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The 504 Program Experiences of Parents of Students with Type 1 Insulin-Dependent Diabetes in One South Texas Public School District

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THE 504 PROGRAM EXPERIENCES OF PARENTS OF STUDENTS WITH TYPE 1 INSULIN-DEPENDENT DIABETES IN ONE SOUTH TEXAS PUBLIC SCHOOL DISTRICT

A Dissertation

by

MARY FRANCES CORNWELL-GARZA

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May 2012

ABSTRACT

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The purpose of the study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. Critical Theory, with an emphasis on social justice leadership, was utilized as the theoretical framework. Six parent interviews were audio-taped, transcribed, coded and analyzed, and a review of students' records was conducted. A pseudonym was used for the name of each child with T1D and their parents.

All of the parents interviewed were in agreement that the school nurses followed the diabetic care plan prescribed by their child's doctors and basic necessary accommodations were implemented in the schools. Parents of students with T1D identified accommodations which they felt best met their child's needs such as the buddy system; unlimited restroom breaks; school meals and snacks; regular blood sugar checks; preferential seating to help maintain focus; and extended time to finish assignments.

Parents of students with T1D gave suggestions and identified areas of concern for improved care for their children. Among the suggestions and concerns were: reinstatement of the buddy system at the high school level; diabetic self-care permission at the high school level away from the nurse's office; school staff education and training; 504 accommodations and instructions left for substitute teachers; unlimited restroom breaks; effective communication between the T1D 504 diabetic management team, school staff, and parents; larger portion sizes for school breakfast, lunch and snacks; a greater variety of foods in the school menu; a more flexible snack schedule; and a more flexible insulin injection schedule.

As a result of this dissertation study, parents of students with T1D were given a voice. In addition, the possibility of continued and increased integration of social justice in the public school setting for students with chronic illnesses such as T1D through the leadership of committed administrators and other institutional leaders was explored and found present but not complete. The findings of the study indicated a need for administrators to be more involved in 504 processes and services for students with chronic illness such as T1D in the public school system.

DEDICATION

The completion of my doctoral studies would not have been possible without the love and support of my family. My mother, Rhea Appenzeller-Cornwell, my father, James Cornwell, my mother-in-law, Imelda Canales-Garza, my husband, Manuel C. Garza, and my three sons, Manuel James, Brian Michael, and Jacob Matthew, wholeheartedly inspired, motivated and supported me by all means to accomplish this degree. Thank you for your love and patience.

A special dedication goes out to my son, Brian Michael, who developed Type 1 diabetes at the tender age of two years old. Brian has not let the disease bring him down, but, rather, he has risen above it. Brian is a role model and inspiration to all who meet him. He has a positive, cheerful outlook on life with the Lord Jesus always walking by his side. He is a leader, retired football warrior, friend to all, and has the kindest of hearts. My prayer for Brian and for all who suffer from the ravages of Type 1 diabetes is that a cure is found in the near future and the suffering may end.

ACKNOWLEDGEMENTS

I will always be grateful to Dr. Shirley Mills and Dr. Anita Pankake, the co-chairs of my dissertation committee, for all of their mentoring and advice. From embracing and helping me to develop my topic, choosing a research design, and organizing data, to manuscript editing, these two ladies encouraged me to complete this process through their infinite patience and guidance and made it fun. My thanks go to my dissertation committee members: Dr. Miguel de los Santos and Dr. Jerry Lowe. Their advice, input, and comments on my dissertation helped to ensure the quality of my intellectual work. Without Dr. de los Santos encouragement to apply for the University of Texas-Pan American (UTPA) Educational Leadership Doctoral Program, I might not have enrolled in the program.

I would like to thank my colleagues at the UTPA library who helped me locate supporting documents for my research. Also, I would like to acknowledge the parents of students with Type 1 diabetes who volunteered to participate in the individual interviews which made this study possible.

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CHAPTER I

INTRODUCTION

Public school administrators, in their role as educational leaders, have an important responsibility in dealing with children and adolescents with chronic illnesses. As dictated by *Section 504 of the Rehabilitation Act of 1973*, school administrators must assure that the letter of the law is adhered to by all school personnel, thus furthering the concept of social justice leadership in the schools. George Theoharis (2007) defined social justice as "…an ultimate concern for situations of marginalization" (p. 223), and advocated that school principals strive to create schools which make every effort daily to promote social justice for all marginalized groups of students within their campus. The focus of this qualitative study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. In the introduction to his study, Edwin Neely (2005) made the supposition that every parent feels as he does, "…that there is nothing more precious than" (p. 24), their own children. Neely (2005) purported that "parents not only appreciate being kept apprised of their child's progress and the educational programs offered; they respond back with comments, ideas, participation and good old "atta boys!" (p. 24). The current study parlays Neely's supposition and aims to answer the research questions that are designed to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. The Juvenile Diabetes Research Foundation International (JDRF) (2005) advised parents of children or adolescents with T1D to strive to forge constructive and enlightening communication with school personnel before the first day of school. The JDRF (2005) also recommended that school personnel involved in the education of a student with T1D know the basics of the chronic disease and the student's individual needs. As mandated by *Section 504 of the Rehabilitation Act of 1973,* an Individualized Education Plan (IEP), defined as a written arrangement of accommodations or services, must be provided to guarantee educational assurances. All students with T1D fall under the *Section 504* umbrella.

Diabetes mellitus is a chronic illness of the endocrine body system which afflicts infants, children, young and older adults alike. Type 1 insulin-dependent diabetes (T1D), formerly referred to as juvenile diabetes, is brought on by the body's self destruction of the Islet cells in the pancreas which produce the hormone insulin responsible for regulating metabolism (Getch, Bhukhanwala, & Newharth-Pritchett, 2007). The chronic condition is not always easily diagnosed. The indication of the prevalence of the disease may be "extreme hunger or thirst, urinating frequently, losing weight unexpectedly, fatigue, blurry vision, and, in girls, having frequent genital yeast infections" (Mishori, 2009a, p. 14). Type 1 diabetes is one of the most widespread chronic childhood illnesses in North America (Cunningham & Wodrich, 2006). Type 2 diabetes, the more common type, is caused "from insulin resistance with inadequate insulin secretion to sustain normal metabolism" (Getch et al., p.46).

In the United States there are approximately 25.8 million people, 8.3 percent of the total population, who suffer from diabetes. Of those 25.8 million people, 7.0 million are as yet undiagnosed (Centers for Disease Control and Prevention, 2011). Approximately 1.7 million of these people reside in the state of Texas. Another 440,468 Texans are believed to have the disease but have not yet been diagnosed (Texas Diabetes Council, 2010). Diabetes, the sixth leading cause of Texas deaths from 2002 through 2007, ranked seventh in 2007 in the national death rate (Texas Diabetes Council, 2010). Complications of the disease may include blindness, cardiovascular disease, kidney disease, nervous system disease, dental disease, and loss of limb. All of these complications are detrimental to the overall health of the patient and create a burden of cost. Health care costs to battle diabetes have skyrocketed. As of 2007, the price tag for diabetes related healthcare was in excess of $174 billion (Centers for Disease Control and Prevention, 2011).

As reported by the Texas Diabetes Council (2010) the most common form of diabetes among youth is T1D. The Council (2010) stated that according to the SEARCH for Diabetes in Youth study, from 2002 to 2005, 15,600 American children and adolescents were diagnosed with T1D. There were 3,600 youth diagnosed with T2D during that same time period. Getch et al. (2007) reported that “Type 1 diabetes occurs more often in children and young adults than any other age group” (p. 46), while “type 2 diabetes predominantly occurs among middle-aged or older adults who are overweight… (p. 47). Unfortunately, they also reported that the numbers of youth being diagnosed with T2D are currently on the rise.

Both Type 1 (T1D) and Type 2 diabetes (T2D), if not controlled with a strategic combination of medication, diet, and exercise, can lead to both short and long-term complications. Short-term complications include hypoglycemia, (low blood sugar), or hyperglycemia, (high blood sugar) (Wagner & James, 2006). Long-term complications of diabetes, according to the findings of the *Diabetic Control and Complication Trial* (DCCT) reported in 1993, are a result of intermittent hyperglycemia over a long period of time. This condition can adversely affect one or more of the major organs of the body causing severe health problems for people with diabetes years after onset (Amillategui, Calle, Alvarez, Cardiel, & Barrio, 2007). In addition, researchers in the DCCT “conclusively established that intensive control of insulin-dependent diabetes mellitus in persons aged 19 to 26 (almost exclusively white, normotensive, nondyslipidemic, of normal weight, and insulin sensitive) reduces by +50% the likelihood of retinopathy, nephropathy and neuropathy" (Vinik & Richardson, 1997, p. 1):

> Therefore, the DCCT and the *American Diabetes Association* (ADA) advocate an intensive treatment regimen with the goal of maintaining blood glucose concentrations close to the normal range to decrease the frequency and severity of complications. The benefits of the intensive treatment outweighed the increased incident of severe hypoglycemia observed in childhood during the trial. To achieve such optimal glycaemic control, frequent blood glucose monitoring and insulin administration when needed should be performed (Amillategui et al., 2007, p. 1073-1074).

Statement of the Problem

Parents of children or adolescents with T1D are advised by the Juvenile Diabetes Research Foundation International (JDRF) (2005) to establish positive and informative communication with school personnel before the first day of school. Arnold, Michael, Hosley and Shawn (1994) maintained through the findings of their study that:

> …with regard to schools and teachers, parents are more likely to engage in communication with schools (or at least feel better about doing so) if they have actively interacted with them. School personnel may want to consider programs that emphasize actual contact between the schools and families and spend less time and money on mailings and information dissemination. The need to collaborate actively with parents is currently a primary focus in terms of both accepted practice standards (p. 264).

