individual students, the symptoms to look for and the procedure that will be put in place have been predetermined. Yet again, the student experience has been removed from the form, and all that remains is information about the reaction. This points to the fact that actions of a staff member have been predetermined before the student's experiences and their name has been identified on the form, which suggests fitting the student to the plan, instead of fitting the emergency planning to individual student needs.

Further analysis showed that this form is not mentioned anywhere else in the SBAP.

There is no information about who is responsible for completing it, where it must go after it is completed, or what work-text-work processes it will be connected to at the school level. This form appears to have been parachuted into the policy and lacks information on its intended use or

intended outcome. This absence of information leaves the reader of this policy, and the schools, disconnected from work-text-work processes and opens it to interpretation, which can lead to differences in the institutional processes at the local environment.

The fourth form provided is the Fanny Pack Laminated Information Card Anaphylaxis Alert. This form provides emergency contact information and information on allergens. It also contains a pre-printed list of possible symptoms that indicates the need for epinephrine, simple emergency management instructions on how to inject an auto-injector, to call 911 to transport the student to the hospital, and when to inject a second dose of epinephrine. When we look back on this forms' inclusion in the Anaphylactic Allergy Individual Plan, we can see another inconsistency in the policy. Within the contents of the Individual Plan, the SBAP lists the Fanny Pack Information Card and the Anaphylactic Alert form as separate text. However, when the forms are actually examined, it appears that these two forms are, in fact, one. This inconsistency may lead to confusion around what should actually be contained in the Individual Plan and may lead to differences in interpretation of texts and what institutional processes are expected to be put in place at the school level.

The fifth form provided is the Epinephrine by Injection Emergency Transportation

Information. This form includes information about the student, such as their medical conditions, what they are allergic to, a photo, and the name of the student's bus driver. It also states, "administer epinephrine by injection. Student must immediately be transported to hospital.

Dispatch will provide specific instructions to drivers." While it can be assumed this is directed to bus drivers in the case of a reaction, it does not specifically say in the text who would use this information or why. It also does not provide any information on symptoms, or specific information for the bus driver on how to administer epinephrine. This is the only piece of text

directed specifically towards bus drivers. Since bus drivers are supposed to wait for specific instructions by dispatch, this lack of information does not include responsibility for coordinating the emergency management. This lack of clarity of responsibility may create an unsafe environment for both anaphylactic students and bus drivers, as bus drivers are not provided with the vital information they need to respond to a reaction, even though they would be the person responsible at the local level.

Another thing to notice when looking across the forms is the mention of the School Medical Emergency File, which is not discussed anywhere else in the policy except in the storage of three forms: 1) The Critical Medical Alert Form; 2) the Administration of Medication: Epinephrine form; and, 3) the Epinephrine by Injection Transportation Information. The lack of information on the School Medical Emergency File creates text (the file) where there is little information about what is to be included, and no information on who is to create it or what the text is to be used for. Two of these three forms (Administration of Medication: Epinephrine and Epinephrine by Injection Transportation Information) are also to be included in the Anaphylactic Allergy Individual Plan, which creates redundancies across the two files. One possible explanation for the lack of mention of this file in the policy is that the School Medical Emergency File was intended to be the School Emergency Plan. Whether they are the same item or not, they are involved in a dead-end process, lacking both information and clarity on the intended utilization of them.

There are also inconsistencies between the information on the forms and the information provided within the policy on where the forms should be stored, specifically with the Critical Medical Alert Form. Within the policy it is listed as one of the components of the Anaphylactic Allergy Individual Plan. However, when the actual form is examined, it says that it is supposed

to be filed in the School Medical Emergency File, the Ontario Student Record, and a copy sent to Transportation Services. The Anaphylactic Alert/Fanny Pack Information Card are also listed as components of the Anaphylactic Allergy Individual Plan, however there is no direction on the single Anaphylactic Alert Fanny Pack Information Card included in the form section as to where it is supposed to go after being completed.

Another concern is indication of *who* is supposed to fill out these forms. Under their listed responsibilities, parents are required to complete the Medical Information form (assumingly, the Critical Medical Alert Form) and the Administration of Medication form. However, there is no information on who is responsible for completing the Anaphylaxis Emergency Plan, the Anaphylaxis Alert Fanny Pack Information Card, or the Epinephrine by Injection Transportation Information form. With no signature requirement listed on these forms, there is no indication of who must complete or authorize them. This creates a dead-end procedure within the institutional processes (see map in Figure 13), with pieces of text that must be completed in the individual plans with no indication of who must complete the actions of collecting the information and completing the forms. Without a person to complete the institutional process, it cannot move forward.

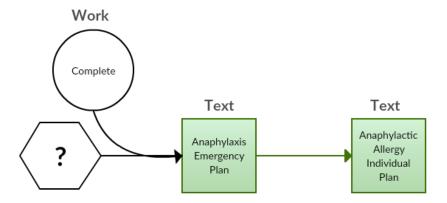


Figure 13: Unclear institutional processes around provided text within the School Board Anaphylaxis Policy

Appendices and Information Sheets Provided by the School Board Anaphylaxis Policy

The first appendix to draw attention to is the Annual Anaphylaxis Procedures Checklist, which Principals are directed to use within the completion of yearly reviews of school procedures. A procedural checklist routinizes actions and work-text-work processes, and may create a checklist mentality in the management of anaphylaxis. The daily and emergency management of anaphylaxis is an active process that supports a complex life experience and when routinized as a checklist can set it up as taken for granted.

There are also similarities in the gaps seen in the checklist as with the ones seen throughout the policy. Similar to where the training provided to staff was unclear, in the checklist the only training that is specified is in the use of auto-injectors. This means that staff can be taught how to inject epinephrine, without knowing information about allergens, avoidance, and symptoms of anaphylaxis, and still be in complete accordance with the SBAP. Again this lack of specific information may create an unsafe environment where staff are partially prepared for an emergency and on how to prevent or identify an anaphylactic reaction without assistance.

Similar to the policy content, we see actions that are deemed necessary by the checklist, but are not specific enough to provide the responsible person information on what is *actually* intended. For example, the checklist says that information sharing must be in place for students, parents and parent organizations, but it does not specify what sort of information would be shared to these groups. It also says that a range of procedures must be in place (around holidays/celebrations, field trips, school busses and school bus emergencies), yet it does not provide specific information on what these procedures should entail or what actions are required. This creates another dead-end in the institutional processes, where different schools can create different procedures, which prevents the ruling relations from coordinating the local environment and creating the intended effects.

An interesting mention in the checklist is the planning and implementing of role-playing sessions. While these sessions would be beneficial in the training of staff, this is the first mention of any type of simulation or role-playing. It also does not specify who holds responsibility for these sessions, the training content (identification of anaphylaxis, treatment, emergency response, auto-injector use, etc.), or the intended outcomes of the sessions. This is an example where beneficial institutional processes could have coordinated the actions in the local environment in a way that would benefit both staff and students, but the text has not provided enough information for this to occur.

The next, and final, group of appendices that are provided are sample letters to be sent home to parents, which focus on students not bringing allergens into the school. This is tied to the Teacher and Principal's responsibilities to send home letters to parents asking them to not send in allergens, and the Principal's responsibility to establish allergic student's classrooms as "allergen-free" using a cooperative approach. However, sending a letter home does not follow

the co-operative approach, as the letter is text that is coming from the institution that holds the power of the institution (logos, signatures, etc.), suggesting to the parents that not sending allergens with their child/children is the next acceptable action. A letter being sent home removes any discussion that could have occurred. This leads to the conversation being between the text (being activated by the person) and the reader, and removes the Principal from the cooperative approach. This leaves the parents unable to discuss the letter or be involved within the co-operative approach.

In the first of the three sample letters, it states, "after discussion with school staff and other knowledgeable parties in the medical community, it has been suggested that the best way to provide a safe environment for this student would be to enlist the support of the parents to help make this classroom a 'peanut and nut free environment'." This brings in the power of the school institution and medical institution, without naming a specific group that could be held accountable. This sense of power behind the text and the actions it requests further prevents any discussion of the actions. The text does create a sense of a cooperative approach by using words such as "suggest" and "enlisting support", but the actions deemed necessary by this text remove the cooperative aspect. By using language such as, "I realize this request poses an inconvenience for you when packing your child's snack and lunch, however, I wish to express sincere appreciation for your support and understanding of this potentially life-threatening allergy," creates an expectation of support, that complying is the necessary and acceptable action.

We see similarities within the second sample letter to parents. This letter uses language such as, "we felt that all parents would like to be aware that there is a child/children in our school with a severe life-threatening food allergy to peanuts and tree nuts." After stating that allergies can be life threatening and can cause death within minutes, it says, "although this may or may

not affect your child's class directly, we want to inform you so that you may choose to send food with your child to school that are free from peanuts or nut products." Writing the letter in this way removes the banning of peanuts and the placement of the school or School Board as the "bad guy". Instead, it frames these allergies as life threatening and gives the parents the choice whether they will send in these deadly allergens in to the school. This removes the option (or creates the options as "good" and "bad") for the parents of other students in the school, removing the cooperative approach.

# The Work of School Systems in Anaphylaxis Management

With the move from policy to School environment, we see much clearer work-text-work processes and are able to map out how they come to be in the local School environment. We can also connect the Boss Text (Sabrina's Law and the SBAP) to these work-text-work processes and develop an understanding of how they co-ordinate actions in the Schools.

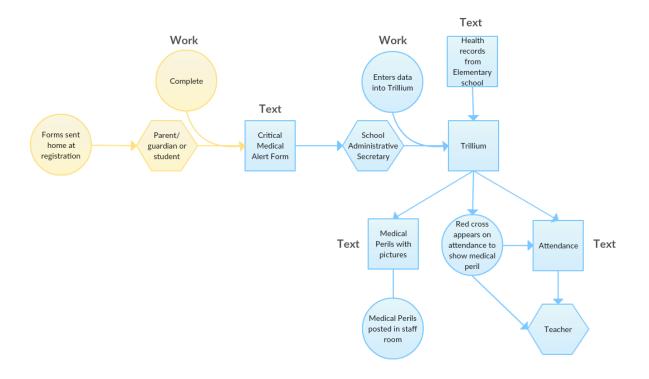


Figure 14: Work-text-work processes around anaphylaxis management in Schools

For both Schools, the process of anaphylaxis management (shown in Figure 14) begins with the Critical Medical Alert form. This form is given to students when they register every school year, and their parent/guardian or the student (when of age) must complete and return the form to the Secretary. At this point the School Administrative Secretary, or the person responsible for all student data (personal information, marks, medical perils, etc.) inputs the medical peril information into Trillium, a data archival system. Health records from elementary schools also follow the student to high school through the Trillium system. From here, two main things occur. First, a list of students' medical perils, along with their pictures, are printed from the Trillium system and posted in staff rooms where they become accessible to all staff, but not students. Second, a red cross appears on the attendance lists beside the names of students with medical perils.

Within this initial process, we can see the coordinating actions of the Boss Text (both Sabrina's Law and the SBAP) (see example in Figure 15). With the Critical Medical Alert forms (text creates by the SBAP) being sent home and returned with the required information, we can see the action of the Boss Text. Sabrina's Law's coordinating actions can be seen through the School Anaphylactic Policies containing a requirement that parents/guardians/students are asked about life-threatening allergies upon registration. The actions of the SBAP can be seen, with the responsibility of parents/guardians to complete the required forms and the responsibility of the principal in ensuring that these forms are completed. These Boss Text have created institutional processes and text to be used within them, connecting Principals, the School Administrative Secretary, parents/guardians and students into processes, without their direct knowledge of the coordinating work the Boss Texts have done to create this everyday experience.

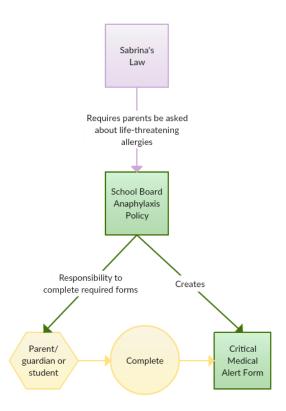


Figure 15: Coordinating actions of the Boss Text in the local environment

Another institutional process can be seen within the anaphylaxis training of staff members. Within both Schools, there was mention of the training staff members received on how to use auto-injectors if an anaphylactic reaction occurred. The Vice-Principal of School 1 described it as "Epi-Pen training", which was run by a staff member who had anaphylactic allergies. A Guidance Counselor from the same School further described, "at the beginning of the year, at [the] first staff meeting we also receive training about how to administer the epi-pen in case there are any new teachers there, or in case we have forgotten." One teacher described his experience assisting a neighbour experiencing an anaphylactic reaction:

Little boy came running over to my house, saying my grandpa is in trouble... So I went over to the house, and he had had an allergic reaction, and he was kind of fumbling with the epi-pen, and I knew how to administer it, so I basically said, so you mind if I administer it, and he just gave it to me and I plucked him in the thigh and that was it.

When I asked how he knew how to use an auto-injector, he explained, "we are taught every year, quick reminder how to use the epi-pen." For this teacher, the training he received every year gave him the knowledge he needed to inject an auto-injector, and made him feel comfortable in responding to an anaphylactic reaction in School. While interviewing a group of three teachers at School 2, they similarly expressed familiarity with how to use an auto-injector and felt confidence about what to do if an anaphylactic reaction occurred ("pen, boom, call the ambulance"), yet all expressed concern about not knowing exactly where students kept their auto-injectors, and admitted that they probably weren't prepared for a reaction. The development of this institutional process can be seen in both Boss Texts; for example, within Sabrina's Law it states that School Anaphylaxis Policies must contain "regular training on dealing with life-threatening allergies", and the SBAP states that the School must involve all staff in appropriate training. Within these situations, we can see the direct coordinating actions of the Boss Text on

the local school environment. All staff members in both Schools receive training on anaphylaxis, because the Boss Text has created this as a necessary institutional process that must be in place within school anaphylaxis management. However, we also see the effects that non-specific Boss Text can create in both Schools, with training being described as "Epi-Pen training", or a quick reminder of how to use an auto-injector. There was no mention from staff about learning how to prevent or recognize an anaphylactic reaction.

# Development of the Health Binder

Within School 1, I had the opportunity to speak to the Vice Principal responsible for Health and Safety within the School. One of her responsibilities every year was the development of the Health Binder (see map in Figure 16), a storage place for medical peril information that she could access as needed. For the development of this binder, the Principal would begin by printing off lists from Trillium of students with reported medical perils and compare it to the "pink forms" (Critical Medical Alert Forms) that were received in the current year. If there was a student with a reported medical peril in past years, and there was no Critical Medical Alert Form submitted for the present year, a Secretary would give the student a new form for them or their parent/guardian to fill out and bring back. The medical perils would then be highlighted on the list. Specific to anaphylaxis, she would highlight which students needed auto-injectors and highlight where the epi-pens were stored. She would then confirm the location of their auto-injector, and the papers would be filed in the Health Binder.

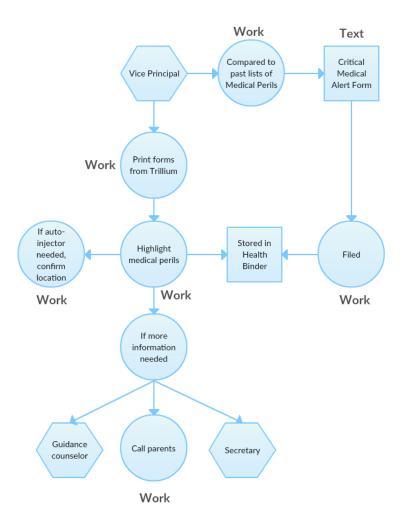


Figure 16: Development of the Health Binder in School 1

In this process, we can see the coordinating actions of the ruling relations, with the Boss Text creating the necessary institutional process involving the Principal's responsibility to identify anaphylactic students, to ensure parents/guardians complete medical forms, and ensure that auto-injectors are stored in known locations (on the student, in the office, or both), which is then carried out in the local environment (the School).

#### Staff Member Learning

During the interviews with staff members, I asked how they learned about their responsibilities around anaphylactic allergies in Schools. I did this to find out what staff deemed important in assisting them in this learning process.

The Vice-Principal in School 1 responsibilities' focused on Health and Safety within the School, which included anaphylactic allergies. When I asked her where she learned how to do this work around anaphylaxis (such as the development of the Health Binder), she responded:

I have been doing it for quite a while, I think that you know every year you might add something new, or something has happened, and you are like, why didn't I do that before, but also at our admin association, so all administrators from the high schools meet once a month, and there we have the opportunity to bring best practices. So throughout the years we brought different things that we have done, and I am sure along the way at some point health and safety was there.

For this Vice-Principal, she learned how to do her job through her own experience and the experience of others in a similar position. Interestingly, later in the interview it came up that her daughter had a medical peril (epileptic):

I think that from a mother's perspective, that when I send my kid to school, I want her to be safe, so I think I took a different viewpoint of what it meant to be safe in school... I think my role as a VP has helped make sure that I did a really good job in my role as a mom, because I knew exactly what should happen.... However, when this daughter went to high school, she went to the high school where I was at, so I made sure she was safe, so if I am going to do it for my own kid, I am going to do it for other people's kids too.

In this situation, her role as a mother and as an administrator worked together and complemented each other. Having a child with a medical peril affected how she viewed the responsibilities of

her job ("safe in school") and her role as an administrator helped her ensure that her child, and all other children with medical perils, were safe.

When I asked other staff members the same question, I received similar answers. When I asked a Supply Teacher within the School Board how she learned about how to manage allergies, she said, "just over the years, just learning more and more about anaphylaxis, and what it entailed." A Guidance Counselor in School 1, noted that she learned about anaphylaxis through training:

A bunch of years ago we received training at a staff meeting initially about Sabrina's Law, and about the fact that the epi-pens, students are supposed to carry their own epi-pen, that we also have one in the school, and then each year we go through at the ... first staff meeting we also receive training about how to administer the epi-pen in case there are any new teachers there, or in case we have forgotten

I also spoke with the Guidance Counselor about what would happen if a student was concerned about their surroundings, for example if there were allergens present. When I asked about how she learned how to handle a situation like this, she explained, "it is not any special training that we have to deal with that [concern with allergies] ... you have to address their concern. It is a safety concern.... Yea, so it is just part of the job." For both the Guidance Counselor and the Supply Teacher, it was through experience that they learned about anaphylactic allergies. They did not read a piece of text to learn about how they were supposed to handle anaphylactic allergies in Schools, it was through on-the-job learning and hands on training.

This learning through experience was also seen in School 2. I had the opportunity to speak with the School Administrative Secretary, who had only been working in the position for a

month and a half. When I asked her how she learned about the work around inputting medical perils into Trillium, she responded, "through training. The person who was in the position previous showed me what we have to do at the beginning of the year. It is not just in regards to that [anaphylactic allergies], but into all students and their medical concerns.... Hopefully I will learn more going into the new school year, because all the stuff had been done for me already." For her, she learned the work and the institutional processes she was involved in through word-of-mouth, and would experience them in the coming school year. Yet again, there was no book or text she sat down to read, it was through experience and the experience of others that she learned the work involved in her job around anaphylactic allergies.

It is important to consider where staff learned their roles and responsibilities around anaphylactic allergies from, in order to discover the avenues that impact their learning in positive ways. Through this, we have seen that the majority of staff learned through experiences, whether it be their own, others, or group training. This suggests that creating new text or Boss Text around anaphylactic allergies may not have a direct effect on staff or on their jobs around anaphylactic allergies. If Boss Text is to be effective on knowledge acquisition or learning of staff members, these results reinforce an experience created as an institutional process. The present, indirect actions of the Boss Text on staff members is through the development of institutional processes that become "part of the job" (top image in Figure 17). By creating institutional processes that allow for staff member learning through experience, this will assist in integrating the change within Boss Text to the local Environment (bottom image in Figure 17).

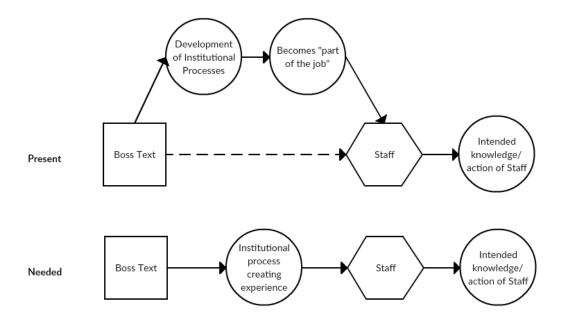


Figure 17: Pathways for knowledge transfer from Boss Text to School Staff

Staff members did not learn about their roles or responsibilities by reading or interacting with either of the Boss Texts (Sabrina's Law or the SBAP). First-hand experience, from home life, training, or on the job learning, was what provided staff the knowledge and empathy to work with anaphylactic allergies.

# The Work Within the School in Preparation for Supply Teachers

Data showed there were big differences between the two Schools relating to preparation of material for supply teachers. According to the SBAP, it is the teacher's responsibility to leave an Anaphylactic Allergy Individual Plan for supply teachers, which falls under Risk Reduction Responsibilities. It is then the Principal's responsibility to ensure that supply teachers are made aware of the Anaphylactic Allergy Individual Plan.

This was partially seen in School 2, with the teachers creating a folder for incoming supply teacher, including medical perils and emergency directions (see map in Figure 18). When asked if anyone made sure these folders were in place, a secretary replied, "it is a given, it is

always there... We also have a buddy system, where you are away and you need some help, I will help you and vice versa, but this is a given." In School 2, it is the responsibility of the teacher to participate in the work-text-work processes put in place by the SPAB. The teacher is responsible for activating the SPAB and understanding what needs to go into an Anaphylactic Allergy Individual Plan. They must then go through the work of creating the folder with all (or in this case, most) of the information required by the text, creating the output text that will be later used in other institutional processes.

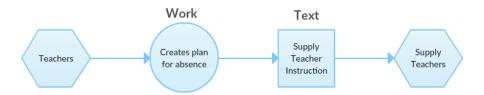


Figure 18: Creation of Supply Teacher information in School 2

In School 1, however, the Lead Administrative Assistant took the responsibility of preparing supply teachers for their time in the School (seen in Figure 19). At the beginning of every semester, the Lead Administrative Assistant would create Substitute Teacher Packages for every teacher. This package not only contained information such as maps of the School and lock down/fire drill procedures, it also contained Student Emergency Data, divided by class, and an instruction sheet on how to use an auto-injector (EpiPen® and EpiPen Jr.®) which was visible through the transparent front cover. Student Emergency Data is information provided for every student with a medical peril, and includes general information such as their birthday, homeroom, and transportation to School, and medical information such as their allergens, instructions on what to do if a reaction occurs, and a picture of the student. On the Student Emergency Data sheets, the Lead Administrative Assistant would highlight information regarding auto-injectors, whether the student needed one and where it was kept (either on their person or in the office).

She would also introduce the supply teachers to the package, "I have always just gone through with them quickly, especially if it is a new teacher. I let them know the first part is Student Emergency Data, life threatening situations that might appear, that could happen in their classroom, make them aware." In School 1, the work-text-work processes that were originally deemed to be the teacher's and Principal's responsibility had been taken on by the Lead Administrative Assistant, with her doing the work to create the text (the Anaphylactic Allergy Individual Plan), and then ensuring the supply teachers were introduced and aware of the text. By the Lead Administrative Assistant taking on these responsibilities, it ensures that the Anaphylactic Allergy Individual Plan are created (albeit, under a different name), that supply teachers are aware of it, and that these text and actions are coordinated throughout the school environment, and are the same for every teacher and every supply teacher involved in the processes.

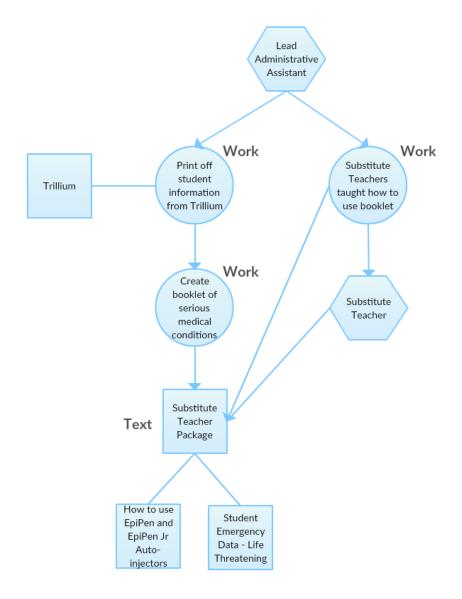


Figure 19: Creation of Supply Teacher information in School 1

Within these two Schools, we do not see the exact actions that the SBAP intended to occur. However, we do see a variation of the Anaphylactic Allergy Individual Plans being formed (under differing names and with different amounts of information), and we see the transmission of information to supply teachers (through differing actions).

Disjunctures between the Perceived Roles of Individuals within Schools

Within both Schools, there were differences in the perceived responsibilities of staff members. I had two experiences where staff members discussed important responsibilities of a particular school staff with regards to anaphylaxis management, yet when I spoke with the person directly, they did not feel they had any special responsibilities compared to other staff members.

Within School 1, while discussing her work in developing the Health Binder, the Vice-Principal said, "once I know a student has a particular issue, that I need to know more about, I make sure that their Guidance Counsellors have a relationship with them." She went on to explain, "the Guidance Counsellors [are] the case manager[s], so the Guidance Counsellor is the one that needs to know all the information about a particular student... so all the Guidance Counsellors have met with their students who are anaphylactic or diabetic, and have made a plan". The Vice-Principal identified the Guidance Counsellor as the person responsible for creating a relationship with a student with a medical peril, and creating a plan with this student in how to manage within the school setting. However, the Guidance Counsellor within the School had a different view of this process. When asked about her responsibilities in relation to allergies within the School, she replied, "I personally don't have any duties that are different than any other teacher, but all of us have the responsibility that if we see a student having an anaphylactic reaction, that we know we can get the epi-pen... and that we can administer the epi-pen without any fear of consequence." In this situation, the Vice-Principal believes that the Guidance Counsellor is a point of contact between the School and the students with anaphylaxis. The Guidance Counsellor, however, did not see this as part of her responsibility. As a result, this lack of communication within the school system disconnected work-text-work processes around

anaphylaxis management as well as roles and responsibilities for work. While we still see a system of emergency anaphylaxis management (staff having a responsibility to act), this disjuncture between the perceived responsibilities is a gap in daily anaphylaxis management at the school level. By having an expectation of a connection point between School and student, without there being one, can create a place where the daily needs of anaphylactic students are not being addressed.

Similarly, in School 2 while discussing the First Response team in the case of anaphylactic reaction occurring, numerous staff members stated that the Phys. Ed. department would be called since they had first aid training and were prepared to deal with any emergency situation, including an anaphylactic reaction. However, when I spoke with two teachers from the Phys. Ed. department, they explained that they were unsure of why they would be called in the case of an anaphylactic reaction, and indicated they had no special training on how to react to an allergic reaction. They explained that the St. Johns Ambulance First Aid course they receive did not contain any information on anaphylactic allergies, and that they received the same auto-injector training as other staff members. This again identifies a lack of communication that can lead to confusion over the roles people are supposed to fill. An institutional process is created within the School where if a reaction occurs, a specific person or group of people will be called to assist, because they have special training. However, if this group does not have the training that they are believed to, this leads the reasoning for the institutional process to be faulty creating an unsafe environment for anaphylactic students.

The Discussion of Boss Text in the Local Environment-School Staff

One of the things I tried to do in all interviews was to ask staff members what they knew about the Boss Text (Sabrina's Law and the SBAP). Overall, neither Boss Text was brought up

naturally within the interview, and it was through probing that they were discussed. The majority of the discussion focused on Sabrina's Law, and the only mention of the SBAP was by the Vice-Principal of School 1, "we actually have an anaphylaxis plan on our board websites, so really if you don't know anything, just follow it. It has got sample letters that can go home. You know it is pretty good." Despite the SBAP creating many of the institutional processes that these staff members are involved in, the majority are not familiar with it. Furthermore, despite the collection of weaknesses, dead-end processes and confusing text provided by the SBAP, it is described as something to follow if an individual does not know anything about how to manage anaphylactic allergies in schools.

Through the discussions of Sabrina's Law, the two main themes mentioned by staff was a responsibility to act, and protection from legal action. The ladies working in the Attendance Office of School 2 described Sabrina's Law as, staff had a responsibility to know if someone in their classroom had an anaphylactic allergy, and that if there was a reaction, they had a responsibility to help and could not walk away. When speaking with the Guidance Counselor of School 1 about Sabrina's Law, she explained, "my only understanding of it is that teachers have an obligation to act, and that they were free from being sued for acting, if they administer it wrongly or anything like that, it is not an issue." The Vice-Principal of School 1 described it as, "Sabrina's Law is about not being held liable if you do things in the best interest of the student if they are having an anaphylaxis event, because you know I think we always have to ere on the side of life versus the possibility of death." When speaking with a Teacher from School 2 who also had anaphylactic allergies, she said:

What I understand it to state is that if there is a situation where a child who is known to have anaphylactic allergies, appears to be moving towards anaphylaxis, even says I think

I ate something, you can give the epi-pen without risk of being called to task.... So as it turns out, it wasn't a reaction to peanuts or whatever... You will not be hauled on the carpet and charged with malfeasants by having given the epinephrine, because it is better to give it when it is not needed, than not give it when it is.

Throughout the discussion of Sabrina's Law with School Staff, there was no mention of individual plans or preauthorization to inject epinephrine. The focus was on a responsibility to act and a protection from legal action, the first being something that is not ever mentioned in Sabrina's Law. When Sabrina's Law is examined, however, there is no mention of staff members' responsibility to act in the event of an anaphylactic reaction. Staff members have attached this responsibility to Sabrina's Law in their "picture" of what Sabrina's Law entails. They have created an addendum of sorts because of the responsibility they have around student safety.

#### Disjunctures Between Policy and School Environment

While going through the school environment, there were a number of institutional processes and actions created by the Boss Text that were not seen. For example, Principal's responsibilities as listed in the SBAP include:

- Convene a meeting with parents/guardians of the anaphylactic students and appropriate staff to develop an Anaphylactic Allergy Individual Plan which includes medical information related to the type and severity of allergy, past incidents of anaphylactic reactions, monitoring and avoidance strategies, appropriate treatment, and other health considerations
- Train the Emergency Response team to handle an anaphylactic reaction. Maintain an upto-date list of school personnel who have received anaphylactic training
- Carefully review the safety plan for anaphylactic students prior to field trips. Discuss concerns with the School Superintendent as required

- Work with School Council to increase community awareness of anaphylaxis, its avoidance, and its treatment
- Use the Anaphylaxis Procedure Checklist to conduct a yearly review of school procedures

However, when I was discussing the work of the Vice-Principal in charge of Health and Safety within the School, there was no mention of any of these responsibilities being taken on by any staff member within the Schools.

When looking at teachers' responsibilities in schools, the majority of these responsibilities focused on daily management, risk reduction, and preventing students from coming in contact with allergen:

- Share and review anaphylaxis avoidance procedures with the anaphylactic student/parents/guardians
- Conduct food safety discussions with all students at beginning of year and at regular intervals throughout the year while respecting the student's need for privacy
- Stress the importance of not sharing lunches, snacks, utensils or containers. Reinforce hand washing before and after eating

However, at the school level, this wasn't seen. Three teachers from School 2 described anaphylactic allergies as a non-issue within their classrooms. They were something that they dealt with as they came along (if a student expressed concern). Similarly, in School 1, one teacher explained that she would be mindful of students who were nervous around food and take that into consideration when deciding if food could be brought into the classroom. However, the amount of involvement of staff that the SBAP requires was not seen within Schools.

Furthermore, in either School there was no development of Anaphylactic Allergy

Individual Plans for the students, no School Anaphylactic Management Plan, and the majority of

text required in such a Plan was not mentioned in the school environment. Out of the six forms that were to be included, only the Critical Medical Alert form was used within both Schools.

These disjunctures between what the policy states as necessary institutional processes and actions at the school level work against the coordinating actions of the Boss Text on the local environment.

#### **Anaphylactic Students Experience within School Environments**

Within this research, six adolescents (ranging from 14-16 years of age), and 5 parents were interviewed. A complete list of Student Information can be seen in Appendix C.

For the majority of the adolescent students in this research, school was a reasonably safe environment. When I asked Kurtis about what he thought his school could do to help him with his allergies, he replied, "I feel pretty safe at school." Kurtis also explained that he had not felt nervous about eating at the school, or having others eat around him. His sister, Meghan, added, "I don't feel like it is a problem", explaining that, "I don't really tend to think about it [allergies] a lot at school." For both Kurtis and Meghan, they felt confident in how they managed their own allergies, which helped them feel confident in school environments.

Vanessa had similar experiences in school, explaining to me that her allergies don't make her feel different during the day. She further explained that she does not feel nervous at school, because, "I know not to eat other people's food and I know I am good with it [managing her allergies] ... I don't worry about it on a daily basis." Similar to Kurtis and Meghan, Vanessa felt confident in her abilities to manage her own allergies, and this confidence and control helped her feel safe at school.

This was a bit different for Katherine, as she described school as "a little bit more tricky, especially if you get something from the cafeteria, they don't always have labels on them, or ingredients. So you have to ask the ladies if you are getting something." She then explained that because of this, she usually brought food from home for lunch. When asked if she ever felt concerned about other students eating around her, she replied,

Definitely. There are some people that bring nuts to school... you have to be cautious around them, and you know when people are coming near you, usually it is either me or my friend that reminds them, I have allergies, so wash your hands if you are going to do something. It is just precaution; it is not as concerning or anxious or paranoid as I was earlier [when she was younger]

For Vanessa, it was times when she was not in control when she becomes uncomfortable in school; for example, when she could not check ingredients herself and had to depend on the people in the cafeteria to read the label. However, she worked to decrease these negative feelings by taking back control over her allergies, packing her own lunch and advocating for herself.