Therefore, school personnel involved in the education of a student with T1D should strive to forge warm and positive lines of communication with students' parents and should know the basics of the chronic disease and the student's individual needs. According to JDRF (2005), each student with T1D should have an Individualized Education Plan (IEP), a written arrangement of accommodations or services. An IEP is an educational assurance provided by *Section 504 of the Rehabilitation Act of 1973*. All students with T1D are safeguarded by this federal law:

> *Section 504 of the Rehabilitation Act of 1973* states that "no otherwise qualified handicapped individual" can be excluded from programs or activities receiving federal financial assistance simply because of his or her disability. The handicap is defined as an impairment that substantially limits one or more of such a person's major life activities. "Programs or activities" include all kinds of schools as well as social services like day care centers. The act gives parents of children with type 1 diabetes the right to develop, with the school's agreement, a plan to accommodate any special needs as a result of the condition (JDRF, 2010a, p. 1).

Two other federal laws, the *Individuals with Disabilities Education Act* (IDEA) of 1975, and the *Americans with Disabilities Education Act* (ADA) of 1990 replicate numerous requisites of *Section 504 of the Rehabilitation Act of 1973* (JDRF, 2010a).

On May 26th of 2005, House Bill (HB) 984 went into effect in the state of Texas to work in conjunction with the three previously mentioned federal laws which protect individuals with T1D. HB 984 enhances the Texas Health and Safety Code by requiring:

> …that in each school in which a student with diabetes is enrolled, the school principal shall seek school employees who are not health care professionals to serve as unlicensed diabetes care assistants (UDCAs) to care for students with diabetes, and make efforts to ensure that the school has at least one UDCA if a full-time school nurse is assigned to the school, and at least three UDCAs if a full-time school nurse is not assigned to the school. The law recognizes the roles of the principal, school nurse (when available), and school

> employees as well as those of the student’s physician and parent/guardian (Texas Diabetes Council, 2009, p. 4).

According to Hayes-Bohn, Neumark-Sztainer, Mellin, and Patterson (2004), “children typically spend one-third of the day in school, so school personnel play an integral role in daily care” (p. 166). Therefore it is essential for school officials to assemble a reliable, conscientious diabetic management team of primary caregivers to attend to the needs of students with T1D. This group should be comprised of the student with diabetes, parents, an endocrinologist, the school nurse, teachers, counselors, and administrators.

Upon entering the public school system, parents of students with T1D may or may not be well-versed in how the 504 program operates to benefit their child’s health and education. Regardless of their knowledge about the 504 Program, parents of students with T1D are vital participants in the makeup of the 504 committee. It is not common practice, however, to ask parents of students in 504 programs for feedback on their experiences and satisfaction with those programs. Parents may be fearful for their child, wondering who will keep track of their blood sugars and diabetic regimen during the school day. Good communication is necessary but may also be problematic. The public schools receive little feedback regarding parent experiences and satisfaction with school services provided through the 504 program for students with T1D. Parents of students with chronic illnesses such as T1D should be given a voice to assist the schools in better serving the needs of their students with T1D.

Purpose of the Study

The purpose of this study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. The study is qualitative, utilizing a descriptive research design comprised from the data of a multiple case study to answer the research questions. The system of measurement was individual interviews, which were audio-taped, transcribed, coded and analyzed, in addition to a review of student school records, to explore the research questions.

Research Questions

Several issues of concern to parents of students with Type 1 diabetes (T1D) constituted the research questions addressed in the study. The research questions were:

1. How do parents of students with Type 1 insulin-dependent diabetes describe their experiences and satisfaction with school services provided through the 504 program for their child and the quality of communications between and among the members of the 504 team?
2. What are the perceptions of parents of students with T1D about the best 504 practices and accommodations to help facilitate their child’s learning in the classroom?
3. According to the perceptions of parents of students with T1D, what concerns do they have regarding their student’s overall care at school?

The study offers useful information regarding satisfactory accommodations and possible improvements needed to accommodate the health and education of students with T1D. After reporting the findings of the study, the parent’s voice to assist the schools in better serving the needs of their children with T1D should improve.

Significance of the Study

A significant study, according to Gay, Mills and Airasian (2006), is one that contributes to the understanding and advancement of educational practice or theory. The results of this study may be particularly useful to public school districts. Parent feedback, gleaned from the parent interviews conducted in the study, is significant because such information can guide change in the 504 programs of the public schools. Such information can help to close the learning gap between 504 students with chronic illnesses such as T1D and general education students. Educators across the state of Texas and the nation, for that matter, are all searching for answers to close the learning gap for special populations of students. The Texas Department of State Health Services and Child Health and Safety Branch (2009) has established that "a student's school performance suffers when their blood sugar is too high or too low. Without treatment, both high and low blood sugar levels can affect the child's ability to concentrate on schoolwork and participate in school-related activities" (p. 377). In response to the needs of students with diabetes, the Texas Department of State Health Services and Child Health and Safety Branch (2009) have jointly published the *Texas Guide to School Health Programs*. The guide states that all children with diabetes, who are enrolled in Texas public schools, must have an Individualized Health Care Plan (IHP). The IHP must include an Emergency Care Plan (ECP). The involvement of the school nurse with the development of the IHP is essential. "The school nurse will become the case manager for the child and establish school treatment and emergency plans, coordinate school health care, and educate other school personnel about the monitoring and treatment of symptoms" (The Texas Department of State Health Services and Child Health and Safety Branch, 2009, p. 377). Two other key figures to round out the membership of the IHP are the student's parents and the student's medical specialist, usually an endocrinologist. Such a plan, the IHP, is in keeping with the requirements of the three federal statutes which protect the rights of students with T1D, *Section 504 of the Rehabilitation Act of 1973*, ADA, and IDEA.

The most pertinent questions of the study include: What do parents of students with Type 1 insulin-dependent diabetes have to say about their experiences and satisfaction with school services provided through the 504 program for their child? and What is the quality of communications between and among the members of the 504 team? Wilson, Pentecoste, and Nelms (1983) stated that “one of the educational problems that has been widely published in the press and articulated by parent groups has been the difficulty of communicating with the school” (p. 402). The study is designed to gather parental feedback and input that may help educators in determining what the best 504 practices and accommodations needed to help facilitate learning for each student with T1D in their classrooms. Such valuable parent feedback may constitute change in the 504 programs of the public schools and help close the learning gap between 504 students with chronic illnesses such as T1D and general education students.

Theoretical Framework

The theoretical framework for this study was Critical Theory and Practice with an emphasis on social justice leadership. “Critical theory examines the current structure of society, in which dominant socioeconomic groups exploit and oppress subordinate groups” (Bennett deMarrais & LeCompte, 1999, p. 27). Over a hundred years ago, Horace Mann, the great American educational statesman, proposed and argued for a common school where all children would be equalized in their level of education (Walker, 2006). The fruition of that idea became what we now know as American public education. However, the equality of education has never completely materialized in American education. According to Walker (2006):

> while we tout our ideological dedication for equality and social justice, schools continue to shape and be shaped by an educational system challenged by changing demographics and characterized by blatant inequality and failure. For well over a century, educators in the United States have confronted the issue of organizing our schools to support an increasing diverse population and provide a socially just environment” (p. 114).

Type 1 diabetes afflicts young people across all populations and is indiscriminant among people of various levels of socio-economic status. A well known phrase is “the squeaky wheel gets the oil,” meaning that those who speak up or demand their rights will be granted benefits that sometimes may elude the less educated, underprivileged, or other unfortunate souls. Intentional or not, there is a possibility that the individuals in positions of power in the public schools, (administrators, counselors, nurses, and teachers), may pay more attention to the needs of students with T1D who have parents that are well educated and come from a middle class to wealthy background than to those students who hail from a lower socio-economic background. There is a possibility that some students, because of their backgrounds, may be discounted or disregarded.

In her *Practical Introduction to Critical Theory*, Patricia H. Hinchey (1998) emphasizes that the key is awareness. If one is aware of the questions to ask, one can work to develop better practices in order to become an educator of social change. This advice relates specifically to the topic of the research; a study to report on the 504 Program experiences of the parents of students with Type 1 insulin-dependent diabetes in one south Texas public school district. Such valuable feedback can shed light on whether or not all of the parents interviewed in the study, which represent different socio-economic backgrounds, believe that their child with T1D is receiving appropriate school services and accommodations to facilitate successful learning outcomes in the classroom.

Limitations of the Study

As in most studies in the field of education and other disciplines, there were several limitations in the study. The population and sample size was small. A group of six sets of parents of students identified with T1D from one South Texas public school district were identified for participation.

External validity also presents some limitations. External validity is the degree of reliability to which the results of the study may be replicated with another population in another setting. (Gay, Mills & Airasian, 2006). External validity may be affected because students in the identified south Texas school district of this study are unique. The demographics of the student population include a district enrollment of over 30,000, and primarily of Hispanic ethnic background. The district spans 945 square miles and is one of the geographically largest in the United States. The population make-up will be hard to replicate or generalize to other groups and environments outside of the Rio Grande Valley of south Texas. However the perceptions of parents of students with Type 1 insulin-dependent diabetes (T1D) regarding their 504 Program experiences may have more commonality.

It is imperative to mention that the researcher of the study came with a bias. The researcher is the mother of a 20 year old son who was diagnosed with T1D at the age of two. The researcher has her own experiences as a parent of a student with T1D and personal views about the 504 Program, diabetic management team, and accommodations provided in the school setting. Therefore, the researcher took particular care to remain objective and distance herself from her personal feelings as a parent and function strictly as a researcher.

Delimitations of the Study

The study is feasible and possible to carry out across the general population. Regardless of the fact that the established boundary of the study is primarily relegated to the area of south Texas where the local population is predominately Hispanic, the exact same study could be carried out in a different area of the United States with a dissimilar population and state public school system. The rational for such an assumption is that Section 504 is a federal law. In addition, the experience of parents of students with T1D is likely to be similar no matter what part of the United States in which they live, as Type 1 diabetes knows no color or socio-economic background. Type 1 diabetes strikes indiscriminately.