Bernardo explained that he rarely feels uncomfortable during the day because of his allergies, and that it is similar to how he felt before they developed. However, he did tell me about a specific experience in school where he had difficulties because of his allergies. When telling me about his day, he explained that at lunch, he would try to be first in line to use the microwaves, and he would avoid sharing the microwave with anyone else. He explained, "I can use the microwave when it is clean, and I know there is nothing [in it], and I try to avoid sharing the microwave with other people just in case something gets in my food." He explained that in Asian cultures shellfish was very common, and he had seen fellow students warming up food containing shellfish in the microwaves. Since he had only had the initial reaction, he wants to avoid having another. Similar to the other students, Bernardo feel more comfortable within his

school by gaining control of the situation. By being first to the microwaves and not sharing, he could feel more confident in his ability to avoid having another reaction

Akash's experience at school was not as positive. When asked about what staff at his school did to help him prevent a reaction, he explained, "they just tell the other students, if you have this food [allergen], eat it somewhere else." When I asked how this made him feel, he explained, "[I feel] angry for them that they can't eat [allergen] if they like it, and kind of mad for me, because I can't eat it either." His mother, Mrs. Nadvi, told me that he could get very upset when people ate allergens around him. When I asked him if he would tell a Teacher or Principal how he felt, he said he would not want to. When speaking about his day, Akash explained to me that he does not eat lunch at school, and instead plays basketball. Mrs. Nadvi, explained that even if she packed him lunch, he would not eat it. When I asked him about this, he said, "I like to play basketball more than eating lunch." For Akash, gaining control over his environment and feeling comfortable at school meant removing the need to eat.

Overall, students felt confident in their abilities to manage their own allergies, yet expressed negative emotions or described difficult experiences when losing control. An interesting note is that unlike the Boss Text and school environments, which focus on dealing with the reaction, students focused on the everyday management of their allergies. When I asked about how they managed their allergies in schools, almost all the students talked about avoiding allergens, reading labels, packing their own lunch and being aware of the surroundings. None of them spoke about what would happen if they had a reaction. For a student with anaphylactic allergies, the focus was on navigating the day-to-day management of their allergies.

Missing Institution Processes within the Everyday Experience of Anaphylactic Students in Schools

As in the school environment, when we look between the institutional processes put in place by the Boss Text and the experiences of anaphylactic students in schools, there are a number of actions and procedures missing and/or disconnected. In the SBAP, one of the responsibilities of the Principal is to convene a meeting with parents/guardians of anaphylactic students and appropriate staff members in order to develop an Anaphylactic Allergy Individual Plan. However, in general anaphylactic students and parents said they found there was very little involvement of the School or staff members in anaphylaxis management. Furthermore, the families' knowledge of the processes within the schools around anaphylaxis management was limited and they were unsure, confused and raised questions about it during the interviews.

When I asked the students and their parents about what the school does to help anaphylactic students, the general consensus was that they were unsure. Vanessa's mom, Sheri, said that she would send the health form in at the beginning of the year, and there was no further contact after that. Bernardo told me that outside of putting some posters up asking students to not bring in peanuts, he was not sure what else the schools did. Meghan explained to me that she had seen some of the teachers ask students to put away allergens (in this case, a peanut butter sandwich). Kurtis added to this by saying "they do announce that some students have peanut [allergies] and make everybody aware of that fact. So they kind of discourage people to bring peanut products into the school." When I asked Katherine what the school or School Board does to help, she replied, "I really don't know that much about what the School Board or the school does... I usually rely more on myself for allergies."

Meghan, Kurtis, and Katherine also talked about how some teachers would ask about their allergies and inquire about where their auto-injectors were located. Kurtis explained, "well I know one of my classes, we had an ice cream day the one time, and that teacher was asking me about it, and I told her that [it was in his backpack] ... I have had a few teachers ask me, most of my teachers ask me." Meghan, Kurtis, and their mother Rebecca then discussed their different experiences of staff members asking where their auto-injectors were:

Rebecca: So I don't think there is anybody that has really said you need to have an epipen at the office. It is your choice if you do that.

Kurtis: Well they make sure we have one on us.

Rebecca: Well did anyone ask you about that.

Kurtis: Yea. Every like new semester somebody asks.

Rebecca: Oh, well okay that is good. So I didn't know that.

Meghan: I don't think anyone asked me.

Rebecca: Nobody has asked you.

Meghan: No.

Rebecca: Okay.

Kurtis: Like last year I know I was called down to the office, and they asked me if I had

one on me, and if I had one at the office.

Rebecca: Oh, okay. Well that is good.

Researcher: So is that a secretary asking you.

Kurtis: I think it was the secretary, yea.

Researcher: Okay and Meghan you never had that?

Meghan: I don't remember that.

Katherine had a similar experience as Kurtis, "all my teachers know that I have severe allergies. On the first day of school they ask where the epi-pen is, so they know in advance... they all just check what you are allergic to usually. Not all the time, and just make sure that they are aware of it in case of an emergency." In the SBAP, one of the responsibilities of the Principal is to "ensure

the EpiPen®/Allerject<sup>TM</sup> and Asthma inhalers are kept with the student as well as an additional one in [a] safe and secure location known to and accessible by all staff." Yet the students in this study had varying experiences of these processes that should have been coordinated by the Boss Text.

The training that staff members receive was only discussed in one interview, with Vera, Katherine's mom. She explained that Sabrina's Law pushed for staff to have training on how to use auto-injectors, but said: "I don't know how often they do receive it ... I think they have sessions. I think once a year or at the beginning of the school year... just how to use epi-pen." The training of staff members is a key component of both Sabrina's Law and the SBAP that occurred in both schools. Yet, the majority of anaphylactic students and their parents were unaware when and if this happened. This is an example of where there is a clear coordinating action of the Boss Text on the local environment, but those directly affected (e.g., students and parents) are disconnected from the work-text-work processes within the school context where they manage anaphylaxis.

Overall, these students, who are in two schools with similar institutional processes around anaphylaxis management, and are under the same SBAP and legislative environment, have vastly different experiences of *what* the school does to help anaphylactic students. They are also removed and unfamiliar with the processes in place to help them within the schools.

The Text Connecting Anaphylactic Students and Parents to the Ruling Relations

There is a number of text and forms created by the SBAP that could play a part in the everyday life of students with anaphylaxis and their families. These include: Critical Medical Alert Forms, Administration of Medication: Epinephrine Injection, Anaphylactic Allergy

Individual Plan, letters to the school community about avoiding bringing allergens into the school, peanut/nut avoidance signs, Medical Peril information sheets, Emergency Transportation Information, and Anaphylaxis Alert Fanny Pack Information Cards. From our data, we see a decrease in the number of texts actually used at the local school level, with only Critical Medical Alert forms, letters to the school community, peanut/nut/ avoidance signs, and Medical Peril information sheets, being used. Students and families had even less experience with these forms. Across all the interviews with anaphylactic students and families, four main texts were found that hooked them into the school processes: 1) Critical Medical Alert forms; 2) signage around the school, 3) Medical Peril information sheets (mentioned by one parent); and, 4) attendance lists (mentioned by one student). This progressing of the text through the ruling relations to the Student Experience can be seen in Figure 20, below.

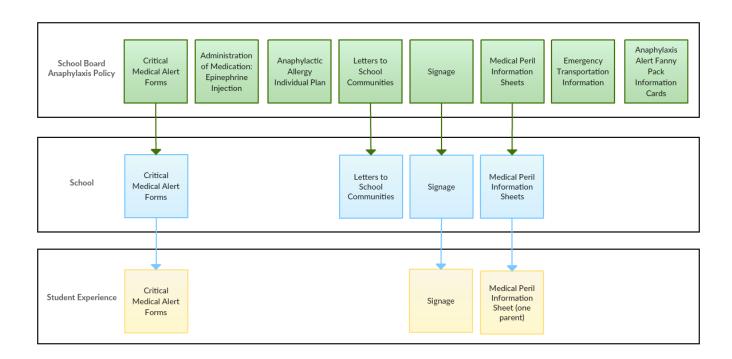


Figure 20: Movement of Text from School Board Anaphylaxis Policy (Boss Text) to Everyday Experience of Anaphylactic Student

Health forms sent home at the beginning of the year were mentioned often, however neither parents nor allergic students knew what *actually* happened to these forms after being collected. Katherine explained it as, "I just know that every year we have to fill them out with all my allergies, what I have, and I don't know what they do with those forms." While Kurtis and Meghan were unsure of what happens to the health forms after being sent to the school, Kurtis said, "I am sure they do something with them, because I have had teachers ask me about it and I have been called to the office about it [allergies]. So somebody probably reads them." Meghan then added, "they probably inform the teacher, they probably tell them that there is someone in that class that has an allergy." This process is depicted in Figure 21. To Meghan and Kurtis, the work-text-work process that they had experienced involves the work of them (or their parent) filling out and returning the Medical Peril form (the text), which then informs and dictates the actions of the staff and teachers (communicating with them about their allergies).

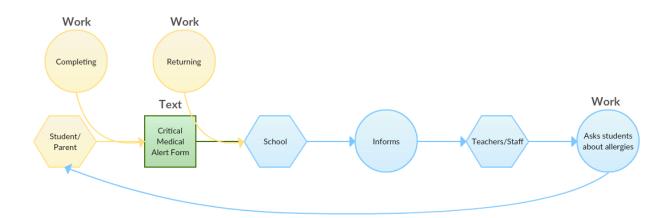


Figure 21: Student experience of the work-text-work processes around Medical Peril forms

These work-text-work processes are not always seen as clear or logical to families. While talking about the health forms, Vanessa's mom, Sheri, expressed that "they never seem to keep them. You fill one out brand new every year." To Sheri, the work-text-work process appears

faulty, with the initial work and text having to be redone every year, and the work of the school staff lacking (throwing out the forms).

Another text that hooked allergic students into the processes within the school systems was the attendance sheets. Within this School Board, a red cross appeared on the attendance list beside the names of students with medical perils. When asked about how a teacher would know she has an allergy, Katherine explained, "on the attendance list there is a little symbol to show that I have a medical problem." She then went on to say that while it can be embarrassing to have people ask what the symbol meant, "it is nice to know that they are aware of it, and that they will take precautions to make sure that kind of stuff [reaction] doesn't happen to me." With the attendance sheet, students are being hooked up into the extralocal processes, most of the time without even realizing it. These extralocal forces involve the work-text-work processes within the school system that are invisible in the local setting, leading to the identification of students in the text as having a medical peril.

One of the responsibilities of the Principal in the SBAP is to, "ensure that peanut/nut/allergy avoidance signs are prominently displayed at all school entrances and around allergen-free classrooms." This created the institutional process that led to the hanging of signage designed to inform other about allergies and prevent accidental exposure to allergens. When discussing signage around the school with students, there were varying experiences. Katherine explained, "I think I have seen a few. I can't really remember 100% right now, but I am pretty sure there are some signs." Kurtis further explained that he had seen signs on some classroom doors explaining that there were students with allergies in those rooms. He also commented that "I feel pretty confident in handling my allergies myself, I don't think I would really need those signs there, but I guess it is good to have, so everyone is aware of it." His sister Meghan went on

to say, "I noticed they had a lot more in elementary schools. I haven't noticed a lot in high schools." For Meghan, the signs were a positive effort from the school, "I like them there, I feel more safe in the school." This is another example of allergic students being hooked up into institutional processes without being fully aware of the processes or intent.

Another example of varying experiences of institutional processes can be seen with the Medical Peril information sheets that are posted in staff rooms. In this situation, only one mother was aware of the posting of lists of medical perils in areas where teachers were able to see them. When talking about how anaphylaxis management by schools has changed since Katherine was first diagnosed, Vera (her mother) mentioned that schools post the medical information and students' pictures on the walls of the office. From investigating the school environment and mapping the Boss text, we know that the posting of medical perils is a common institutional process that occurred in both schools. By having their medical information and picture involved in these institutional processes, this hooked the students, most of them unknowingly, into the institutional processes in place in the school. By a teacher activating this text (the Medical Peril information sheet) and seeing a picture of the student made them aware of the student's allergies (see map in Figure 22). This also leads to the required action by the SBAP, causing the teacher to be aware of the student while they are in their classroom. The identification of the student by their textual image (their picture) and the awareness of them in the institutional processes hooked the student, unknowingly in most cases, into the ruling relations.

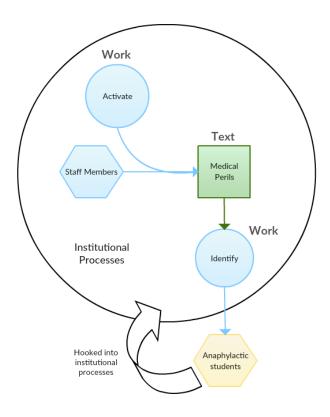


Figure 22: Identification of students through posted Medical Peril information

As in the school environment, none of the parents or students mentioned auto-injector consent form or emergency transportation information. Within this situation, we can see that even though these were text created by the Boss Text (specifically, the SBAP) and placed within institutional processes that must occur in the local environment, the school level creates a barrier between the Boss Text and the students. Similar to what we saw in Figure 22, this showed that if an intended institutional process is not set in place at every level of institution, the intent of the Boss Text is blocked from the everyday experience.

### Food Bans within School Environments

Food bans were an unclear area for both parents and students, with some families believing that peanuts and nuts were banned from the schools, some saying that only peanuts were not allowed, and others explaining that the schools suggested against bringing peanuts and

nuts in, but did not ban them. In a discussion between siblings Kurtis and Meghan, Meghan first expressed that their school had a nut ban, in which Kurtis disagreed, saying that he had seen people with allergen-containing food in the schools. The possibility that while the school may not have a nut ban, there may be allergen/food bans in specific classrooms by the teachers was then raised. Vanessa echoed this by saying that her school was not nut-free. Akash in contrast explained there were no peanuts at school, and it felt safer because of it. On the other end of the spectrum, while Katherine was "pretty sure" that there was a peanut ban in her high school, she had an experience where a staff member had brought in cookies containing nuts for a school event, leaving her unable to eat the provided treats.

This differing knowledge extended beyond the students and parents to the school staff. The Vice Principal of School 1 explained that with peanuts, "we can't truly ban it, because if we ban it, we have to police it, and if you police it with a building with fourteen hundred and fifty people, there is bound to be a mistake, and so we want parents to know that we encourage nut free, but we cannot guarantee nut free." She further explained that the school encourages a peanut and nut free environment. However, another staff member from the school said, "we do have a no nut policy in the school." Then, when we return to the SBAP, it says that peanuts and nuts are not allowed in schools. This differing experience of allergen bans within schools spreads across environments (see map in Figure 23) creating a disconnect between the institutional processes created by the Boss Text, the school level procedures put in place, and the experience of allergic students, families, and staff within the school.

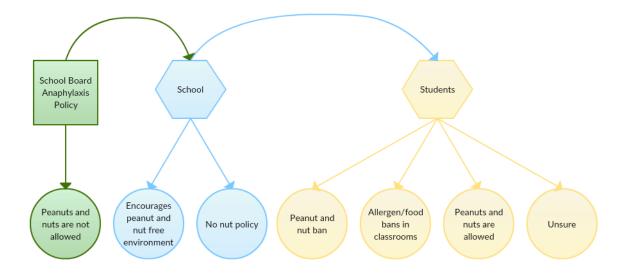


Figure 23: Differing experiences of food bans

The work of managing allergies at home compared to at school

For many of the adolescents, home was a place where there was a decreased amount of work involved in managing their allergies. Bernardo describes it as, "at home my parents do help manage it [allergies]. They try to avoid cooking shrimp and stuff like that, just because they know that is something that I can't eat." For Bernardo, his parents help by taking on some of the work involved in both providing food and managing his allergies, by preventing his allergen (shellfish) from being present in the daily meals. Because of this, home becomes a place where managing his allergies is easier.

When asked if managing his allergies are different at school compared to at home, Kurtis provided a similar answer, "I would say yeah, because at home I am not really offered [the] food that I am at school.... If I get offered food here from say my parents, I know it is fine." Like Bernardo, Kurtis's parents assume the work of determining if food is safe and avoiding allergens. This transfer of work from adolescent to parent makes the work of managing allergies at home much easier for the adolescent.

Katherine also replied, "I feel like at home everything is kind of build around that [allergies]... it's just very safe... I know what I can eat and what I can't eat, but at school it is a little bit more tricky." She went on to describe it more specifically, "I think at home it is the people, my family, they care, and they are more aware of it [allergies], and they don't want anything to happen, but at school you don't know most of the school... they don't know about your allergies." Similar to Bernardo and Kurtis, Katherine felt being at home was easier for managing her allergies as the work was taken on by her family. Her parents are more aware not only of her allergies, but what she must to do manage them. Because of this, they take on some of the work involved (such as label reading and determining what foods are safe to eat), which decreases the work that Katherine does to protect herself. Yet, at school, Katherine is solely responsible for this work.

Akash revealed insights into the emotional work of managing allergies at home and at school. When placing home and school on a scale from "happy" to "not happy", he described it as, "home is happy... school is in the middle." His mother then went on to explain that "he gets very upset" when people eat things around him that he cannot eat because of his allergies. They also explained that they do not keep any peanuts or nuts in the home, and he can eat any of the food. For Akash, being around allergens involves emotional work, feeling unhappy and upset. However, when he is home, where there is no food that he is allergic to, his emotional work is removed and he can feel happy.

In contrast, some of the adolescents felt that the work of managing allergies at home was not much different compared to school. For example, Vanessa describes it as, "I know that... most of the food in our home is safer, and [at school] I would only eat the food that I pack for myself." For Vanessa, by bringing the "safer" food from home to school, meant the management

of her allergies at school were the same amount of work, as at home. Vanessa is utilizing the work her mother does at home to determine that the foods present are safe for her to eat, and moving this to create a safer environment for herself at school. Meghan had a similar response, "I only really eat with my friends that I know that they know about my allergies, so I don't really think about it that much. It is not that different at home or at school." For Meghan, by eating with people that are familiar with her allergies, this could mirror her experiences at home (with her family), creating a safe environment for her to be in.

The discussion of Boss Text in the local Environment-Parents and students

The Boss Text, or Sabrina's Law, is a part of the extralocal forces that shape the local environment, however few families were aware of what it entailed. While three parents had heard of Sabrina's Law, only two were aware of portions of the legislation. Two parents had never heard of the legislation. None of the students were familiar with Sabrina's Law.

When talking to Vanessa and Sheri about whether there was anything that deemed the schools responsible for protecting anaphylactic students, Sheri mentioned Sabrina's Law, however she was not sure what it entailed. So while Sheri was aware that there were extralocal forces in place that affected the local environment, she was unfamiliar with the specifics behind the Boss Text. For Rebecca, she was unfamiliar with most of Sabrina's Law, but was aware of the Immunity section, "I know teachers are allowed to use or anybody really is allowed to use any epi-pen on somebody who they think is having an allergic reaction without any repercussions, so if I thought that you were having an allergic reaction, I could grab an epi-pen and use it on you, and you couldn't sue me later, saying why did you do that to me." Vera was more familiar with Sabrina's Law, knowing why it was developed (from Sabrina Shannon's death), as well as some aspects within it, "it has pushed them to have training on epi-pens, and so

they are more aware of it... people have to be identified, and procedures have to be in place. Emergency plans have to be in place." Vera also believed that the forms used within the schools came from Sabrina's Law. These moms were partly aware of the Boss Text that shaped the local school environment, but not the processes in which it does this. The data showed that parents and adolescents are separated from the extralocal processes within the ruling relations. While these moms were aware of the Boss Text, they were removed from the work-text-work processes that cascade down from the legislation, affecting and shaping the environment that they and their children must navigate through on a daily basis. This separation is even more prominent for Isabella and Mrs. Nadvi, who had never heard of Sabrina's Law.

When parents and children were asked about what they would include in legislation or in the processes within schools to protect anaphylactic students, there was a wide range of answers. Akash suggested banning peanuts and almonds. Kurtis suggested against banning peanuts and nuts, but not allowing cafeterias to sell anything containing those allergens. Vanessa touched on the difficulties in food bans, "I want to say make things nut free, but that just punishes everybody." Meghan also touched on food bans, and the differentiation between the needs of younger allergic students, "I think that it is good to have the ban in elementary school, because the kids aren't as aware of it, but in the high school, people are more aware, so I don't think the ban is really necessary." For Bernardo, food bans were unfair to others, "just because a certain group might be allergic to something, you are not going to completely want to ban certain foods.... I love shrimp, but I am highly allergic to it... They like it. So that is why you can't really say for people to ban something like that food." Across these students, they had very different views of food bans within schools. I suggest that this is because allergies, the management of these allergies, and a person's perceived need for a food ban are very personal

and differing experiences. What Akash needs is very different from what Bernardo needs, because they have different allergies and different experiences in managing them.

Some of the answers closely matched the work and processes that School Boards and Schools were already doing to create a safer environment for students with allergies. Kurtis suggested, "making sure that everybody who does have allergies would have an epi-pen on them at all times too, or at least one in the school somewhere for them." Sheri's suggestions involved keeping a list of people who have allergies as well as what they are allergic to, symptoms, severity of reaction, and contact information. She also suggested training for individuals responding to a reaction, "they are going to need to know what to do, so that they are not panicking and doing the wrong thing."

Other answers revolved around continued education and awareness of allergies. Vera's said:

I think more continuing education and information and awareness. I think it's not healthy for anybody to enforce on people... your kid is highly allergic, so they create some bubble for him or her and I don't think that is going to benefit anybody. Maybe it is going to keep the child safe at that point, but I think down the road it is better to educate everybody to make him safe, so he can actually while in school [be] protect[ed] and learn to be safe when he is out of school.

Katherine also touched on the importance of educating not only staff members, but other students as well:

You should make the students or people aware that people have allergies. Not as much just the teachers, but the actual people in the class, because the teachers don't always know what to do. Sometimes they panic as well. It is just extra reassurance for those kids who have allergies, but I don't feel as if it needs to be this whole huge, huge deal, you know, embarrass the students and put them in the headlights.... It should just kind of be a

causal mention that some kids have allergies. They can be severe. Just sometimes take precautions if you know someone has it.

Isobella had a similar answer, "maybe make a campaign to be more aware of the different allergies." For these families, education is key. By others being aware of what allergies are and how to prevent them, this helps anaphylactic students be safer in schools.

The increased Work involved for Students and Supply Teachers

Having a supply teacher in the classroom had the potential to create a different environment for allergic students, because it is a change in the daily activities. Katherine explained, "with supply teachers, usually they don't know about allergies. They just see that little cross thing on your attendance list and they just assume that you know, oh she has something, if something is serious, I am sure someone will know what to do." She then went on to explain that the only time she had a supply teacher ask about the attendance cross and her medical peril information was a long-term supply who stayed in the classroom for three months; "so obviously he asked, he was there for a long time. He had to make sure he knows, but the ones that are there for a day, one period, they are not going to know everything about a student for one class." For Katherine, a supply teacher did not take on the work that her usual teacher did by being aware of her allergies, of the surroundings, and of the procedures if a reaction occurred. This shifted that work to Katherine, who must now do all the work of managing her allergies in the classroom without the help of a teacher or adult.

Meghan spoke of an unsettling experience with a supply teacher four years ago, when she had a minor reaction after eating nut-containing cheerios, "we had a supply teacher, and she didn't really do anything about it...I went up and told her and I don't think she really realized... or she didn't really think it was serious I don't think... I kind of waited to see if there would be a

big reaction." She explained that she waited to see if the itchy face and legs she was experiencing would get worse, but it did not develop into a full-blown reaction. During this, Meghan felt, "kind of worried because they weren't really listening to me and I was kind of mad." For an allergic student, it is expected that if there is a reaction in class, they will be assisted by the teacher or other staff in reacting to the reaction. However, when Meghan had a reaction, the supply teacher was unaware of the severity of the situation and the work they were responsible for in assisting her. Meghan was left to do the work of dealing with a reaction alone, having to wait it out in her seat.

One supply teacher in the School Board also voiced concern. Anabelle has been an occasional teacher in the School Board for eight years, as well as having her own class. When asked whether having an anaphylactic student in a class changes anything, she said that it didn't, "just be aware that they are there... you know who is anaphylactic and you just keep a watch in the classroom, depending on what they are allergic to... generally just make sure that no one is eating [allergens]." When asked about advice to give other supply teachers, she said, "just tell them to make themselves familiar, just make sure that they take a few minutes before the class comes in and review the information that the teacher left, whether it be in the plans or the supply book... they need to be aware of who the kids are and note where the epi-pens are located." Through this conversation, the topic of training at the beginning of the year was brought up. Despite all teachers and staff being provided with auto-injector training at the beginning of the year, Anabelle explained that supply teachers do not receive any training. When asked how this made her feel, she explained, "it makes you feel that you are not a real teacher, you are not worthy enough to receive training, but as a teacher you have certain responsibilities. We all take it upon ourselves to learn these things, whether it is provided or not." When asked how this could be remedied, she explained that there was yearly mandatory online training run through the School Board on topics such as concussions, and suggested that anaphylaxis training be added into these modules, since every teacher (not just occasional teachers) must complete this training yearly.

These results suggest that there is a major gap involving supply teaching and anaphylaxis management. Supply teachers are disconnected from the local institutional processes at the school level around anaphylaxis management. Students, while separate from these institutional processes and unaware of disconnects between supply teachers and school anaphylaxis management, expressed knowing the difference when a supply teacher is present. The work involved in anaphylaxis management is not divided in a way that is effective for either party. Students feel left to do the work of managing their allergies and reactions on their own, and supply teachers feel left to do the work of learning how to assist anaphylactic students on their own. This disjuncture in the extralocal environments around supply teachers creates an unsafe environment for both students and supply teachers, leaving both parties feeling uneasy and alone.

The Disjuncture Between the Intent of the Boss Text and the Intent of Anaphylactic Students

The intent of text such as Sabrina's Law and the SBAP is focused not directly on the student, but on the environment within the school. They create a safe environment where staff are aware of and (partly) prepared to deal with an anaphylactic reaction. However, the intent of anaphylactic student is different from the intent of the Boss Text. The students work to interact and move through this environment safely. Within the school setting, it is through the environment that school based anaphylaxis management and the everyday experience of an anaphylactic student intersect. It is not the Boss Text's direct actions that affect the student, but through the textual processes created by the Boss Text that the extralocal forces are felt in the

everyday experience. This is how the legislation and policies affect and shape students experience, through the environment they move through within schools.

## The work of being included

Food is innately social, but for a food allergic student, there is extra work involved in these social interactions. Food and their food allergies may affect how they are able to participate in social interactions, or if they are included at all. Within the students involved in this study, there were varied experiences of the work involved in being included in social interactions.

Meghan was involved in Pathfinders (a division of Girl Guides), and there were a number of girls with allergies in the group. She explained that before any camping trip or activity involving food, the Guides would remind and review with everyone the allergies in the group and the foods not to bring. To her, this was a positive experience, "I don't really like being the only one, so it is kind of nice having other people [with allergies]." In this situation, the Guides take on some of the work of advocating for people with allergies, as well as work to create an inclusive environment by educating others about allergies and allergens. This helped Meghan feel more comfortable and included within these social events.

For Bernardo, whose family was originally from a coastal region, his shellfish allergy affected his social inclusion during family parties. He said that when "my family from [home country] come here to visit us, we do throw parties, there is shellfish, but I just have to stay out of the way because I'm not like 'oh no, we cannot have shrimp'…because I know how good it is." Bernardo was still able to be included in the party without putting himself at risk or denying specific food to others. However, he must still be aware of his surroundings and the foods around

him to protect himself from coming in contact with shellfish. He does this work to prevent his or others social interactions from being affected by his allergies.

On the other hand, Katherine had more negative or difficult situations involving her allergies and social interactions. At a recent birthday party, she was unable to eat the cake, and ate an apple instead. She continued in saying, "it was a really sweet apple. So it was okay." In this situation, Katherine had to adapt and find other ways to be included in the social event. While she may have been unable to eat the cake with everyone else, she was still able to *eat*.

Another experience Katherine had involved her not being invited to birthday parties. Her mother, Vera, explained this as, "when they talk and we invite them and they come, no problem. But when they have parties, I guess people are just too scared." In these situations, Katherine was excluded from social events because of her food allergies. While Vera and Katherine were upset about this, they understood the actions, with Vera explaining, "you cannot blame them, because you know they want to be safe too." When asked about what she would prefer people do instead of be fearful or exclude her, Katherine answered, "I would prefer people just ask me, because I am not afraid. I would be glad to tell them what I am allergic to. What I am allowed to eat... It is just asking question about what you are allowed to eat. It is not that big a deal." For Katherine, her allergies had negatively affected her ability to be included in social interactions. To try to prevent this exclusion, Katherine was willing to do the work of informing and educating others to alleviate those worries and to allow her to participate in these social interactions without either group being fearful.

Food sharing is another form of social inclusion that is a very primal and intimate experience, but for a food allergic student it can pose health risks. Within the students involved

in this project, there were different responses to food sharing. For Vanessa, food sharing was a social experience that she could not participate in. She described it as, "declining something... and people will say 'oh you don't like my stuff'. That is not the reason." Vanessa later said that she shared food with friends before, however after a close call with a muffin containing nuts, she no longer accepted any food from people around her. For Kurtis, on the other hand, if a friend offered him food he would check the label, "I have to read the label, because not everyone knows that I am allergic, so I have to make them aware of that fact, and then get them to...read the label." There was more of an openness to food sharing for him, however not without confirming that the food did not contain any possible allergens. With Katherine, we see a similar openness in whether she would eat a provided food or not, however the way she determined its safety differed. She describes it as:

It depends on the food, because certain foods I know I am allowed to eat. Like if it was goldfish or something, I am allowed to eat that, but if it is like a cake or a brownie or something, I would stay away from that, because it... probably has eggs in it.

For Katherine, there are categories of food that she is allowed and not allowed to eat. If it is something where she does not want to "risk it", she would politely decline. Even within a similar social experience, food sharing amongst friends at school, these three students have different ways of responding to this possible risk in ways that make them feel safe, and differently types of work they put into it.

### Friends and Food Allergies

Friends were seen as important players in anaphylaxis management in school systems, taking on work involved in advocacy and emergency preparedness. When asked about if she feels concerned about having other people with allergens around her, Meghan responded "my

friends all know about my allergies, so I don't really feel concerned." For Meghan, her friends become a barrier against allergens. By knowing about her allergies, they will not bring food that she is allergic to in their lunch. By them taking on the work of being aware of allergens in the food around her, they help Meghan protect herself from a reaction in school.

For Vanessa, her friends were the ones who would assist her if she had a reaction.

Vanessa kept her auto-injector in her backpack, and when asked if anyone knew it was in there, responded, "most of my friends know that it [auto-injector] is there." She also said that after a scare with a muffin containing nuts, she told her friends where her auto-injector was. For Vanessa, her friends were the ones who would take on the work of getting her auto-injector if she was unable to at the time of a reaction.

Katherine described her friends as people who knew she has allergies and would know what to do in an emergency, "all my friends know [location of auto-injector], so if the teacher didn't know what to do, my friends would help out. They all know about my allergies." Her friends were also advocates for her in situations where others had allergens near her, "when people are coming near you [with allergen] usually it is either me or my friend that remind them, I have allergies, so wash your hands if you are going to do something." The roles that her friends took on were important to Katherine, she said, "it shows that they do care... they have my back if something happens, that they will always be there." Katherine's friends assisted in the work of managing allergies, through advocating and knowing what to do in an emergency. However, Katherine also explained that taking food from friends could be difficult, "If my parents told me I could eat something, I have to trust them. With friends, it is a little more difficult because they say you should be fine. It is better to know that someone like myself or my parents has read the ingredients and it is true that I won't have any reaction to it." For Katherine, having her friend

help her in the work of managing her allergies is a balance. While she appreciated the work that her friends did, she would not transfer responsibilities to them that could put her at risk of a reaction, this work she took on herself. This could be because of the different between experiential knowledge and learning about allergies second hand. Her friends, while aware, respectful and mindful of her allergies, have not experienced or seen a reaction for themselves. This level of awareness that Katherine and her parents possess of allergies leads them to be more careful and thorough in reading labels and in determining the safety of food, experiences that her friends do not share.

### **Summary of Results**

Sabrina's Law begins to develop the institutional processes that must occur at school levels, creating a balance between risk reduction and emergency response. This legislation also creates anaphylactic students and families as passive participants in school management by creating procedural work that occurs around them, without their input. As we moved to the SBAP, we can see that while the institutional processes created by Sabrina's Law are included and expanded on, institutional processes around risk reduction and daily management are left to the responsibility of individual schools to develop and implement. These analyses revealed a number of dead-end processes; for instance, the lack of specific information in the SBAP to develop required institutional processes meant essential processes were left to interpretation. Students and families continue to be created as passive participants in anaphylaxis management, with parental responsibilities focusing on their child's ability to manage their allergies.

Institutional processes around anaphylaxis management in schools continue to remain a responsibility of the school itself, and we can see a movement towards more "filing-cabinet" processes. At the school level, we see the focus of anaphylaxis management as routinized on

creating "filing-cabinet" processes and emergency preparedness. Staff members learning was mainly from experience, with disconnects between them within school environment and the Boss Text (Sabrina's Law and the SBAP). The everyday experience of anaphylactic students in the school environment revealed disjunctures between students and institutional processes with students taking on the work of managing their allergies and having little information and assistance from the school environments they navigate.

# **Chapter 6: Discussion**

To date, the research around adolescents with anaphylaxis and anaphylaxis legislation or policies have been separate domains. Research on adolescents and anaphylaxis have examined the process and tensions involved in transitioning responsibility for allergies from parents to children (Akenson, Worth & Sheikh, 2007; Fenton, et al., 2011; 2013; Gallegher, et al., 2012), as well as how adolescents manage their allergies (Akenson, Worth & Sheikh, 2007; Fenton, et al., 2011; 2013; Monks, et al., 2010). Adolescents have also been shown to be at high risk for fatal reactions (Bock, Muñoz-Furlong & Sampson, 2001; 2007; Muñoz-Furlong & Weiss, 2009). Within school environments, there has also been a focus on adolescents' experiences within schools and of Sabrina's Law and School Board policies (Fenton, et al., 2011; 2013; Dean, et al., 2015; Elliott, et al., 2015).