The researcher was in a position to receive permission from the district's superintendent, and, was assisted by the district's nurse coordinator and campus nurses, in identifying and approaching the parents of students with T1D for the study. The researcher worked closely with the nurse coordinator in the district. Parent access and the fact that the study provided a voice for parents of students with T1D were strong points towards the success of the study.

Definition of Terms

The following is a list of terms defined with the constructs of this study specifically in mind. It is essential for the reader to study and comprehend each term in order to synthesize the principle concepts of the study.

A1C. A test designed to approximate the average blood glucose level over the course of a two to three month period by measuring the concentration of glucose attached to the hemoglobin in the blood (Betschart Roemer, 2011).

Blood glucose. Blood glucose is a simple sugar located in the blood, the result of food broken down by enzymes in the stomach, providing the body's chief source of energy (U.S. Department of Health and Human Services, 2010).

Chronic disease. A chronic disease is an illness with a long duration (Getch, Bhukhanwala, & Newharth-Pritchett, 2007).

Continuous subcutaneous insulin infusion (CSII). Also known as Insulin Pump Therapy, CSII therapy is a diabetes treatment alternative whereby a tiny catheter, connected by plastic tubing to a computerized pump containing insulin, is inserted directly under the skin, delivering a constant supply of insulin to the body along with extra insulin at mealtimes (U.S. Department of Health and Human Services, 2010).

Critical theory. Critical Theory, established by the Frankfurt School, states that all knowledge is authentic but prejudiced against marginalized groups of students (Bennett deMarrais & LeCompte, 1999).

Endocrinologist. An endocrinologist is a medical doctor who specializes in diseases related to the endocrine glands that discharge hormones which regulate organs of the body and metabolic activity (Thorndike & Barnhart, 1988).

External validity. External validity is the degree of reliability to which the results of the study may be replicated with another population in another setting (Gay, Mills & Airasian, 2006).

Glucose. The body's chief supply of energy which is derived from carbohydrates broken down by the digestive system (Betschart Roemer, 2011).

Hyperglycemia. Hyperglycemia is the condition of a high amount of sugar or glucose in the blood. Over a prolonged period of time, hyperglycemia may lead to serious complications such as blindness, kidney failure, and amputations of the extremities (Wagner & James, 2006).

Hypoglycemia. Hypoglycemia is the serious condition of a low amount of sugar or glucose in the blood (Wagner & James, 2006).

Insulin. Insulin is a hormone manufactured in the pancreas and secreted into the bloodstream that regulates metabolism (U.S. Department of Health and Human Services, 2010).

Marginalized. A condition in which one finds himself at a disadvantage from the norm or the general population because of a specific circumstance, characteristic, or trait (Bennett deMarrais & LeCompte, 1999).

Multiple case study. A study of numerous individuals that share some common criterion (Creswell, 2007).

Multiple daily injections (MDI). The more traditional treatment route for individuals with diabetes which includes four or more daily injections of insulin to maintain balanced blood glucose levels (Battlelino, 2006).

Pancreas. The pancreas is a gland located close to the stomach which discharges hormones such as insulin into the bloodstream (U.S. Department of Health and Human Services, 2010).

Purposeful sampling. Individuals and sites chosen for inquiry in order to intently illuminate and comprehend the research problem and central reality in the study (Creswell, 2007).

Qualitative research. Research that involves the accumulation, examination, and comprehension of an account and observable information with the purpose of procuring valuable awareness into a specific reality (Gay, Mills, & Airasian, 2006).

Section 504 program. The Section 504 Program was established through the passing of a civil rights law, the *Section 504 of the Rehabilitation Act of 1973,* which was put into place to level the educational playing field for students with a disability which significantly affects their learning (Texas Department of State Health Services, 2009).

Type 1 insulin-dependent diabetes. Type 1 insulin-dependent diabetes, formerly referred to as juvenile diabetes, is a chronic disease brought on by the body’s self-destruction of the Islet cells in the pancreas which produce the hormone insulin, responsible for regulating metabolism (Getch, Bhukhanwala, & Newharth-Pritchett, 2007).

Chapter One Summary

Public school administrators, as educational leaders, are entrusted with the care and critical responsibility of providing a safe and equal opportunity for educational endeavors for all students, including children and adolescents with chronic illnesses. As mandated by *Section 504 of the Rehabilitation Act of 1973,* school administrators must assure that all measures of the law are followed by school staff members to further the cause of promoting social justice leadership in the schools (Theoharis, 2007). Theoharis was adamant that school principals make every effort to advance social justice for all marginalized groups of students within their schools. The focal point of this study was to follow one particular chronic illness, Type 1 diabetes (T1D). Parents value a quality education for their children and are grateful for an interchange of feedback and communication between school personnel and themselves in order to keep abreast of their child's academic and social progress (Neely, 2005). The study ventured to promote Neely's assumption and answer the research questions that were designed to explore and report on the 504 Program experiences of the parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. Parents of students with T1D were heard and, as a result, schools will be able to use parents' feedback to better serve the needs of children with T1D.

As previously mentioned, Type 1 diabetes is the second most common childhood disease, after asthma, afflicting about one of every 400 to 600 Texas youth (Texas Diabetes Council, 2008). It has also been established by the 1993 *Diabetic Control and Complication Trial* (DCCT) that children and adolescents with Type 1 diabetes, in order to avoid the serious complications of the disease, must maintain blood sugar levels within the normal range (Amillategui et al., 2007). Fluctuations in blood sugar levels may lead to recurrent restroom breaks and may affect the attention span of youth with T1D. School absences may accrue due to sick days and doctor visits (JDRF, 2005).

As a result of three major federal laws, *Section 504 of the 1973 Rehabilitation Act*, the *Individuals with Disabilities Education Act* (IDEA) of 1975, and the *Americans with Disabilities Education Act* (ADA) of 1990, schools are required to provide an educational assurance in the form of a written arrangement of accommodations or services known as an Individualized Education Plan (IEP) (JDRF, 2010a). For students with a medical condition which affects their learning, Section 504 provides for an Individualized Health Care Plan (IHP) including an Emergency Care Plan (ECP). Once the plan is in place, all school employees, who are responsible for the care and well-being of a student with T1D, should become well-versed in the details of the IHP as a part of the student's diabetic management team (The Texas Department of State Health Services and Child Health and Safety Branch, 2009). In addition, the Juvenile Diabetes Research Foundation International (JDRF) (2005) urges parents of children or adolescents with T1D to make every effort to forge constructive and enlightening communication with school personnel before the first day of school and throughout their child's educational career. School personnel should build congenial and constructive lines of communication with parents of students with T1D and should know the basics of the chronic disease and the student's individual needs (Arnold et al., 1994). Critical Theory and Practice, with an emphasis on social justice administrative leadership, framed this study.

CHAPTER II

REVIEW OF LITERATURE

The purpose of this qualitative study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. The study was qualitative, utilizing a descriptive research design comprised from the data of a multiple case study to answer the research questions. The system of measurement was individual interviews that were audio-taped, transcribed, coded and analyzed, in addition to a review of student school records, to explore the research questions.

In order to grasp a true picture of past studies related to communication between the parents of students with T1D and the schools and the level of care and types of accommodations afforded students with Type 1 diabetes (T1D) in public school districts, a literature review including the history of the discovery and development of insulin in the early 1920's, studies related to communication between the parents of students with T1D and the schools, and recent research, trends and priorities in diabetes care are proffered. The practical and theoretical framework, Critical Theory, with an emphasis on social justice leadership, supporting the study is also explored.

Several studies similar to the topic of this research have been reviewed and the findings have been recounted in this review of literature. The aim is that new research findings of this study will add to the previous findings of the following studies. The hope is that this study will provide fresh insights into the 504 program experiences of parents of students with T1D in one south Texas public school district.

The History of the Discovery and Development of Insulin

Artifacts of Egyptian papyrus have been unearthed which depicted the symptoms of diabetes dating back as early as 1550 B.C. Prior to 1921, Type 1 diabetes was a literal death sentence with a life expectancy after diagnosis of approximately eleven months. After years of unsuccessful trials to find a treatment or cure for diabetes in research labs around the world, a medical breakthrough or miracle occurred in the spring of 1921 when Frederick Grant Banting, a Canadian physician and scientist, discovered insulin while conducting research at the University of Toronto, Canada. He, along with help from his research assistant, Dr. Charles Best, and with the approval of John James Macleod of the University of Toronto, was able to successfully extract insulin from dog pancreases in enough quantity to conduct experimental research with humans who were already suffering from Type 1 diabetes. Fourteen year old Leonard Thompson of Canada, already close to death, was the first person to receive insulin injections to treat his diabetes. The date was January 11, 1922. “There was a modest lowering of blood sugar and the formation of large abscesses at the injection sites” (Cooper & Ainsberg, 2010, p. 139). A process for refining the insulin was quickly discovered by James Collip, and twelve days later:

> On Monday, January 23, at eleven o’clock in the morning, Dr. Walter Campbell gave Leonard Thompson his second insulin injection—5cc of Collip’s extract. Six hours later, the boy received another injection of 20cc of Collip’s extract. The following day there were two injections of 10cc each. Thompson’s glycosuria nearly disappeared. His blood sugar plummeted from 5.2 milligrams to 1.2 milligrams per cc. It was nothing short of miraculous... (Cooper & Ainsberg, 2010, p. 143),

and placed Leonard on the road to recovery. Leonard Thompson continued insulin treatment until he died of pneumonia at the age of 27. (Cooper & Ainsberg, 2010).

In 1919, at the age of 11 and weighing in at 75 pounds, the daughter of a prominent 20th Century American family, Elizabeth Hughes, was diagnosed with Type 1 diabetes. Elizabeth was born in the Executive Mansion in Albany, New York, as her father, Charles Evans Hughes, was the former Governor of New York, a former Associate Justice of the Supreme Court of the United States, and the 1916 U.S. Presidential election Republican candidate, losing narrowly to Woodrow Wilson. Charles Evans Hughes later went on to be the United States Secretary of State, a judge on the Court of International Justice, and the 11th Chief Justice of the United States. Elizabeth Hughes' parents, in an effort to prolong her life until a long term treatment or cure for T1D was found, tendered the care of Elizabeth to Dr. Frederick M. Allen at his clinic, the Physiatric Institute in Morristown, New Jersey. Dr. Allen was a renowned doctor who had successfully prolonged the lives of patients with T1D by lowering and monitoring their daily intake of calories to a meager 400 calories, basically starving his patients, to achieve the goal of little or no sugar in the urine. Elizabeth Hughes survived under Dr. Allen's care and starvation treatment plan for almost four years. In 1922, at the age of 14, Elizabeth, weighing a skeletal 45 pounds, was the first person in the United States to be given insulin injections by Dr. Banting in Toronto, Canada. Her treatments were so successful, that she lived for another 58 years, injecting herself with insulin more than 42,000 times over the course of six decades, while honing her needles on a whetstone. After leaving Toronto, Elizabeth Hughes went back to school and eventually graduated from Barnard College in 1929. In 1930, she married William T. Gossett, lawyer and eventual vice president and general counsel of the Ford Motor Company, and bore him three children, none of them diabetic. Elizabeth Hughes Gossett died on April 21, 1981 of heart failure at the age of seventy-three. She had virtually kept her T1D a secret from the world outside of her family by obliterating most of the documentation related to her diabetes treatment and any of her father’s papers which eluded to her diabetes. Elizabeth Hughes Gossett has posthumously been criticized for not dedicating a part of her life to advocate for further diabetic research and education, since she so benefited from the opportunity she got at the age of 14 to begin insulin treatments when the drug was not yet produced commercially (Cooper & Ainsberg, 2010).

Since the discovery of insulin by Banting in the spring of 1921, the drug has evolved from limited extractions from dog pancreases, to mass production of insulin extracted from pork and beef pancreases by the Indianapolis, Indiana, based pharmaceutical company, Eli Lilly and Company, in the fall of 1922, to finally, a synthetic “human” insulin called Humulin approved for use by the general public in 1982 by the U.S. Food and Drug Administration. Frederick G. Banting and John J. Macleod received the Nobel Prize in Physiology or Medicine in 1923. Banting divided his share of the award money with his assistant, Dr. Charles Best (Cooper & Ainsberg, 2010).

504 Plans and Special Needs Accommodations

Communication between the Schools and Parents of Students with T1D.

The IDEA Amendments of 1997, authorized by President Clinton, necessitate that U.S. public schools “…provide a free and appropriate public education (FAPE) to all qualified students with disabilities in order to receive federal funding and comply with the law” (Brady, 2004, p. 306). Under the umbrella of Section 504, an individual is presumed to have a disability if the individual “has a physical or mental impairment that substantially limits one or more of such person’s major life activities” (Brady, 2004, p. 311). Chronic diseases, which encircle diabetes, fall under the IDEA category, other health impairment (OHI). Section 504 sanctions three steps to determine Section 504 eligibility: the student referral, the student assessment, and the final eligibility decision. If the student does qualify for services under Section 504, the final three steps: student program formulation, student induction, and later a student reassessment will be initiated in the Section 504 process. A student with diabetes automatically qualifies for Section 504 services (Brady, 2004).

Subpart D of *Section 504 of the Rehabilitation Act of 1973* calls for an individualized accommodation plan (IAP), centered on educational necessity, for each eligible student. An IAP is a written detailed arrangement of modifications designed with the combined input of a team of school personnel who are familiar with the student. The 504 team may include the classroom teacher or teachers, the school principal or assistant principal, the school counselor, the school nurse if applicable, and the parents (Conderman & Katsiyannis, 1995). "The team should review the nature of the disability, determine how the disability affects the student's education, decide if specialized services are needed, document such decisions in the student's file, and review such decisions periodically" (Conderman & Katsiyannis, 1995, p. 43). Such accommodation plans are designed to proffer educational assistance to help level the playing field for students with disabilities defined under *Section 504 of the Rehabilitation Act of 1973* (Conderman & Katsiyannis, 1995).

Getch et al. (2007) compiled significant research to report on the care of students with T1D in schools. The authors noted that students with T1D required vigilance on the part of the classroom teacher. Teachers should be familiar with the symptoms of both low and high blood sugars such as "increased thirst, increased urination, constant hunger, confusion, inattention, blurred vision, headache, and fatigue" (p. 46). These symptoms may occasionally affect the degree of alertness and focus of students with T1D. They may encounter more learning difficulties than other students in the core areas of reading and spelling. Cuningham and Wodrich

(2006) also noted that chronic illness is linked to the possibility of grade failure and placement in special education. During school hours students with T1D:

> …need to have (a) access to the tools for diabetes management (blood glucose testing equipment; insulin delivery systems; and oral, fast-acting carbohydrates and glucagons) (b) sufficient time to adhere to their nutrition plan; and (c) access to personnel who are knowledgeable about diabetes and are able to assist when needed (Getch et al., p. 47).

Even with adequate access to treatment, students with T1D may still suffer from hypoglycemia or hyperglycemia. Current treatments for diabetes do not entirely imitate the body's natural utilization of insulin. As a result, a student's blood glucose levels may fluctuate through no fault of the student. The diabetic management team should be cognizant of this fact and work with the student in a positive, supportive manner to help monitor diabetic control (Getch et al., 2007).

It is critical that students with T1D also participate in their diabetes management to the best of their abilities for their age and maturity level. Students, who totally rely on adults to manage their care, may develop feelings of powerlessness. Such feelings may lead to the development of an apathetic attitude and lack of motivation to strive for good control of their diabetes. When the condition of diabetes is out of control, students may have retention problems, low grades, and a greater possibility of developing complications of the disease (Getch et al., 2007). Getch et al. noted:

> …that children with diabetes are protected under *Section 504 of the Rehabilitation Act* (1973), *Individuals with Disabilities Education Act* (1990), and *the Americans with Disabilities Act* (1990). Under those laws, diabetes has been determined to be a disability, making it illegal for public schools to discriminate against children with diabetes (p. 48).

Getch et al. stated that under Section 504, students with T1D should have an individualized healthcare plan (IHP). The IHP, according to the *American Diabetes Association*, should be developed by the diabetic management team to include the parent or guardian, the student's diabetes doctors, and school personnel. The main goal of the diabetes management team is to maintain target blood glucose levels through "blood glucose monitoring, insulin administration, insulin pump management, meals and snack provision, and symptoms and treatment of hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar)" (Getch et al., 2007, p. 48). Specific instructions for each of these diabetes care interventions should be written clearly in the IHP. Overall, Getch et al. promoted team work by administration, teachers, counselors, and the nurse in providing each child with diabetes an individualized diabetes management plan. Such a plan will enhance the present and future educational well-being of the child.

Lehmkuhl and Nabor's (2008), Hayes-Bohn, Neumark-Sztainer, Mellin, and Patterson (2004), conducted similar studies related to the efficacy of diabetic management teams. Each study produced different results. The majority of the students surveyed in Lehmkuhl and Nabor's (2008) pilot study were content with the support given to them by their diabetic management team and reported lower A1C test results six months later. The authors recommended continued evaluation of support given to students with T1D by their diabetic management team. In Hayes-Bohn et al., both students with T1D and their parents were dissatisfied with several aspects of care within the school; teacher lack of knowledge about diabetes and care of individuals with the chronic disease; unhealthy food selections in the school café and snack machines; and strict school rules and schedules that hampered diabetic self-care. The authors recommended that future research studies be conducted related to diabetic care training for school personnel;

diabetic care management team strategies; studies to change school rules that negatively affect students with T1D; and changing policies on café and snack machine food choices.

Amillategui, Calle, Alvarez, Cardiel, and Barrio (2007) conducted an observational study with a somewhat similar purpose as this research study. Parents answered questionnaires designed “to identify the special needs of children with Type 1 diabetes in schools from the parents’ point of view and the difficulties experienced with full integration, and to define a series of interventions which may improve the situation” (p. 1073). The intention of Amillategui et al. (2007) was to develop interventions to accommodate students and parents as they navigate the school system. Based on data analysis from the study, training sessions on T1D, more nurses in the school setting, and better communication between administration, teachers, and parents are “key factors that may improve the full integration of the diabetic child in this setting” (p. 1073).

Clay, Farris, McCarthy, Kelly, and Howarth (2008) conducted a study to report on the medication regimen from the child and parent’s frame of reference. Medication mismanagement and the effects of such errors on student academic success and school friendships were examined. Children between eight and eighteen years who were patients at Midwestern Children’s Hospital were invited to participate in the study. The children, young adults, and their parents were interviewed using a survey called *Child/Parent Perceptions of Medication Administration in the School Setting*. The findings of the study recognized that missing a dose or running out of medication is the number one concern of parents. Clay et al. (2008) noted that skipping doses of medication can lead to academic, psychosocial, and physical problems for youth. The recommendation was that more research is needed on nurse’s medication distribution best practice and self-management of care for children.

Carroll and Marrero (2006) conducted a qualitative study through the use of focus groups by interviewing the parents of adolescents with T1D. The task was to gauge parental understanding of the physical, mental, and social implications of T1D on adolescents. Various themes surfaced after transcripts of the focus groups were analyzed:

> Themes included how diabetes negatively influences their adolescent's lifestyle, how diabetes makes it difficult for parents to understand developmental challenges experienced by their child, concerns regarding the potential to develop long-term complications, perceptions on how diabetes impacts on their relationship with their child and relationships with peers and how their children's school impacts on their diabetes self-management (p. 1222).