On the other hand, research on anaphylaxis legislation has largely focused on the idea of undue hardship and concern about the separation or ostracizing of anaphylactic students (Marklund, et al., 2007; Resnik, 2013; Sicherer & Mahr, 2010). In particular, research investigating Sabrina's Law focused on such topics as consistencies between School Board Anaphylaxis Policies (SBAP) and Canadian anaphylaxis guidelines, the comprehensiveness of school forms for staff and parents, as well as auto-injector training and staff technique (Cicutto, et al., 2012).

More recently, research involving adolescents at risk of anaphylaxis focuses on experiences, and research examining food anaphylaxis policy focuses on their implementation. From the standpoint of at risk adolescents', there is a need to connect these two contexts as the experiences on the ground of anaphylaxis legislation and policies need to be made visible. By explicating and making visible these processes, this will allow disjunctures to be highlighted and

positive changes to be made. This research, with its utilization of IE, works to address this gap making visible how translocal forces such as Sabrina's Law and the SBAP affect the everyday experience of anaphylactic adolescents.

While IE has not been utilized in the field of anaphylaxis allergies to date, it has been utilized in a number of other legislative and health related fields (see Benjamin, et al., 2016; Ng, et al., 2013; 2015; Turner, et al, 2001). Traditionally, IE discussions tend to appear more like conclusions, with a summary of the key findings and recommendations for change. This is because of IE's rejection of theory and its stress on explicating the actual happenings of the everyday (Smith, 1999). However, because this is the first IE inquiry within the field of anaphylaxis, key pieces of literature will be included in the discussion to bridge the gap between this inquiry, and the more traditional styles of research within the field.

Elliott et al., (2015) compared student and parent experiences within schools between two provinces in Canada: Ontario (legislated), and Quebec (unlegislated). After the implementation of Sabrina's Law in Ontario, parents expressed a change in their roles in schools, shifting from a focus on advocacy and school policy to a focus on education. In Quebec, parents were still heavily involved within the school setting (Elliott, et al., 2015). The researchers suggested that this change in involvement in schools of Ontario parents could affect anaphylactic students' feelings of safety within schools, with students seeing their parents as less involved in their school environment (Elliott, et al., 2015). Other research showed that students felt stigmatized because of protective school policies, with them being separated from classmates while eating, or having pictures hung on the walls of classrooms and buses identifying them as having anaphylactic allergies (Dean, et al., 2015).

However, in this study, these experiences were not found. Both students and parents felt comfortable in how the student managed their allergies within schools, and depended more on themselves than on school processes. Students also did not mention feeling stigmatized, and expressed negative emotions as a result of difficulty around social interactions. A possible explanation of this is timing. The interviews used in the previously mentioned papers were done in 2008, two years after the implementation of Sabrina's Law. The interviews utilized in this research were completed in 2015, a full 9 years after the legislation was implemented. The majority of students would have been kindergarten or Grade 1 when Sabrina's Law was put in place, and had very little experience within an unlegislated environment. Having grown up in an environment where schools are more aware and accepting of anaphylactic allergies could lead to less negative experiences within school settings.

It is also possible that after 9 years, the initial stigmatizing school processes (such as posting pictures of anaphylactic students in common areas and having separate eating areas) have been phased out of anaphylaxis management in schools, with more involvement of overhead processes and educational aspects.

## Student Safety – How Far Does It Go?

The Government of Ontario recognized school safety as a "fundamental prerequisite for student success and academic achievement" (Safe Schools Action Team, 2006, p.4). A key concept through my research is the idea of school and student safety. Teachers and staff members are responsible for keeping students safe while in the schools. While student safety can involve both preventative and reactive measures, the focus for anaphylaxis management in schools has turned to emergency preparedness. Staff members' roles in keeping anaphylactic

students safe centers around being able to react and assist in the case of an anaphylactic reaction occurring.

However, for a student with anaphylactic allergies, management is much more encompassing than just emergency preparedness. For an anaphylactic student, anaphylaxis management involves the work of preventing a reaction before it occurs, reading labels, being aware of their surroundings, and advocating for themselves (shown in data, as well as Fenton, et al, 2011; 2013). The Quality of Life (QoL) research has shown that children at risk of anaphylaxis are negatively affected by restrictions and disruptions of social activities and interactions (Kastner, Harada & Waserman, 2010). In this research, the data also reveals disruptions in students' involvement in social interactions while trying to adapt and integrate themselves back into social events by finding ways they can move around these restrictions or disruptions while still keeping themselves safe (for example, being more aware of their surroundings so others can eat allergens). These students balance the need for social inclusion with the need to protect themselves against allergens. Social context is an important consideration, with the networks of children and youth being shown to affect and contribute to their psychological well-being (Morrison & Peterson, 2013)

This research reinforces the need to acknowledge that anaphylactic student safety extends beyond responses to anaphylactic reactions. Anaphylaxis is a *life* experience, and safety within it cannot be boiled down only to emergency preparedness. By focusing on just the reaction, it removes the emotional and social needs of anaphylactic students

## Anaphylaxis Management- Emergency Preparedness vs. Anaphylaxis Prevention

The results of this study reveal that within the ruling relations, anaphylaxis management is divided, unintentionally and without acknowledgement, into two separate concepts:

Emergency Preparedness and Anaphylaxis Prevention. These two concepts are distinctly different, however they are both grouped under the term "anaphylaxis management", and this research shows that Emergency Preparedness overshadows Anaphylaxis Prevention.

This focus on Emergency Preparedness is understandable. Anaphylactic reactions are scary and unpredictable. School personnel act as surrogate parents for a portion of the day, with the majority having little personal experience with anaphylactic allergies. For these individuals, being able to respond to an allergic reaction and to potentially save the child they are responsible for is understandably the first most important thing to know. Emergency preparedness is also simple and straightforward - knowing how to inject an auto-injector, calling 911, and staying with the child. Emergency Preparedness can and has become routinized within the school systems through the ruling relations.

In comparison, Anaphylaxis Prevention is messy, changes over time, and is adaptive within the context of different environments and experiences. The transition of responsibilities around Anaphylaxis Prevention from parent to child is also a gradual process (Akenson, Worth & Sheikh, 2007). Within these findings, the different experiences that anaphylactic students had affected how they managed their allergies day to day. Students expressed the desire for different levels of involvement from schools, with some preferring more involvement in anaphylaxis management, and others feeling confident in their own abilities to self-manage. These are aspects of life that are difficult to include in institutional processes. Yet, Anaphylaxis Prevention is an individual experience happening within a routinized system, a system that says it has processes

in place for anaphylaxis management. However, this research suggests that the primary focus of the school environment is on Emergency Preparedness, making visible a disconnect between the focus of the ruling relations (Emergency Preparedness) and the student (Anaphylaxis Prevention).

Furthermore, the work done by the Schools to try and incorporate Anaphylaxis Prevention is thwarted by the focus of the ruling relations. The standardized text created by the Boss Text and ruling relations continues to focus on Emergency Preparedness, removing the everyday experience of the anaphylactic student. Because of this, even when Schools try to incorporate Anaphylaxis Prevention into how they assist in the management of anaphylaxis, the textually based institutional processes created by these coordinating actions refocus these processes back onto Emergency Preparedness. If action is taken outside of these institutional processes, such as the work of the Vice Principal (School 1) in creating safe areas for students, we can see Anaphylaxis Prevention happening. However, if the actions are attached to institutional processes and the text created by the Boss Text and ruling relations, Emergency Preparedness becomes the primary focus. For example, this can be seen in the formation of the Health Binder in School 1. The health binder was originally intended as a resource on anaphylactic allergies for the Vice-Principal in her School, which could involve both Anaphylaxis Prevention and Emergency Preparedness. By using the Critical Medical Alert forms created by the Boss Text, which has a focus on Emergency Preparedness, the binder became a storage place for information on students' reactions, not their allergies or the life around them. The focus shifted to Emergency Preparedness by utilizing the text created within the ruling relations and by the Boss Text (the SBAP).

These findings showed that staff members within Schools are looking up for information to use in their local environments. They are looking up into the institutional processes and the ruling relations to determine what should be done at the School Board and School levels. The work done by Staff members is dependent on and shaped by Boss Text that create anaphylactic students and families as passive participants within school environments, preventing anaphylactic families' input in managing their allergies within schools. This leaves families separated from the institutional processes that occur around them. This work makes visible the separation, a disconnect, between the ruling relations and schools that create the institutional processes around anaphylaxis management, and the students and families who are knowledgeable about these allergies and who need to move through the 'coordinated' environments.

## The Incorporation of Anaphylaxis Prevention into the Institutional Processes

With individual management being so personal, this begs the question - can Anaphylaxis Prevention be incorporated into this routinized system? The short answer is yes, but carefully. Anaphylaxis Prevention and all the messy life experiences that go along with it must be incorporated into school anaphylaxis management in a way where they don't become routinized. The work done in schools around Anaphylaxis Prevention must not only involve reducing the risk of allergen exposure, but must also acknowledge the different experience of anaphylaxis management. There needs to be an understanding that students will experience different amounts of work as they navigate through the day to day life of school, and will need different levels of assistance and support. To do this, I suggest *not* including Anaphylaxis Prevention into the upper levels of the ruling relations and Boss Text such as Sabrina's Law. The findings from this research showed that the institutional processes from Sabrina's Law that were incorporated into

the school environment, for example, training, became highly routinized. The higher we move through the ruling relations, the more routinized the institutional processes it creates, appear on the ground. This can be seen in Figure 24, with the Boss Text furthest from the students (Sabrina's Law) having the most routinized institutional processes. Within these findings, it has been shown that the routinizing actions of the upper ruling relations is beneficial for Emergency Preparedness, with all staff members being trained to use auto-injectors and information on anaphylactic allergies being collected at registration. However, Anaphylaxis Prevention has not, and cannot be routinized in this way since it is such a personal experience. Daily management strategies need to be incorporated within the ruling relations in a place closer to the everyday experience of anaphylaxis management. Instead, students and families should able to speak about their allergies and their experiences of managing them in schools (map in Figure 25). In such a circumstance, both the knowledge and needs of the anaphylactic student can be incorporated back into the school system, which is beneficial for both schools and students. By schools utilizing the knowledge of anaphylactic students and families, this will provide them with a clearer picture of how anaphylaxis management occurs in the lives of people with anaphylactic allergies, better preparing them to assist in managing these allergies in schools. For students, this will allow them to speak about what they actually need for anaphylaxis management, and create a space where they can advocate for themselves. This will also bring the anaphylactic student into the institutional process that had happened around them previously, allowing them to see and involving them in the work being done around anaphylaxis management within their schools, work that directly affects their day to day lives

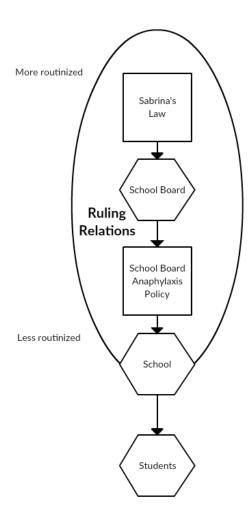


Figure 24: Present coordinating actions of ruling relations

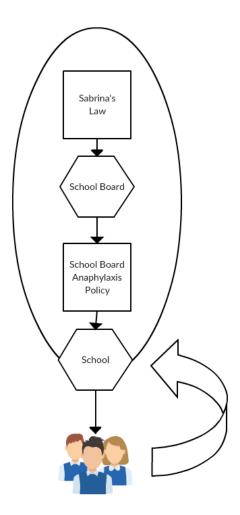


Figure 25: Incorporating of Anaphylaxis Prevention and Students into anaphylaxis management in schools

By incorporating students into the institutional processes of anaphylaxis management, this can help create a space where conversations about student anaphylaxis management needs between parent/guardians/students and a staff member (for example, a guidance counselor) can happen. A "point person" within the school will enable students and families to speak about their needs and allow for more open communication about the support a student feels they need from the school. While some may feel confident with their allergies and not need support from the school, others may appreciate a "safety net".

Another option for integrating student knowledge back into the institutional processes is through the development of student advocates. These students could create a bridge between the everyday experience of anaphylactic allergies and the school systems they move through. Not only would they be able to share their own knowledge and experience of anaphylactic allergies with schools, but could become a voice for other students who do not feel comfortable speaking up for themselves.

#### **Further Recommendations**

Having the ruling relations and the Boss Text coordinate the everyday does have a positive effect that can create safer environments for those directly affected by it. Through these coordinating actions, schools have implemented training for staff on how to use auto-injectors, information is collected from students about their allergies, and staff are made aware of these allergies through textual means. These institutional processes, while mostly working in the background, do create an awareness of anaphylactic allergies and prepare staff members in the event of an emergency.

However, if there is too much room for interpretation, the positive effects of the Boss

Text and ruling relations can be prevented from coordinating the everyday in a beneficial way.

Dead-end processes are where there is text that must be formed or used without information on who is to be involved or what the processes around the text are to include. This lack if information can lead to confusion or the complete removal of the text from the institutional processes put in place at the school level. For example, the intent of School Anaphylactic

Management Plan is to reduce the risk of anaphylaxis, however there is no information provided on its formation or its use. In this study, Plans were not created at the school level, thus the

positive intent of the Plan was lost. Completing these institutional processes within the Boss Text and providing schools the information they need may help in continuing the movement of these institutional processes from their development within the ruling relations to their implementation within the local environment.

Based on the results of this study and in line with the more traditional approach to IE, recommendations have been developed for future investigation. The following recommendations are put forth for Sabrina's Law, the SBAP, and the School environments to help create institutional processes that may assist adolescents in the managing of their allergies in schools.

## Recommendations- Sabrina's Law

As was discussed previously, institutional processes created within Sabrina's Law become routinized in the school environment. Since it is legislated text that applies to every publicly funded School Board and school in Ontario, these processes must also be feasible within all of these environments. Based on my research, one recommendation for Sabrina's Law is identified; the inclusion of more information on what must be included in staff training. At this time, schools focus on how to use an auto-injector and how to respond in an emergency. While this is an important step in Emergency Preparedness, it does not help staff members in assisting in preventing or identifying a reaction. As such, I suggest that mandatory training contains three main topics:

- 1. Prevention strategies (handwashing, removing allergens from surfaces using soap and water, avoiding food sharing).
- 2. Symptoms of anaphylaxis and how to recognize a reaction.
- 3. How to inject an auto-injector, and appropriate emergency response.

Training on these specific topics may ensure that all staff members have basic knowledge in not only the emergency treatment of anaphylaxis, but also provide them the knowledge, experience and skills they need to prevent the spread of allergens and to recognize an anaphylactic reaction if one occurs. Within this research, we can see that institutional processes created by Sabrina's Law become routinized within school systems (training on auto-injector use, collection of information and identification of students). Because of this approach, Sabrina's Law creates a place where the information provided in training can be coordinated across the province, with all teachers receiving essential information on anaphylaxis management as a whole.

Despite the earlier critique of the legislation as not providing enough information about risk reduction strategies and communication plans, I do not recommend the development of specific plans and strategies within Sabrina's Law. The types of risk reduction strategies and communication plans that will be feasible and accepted in different School Boards and within schools depend greatly on the individual environments. Different age groups, types and severities of allergies, and the receptiveness of both staff and parents all determine the effectiveness of different strategies. Since institutional processes put in place by Sabrina's Law become routinized and coordinated across institutions, it is not feasible to provide specific information on risk reduction strategies and communications plans that will be feasible in every environment it coordinates across.

Recommendations- School Board Anaphylaxis Policy

The first recommendation for the SBAP is to complete the work-text-work processes within the policy. At this point, the text creates partial institutional processes, without providing

the reader the information they need to complete them. Every piece of text, every Plan, every File should have clear information on:

- 1. What information or text is to be included
- 2. Who is responsible for creating or completing the text/action
- 3. What it should be used for

Having a Plan or File mentioned once as being something important for the school to develop (for example, the School Anaphylactic Management Plan), and never mentioned again, has the ability to create an unsafe environment for adolescents, with institutional processes being partly implemented or not implemented at all at the local level. Related to this is to correct the discrepancies across the policy in language use. SBAP should be reviewed, and the language used to describe different forms, Plans and Files should be made consistent to prevent confusion for the reader. If it is unclear to the reader how an institutional process should be implemented or what text should be used because of differences in the language used, this could prevent its inclusion in the everyday experience, possibly creating an unsafe environment for adolescents.