Diabetes Research in South Texas

Mier, Bocanegra-Alonso, Zhan, Zuniga, and Acosta (2008) noted that diabetes, a chronic disease, has become a costly, economic burden, and critical public health concern along the U.S.-Mexico border:

> The diabetes death rate for Hispanics living in U.S. counties along the border (46.7 age-adjusted per 100,000 population) is almost three times the rate for non-Hispanic whites along the border (16.3 age-adjusted per 100,000 population), while the overall prevalence rate among U.S.-Mexico border residents from all ethnic groups is almost twice the level of the general U.S. population (15.7% vs. 9.6%, respectively) (p. 154-155).

The researchers conducted a study utilizing the *Medical Outcomes Study Short Form* to measure the physical and mental health domains of the health-related quality of life (HRQL) of adult subjects living along both sides of the U.S.-Mexico border, (Reynosa, Mexico), with T2D. "HRQL is related to an individual's capacity to function to the highest degree possible physically, psychologically, emotionally, and socially and represents the effect of a disease subjectively on an individual" (Mier et al., 2008, p. 155), "and is influenced by biological, social, and environmental factors" (Mier et al., p. 155). The scores on the *Medical Outcomes Study Short Form* did not differ significantly for Mexican versus U.S. subjects. Respondents from the U.S. border area were more likely to have a poor physical health status if they hailed from a low socio-economic status and their supportive relative was uneducated in the area of diabetes care and management. The Reynosa, Mexico respondents were prone to having a poor physical health status depending upon the length of time they had endured the disease and had been on insulin. "Perhaps the most important finding of this study is that clinical depressive symptoms had a statistically significant association with decreased physical and mental health status in both Valley and Reynosa participants" (Miers et al., p. 158).

The findings of an extensive study were reported in 2006 by Daniel Hale and Guadalupe Rupert. The two researchers analyzed medical records and data from the Division of Pediatric Endocrinology and Diabetes at the University of Texas Health Science Center over the course of a nine-year span between January 1990 and December 1998. This group of medical doctors was the exclusive provider of pediatric diabetes management to the south Texas area extending within a 100 mile radius of San Antonio. The researchers found that "compared to European-American (EA) children with type1 diabetes (T1DM), Mexican-American (MA) children were more likely to have a parent with diabetes, to be hospitalized at the time of diagnosis, and to lack health insurance" (Hale & Rupert, 2006, p. 163). The statistics of the study also showed that the occurrence of diabetes in south Texas nearly tripled over the nine-year period with the bulk of the growth due to an increase of students diagnosed with T2DM. Hale and Rupert (2006) advised that "from the interventional aspect, affected children provide the ideal opportunity to develop treatment programs that are truly holistic, incorporating family, school, community and church in the effort to assure that the youth progress through adulthood without diabetes-related complications" (p. 168).

These two studies by Miers et al. (2008) and Hale and Rupert (2006) are of particular interest to the researcher of this study as they mirror themes which were anticipated to be uncovered during interviews with parents of students with T1D. The respondents in Miers et al. (2008) and Hale and Rupert (2006) are residents of south Texas or a Mexican border town. Both studies established that the socio-economic status of the participants of the studies affected their health status. In addition, Hale and Rupert (2006) noted the importance of the schools joining together with the family of students with T1D to develop sound treatment programs to protect students from future complications of diabetes. One goal of the current study was to receive parent feedback on the 504 program in order to provide valuable information to school districts about what parent of T1D students feel best facilitates the learning and health of their child.

Recent Priorities and Trends in Diabetes Care

According to the American Diabetes Association, 2011 federal legislative priorities include, but are not limited to, several programs which may benefit students with T1D in schools. They are discrimination issues; federal funding for research and diabetes prevention programs; health insurance; wellness and diabetes prevention; and bills related to complications of diabetes.

Discrimination Issues

Safe at School legislation falls under discrimination issues. The focus of such legislation is to guarantee that all "students with diabetes are medically safe and have access to the same educational opportunities as peers without diabetes" (American Diabetes Association, 2011a, p.

2). The focal point of such legislation is to allow students with diabetes to self-manage their care, to ensure that school employees are trained to execute standard and emergency diabetic care functions, and to prevent segregation of student with diabetes (American Diabetes Association, 2011a)

Diabetes does not discriminate between the poor, middle class, rich, or famous. It is important that the list of well-known Americans that have lived or are living with Type 1 diabetes is shared with students with T1D. These famous Americans may represent a beacon of hope to children with T1D signaling the very real possibility of living a normal, long, healthy life with T1D and the chance to fulfill their dreams. The men on the list include American Major League Baseball outfielder, Ty Cobb; quarterback for the Chicago Bears of the National Football League, Jay Cutler; Jerry Lewis, comedian and host of the annual Muscular Dystrophy Labor Day Telethon; singer, Tony Bennett; lead singer and musician of the rock group “Poison,” Brett Michaels; and Nick Jonas of the Jonas Brothers, a pop-rock band (“Inspiration and Expert,” 2011).

Also included on the list of well-known Americans that have lived or are living with Type 1 diabetes are the following women: Academy Award winning actress, Halle Berry; singer, actress, and comedienne, Carol Channing; TV actress, Mary Tyler Moore; Jean Smart, an actress, her most memorable role in the TV comedy, “Designing Women;” the runner-up on the ninth season of “American Idol,” Crystal Bowersox; and Supreme Court Justice, Sonia Sotomayor (“Inspiration and Expert,” 2011).

Sotomayor was first diagnosed with T1D at age seven. She was told early on that some careers such as working as a police officer or private investigator were off-limits to people with her medical condition. One of the questions posed to Sonia Sotomayor before her appointment as

Supreme Court justice was whether or not her diabetes would sway or bias her actions and decisions in the high court. The concern of some opponents to her high court appointment was that her lifelong struggle with Type 1 diabetes "might shape her approach to discrimination issues, among others" (Doyle, M., 2009, p. 6A). William Marshall, a University of North Carolina at Chapel Hill professor of Law noted that Sotomayor has gone both ways when determining the outcome of discrimination cases in the past. For example, she ruled in 2001 that a dyslexic woman, Marilyn Bartlett, should get four days to take the New York State bar exam which she had already failed five times. Two days is the time normally allotted for the test. Sotomayor explained that "Bartlett's experts 'have convinced me that the extra time provided to learning disabled applicants merely levels the playing field and allows these individuals to be tested on their knowledge; it does not provide them with an unfair advantage'" (Doyle, 2009, p. 6A). Conversely, Sotomayor ruled against store manager, Rochelle Saks, also in 2001, who was citing discrimination against her employer, the Franklin Covey Co., for refusing infertility treatment medical insurance coverage (Doyle, 2009).

President Barack Obama, in support of Sotomayor, said her determination in spite of the difficulties she faces on a daily basis because of the disease shows that "no dream is beyond reach in the United States of America" (Doyle, 2009, p. 6A). Sotomayor's rise to a position of power such as Supreme Court Justice is a message directly from the President of the United States, Barack Obama, to students with T1D. The message, that all careers are possible even in the face of a chronic disease, was made quite clear with Sotomayor's, a female Hispanic with T1D, appointment.

Discrimination was again at the forefront, not concerning a famous person with T1D, but rather for an average child, Jared Milligan, of Florida. When Jared's parents went to register him for kindergarten, they were informed that Jared would have to attend one of five designated "diabetes schools" out of 98 elementary schools in the school district, rather than his own neighborhood school. An exception would be made only if Jared's parents were able to frequent the neighborhood school to administer insulin whenever needed (American Diabetes Association, 2010b). Jared's parents partnered with "the American Diabetes Association and diabetes healthcare professionals, attorneys, and grassroots advocates," (American Diabetes Association, 2010b, p. 1), to fight for equal rights for students in Florida. As a result of their efforts, a state law was passed to safeguard students with diabetes from discrimination in school. In this case, the parents of Jared Milligan were proactive and sought legal recourse with the help and support of the American Diabetes Association (American Diabetes Association, 2010b). The question remains, however, whether all parents of students with T1D would react in a similar fashion by demanding justice from a school that was participating in discriminatory practices that negatively affected their child.

Wellness and Diabetes Prevention

A law which has passed the Congress and is awaiting President Obama's signature is the *Healthy, Hunger-Free Kids Act*. This law has been enacted to help prevent the alarming rise of Type 2 diabetes in today's youth. "The new law reauthorizes federal child nutrition programs, removes junk food from school cafeterias and vending machines, promotes healthy lifestyles and allows schools more flexibility to provide healthy food choices" (American Diabetes Association, 2010a, p. 1). With the continuous rise in the number of children with both T1D and T2D, it is critical that schools be held accountable for serving nutritious meals to help attack the problem rather than contribute to it.

Christine Tobin, a certified diabetes educator and president of Healthcare and Education for the American Diabetes Association, advocates prevention of diabetes and prevention of the complication of diabetes, (for the approximately 24 million Americans already inflicted with the disease), by following a sound diet along with regular exercise and controlling body weight. Tobin maintains that certain foods known as “super foods” are identified by the American Diabetes Association because they are comprised of sources of nourishment such as potassium, magnesium, calcium, and vitamins A, C and E (Noonan, 2010):

> They are high in fiber, which helps you feel full longer and keeps your glycemic index low so they don’t spike blood sugar (thus increasing hunger). And, Tobin says, they help maintain healthy levels of blood pressure and blood fats (like cholesterol), which are important for all of us but especially so for diabetics (Noonan, 2010, p. 11-12).

Tobin reported that, according to the American Diabetes Association, the ten best super foods for non-diabetics and Type 1 and 2 diabetics alike are: beans; dark, leafy green vegetables; citrus fruits; sweet potatoes; berries; tomatoes; fish high in omega 3 fatty acids to include herring, halibut, mackerel, albacore tuna, and salmon; whole grains; nuts; and fat-free milk and yogurt. Tobin advises anyone intent upon overindulging to choose snacks from one of the ten super foods groups (Noonan, 2010). Food and nutrition directors for American schools would be well-advised to plan school menus with an abundance of the “super foods” recommended by the American Diabetes Association; as such foods are good for all children. Actress and Academy Award winner, Mira Sorvino, and her famous actor father, Paul Sorvino, a Type 2 diabetic, have partnered with Sanofi-Aventis US on its Diabetes Co-Stars awareness campaign. Mira agreed with Tobin that “the best foods to have around for diabetic family members are veggies, beans, and lean proteins like fish or chicken, and it's healthier for everyone to eat that way anyway" ("Fun by the Slice," 2011).

Complications of Diabetes

Dr. Ted Mitchell (2009), the president and CEO of Dallas' Cooper Clinic, recommends a regimen of diabetes care and prevention as a line of defense to delay the onset of the complications of diabetes. Mitchell (2009) advised that people should "address the problem head-on. Ignorance is definitely not bliss when it comes to diabetes" (p. 14). As a way of addressing the colossal problem in America, (approximately eight percent of the population afflicted with the disease), Dr. Mitchell recommended to those individuals who are hesitant to see a doctor for a blood glucose test, that they visit a pharmacy and purchase a glucometer. Before checking blood sugar an individual should forgo eating for at least eight hours. Dr. Mitchell advised that if a blood sugar reading is above 100, an individual should visit a doctor for a checkup. Ignoring the problem of diabetes can lead to complications of the disease which include "damage to the blood vessels, the nervous system, and organs such as the eyes, heart and kidneys" (Mitchell, 2009, p. 14).

Dr. Ranti Mishori, who frequently writes in the recurring "Stay Healthy" column of *The Parade* magazine, reported that a University of Chicago study predicted that "diabetes cases will nearly double in the U.S. in the next 25 years, and the cost of treating the disease will almost triple" (Mishori, 2009b, p. 14). Hence, the doctor maintained that it was imperative to manage the disease through the use of diet, exercise, medicines, and doctor visits. Doctor visits should include blood tests, (A1C, cholesterol, creatinine), blood pressure checks, feet exams, eye exams, flu shots, and a one-time pneumonia vaccine. Dr. Mishori (2009b) agreed that managing diabetes can be overwhelming and advised that keeping a diabetes health record and conversing regularly with a doctor were helpful in keeping the disease manageable and under control.

Students with T1D typically spend one third of their day in school. It only stands to reason that if blood sugars do not remain stable at school, that over time, the health of a student with T1D would be in jeopardy. Therefore, it is critical for the health and future well-being of students with T1D that the 504 diabetic management team work with students to maintain stable blood glucose levels (Juvenile Diabetes Research Foundation International, 2010b).

Health Insurance

One of the most recent and significant accomplishments of U.S. congressional legislation is the *Patient Protection and Affordable Care Act*, also known as the *Affordable Care Act* (ACA). This federal health care reform legislation was enacted in March of 2010 and will be implemented over time. The full force of the ACA will take effect in the year 2014 (American Diabetes Association, 2011b). Before the ACA took effect, people with the pre-existing condition of diabetes could be denied insurance coverage based on their chronic illness. Those who were fortunate enough to have health insurance were sometimes denied coverage of basic diabetes supplies and medicines, such as test strips and insulin. “This lack of affordable access to care led many people to forgo the care they needed to prevent, delay or slow the progression of diabetes” (American Diabetes Association, 2011b, p. 1). As a result, many people developed complications of the disease which could have been prevented if proper healthcare had been provided at affordable costs.

The *Patient Protection and Affordable Care Act* changes all that. Once the law is fully implemented, insurance companies must provide coverage regardless of what pre-existing conditions accompany a person. Until 2014, the ACA has set up “the Pre-existing Condition

Insurance Plan (PCIP) for the specific purpose of providing health insurance coverage to people who otherwise could not get insurance under the old rules" (American Diabetes Association, 2011b, p. 2). The ACA also prevents insurance companies from barring children with diabetes under the age of 19 from inclusion in the health care plans of their parents. In addition, insurance companies will not be allowed to charge higher premiums because of a diabetes diagnosis (American Diabetes Association, 2011b). The question of affordable health insurance is paramount to parents of students with T1D. Diabetic supplies such as syringes, insulin, glucometers, and test strips are costly. Affordable access to diabetic care supplies is the key to controlling blood sugar levels in order to stay healthy and be able to attend school and focus on daily lessons.

Federal Funding for Research and Diabetes Prevention Programs

Federal funds have been utilized to conduct research to strengthen diabetes prevention programs and to ultimately search for a cure for T1D. In a surprising turn, two different studies have reported that the environment may play a part in the onset of both T1D and T2D. A study conducted by Children's Hospital in Boston revealed a connection between air pollution and Type 2 diabetes. The study conducted in conjunction with Dr. Allison Goldfine of Harvard's Joslin Diabetes Center determined that "air pollution might cause chronic low-grade inflammation," (Listfield, 2010), which can lead to a predisposition for Type 2 diabetes.

Additionally, Type 1 Diabetes is on the rise and may also be linked to the environment. A British medical journal, *The Lancet*, published the findings of a recent study which dissected the diabetes registries of 17 European countries. The study showed that:

> Type 1 diabetes in children under 15 is increasing by about 4% a year, with higher rates of increase in the younger age groups (5.4% for those up to age 4, and 4.3% for those

> ages 5 to 9). Girls showed higher rates of increase than the boys. The incident of new cases in those under age 5, the authors reported, is expected to double by 2020 (Mishori, 2009a, p. 14).

In conjunction with the British study, Dr. Dana Dabelea of the University of Colorado in Denver reported that there is a definite increase in the prevalence of T1D diagnoses in the United States. She stated that the culprit may be environmental metamorphoses which affect our children (Mishori, 2009a).

In response to the fact that over 15,000 children a year are diagnosed with T1D, the *Juvenile Diabetes Research Foundation International* is working in unison with researchers at the University of Massachusetts Medical School to fund and develop a vaccine that would prevent type 1 diabetes. Researchers "hope to retrain immune cells so that they'll tolerate the body's insulin-producing cells instead of attack them. They have established a two-year plan to evaluate and test the drug" (Dickman, 2009, p. 4). These are just a few of the projects that the federal government is funding in search of the elusive cure to T1D. The hope is to eventually eradicate the disease so that youth with T1D can live a life free of needles, finger pricks, and the dread of the complications of diabetes.

MDI Versus CSII Treatment

A decision which all parents of students with T1D must make is which method of insulin treatment their child should receive. The goal will certainly be a balance of the tightest blood glucose control possible, while avoiding episodes of hypoglycemia. Glycaemic control can be measured by a simple blood test, called a hemoglobin A1c test, performed in a doctor's office or clinic. "A near-normal hemoglobin A1c (HbA1c) serves as a major goal of insulin therapy in the pediatric age group" (Danne, von Schütz, Lange, Nestoris, Datz, & Kordonouri, 2006, p. 25).

The school's 504 diabetic management team works with students that are following the regimen of multiple daily insulin injections (MDI) or continuous subcutaneous insulin infusion (CSII) treatment, more commonly known as insulin pump therapy. Members of the team must be familiar with both regimens so as to be of assistance to students.

The *Diabetes Control and Complication Trial* (DCCT) and the *American Diabetes Association* (ADA) advocated maintaining tight blood glucose control (Amillategui et al.). In order to achieve this goal, patients must endure multiple daily insulin injections (MDI), usually four to five shots a day. An alternative to MDI is continuous subcutaneous insulin infusion (CSII) treatment, or insulin pump therapy. A catheter, (connected to plastic tubing leading to a reservoir filled with insulin placed inside a small (beeper-sized) insulin pump), is placed by injection on the stomach, upper leg, or upper buttock region of a patient. The small pump delivers a continuous amount of insulin, (basal rate), over the course of two to three days, after which the site must be changed out and moved to a different location on the body. Extra insulin must be given at meal or snack time by programming the amount of insulin into the pump that is needed to match the food intake of the patient. This was called bolus insulin (Battlelino, 2006). A presupposition was that in the world of Type I diabetes treatment, the most current technology was likely the safest and most reliable method of maintaining good glycaemic control. The insulin pump has been in use and continued development for over 25 years (Battelino, 2006). Therefore, it is considered by some individuals to be the best treatment method for Type 1 diabetes.

Sherr and Tamborlane (2008) noted that tight blood glucose control such as that provided by CSII can lead to dangerous episodes of hypoglycemia. "The fear of hypoglycemia remains a major obstacle that prevents patients and parents from achieving HbA1c goals" (p. 355). In addition, the authors noted that, while the insulin pump was convenient and allowed a lifestyle more in sync with the normal non-diabetic population, the insulin pump and the medical supplies that accompany it were acquired at considerable cost. The insulin pump sells for approximately $6000. A three month supply of insulin reservoirs and infusion sets run the average consumer well over $1000. Group insurance, private insurance, Medicaid or Medicare are crucial to defraying cost and making the insulin pump affordable for all individuals with Type 1 diabetes. However, there are many people who fall through the cracks of the health care system in the United States and can not afford the insulin pump. Because of the high cost of the insulin pump and pump supplies, there is not equal access or fairness in owning and utilizing an insulin pump (Sherr & Tamborlane, 2008). For example, it would be doubtful that the child of illegal immigrants, living in the United States and attending U.S. public schools, would have the opportunity to use an insulin pump.

Sherr and Tamborlane (2008) have reviewed treatment regimens for Type 1 diabetes mellitus (T1D) since the 1970's. Thus the use of multiple daily injections (MDI) has been chronicled along with the evolution of continuous subcutaneous insulin infusion (CSII), also known as insulin pump therapy. Sherr and Tamborlane (2008) noted that "Adolescents on CSII reported less difficulty in coping with diabetes" (p. 353). In addition, the pair stated that patients and their families reported more freedom to enjoy everyday life activities and; hence a better quality of life, while awaiting the arrival of new technologies such as continuous glucose sensors and the artificial pancreas (Sherr & Tamborlane, 2008).