The second recommendation that should be investigated is the utility of reducing redundancies across forms. At the school level, only one form is utilized to collect information from anaphylactic students and families, yet there are 5 forms provided by the SBAP. This could create an unsafe environment for adolescents, with single forms not collecting all the required information. Future investigation could investigate the utility of a single, stand-alone form that would provide the schools and staff members with the information they need. Requested information on this form could include

- 1. What the student is allergic to
- 2. Asthma status

- 3. The location of auto-injectors in the school (on student, in office, both)
- 4. Common signs and symptoms of that student's anaphylactic reactions
- 5. Recommended Immediate Emergency Response
- 6. Authorization for Administration of Epinephrine Injection
- 7. Emergency Contacts

By having a single, stand-alone form that all schools can utilize, this will ensure that all the information needed by the school is collected. The utility of creating one emergency management sheet should also be investigated. At this time, information on emergency management is scattered across the forms provided by the SBAP, with different groups receiving different amounts of information. I suggest the formation of a single emergency management sheet which including:

- 1. All possible symptoms of an anaphylactic reaction
- 2. How to use an auto-injector
- 3. Appropriate emergency response

This recommendation would assist in the development of an emergency management sheet that could be usable by everyone in contact with any anaphylactic student, including staff members, supply teachers, bus drivers and transportation services. This will ensure that every person in contact with students will be able to act in the event of an emergency, instead of depending on information from others, as we saw with bus drivers being dependent on dispatch to provide further instructions.

The third recommendation for investigation focuses on risk reduction strategies. As I described in the recommendations for Sabrina's Law, risk reduction strategies are context specific, and what works in one school does not necessarily work in others. However, what I suggest for further investigation is the inclusion of a list of risk reduction strategies that schools

may use, as well as the situations or environments in which they may be useful. Types and severities of allergies can change over time, and there is a need for more acknowledgement of the dynamic nature of this experience, and appropriate risk reduction strategies for it. For example, food bans may be utilized in cases where there are severe allergies and/or younger children. However, for older students or when the allergies are not as severe, strategies around education, hand-washing and washing tables after eating may be more effective. Providing schools with different options for risk reduction may help schools reflect on their own environment and the students' needs within it to determine the risk reduction strategies that are most effective for them.

The fourth and final recommendation for future investigation centers around supply teacher training. Based on this study data, there is a gap in Emergency Preparedness in schools, with supply teachers not receiving anaphylaxis training. Based on policy analysis and data, we learned that supply teachers work within a School Board, and not at specific schools. School Boards mandate that schools run anaphylaxis training for all staff members. With supply teachers not being attached to a specific school, they fall through the cracks between the two institutions, not receiving the training they need around anaphylaxis management. This has also been reported in the literature, with one Casual Relief Teacher (supply teacher) explaining that they do not receive professional development since they are not affiliated with a specific school (Eastwood & Cutter-Mackenzie, 2010). In my research, anaphylactic students felt that they could not depend on a supply teacher in the same way they do their regular teacher, despite the students being unaware of this disconnect and the institutional processes behind it. In response, students were forced to take on more responsibilities and added work for managing their allergies in response to supply teachers. What a supply teacher suggested is the inclusion of anaphylaxis

education run as mandatory modules by the School Board. Providing information on anaphylactic allergies through yearly mandatory modules could ensure that all staff members of the Board, including supply teachers, receive the information they need to respond in the event of an emergency.

### Recommendations- School Environment

Outside of creating a conversation between parents/guardians/students and staff about the needs of the student, I have two further suggestions for investigation at the school Level, both centered around communication. The first recommendation is that there be clearer communication between staff members about what an individual's role is, why they have that responsibility, and if they have the tools and knowledge to perform the role. These research results found two separate situations where an individual was either unaware or unsure of why they had specific responsibilities in regards to anaphylaxis management. This circumstance creates a gap in how anaphylaxis management occurs within schools, possibly leaving students at risk of serious consequences. I suggest that there be more open conversation about the importance of different roles within school anaphylaxis management, the reasoning behind their assignment, and discussion around the skills needed to take on that responsibility. The broken connections across schools need to be re-connected and conversations opened, allowing school staff to be knowledgeable, confident, and ready for any situation around anaphylactic allergies in schools.

The second recommendation centers around communication with parents, guardians and students. In this study, anaphylactic students and their families are interacting within a system that they are unfamiliar with. They do not know what happens within the school around anaphylaxis management, yet their life depends on their own abilities to manage their allergies in

schools. Thus, further investigation needs to be focused on the utility of having an open house at the school, allowing families to come in and learn about the institutional processes in place and the work of the school around anaphylaxis management.

## The Importance of Connections Across Local Environments and Ruling Relations

The idea of "legal teeth" has been discussed previously in literature, with the suggestion that despite schools and School Boards having a legal mandate to implement Sabrina's Law and SBAP, without resources for implementation or a governing body responsible for monitoring and enforcing compliance, we will not see desired improvements (Cicutto, et al., 2012). However, with a growing number of complaints towards schools around anaphylaxis management, it is vital that School Boards and schools not only follow Sabrina's Law and their SBAP, but are knowledgeable about their responsibilities around anaphylaxis management.

This issue is highlighted in the Human Rights Case for Elodie Glover, who has severe egg and dairy allergies. Her mother, Ms. Glover, filed the complaint with the Humans Rights Tribunal, saying that her daughter had been discriminated towards by how school officials handled her allergies. She also explained that the school was not following its own School Board Policy by not putting together an individual emergency anaphylaxis plan, despite having all the required paperwork (Carter, 2014). She explained that the school had been "winging it all along, but she wanted an accommodation plan to actually plan out what would be appropriate" (Bennett, ND). While the school did have an Anaphylaxis Plan for Elodie, it only said she had allergies, exercise-induced asthma, and listed the steps that should be taken in an emergency (Bennett, ND).

The consensus among the parents is there is nothing in place to properly guide schools to make appropriate choices when handling children with anaphylaxis, she [Ms. Glover] says. Every case is unique, but she says their needs aren't being met on an individual basis (Escott, 2014)

Within this situation, the School had emergency measures in place in the event of a reaction, but the Human Rights case was put forward for two main reasons. First, the prevention side of anaphylaxis management was not being properly addressed. This highlights the importance of incorporating Anaphylaxis Prevention and daily management back into anaphylaxis management in schools. Second, the School was not following the School Board policy. This highlights the need for more connections across institutions (government, School Board and schools) and the text created by them. Schools are responsible for the actions put in place by the School Board Policies, and there is a need for these actions to be understandable, implementable, and feasible for the different environments within schools.

## **Addressing the Research Questions**

Through this research, I have been able to show that translocal forces such as the School Board Anaphylaxis Policy and Sabrina's Law have an effect on students' experience through the environment they interact in. While students' and families are hooked into the institutional processes through text, they are unaware of the work being done around them within Schools. The majority of institutional processes created by the Boss Text have become "filing cabinet" processes, occurring around anaphylactic students without interacting with them.

Through the mapping and analysis of the Boss Text and local environment, we can see the movement of institutional processes from their formation in the translocal and in the text, to their implementation in the everyday experience. However, we can also see with the movement through the translocal down to the local, parts of the text are lost, unclear, or not implemented.

We can also see that Anaphylaxis Management has been split into two separate concepts: Emergency Preparedness and Anaphylaxis Prevention. Emergency Preparedness becomes the main focus of the Boss Text, and because of this, the institutional processes put in place within school systems. This is a disjuncture from the focus of students with anaphylaxis, who's focus is on the day-to-day management, or Anaphylaxis Prevention.

Utilizing IE within this research has been beneficial for a number of reasons, the first being that it allowed me to connect the legislative and translocal environment to the everyday, which I believe is essential for research such as this. Anaphylaxis management does not happen in a bubble, and students managing their allergies happens within the environment that is controlled by the legislation, as much as the legislation occurs in environments with real people managing their allergies in very personal and different ways. I suggest that while it is beneficial to look at either separately, it is as important to consider the two together and to understand how the work of both happens in the local and translocal environments.

An IE approach has also allowed me to visualize the "bottle necks" throughout the institutional processes. For example, having the Boss Text and the text it creates focus on Emergency Preparedness pushes all institutional processes in the local environment to share in this focus. Another example is that in the visualization of the Boss Text and School environment, we were able to see that each level affects the next level directly below it, and no further. So Sabrina's Law affects the School Board Anaphylaxis Policy, which affects the School environment, which affects the students. If there is a level or text that does not include an

institutional process set up by the Boss Text before it, the institutional processes are effectively lost, unable to reach the student. Because of this, there is a need for everything within the process to work coherently together so that the positive effects can continue to work down to reach the student.

IE is a powerful and useful methodology for developing an understanding of the unseen forces that shape and affect the everyday experience of anaphylactic students in different settings, as it helps to understand how the everyday came to be, and to explicate the forces that, while unseen and usually unknown, shape and coordinate these experiences.

## Limitations

As with all studies to date, and all studies to come, this research does have its limitations. The first being the issues around access to individuals. In School 2, they invited me in on one of the last days of the school year, a month before the retirement of the Vice-Principal I had been in contact with (which I did not know till the day of). Because of this, I was unable to speak with a number of staff members within the School, as they were too busy with final exams and assisting students prepare for graduation. I was left on my own for the majority of my time at the School, to find staff members as I was able to. However, I took advantage of my given "free-rein" by exploring the School, examining the text and posters I could find around anaphylaxis, and to speak with whoever crossed my path. Through my wandering, I found myself in the staff room, having an impromptu conversation with three teachers that provided me valuable information about teachers views on anaphylaxis management that I feel would not have come up in a one-on-one interview. Despite me being limited in who I spoke to, I took full advantage of the opportunity to find different viewpoints within the school.

Another limitation focuses around the acknowledgement that this research occurred within one School Board, and in two Schools. I do not pretend that the findings at the local level are representative of the larger populations. However, with IE one of the key characteristics is the explication of translocal forces, or forces that occur *outside of the local* and coordinate *across environments*. While the specific findings from students' experience or even school level processes may not be representative of the entire populations, the translocal findings may be extended beyond this research to other environments. The importance of specific training inclusions in Sabrina's Law, the consideration of the split between Anaphylaxis Prevention and Emergency Preparedness, and the importance of having each level within the translocal and local environments work cohesively together and not create bottle necks for institutional processes are all findings that are applicable across institutions, because they are findings from the forces that coordinate across different environments.

The final limitation is of the researcher, with me being new to IE and (relatively) new to qualitative research. IE is not an easy sociology or methodology to understand, though I do not claim that there is every an "easy" methodology. As I touched on in "The Researcher's Role in IE," there is a need to untangle everything, the concepts and theoretical underpinnings of the sociology, the movement to a methodology, my ideas and thoughts behind this project, qualitative research, and research in general. Taking on an IE project for a Master's thesis was probably more than I could chew comfortably. However, instead of seeing this as a limitation of myself, I took this as an opportunity to overcome a challenge, and a place for me to grow. I took advantage of the resources I had (reading every book I could borrow or buy) and the knowledge of the people around me, so willing to help me puzzle out difficult concepts that they had struggled through already. While I am not willing to say I am an expert in IE, I can certainly say

I feel more confident with it now than I ever thought was possible when I first tried to read Dorothy Smith's work.

## **Strengths**

One of the strengths of this research is that it looks at anaphylaxis management in a completely different way as compared to previous literature. Using IE as a methodology makes visible the work and text within the translocal, which is most often unseen and unquestioned, yet essential for coordinating the activities of those in the everyday. Showing how knowledge moves through institutional processes to action allows the disjunctures in school-based anaphylaxis to be exposed, highlighted, and identified for further investigation. Spanning across all levels of anaphylaxis management in schools also provides direction for future research across Boss Text, institutional processes and local levels.

Another strength of this research is that it acknowledges that the experience of anaphylaxis management does not occur in a bubble, separate from all other forces. While other studies have focused on understanding the experience of anaphylaxis management, this study looked at how this experience is shaped by the translocal forces. Change will not be as effective if the institutional processes surrounding the experience are not accepting of or fight against the change. It is through the acknowledgement and understanding of these outside forces that effective change can be made.

# My Journey through IE

My experience with IE was not always a positive one. Throughout this journey, there were many times where I felt frustrated and fed up, wishing I had gone into epidemiology instead (numbers I understand). I constantly struggled trying to read and understand the

theoretical writing of Dorothy Smith and other IE investigators. I couldn't just learn about IE, but also had to familiarize myself with the sociology that it fought against and the theoretical work it was built on, so I could understand why IE was so different. When I finally began feeling slightly comfortable with the theoretical side of IE, I realized that there was a lack of information on how to actually *do* an IE inquiry. The methods section of IE research papers seemed either too vague or too theoretical for me to understand what was done. It was only through Campbell and Gregor's primer on IE and the amazing assistance of Nancy Novak that this research was even completed.

However, through the struggles and frustration, I would have moments of sheer amazement at what I was doing and what IE could show. When I started seeing the disjuncture as I moved through the ruling relations, and started understanding how little these institutional processes actually affect students, I began feeling like I was doing something that could actually help. My hope is that the findings from this research will be used to continue working towards a safe and inclusive environment for anaphylactic students in schools.

I also hope that by opening up about the struggles I had wrapping my head around IE, it will help other researchers not feel alone in this same experience. Struggling to understand IE is not a weakness, but a sign of strength, because you haven't put the book down yet. IE is truly an amazing way of looking at the world, and having the perseverance to struggle through it shows a dedication to creating lasting change.

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# **Appendices**

# **Appendix A: Provincial Responses**

Table 2: Provincial responses towards anaphylaxis

Province	Leading Group	Document	Notes	Reference
Alberta	Alberta School Boards Association	Policy Advisory: Anaphylaxis	Provides recommendations for policy formation and recommended elements, voluntary	Alberta School Board Association (n.d.)
Manitoba	The Legislative Assembly of Manitoba	The Public Schools Amendment Act	Requires that each school board have an anaphylaxis policy in place to meet the needs of students, but does not give any further instructions	Bill 232, 2008
New Brunswick	New Brunswick Department of Education and Early Childhood Development	Extreme Allergy Management and Emergency Plan	Provides a management plan outline, but no further information on its use	Extreme Allergy Management and Emergency Plan, 2008
	New Brunswick Department of Education	Health Support Service Policy	Requires the provision of health support services, for students with anaphylactic reactions this includes management plans, allergen limitation, medical management and training for staff	Policy 704, 2008
Prince Edward Island	Department of Education & Department of Health	Information Handbook on Anaphylaxis	Provides guidance for procedures and policies, as well as includes information on symptoms, management and responsibilities of involved parties	Information Handbook on Anaphylaxis, 2006
British Columbia	Ministry of Education	Anaphylaxis and Child Safety Framework	Provides guidance on the management and prevention of anaphylaxis and in policy formation for school boards  Legislation requiring all	Anaphylaxis and Child Safety Framework, 2007 Anaphylaxis

		Protection Order	school boards to develop and implement anaphylaxis policies	Protection Order, 2007
Nova Scotia	Ministry of Education	Policy Directives and Guidelines	States that schools should work with parents to ensure staff are aware of food allergies and how to support children, but no further direction	Policy Directory and Guidelines, 2006
	Ministry of Education and Ministry of Health Promotion	Food and Nutrition Policy for Nova Scotia Schools	States that schools should work with parents to ensure staff are aware of food allergies and how to support children, parents are responsible for notifying the schools and make informed decisions on food. Directs readers to school board specific guidelines, no further direction	Food and Nutrition Policy for Nova Scotia, 2005
Saskatchewan			No policies or guidelines in place at this time. In 2013, the Saskatchewan School Board Association resolved to develop appropriate policies and procedures for students and staff with anaphylaxis	Media Releases, 2013
Newfoundland and Labrador	Department of Health and Community Services	Standards and Guidelines for Health in Child Care Settings	Provides information on the difference between food allergies and food intolerances, common allergens, symptoms, and strategies for management of food allergies in child care	Standards and Guidelines for Health in Child Care Settings, 2005
Quebec			Each school board and regional child care setting are responsible for developing and maintaining anaphylaxis protocol	Charlton, 2013
Yukon	Yukon Education	Anaphylaxis Policy	Provides definitions involving anaphylaxis, standards and procedures	Anaphylaxis Policy, 2012

	to follow in the event of a reaction, as well as roles and responsibilities of parents and administrators	
Northwest Territories	No provincial/territorial policies involving anaphylaxis	Boye & Godefroy, 2011
Nunavut	No provincial/territorial policies involving anaphylaxis	Boye & Godefroy, 2011

# **Appendix B: Interview Guides**

Table 3: Interview Questions (Anaphylactic Adolescents)

Question	Prompt		
Could you tell me about yourself?	Age		
	School		
	Grade		
Are you allergic to anything?	Specific Allergen		
	Reaction		
	How long have you had this allergy?		
Have you ever had a reaction?	Do you remember it?		
Have you ever had a reaction at school?	If yes- what happened		
	If no- what happen if a reaction did occur at		
	school?		
Could you tell me about an average day at	Do you have to do anything special before		
school for you?	eating or sitting at a desk?		
	How do you feel during your day?		
	Could you tell me more about how you		
	manage your allergies?		
Is managing allergies different at school	How so?		
compared to at home?			
Where did you learn about how to manage	Parents		
your allergies in school?	Doctors		
	Books/other text		

Table 4: Interview Questions (Parents of Anaphylactic Adolescents)

What are the ages of your child(ren) with	How long have they had these allergies?		
anaphylactic allergies?	When was their initial reaction? To what		
When they were first diagnosed with	People, text		
anaphylaxis, how did you learn about			
managing these allergies?			
When they first started going to school, how	Did they have policies in place to help manage		
did you share this information with school	allergies?		
personnel?	Did they provide you with information?		
What about when your child(ren) went to high	How was this different than elementary		
school?	school?		
	Did you still provide information?		
	Did the school have policies in place?		