Tadej Battelino, MD, PhD (2006) reported on the advantages of CSII for children and teenagers with Type 1 diabetes. He cited a 2003 study by Weintrob and colleagues, and a 2004 study by Doyle and colleagues. Both studies reported lowered HbA1c levels in patients following CSII treatment. Battelino (2006) also recounted a 2004 study conducted by Shehadeh and colleagues stating that:

> Teens and their parents reported in a content-analyzed interview high levels of satisfaction with pump therapy and increased adolescent responsibility for the diabetes regimen. In addition, adolescent pump users reported few issues related to body image, appearance, or social aspects of pump dependency (p. 22).

According to Battelino (2006), the continued prospects of the insulin pump look favorable for years to come, especially with foreseeable technological advances in mind.

Danne et al., (2006) presented a research review article reporting the data and conclusions of several studies. The group cited a 2003 study conducted over the course of one year by Kordonouriby and colleagues which documented lower HbA1c levels in children 12 and younger on CSII treatment as compared to children on MDI regimen. Danne et al. also noted that patients in the Kordonouriby et al. study who were on CSII treatment “had a more favorable development of body weight and significantly lower daily insulin requirements than those with MDI over 1 yr” (p. 26). Danne et al. lauded the new technology of insulin pumps that now includes electronic memory read-outs of blood glucose readings. The group also recommended a team effort between health care personnel and the families of youth with Type 1 diabetes in order to maintain good diabetic management. “In conclusion, good arguments can be found for selecting many pediatric patients for CSII. Apart from an apparent lack of the ability to understand and use the technology, few contradictions can be found for pumps in kids” (Danne et al., p. 27).

Sullivan-Bolyai, Knafl, Tamborlane, and Grey (2004) chronicled their qualitative study conducted to report on parents of children with Type 1 diabetes and their experience of converting from MDI to using CSII for their child's insulin therapy. Parents were interviewed and results compiled through the use of NVivo software. The researchers surmised from the five major themes of the study that the insulin pump provided all members of the family with a renewed sense of freedom for life's activities. Sullivan-Bolyai et al. concluded that "CSII is an excellent tool for improving glucose control in young children with type 1 diabetes and for giving parents back some semblance of the life they knew before their children were diagnosed" (p. 322).

Mack-Fogg, Orlowski, and Jospe (2005) conducted a study to determine if CSII treatment was trustworthy and efficient for preschoolers and elementary students with Type 1 diabetes. Seventy participants joined in the study which was conducted by evaluating data from clinic visits of the children. Weight, blood glucose monitoring, and HbA1c data were gathered and evaluated. As per Mack-Fogg et al.:

> The results of this study demonstrate that CSII improves control, as measured by HbA1c, without increasing the frequency of severe hypoglycemia in a self-selected population of young children. These include quality of life issues for the child and family, use of pumps in a broader cross-section of the pediatric diabetes population, and a better understanding of glucose variability while using CSII (p. 20).

Mack-Fogg et al., for the most part proponents of CSII treatment, also reported an alarming trend among pediatric endocrinologists. Pediatric endocrinologists have been known to be cautious "about offering CSII to younger children. This hesitancy arose from concerns centered around potentially increasing the incidence of hypoglycemia and the subsequent negative effects on cognitive development" (p. 19).

Battelino (2006) noted that, "With all of the demonstrated benefits of CSII treatment, good metabolic control still depends on SMBG" (p. 22). Thus self-monitoring of blood glucose (SMBG) can make a difference in HbA1c with CSII treatment or MDI treatment as long as there was daily continuous SMBG. Battelino (2006) stated that "the final success of any treatment modality still largely depends on the enthusiasm and skill of every member of the multidisciplinary team, including the diabetes nurse specialist, dietitian, social worker, and pediatric endocrinologist" (p. 22). Such a team can be created using CSII or MDI. Danne et al. (2006) acknowledged that some medical clinics require high diabetic knowledge and tight blood glucose control readings before allowing a patient to begin CSII. Such standards may include:

> Appropriate knowledge (carbohydrate counting, correcting abnormal blood glucose, understanding sick-day management), skills (performing 4-6 self blood glucose tests/day, inserting catheter, dosing with trial pump), and attitudes (willing to wear pump, motivation) or certain metabolic criteria for CSII [such as A1c < 8.5%, no recurrence of diabetic ketoacidosis (DKA) in past year] (p. 26).

Sullivan-Bolyai et al. (2004) were careful to record parent fears and concerns as their children with Type 1 diabetes made the switch from MDI to CSII in their qualitative study:

> Several parents, including a few fathers, initially hesitated to have their children on the "mini life-support system." Some worried that the catheter would fall out or that the pump would malfunction and the child would receive too much insulin. Several fathers expressed fears that other children at school might press buttons out of curiosity or would bully the child. One father expressed sadness (while being resigned because of improved glucose control) that his child would carry an "albatross," constantly reminding him that he had diabetes. Another father initially didn't like the "harness" and was concerned that

> his son not be stigmatized by it. A few parents with very young children initially expressed concern with the size and weight of the pump (p. 319).

Parents in the study noted that while CSII treatment had its advantages to MDI therapy, it was by no means a cure for diabetes. CSII still took vigilance and care by both the child and the diabetic management team to ensure good glycaemic control (Sullivan-Bolyai et al.).

Sherr and Tamborlane (2008) cited several studies in their article, one by De Beufort and colleagues in 1989, and the other by Pickup and colleagues in 2002, which both "demonstrate that the CSII arm had significantly lower HbA1c levels" (p. 354). In addition, Sherr and Tamborlane (2008) reported that the Lawson-Wilkins Drug and Therapeutics Committee, along with a consensus committee that studied the evidence in favor of utilizing the insulin pump in pediatrics, determined that CSII is "the most physiologic method of insulin delivery currently available. It was also noted that CSII offers the possibility of more flexibility and more precise insulin delivery than MDI" (p. 356).

Battelino (2006) noted in his article that "clinical studies demonstrate that CSII therapy reduces glycosylated hemoglobin A1c (HbA1c) with a concomitant decrease in the rate of hypoglycemic events, without excessive weight gain and with an increase of patients' treatment satisfaction in all pediatric age groups" (p. 20). Danne et al. (2006) joined the fray by stating that "although the average glycemic control is not very different from those on multiple daily injections, fewer patients are seen in the segment of very high and very low HbA1c with CSII" (p. 25).

Finally, there was the reminder that the study conducted by Mack-Fogg et al., (2005) resulted in "the mean HbA1c decreased significantly during CSII" and "hypoglycemic episodes decreased with CSII in the 10- to 12-yr-old group ($p < 0.02$) and demonstrated a strong trend (mean of 0.46-0.22 events per patient year, $p < 0.06$) overall" (p. 17). The convenience and popularity of the latest technology in terms of diabetic care is buffered by parent and child fears of the unknown and, also, the cost of the new technology. While the 504 diabetic management team must leave the treatment choice, MDI versus CSII, up to the parent, endocrinologist, and the child with T1D, the team members must be knowledgeable and supportive of both insulin treatment methods (Getch et al., 2007).

Critical Theory as Theoretical Framework

Critical theory is the theoretical framework for the dissertation topic chosen for this study. Theories are explanations of how organizations and society, in general, operate:

> Critical theory does not involve mere fault-finding; rather it requires unearthing or deconstructing hidden assumptions that govern society –especially those about the legitimacy of power relationships – and debunking or deconstructing their claim to authority. (Bennett deMarrais & LeCompte, 1999, p. 27).

Critical theory originated in Germany in 1923 with the establishment of the Institute for Social Research at Frankfurt am Main. The institute later became known as the Frankfurt School. Initially the work of the school was a Marxist critique of capitalist society. The group, predominately Jewish researchers, running the school immigrated to France in 1930 because of the Nazi rise to power. Some of the original members were Max Horkheimer, Theodor Adorno, Herbert Marcuse, Frederich Pollack, Franz Neumann, and Eric Fromm (Peters, Lankshear & Olssen, 2003). The group of researchers left France after a few years and headed for the United States. The group was allowed to establish their Institute at Columbia University in New York. In 1950, after the war, the group traced its steps back to Frankfurt, Germany. New members such as Jürgen Habermas and Alfred Schmidt joined at that time (Peters et al., 2003). Horkheimer, director of the Frankfurt School as of 1930, coined the term "critical theory". Under Horkheimer's leadership, the theoretical program of the school became more humanistic and philosophical Marxist, "shifting the frame of reference away from a focus on the economy and exploitation toward a critique of culture and a concern with alienation" (Peters et al., 2003, p. 3). Horkheimer's humanistic version of critical theory eventually led to the philosophies of modern day critical theorists and critical educators. Major contributors to critical theory as we know it today are Paulo Freire, Henry A. Giroux, Maxine Greene, Gloria Ladson-Billings, and Henry Levin to name a few (Torres, 1998). One of the leading critical theorists of the last fifty years was Paulo Freire, the Brazilian philosopher and educator. Born in Recife, Brazil on September 19, 1921, Freire "was a pedagogue who expanded our perceptions of the world, nourished our will, enlightened our awareness of the causes and consequences of human suffering, and about the need to develop an ethical and utopian pedagogy for social change" (Torres, 1998, p. ix).

Lynn, Benigno, Williams, Park, and Mitchell (2006) painstakingly defined and dissected critical theory by recognizing three critical frameworks:

- Marxism/ Neo Marxism, an approach to exploring the effect of capitalism on cultural, social, and political structures, (schools);
- Critical race theory (CRT), which was an analytical method to examining race and racism in the law, society and schools; and
- Critical feminist theory and black feminist theory, which, dissimilar from traditional Feminism, presented an appraisal of gender domination and conveyed a pedagogical approach to altering gender relations.