How did you help prepare your child(ren) for	Did you get information or suggestions from		
managing their allergies in high school?	somewhere or someone? (people and		
	documents)		
What level of involvement is there now for you	Do you still pack their lunch? Do you remind		
in helping manage your child(ren)'s allergies in	them to carry their epi-pen?		
school?			
Are you familiar with Sabrina's Law? School	If yes- could you tell me about what these say?		
board policies?	If no- what sort of information do you think		
	should be included?		
If you met a parent, who had a high school age			
child, and they were just diagnosed with			
anaphylaxis, what information or suggestions			
would you give them?			

Table 5: Interview Questions (Key Informants)

Question	Prompt		
What is your position in the school?	How long have you worked there?		
If there was an anaphylactic student in the	What are your responsibilities?		
school, what would your relationship be with			
them?			
From where did you learn of these	Principal, other teachers, text?		
responsibilities?			
If you had a student with anaphylaxis, how	How would you help them manage their		
would that change what you did (in specific	allergies?		
environment)?			

# **Appendix C: Student Information**

Name: Meghan (sister of Kurtis)

Parent: Rebecca

Age/Grade: 14 years old, Grade 9

School: School 1

Allergies: Peanuts, tree nuts (not almonds), fish, sesame Extracurricular activities: Tennis team, art, Pathfinders

Past reactions: Remembers past reactions (sesame allergy diagnosed a few years ago)

Name: Kurtis (brother of Meghan)

Parent: Rebecca Age/Grade: Grade 11 School: School 1

Allergies: Peanuts, nuts (except almonds)

Extracurricular activities: Tennis through school, hockey and soccer outside of school, co-op

Past reactions: Remembers past reactions, had reaction within last few years

Name: Katherine Parent: Vera

Age/Grade: 15 years old, Grade 10

School: School 1

Allergies: Peanuts and most tree nuts, eggs

Extracurricular activities: Orientation group at school, photography

Past reactions: Does not remember past reactions

Name: Akash Parent: Mrs Nadvi

Age/Grade: 15 years old, Grade 10

School: School 1

Allergies: Peanuts and nuts, seasonal allergies

Extracurricular activities: Basketball (at recess, no organized sports) Past reactions: Remembers past reactions (when he was younger)

Name: Vanessa Parent: Sheri

Age/Grade: 16 years old, grade 11

School: School 2

Allergies: Peanuts and most tree nuts

Extracurricular activities: Enjoys arts and sciences

Past reactions: Does not remember past reactions (last one was when she was much younger)

Name: Bernardo Parent: Isabela

Age/Grade: Grade 10 School: School 2

Allergies: Shellfish, dust

Extracurricular activities: Basketball and football (for a small period of time)

Past reactions: Remembers reaction (only one, at time of diagnosis two years ago)

## Appendix D: Sabrina's Law

## Sabrina's Law, 2005

S.O. 2005, CHAPTER 7

## Consolidation Period: From January 1, 2006 to the e-Laws currency date.

No amendments.

#### **Definitions**

1. (1) In this Act,

"anaphylaxis" means a severe systemic allergic reaction which can be fatal, resulting in circulatory collapse or shock, and "anaphylactic" has a corresponding meaning; ("anaphylaxie", "anaphylactique")

"board" means a district school board or a school authority; ("conseil")

"consent" means consent given by an individual with the capacity to provide consent to treatment for the purposes of the *Health Care Consent Act, 1996*; ("consentement")

"employee" means an employee of a board who regularly works at the school, in the case of a school operated by the board. ("employé") 2005, c. 7, s. 1 (1).

### Expressions related to education

(2) Expressions in this Act related to education have the same meaning as in the Education Act, unless the context requires otherwise. 2005, c. 7, s. 1 (2).

## Establishment of policy

2. (1) Every board shall establish and maintain an anaphylactic policy in accordance with this section. 2005, c. 7, s. 2 (1).

#### Contents of anaphylactic policy

- (2) The anaphylactic policy shall include the following:
  - 1. Strategies that reduce the risk of exposure to anaphylactic causative agents in classrooms and common school areas.
  - 2. A communication plan for the dissemination of information on life-threatening allergies to parents, pupils and employees.
  - 3. Regular training on dealing with life-threatening allergies for all employees and others who are in direct contact with pupils on a regular basis.
  - 4. A requirement that every school principal develop an individual plan for each pupil who has an anaphylactic allergy.
  - 5. A requirement that every school principal ensure that, upon registration, parents, guardians and pupils shall be asked to supply information on life-threatening allergies.
  - 6. A requirement that every school principal maintain a file for each anaphylactic pupil of current treatment and other information, including a copy of any prescriptions and instructions from the pupil's physician or nurse and a current emergency contact list. 2005, c. 7, s. 2 (2).

### Contents of individual plan

(3) An individual plan for a pupil with an anaphylactic allergy shall be consistent with the board's policy and shall include:

- 1. Details informing employees and others who are in direct contact with the pupil on a regular basis of the type of allergy, monitoring and avoidance strategies and appropriate treatment.
- 2. A readily accessible emergency procedure for the pupil, including emergency contact information.
- 3. Storage for epinephrine auto-injectors, where necessary. 2005, c. 7, s. 2 (3).

#### Administration of medication

3. (1) Employees may be preauthorized to administer medication or supervise a pupil while he or she takes medication in response to an anaphylactic reaction, if the school has up-to-date treatment information and the consent of the parent, guardian or pupil, as applicable. 2005, c. 7, s. 3 (1).

#### Obligation to keep school informed

(2) It is the obligation of the pupil's parent or guardian and the pupil to ensure that the information in the pupil's file is kept up-to-date with the medication that the pupil is taking. 2005, c. 7, s. 3 (2).

### Emergency administration of medication

(3) If an employee has reason to believe that a pupil is experiencing an anaphylactic reaction, the employee may administer an epinephrine auto-injector or other medication prescribed to the pupil for the treatment of an anaphylactic reaction, even if there is no preauthorization to do so under subsection (1). 2005, c. 7, s. 3 (3).

#### **Immunity**

(4) No action for damages shall be instituted respecting any act done in good faith or for any neglect or default in good faith in response to an anaphylactic reaction in accordance with this Act, unless the damages are the result of an employee's gross negligence. 2005, c. 7, s. 3 (4).

#### Common law preserved

- (5) This section does not affect or in any way interfere with the duties any person may have under common law. 2005, c. 7, s. 3 (5).
  - 4. Omitted (provides for coming into force of provisions of this Act). 2005, c. 7, s. 4.
  - 5. Omitted (enacts short title of this Act). 2005, c. 7, s. 5.

# **Appendix E: School Board Anaphylaxis Policy**

# **Anaphylaxis Policy**

DATE OF ISSUE: July 2003

Revised: November 1, 2005, October 15, 2012, May 2014 consolidated with August 2015

MEMO TO: All Staff

FROM: Director of Education

#### **PURPOSE**

In accordance with Sabrina's Law, 2005 – An Act to Protect Anaphylactic Pupils, it is the policy of the School Board to establish and maintain a policy for students diagnosed with anaphylactic allergies.

## REFERENCES

- . Bill 3, Sabrina's Law, 2005 An Act to Protect Anaphylactic Pupils
- · Education Act and Regulations
- OPHEA Guidelines
- Anaphylaxis Canada
- · Asthma Society of Canada
- Canadian Society of Allergy and Clinical Immunology
- · Canadian Allergy, Asthma and Immunology Foundation

### **FORMS**

- 01 Critical Medical Alert Form
- 02 Anaphylactic Allergy Individual Emergency Plan Title Page
- 03 Administration of Medication: Epinephrine
- 04 Anaphylaxis Emergency Plan
- 05 Anaphylaxis Alert Fanny Pack Information Card
- 06 Epinephrine by Injection Transportation Information
- 07 Notice of Intent Regarding Painting and Carpeting

#### APPENDICES

- Appendix A How to Use an EpiPen® and EpiPen Jr.® Auto-injectors
- Appendix B How to Use an Allerject ™
- Appendix C Annual Anaphylaxis Procedures Checklist
- · Appendix D Sample Letter from Teacher/Principal
- · Appendix E Sample Letters from Principal

#### COMMENTS AND GUIDELINES

#### BACKGROUND

#### A. Anaphylaxis - What is it?

Anaphylaxis is a serious allergic reaction that is rapid in onset and may cause death. While fatalities are rare, anaphylaxis must always be considered a medical emergency requiring immediate treatment. Signs and symptoms of a severe allergic reaction can occur within minutes of exposure to an allergen (a substance capable of causing an allergic reaction). In rarer cases, the time frame can vary up to several hours after exposure. The most common allergens include certain foods and insect stings. Less common causes include medications, latex, and exercise. Symptoms of anaphylaxis generally include one or more of these four body systems: skin, respiratory, gastrointestinal and/or cardiovascular. Breathing difficulties and low blood pressure are the most dangerous symptoms and both can lead to death if untreated. Anaphylaxis is an unpredictable condition as signs and symptoms can vary from one person to the next and from one episode to another in the same person.

Epinephrine is the first line treatment for anaphylaxis. This life-saving medication helps to reverse the symptoms of a severe allergic reaction by opening the airways, improving blood pressure, and increasing the heart rate. It is recommended that epinephrine be given at the start of a known or suspected anaphylactic reaction. In normally healthy individuals, epinephrine will not cause harm if given unnecessarily.

There are currently two epinephrine auto-injectors available in Canada: EpiPen® and Allerject™.

There are six key recommendations in the emergency management of anaphylaxis, including:

- Epinephrine is the first line medication which should be used for the emergency management of a person having a potentially life-threatening allergic reaction.
- Antihistamines and asthma medications should not be used as first line treatment for an anaphylactic reaction.
- All individuals receiving emergency epinephrine must be transported to hospital immediately (ideally by ambulance) for evaluation and observation.
- Additional epinephrine should be available during transport to hospital. A second dose
  of epinephrine may be administered within 5 to 15 minutes after the first dose is given IF
  symptoms have not improved.
- Individuals with anaphylaxis who are feeling faint or dizzy because of impending shock should lie down unless they are vomiting or experiencing severe respiratory distress.
- No person experiencing anaphylaxis should be expected to be fully responsible for selfadministration of an epinephrine auto-injector.

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#### 1. What does an anaphylactic reaction look like?

An anaphylactic reaction can begin within seconds of exposure or after several hours. Any combination of the following symptoms may signal the onset of the reaction:

- Tingling in mouth
- · Hives, rash, itching
- Generalized flushing
- Swelling-eyes, ears, lips, face, tongue
- · Constriction in throat, mouth and chest
- Constriction in breathing, swallowing
- Wheezing, sneezing, coughing and choking
- Hoarseness
- · Vomiting, stomach upset, diarrhea
- Anxiety
- Light headedness
- · Loss of consciousness
- Coma and death

Hives may be entirely absent, especially in severe or near-fatal cases of anaphylaxis. Symptoms do not always occur in the same order, even in the same individuals. Time from onset of first symptoms to death can be as little as a few minutes if the reaction is not treated. Even when symptoms have subsided after initial treatment, they can return as much as 8 hours after exposure, regardless of the initial reaction severity.

#### 2. Reducing the Risk

Avoidance of a specific allergen is the cornerstone of management in preventing anaphylaxis. Research is underway to better understand anaphylaxis. At present, the severity of reactions cannot be predicted. Therefore, it is not possible to identify which patients are most at risk for severe allergic reactions. Until there is a cure, avoidance of the allergen(s) is the only way to prevent an anaphylactic reaction. Measures can be taken to reduce, but not completely eliminate, the risk of exposure.

Eliminating allergens from areas within the school where the anaphylactic child is likely to come into contact may be the only way to reduce risk to an acceptable level. The less allergen brought into the school the less risk of anaphylactic reactions. While schools cannot guarantee that an environment is completely safe, the School Anaphylactic Management Plan will include necessary measures and procedures to reduce the risk of anaphylactic reactions and assist staff in making the school as "allergen-free" as possible.

The greatest risk of exposure is in new situations, or when normal daily routines are interrupted such as supply teachers, shared birthday treats or school trips. Young students are at the greatest risk of accidental exposure but many allergists believe that more deaths occur among teenagers due to their increased independence, peer pressure, and reluctance to carry medication.

### B. Painting and Carpeting in Schools

The SB has a protocol for notification when painting and carpeting work is being considered at a site. At times when painting or carpeting work is being completed at schools or work sites, parents, students and staff should express concerns regarding individuals who are environmentally sensitive.

Painting and carpeting in schools and work sites procedures:

Principals/ Vice Principals, Senior Managers are requested to send notice of intent (Form APH005-

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- 07) to parents and staff at least one (1) week in advance of time when painting or carpeting installation is scheduled to occur at the school/worksite.
- Whenever possible, painting and carpeting installations will be scheduled during school breaks or summer vacation periods. However, this is not always possible.
- Special arrangements may have to be entered into between the Principal and parents of students who are deemed to be environmentally sensitive during the time scheduled for painting or carpet installations.

## C. RISK REDUCTION - ROLES AND RESPONSIBILITIES

Parent/Guardian (or Student where appropriate)				
Provide a letter from the physician, diagnosing the allergy/asthma and its severity.				
Complete the required forms "Medical Information and "Administration of Medication: EpiPen®/Allerject™ Injection				
It is recommended that parents/guardians provide two auto-injector EpiPens®/Allerject™; one to be kept with the student at all times, the second to be stored at the school according to the Emergency Plan. Renew EpiPens®/Allerject™ before the expiry date.				
Provide fanny pack/backpack for transport of EpiPen®/Allerject™ with student. It is recommended that a laminated card with important information be carried in the fanny pack with the EpiPen®Allerject.™				
Be sure your son/daughter wears a Medic-Alert® bracelet.				
Help your son/daughter develop coping skills to avoid the allergen and recognize and communicate the symptoms to an adult.				
hool Principal				
Use school registration/health forms to identify students who are anaphylactic and/or asthmatic.				
Ensure that parents/guardians complete all required school medical forms				
Convene a meeting with parents/guardians of the anaphylactic student, and appropriate school staff to develop an Anaphylactic Allergy Individual Plan which includes medical information related to the type and severity of allergy, past incidents of anaphylactic reactions, monitoring and avoidance strategies, appropriate treatment, and other health considerations.				
Each September, share and review anaphylactic procedures for the student with staff, supply staff, bus drivers, volunteers, and others having contact with the student. Ensure Bus Drivers are aware of the Epi-Pen®/Allerject™ and Asthma inhaler Emergency Transportation Information.				
Ensure that supply teachers are made aware of the Anaphylactic Allergy Individual Plan for students.				
Post Anaphylaxis Alert forms in the office, staff room, cafeteria, and other common areas and ensure that all staff could identify these students.				
Train the Emergency Response team to handle an anaphylactic reaction. Maintain an up-to-date list of school personnel who have received anaphylactic training.				
Ensure the EpiPens®/Allerject™ and Asthma inhalers are kept with the student as well as an additional one in safe and secure locations known to and accessible by all staff.				
Carefully review the safety plan for anaphylactic students prior to field trips. Discuss concerns				

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	with the School Superintendent as required.
_	Establish the anaphylactic student's classroom as an "allergen-free" area, using a co-operative approach with students and parents. In September, send a letter home with every student in the school requesting the school community avoid sending the allergen to school. When the school community recognizes the right of parents to feed their children whatever they choose, but acknowledges the right to life and safety as greater, most families are receptive to procedures that protect the allergic student.
	Ensure constant lunch supervision.
	Ensure that peanut/nut/allergy avoidance signs are prominently displayed at all school entrances and / around allergen-free classrooms. Signs will be provided through Student Services.
	Work with School Council to increase community awareness of anaphylaxis, its avoidance, and its treatment.
_	Ensure garbage containers are removed from doorways to reduce the risk of insect-induced anaphylaxis. Consider having students eat all food indoors during the time when bees and wasps are prominent.
_	School fundraising activities should avoid products containing the very allergens that parents are being asked to avoid sending with their children to school.
	Enforce disciplinary procedures for dealing with bullying and threats. (i.e. a student with a peanut butter cookie chasing an anaphylactic student).
_	Use the Anaphylaxis Procedure Checklist to conduct a yearly review of school procedures.
Cla	assroom Teacher (As age appropriate for the student)
_	Share and review anaphylaxis avoidance procedures with the anaphylactic student/ parents/guardians.
_	Ensure a letter is sent home to all parents informing them that there is an anaphylactic student in the classroom and explaining the need for an allergen-free classroom.
_	Send home a reminder letter before Halloween, Christmas and Easter asking parents to avoid sending treats to school containing the allergen.
_	Leave the Anaphylactic Allergy Individual Plan information, including a photo, regarding the anaphylactic student in an organized, prominent and accessible format for supply teachers.
	Conduct food safety discussions with all students at beginning of year and at regular intervals
	throughout the year while respecting the student's need for privacy.
_	throughout the year while respecting the student's need for privacy.  Stress the importance of not sharing lunches, snacks, utensils or containers. Reinforce hand washing before and after eating.
	Stress the importance of not sharing lunches, snacks, utensils or containers. Reinforce hand
_	Stress the importance of not sharing lunches, snacks, utensils or containers. Reinforce hand washing before and after eating.  Encourage/organize celebrations and activities that are not focused on food. Be aware of hidden
_	Stress the importance of not sharing lunches, snacks, utensils or containers. Reinforce hand washing before and after eating.  Encourage/organize celebrations and activities that are not focused on food. Be aware of hidden allergens in play dough, bean bags, counting aids, pet foods and bird seed etc.  Consistently communicate with the anaphylactic student/parents/guardians of special occasions

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Anaphylactic students should not be involved in garbage disposal, yard clean-ups, or other
activities that could bring them into contact with food wrappers, containers, or debris.

#### D. RISK REDUCTION - PEANUT BUTTER SUBSTITUTES

Board Policy states: "The CEO shall not cause or allow conditions, procedures, actions, or decisions that are unsafe or unhealthy". Since exposure to peanut butter and/or other nut-containing products could prove harmful or fatal to some students, peanut butter and all products containing nuts of any kind are not permitted in Schools.

Additionally, since school administrators, staff and volunteers are not food experts and are not qualified to decide what is (or isn't) real peanut butter, students arriving at school with a peanut butter substitute will be dealt with using the same protocol used for students who arrive at school with real peanut butter.

Despite its best efforts to limit the presence of nut-containing food products parents of anaphylactic children should be aware the School Board cannot and does not guarantee schools are allergen free.

#### E. EMERGENCY PLAN

Even when precautions are taken, an anaphylactic student may come into contact with an allergen while at school. It is essential that the school develops an emergency plan and involves all staff in appropriate training. A separate emergency plan, the Anaphylactic Allergy Individual Plan, should be developed for each anaphylactic student and will include:

- 1. Critical Medical Alert Form
- Administration of Medication: EpiPen®/Allerject™ Injection Consent
- 3. Medical Information
- 4. Fanny Pack Information Card
- An EpiPen®/Allerject™ Emergency Transportation Information
- Anaphylaxis Alert
- How to Use the EpiPen®/Allerject™ Auto-Injector

Fatalities are more likely to occur away from home, and are usually associated with delayed treatment or failure to treat with epinephrine. Those in positions of responsibility should never assume that the student will self-inject in the face of an emergency; a severe allergic reaction may be so incapacitating as to inhibit the ability to self-administer, regardless of age.

#### F. SABRINA'S LAW GRANTS IMMUNITY TO NON-HEALTH CARE STAFF

Anaphylactic students usually know when a reaction is taking place. School personnel should be encouraged to listen to the student. If it is suspected that the student has been exposed to an allergen and a suspected anaphylactic reaction is starting to take place, there should be no hesitation in administering the EpiPen®/Allerject.™ Sabrina's Law, 2005 "provides that no actions for damages shall be instituted respecting any act done in good faith or for any neglect or default in good faith in response to an anaphylactic reaction, unless the damages are the result of an employee's gross negligence." Accidental administration of the EpiPen®/Allerject™ is not a cause for concern, according to the Canadian Paediatric Society. There is little danger in reacting too quickly, and grave danger in reacting too slowly.

#### Review Process

This Administrative Procedures Memorandum will be reviewed not earlier than April 2017 and every three years thereafter.

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# Critical Medical Alert Form School Year

# To be completed for $\underline{\mathsf{HIGH}\;\mathsf{RISK}}$ medical conditions $\mathsf{ONLY}$

To be completed by Parent/Guardian					
Name of Student: Gr			Date of Birth:		
Home Address:			Home Teleph	ione:	
Dangerous, Life-Threatening Condition	ons:				
☐ Anaphylactic Allergies Trigge	ers (please specify)				
□ EpiPen®/Allerject™ (carried	d by student)	2nd EpiPe	en®/Allerject™ (k	ept in Main Office)	
☐ Asthmatic Triggers (please spe					
□ Inhaler (carried by student)		nt in Main (	Office)		
□ Diabetic □ Epileptic □ H	•	•	•	71117.08	
• •	emophinae B n	curt cond	ition 🗀 sci	Zures	
Other - Please specify					
Recommended Immediate Emergenc	y Response:				
Medication(s) Prescribed:					
Parent/Guardian:	1 <sup>st</sup> Contact Phone Numbe	r 2 <sup>nd</sup> Cont Number	act Phone	Cell:	
Parent/Guardian:	1 <sup>st</sup> Contact Phone Number	r 2 <sup>nd</sup> Cont Number	act Phone	Cell:	
Emergency Contact:	Relationship:	Contact	Phone Number	Cell:	
Authorization	for Administration of	f Epineph	rine Injection		
In the event that my son/daughter is not capable of self-administration, I hereby authorize and instruct the Principal, or designate(s), to administer epinephrine by injection to my son/daughter, for the purpose of providing temporary emergency response to a perceived life-threatening occurrence which may be seen to result from an allergic reaction.					
My signature shall be your good and sufficient authority to administer epinephrine by injection, and recognizing that staff are not medically trained, I shall not hold the person administering the medication, the School Board or any of its school personnel liable for any action whatsoever which may arise out of the said medication administration, either at this given time, or at any given time in the future.					
Parent/Guardian Signature: Date:					
Personal information on this form is collected under the authority of s. 265(1)(d) of the Education Act, and pursuant to sections 28(2) of the Municipal Freedom of Information and Protection of Privacy Act. The information collected on this form will be used for providing					
emergency medical treatment. Any questions regarding the collection of this information should be directed to the prioritian of the school.  This form is kept in the School's Medical Emergency file, the OSR and provided to transportation service as required.					

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FORM	0

# Administration of Medication: Epinephrine Injection

Student Name:	
Date of Birth:	
School:	
Name of Principal:	
I hereby authorize and instruct the Principal of the School, or his/her designate(s) to administe by injection to my child for the purpose of providing temporary emergency response to a threatening occurrence which may be seen to result from an allergic reaction, the symptoms	er epinephrin perceived life
Symptoms:	
In the event that my child is not capable of self-administration, my signature shall be your go sufficient authority to administer epinephrine by injection, and recognizing that staff are not trained, I shall not hold the person administering the medication, the Board or any of its school personnel liable for any action whatsoever which may arise out of medication administration, either at this given time, or at any given time in the future.	medically School
DATED:	_
Signature of Authorizing Parent/Guardian:	_
Note: This form is to be retained in the Anaphylactic Allergy Individual Plan file, the School's Medical Emergency file	and the

Note: This form is to be retained in the Anaphylactic Allergy Individual Plan file, the School's Medical Emergency file and the student's OSR File.

Information on this form is collected pursuant to the board's responsibilities set out in the Education Act Information on this form will be used to administer an <u>EPIPEN</u>. Questions regarding the collection of this information should be directed to the school principal.

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Student Photo

				• ,		
ame:					*** MEDICAL PERIL ***	
rthd	ate:	Gender:	Grade:	0		
omeroom: Teacher:		Transport:				
edica	al Details:					
rent	/ Guardian / Emergency	/ Contacts:				
G:	(Mother)	н	l:	B:	C:	
٠.		u	1.	D.	C:	

#### Rin Ho Par PG PG: H: B: EC: H: B: C: EC: H:

Anaphylaxis Emergency Plan For:

#### Location of Auto-Injector(s):

Nai

A person having an anaphylactic reaction might have ANY of these signs and symptoms:

- Skin system: hives, swelling, itching, warmth, redness, rash
- Respiratory system (breathing): coughing, wheezing, shortness of breath, chest pain/tightness, throat tightness, hoarse voice, nasal congestion or hay fever-like symptoms (runny, itchy nose and watery eyes, sneezing), trouble swallowing
- Gastrointestinal system (stomach): nausea, pain/cramps, vomiting, diarrhea
- Cardiovascular system (heart): pale/blue colour, weak pulse, passing out, dizzy/lightheaded,
- Other: anxiety, feeling of "impending doom", headache, uterine cramps, metallic taste

#### Early recognition of symptoms and immediate treatment could save a person's life.

Act quickly. The first signs of a reaction can be mild, but symptoms can get worse very quickly.

- Give epinephrine auto-injector (e.g., EpiPen® or Allerject™) at the first sign of a known or suspected anaphylactic reaction. (See attached instruction sheet.)
- 2. Call 9-1-1 or local emergency medical services. Tell them someone is having a life-threatening allergic reaction.
- 3. Give a second dose of epinephrine in 5 to 15 minutes IF the reaction continues or worsens. Go to the nearest hospital immediately (ideally by ambulance), even if symptoms are mild or have stopped.
- 4. The reaction could worsen or come back, even after proper treatment. Stay in the hospital for an appropriate period of observation as decided by the emergency department physician (generally about 4 hours).
- 5. Call emergency contact person (e.g. parent, guardian).

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FORM	05
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# Front of Card FANNY PACK LAMINATED INFORMATION CARD ANAPHYLAXIS ALFRT

ANAFIITLA	MIS ALLINI	
Student's Name:		
This student is allergic to:		
Use the Epinephrine Injector immediately if a	ny of these symptoms appear:	
Tingling in mouth	Wheezing, sneezing, coughing and choking	
Hives, rash, itching	Vomiting, stomach upset, diarrhea	
Generalized flushing     Anxiety		
<ul> <li>Swelling-eyes, ears, lips, face, tongue</li> </ul>	Light-headedness	
Constriction in breathing, swallowing	Loss of consciousness	
Epinephrine Injector directions:  1. Pull off safety cap 2. Place black tip on thigh 3. Press hard into thigh until you hear the click 4. Hold for 10 seconds		
4. Hold for to seconds		

Call 911 to transport to hospital. If symptoms continue or worsen after 5-15 minutes and ambulance has not arrived, a second injection must be given.

# Back of Card FANNY PACK LAMINATED INFORMATION CARD ANAPHYLAXIS ALERT

Name of Student:
Address:
Parent Phone Number:
Parent Phone Number:
School Name:
School Phone Number:

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FORM 06

# Epinephrine by Injection Emergency Transportation Information

School Year:			
Student Name:			
School:	Grade:		рното
Parent Name:			
Telephone/Home #			
Telephone Work #			
Location of the Epinephrine Injector:			
Medical condition:			
Allergy to:		_	
Administer epinephrine by injection: Studer provide specific instructions to drivers.			•
School Bus Operator:			
A.M. Bus:	_ Driver:		
Mid-Day Bus:	_ Driver:		
P.M. Bus:	Driver:		
DISPATCH 1. Obtain exact location/time of adminis 2. Call 911 3. Call Supervisor of Transportation	stration.		

Distribution List: 1. School Bus Driver 2. Transportation Department

4. Provide specific instructions to driver.

Note: This form is to be retained in the Anaphylactic Allergy Individual Plan file, the School's Medical Emergency file and the student's OSR File.

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#### ANNUAL ANAPHYLAXIS PROCEDURES CHECKLIST

#### A) Information and Awareness

- · Allergy alert form on file
- · Consent to administer epinephrine on file
- · Anaphylactic student identified to all staff
- · Allergy-alert form placed in key locations
- Instructions on use of auto-injector posted in student's classroom
- Information placed in visible location for supply teachers
- Transportation Information forwarded to bus/taxi driver and Transportation Department

In-service, including training in use of auto injector, provided for

- Teaching staff
- Substitute teachers
- Volunteers

- · Support staff
- Bus drivers
- Others

Information sharing in place for

- Students
- Parents
- Parent organizations

Letters asking for cooperation sent to

- · Parents of students in class
- All parents in school

## B) Monitoring and Avoidance Strategies

- Allergen-free areas established
- · Safe lunchroom and eating area procedures established
- · Staff alerted to non-food allergens in school
- · Procedures for holidays and special celebrations established
- · Procedures for field trips established
- School bus procedures established
- · Review process in place

#### C) Emergency Response

- · Anaphylactic Allergy Individual Plan on file for each anaphylactic student
- Rapid communication strategy in place
- · Auto-injectors stored in safe and accessible location
- · School bus emergency procedure in place
- Role-playing session planned
- Role-playing session implemented

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### SAMPLE LETTER FROM TEACHER/PRINCIPAL

TO PARENTS
FROM THE CLASSROOM TEACHER AND PRINCIPAL

Dear Parents/Guardians:

I am writing to you on behalf of one of our student and their parent(s). This student has a life threatening reaction to peanuts and all types of nuts. If peanut butter or even the tiniest amount of peanut or any type of nut enters their body (through eyes, nose or mouth), their body triggers an immediate defence and sends out extra antibodies to fight the allergen. Within their body they experience very strong reactions: their face swells and breaks out in hives, their throat swells and tightens. Without immediate medical treatment they could die within minutes.

After discussions with school staff and other knowledgeable parties in the medical community, it has been suggested that the best way to provide a safe environment for this student would be to enlist the support of the parents to help make this 'classroom a "peanut and nut free environment". This means that each child entering this class is asked to bring a peanut and nut free snack and lunch. Though it sounds simple, it means no peanut butter sandwiches or peanut butter cookies. Other foods like muffins, granola bars and cereals will require reading labels before being packed in your child's snack or lunch. Our concern is for foods where peanuts or other nuts might be a "hidden" ingredient. Please ask your child to avoid sharing their snacks and lunches with other students.

I realize this request poses an inconvenience for you when packing your child's snack and lunch, however, I wish to express sincere appreciation for your support and understanding of this potentially life-threatening allergy. In the very near future the school will announce a parent meeting for you to become acquainted with this situation. Literature will be provided suggesting healthy and nutritional alternatives to peanuts/nuts and their by-products.

Sincerely, Teacher Principal

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#### SAMPLE LETTERS TO PARENTS OF THE SCHOOL FROM THE PRINCIPAL

Dear Parents/Guardians:

We felt that all parents would like to be aware that there is a child/children in our school with a severe life-threatening food allergy to peanuts and tree nuts (anaphylaxis). This includes any food that contains peanuts/nuts in it. This is a medical condition that causes a severe reaction to specific foods and can result in death within minutes.

All our staff have been made aware of this situation and have been instructed in the correct procedures regarding anaphylaxis.

Prevention, of course, is the best approach. Although this may or may not affect your child's class directly, we want to inform you so that you may choose to send foods with your child to school that are free from peanuts or nut products. In a school setting, cross-contamination is the greatest risk for this type of allergy. Trace amounts of peanuts/nuts can be left on gym, equipment, computer keyboards, pencils etc.

We endeavor to make the school a safe environment for all students. Anyone wishing further information about anaphylaxis may contact the school.

Thank you for your support. Sincerely,

School Principal

#### SAMPLE ITEM FOR SCHOOL NEWSLETTERS

We felt that all parents would like to be aware that there is a student (or several students) in our school with a severe life-threatening food allergy to peanuts and nuts (anaphylaxis). This is a medical condition that causes a severe reaction to specific foods and can result in death within minutes. Although this may or may not affect your child's class directly, please send foods with your child to school that are free from peanuts or nut products. There will be more information about anaphylaxis at our Meet the Teacher Night.

Thank you for your understanding and co-operation.

#### SAMPLE HOLIDAY REMINDER LETTER

Halloween is fast approaching! We have a number of students at (school) who have peanut and nut allergies. We ask you to be extra careful in checking labels and avoid sending any Halloween treats to school that may contain peanut or nut products. This is a life threatening situation for these children. Thank you once again by showing your care and concern for all children by helping to provide a safe learning environment

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# **Appendix F: Resources**

## **Conference attended:**

9<sup>th</sup> Annual AllerGen Trainee Symposium April 30-May 2 2014, Vancouver, Ontario Registration and travel funded by AllerGen

7<sup>th</sup> Annual Community Conference Managing food allergies: Working together for a safer future May 10, 2014, Markham, Ontario Registration funded by Food Allergy Canada

10<sup>th</sup> Annual AllerGen Trainee Symposium April 29-May 1, 2015, Toronto, Ontario Registration and travel funded by AllerGen

8<sup>th</sup> Annual Community Conference Allergy Information Service: Information You Can Trust May 23, 2015, Toronto, Ontario Registration funded by Food Allergy Canada

16<sup>th</sup> Annual International Medical Geography Symposium July 5-July 10, 2015, Vancouver, Ontario Registration and travel funded by ASNPN travel grant and CDPI seed grant funding

8<sup>th</sup> Annual Research Conference Connecting and Collaborating: Globalizing Advances in Allergic Disease Research May 29-June 1, 2016, Vancouver, Ontario Registration and travel funded by AllerGen

# **Institutional Ethnography training completed:**

Ethnography 2014 with Dorothy Smith, PhD & Susan M. Turner, PhD Weekend Workshop: Incorporating Texts into Institutional Ethnographies June 6-8, 2014
Registration funded by AllerGen NCE

# **GRS** funding:

This research project was funded (\$10,000) by UW Chronic Disease Prevention Initiative Seed grant (2014), which supported graduate student (GRS), transportation (travel costs for interviews), transcription costs (interviews), and conference attendance (presentations).