Lynn et al. quoted Beverly Gordon when defining critical theory:

> Critical theory seeks to understand the origins and operation of repressive social structures. Critical theory is the critique of domination. It seeks to focus on a world becoming less free, to cast doubt on claims of technological scientific rationality, and then to imply that present configurations do not have to be as they are (p. 18).

George Theoharis (2007) conducted a study of a subgroup of principals who were social justice activists in an attempt to augment the practice and comprehension of social justice leadership. Theoharis (2007) based his study predominantly upon critical theory. The researcher noted that, for his study, social justice leadership was defined:

> … to mean that these principals make issues of race, class, gender, disability, sexual orientation, and other historically and currently marginalizing conditions in the United States central to their advocacy, leadership practice, and vision. This definition centers on addressing and eliminating marginalization in schools. Thus, inclusive schooling practices for students with disabilities, English Language Learners (ELLs), and other students traditionally segregated in schools are also necessitated by this definition (p. 223).

The study focused on the identification of principals who were on a mission to seek social justice for marginalized groups of students within their schools. Theoharis (2007) documented both the battles and achievements of the subgroup of principals. The researcher notes "…that social justice cannot be a reality in schools where students with disabilities are segregated or pulled out from the regular classroom, or receive separate curriculum and instruction" (p. 222). These words indicate that Theoharis (2007) was a firm believer in the practice of inclusion of 504 and special education students in the regular classroom. The researcher's intent was to discover how educational leaders accomplish social justice, what type of resistance they encounter on the job, and how, as educational leaders, they cope and persevere in their quest for social justice on their respective campuses. After conducting interviews and synthesizing the information collected, Theoharis (2007) found that the group of principals pursued social justice in their schools by "…(a) raising student achievement, (b) improving school structures, (c) recentering and enhancing staff capacity, and (d) strengthening school culture and community" (p. 231). Pull-out programs for marginalized students such as ELLs and special education students were dissolved as a part of the restructuring programs of the study group of principals, book study groups were organized to facilitate the social justice learning of the school staff, and each principal worked diligently to create a positive congenial school climate by developing cordial relations with staff, students, parents, and the community surrounding the school. The principals in the study also utilized an effective toolbox of proactive strategies to further their quest for social justice in their schools. "These strategies included communicating purposefully and authentically, developing a supportive administrative network, working together for change, keeping their eyes on the prize, prioritizing their work, engaging in professional learning, and building relationships" (Theoharis, 2007, p. 244).

Theoharis (2008) continued his investigation of social justice leadership by conducting a study of seven urban school principals across grade levels, (elementary, middle, and high school). The researcher's goal was to identify the leadership traits of the seven principals which personified a principal's commitment to the pursuit of social justice in the schools. After conducting interviews and synthesizing the information gathered, Theoharis (2008) formulated three shared themes or traits: "arrogant humility, passionate leadership, and a tenacious commitment to social justice" (p. 3). The operational definition of arrogant humility was the conviction of the principal that he or she was correct in pursuing their vision of social justice tempered by the fact that each principal had self-doubts and was willing to admit that they were wrong. The operational definition of passionate leadership was:

> …having a tightly interwoven connection between the principal position and the person doing that job. It is caring so deeply, having such commitment and maintaining sincere enthusiasm about this work that there is little separation between the leadership and the leader (Theoharis, 2008, p. 16).

Finally, the operational definition of a tenacious commitment to social justice, according to Theoharis (2008), is that the principals in the study sustained a fixed and determined focus on equity and justice for their personnel and for themselves. The researcher concluded that "social justice leadership is a calling, not a position for which you apply" (p. 22).

According to Lynn et al. (2006), "not only do critical theorists attempt to discover why oppressive structures exist and offer criticisms of their effects; they also explore the ways in which we can transform our society" (p. 18). In just such a way, the current study, which aimed to report on the 504 Program experiences of the parents of students with Type 1 insulin-dependent diabetes (T1D) in one South Texas public school district, is designed to query parents to discover if social justice has been served for students with chronic illnesses such as T1D in the public schools. One of the parent interview questions asks, "How are the school administrators actively involved as a part of your student's diabetic management team?" The question is intended to measure, through codes and themes developed after analyzing the interview transcriptions, if the educational leaders of a campus are actively involved, as a part of a student's diabetic management team and empathize with the plight and special needs of students with T1D. If so, social justice leadership will, indeed, be served on that campus as the administrator will strive to provide all necessary accommodations for the student with T1D to better serve his or her needs.

Questions commonly asked by critical theorists were: “What determines power?” “Who has the power?” and “How is power utilized to benefit those individuals who are already in power?” (Lynn et al., 2006). In the public schools, administrators have historically had significant power. Administrators may wield such power in a variety of ways dependent upon their leadership traits or individual priorities (Theoharis, 2008). According to the subjects (school principals) of Theoharis’s study (2008), attaining social justice for marginalized students was tantamount to their fervor to become school leaders, and, thus, became part of their daily proceedings.

Critical Theory and Education

Kim and Taylor (2008) used critical theory as the theoretical framework for a study they conducted. The authors chose the theory because they felt it provided “valuable insights for studying the relationship between theory and society” (p. 208). The definition Kim and Taylor (2008) gave for critical theory was as follows:

> Critical theory refers to a school of thought and a process of critique regarding notions of money, consumption, distribution, and production, all of which are promoted by relationships of domination and subordination… Critical theorists consider the ability to look at the contradictions of society and those of education in particular as starting points for developing forms of social inquiry that question what is real verses what should be (p. 208).

Kim and Taylor (2008) understood that a major concern of critical theory was just who benefited from education. Critical theorists generalized that schools systematically work to benefit the dominant group culture so as to ensure the continuation of that group's superiority over marginalized groups. "A school program that is not beneficial to students represents social reproduction and social control and reinforces existing inequalities" (Kim & Taylor, 2008, p. 208). An example of such an inequality was that of the Florida school district, previously mentioned, where kindergartener, Jared Milligan, a Type 1 diabetic, was told he must choose to attend one of five designated "diabetes schools" out of 98 elementary schools in the school district, rather than his own neighborhood school. This arrangement was made in the best interest of the school district rather than in the best interest of Jared, the child with diabetes. If all of the other students were attending schools according to the school zone which included the neighborhood that they lived in, then so should Jared. Fortunately, Jared's parents were knowledgeable enough to get an attorney and team up with the American Diabetes Association. Their alliance was successful in court and Jared won the right to attend his neighborhood school and still received all accommodations that were available at the "five diabetes schools;" hence a victory not only for students with diabetes, but a precedent was set in court for all marginalized groups of students (American Diabetes Association, 2010b).

In another case, as reported by writer Neal Morton in the Sunday, October 16, 2011, edition of the newspaper, *The Monitor,* the mother of Arnold Lopez, an 11 year old with T1D, complained that her son was not given proper accommodations at his elementary campus within the IDEA Public Schools, a Texas charter public school system. On September 8th, 2011, her son needed to use the restroom and a substitute teacher told him he couldn't go. When Arnold persisted and made his way to the door, the substitute barred the door to keep Arnold from leaving the classroom. *The Monitor* reported that:

Arnold said he never faced such discomfort at PSJA's Napper Elementary, where every

> absent teacher left a note specifically explaining his condition to substitutes. The humiliating incident could have been prevented, mother Marina Lopez said, if campus leaders and staff met with her before his transfer to the charter school's Alamo campus in August (Morton, 2011, p. 1A).

As a result of the incident, the mother, Marina Lopez, lost confidence in the IDEA Alamo elementary campus. She no longer trusted that the staff would accommodate her son's T1D to keep him safe and healthy at school. "Frustration high, Lopez eventually transferred her son to Sauceda Middle School in Donna on Sept. 20" (Morton, 2011, p. 1A). The newspaper article went on to document that, "Any schools, including charters, that accept federal education funds must provide proper diabetic care under Section 504 of the Americans with Disabilities Act" (Morton, 2011, p. 15A).

Douglas Kellner (2003) suggested developing a critical theory of education for the new millennium. Kellner (2003) argued that "democratic reconstruction of education needs to build on and synthesize perspectives of classical philosophy of education, Deweyean radical pragmatism, Freirean critical pedagogy, poststructuralism, and various critical theories of gender, race, class and society" (p. 51). According to Kellner (2003) there was a tremendous need for change in education as a result of the Great Transformation brought on by the current technological revolution across the globe. Along with the technological revolution, demographic and socio-political changes were taking place worldwide caused by immigration patterns. Racial and ethnic diversity was apparent throughout many countries. "This creates the challenge of providing people from diverse races, classes, and backgrounds with the tools and competencies to enable them to succeed and participate in an ever more complex and changing world" (p. 52). The current study will undoubtedly include several, if not all, subjects in the sample population who are Hispanics from a low socio-economic background. Not only are students with T1D from the sample population a minority and possibly marginalized group because of their chronic illness, but the Hispanic population in Texas has historically been a minority and marginalized group, thus tying the study to a quest for social justice and a Critical Theory framework.

Kellner (2003) explored critical theory in depth. Critical theory was originally developed in the Frankfurt School. Kellner, however, embraced a broader version of critical theory which was developed by German-American exiles. In the Enlightenment project, license was given to question and criticize authority:

> The Kantian sense of critique, for example, required putting in question all the ideas of reason, morality, religion, aesthetics, and other dominant ideas to see if they could be well grounded and legitimated. Kantian critique aims at autonomy from prejudice and ill-grounded ideas and requires rigorous reflection of one's presuppositions and basic positions and argumentation to support one's views (p. 53).

Later, although Marx never fully developed his philosophy of education, his idea of socialism did include a free and public education for the masses; it was required to free them from the heel of the ruling class (Kellner, 2003). In the twentieth century, John Dewey built upon Marx's idea of a free and public education. Dewey's idea of a progressive education was to link education and democracy (Kellner, 2003):

> For Dewey, education was the key to making democracy work since in order to intelligently participate in social and political life, one had to be informed and educated to be able to be a good citizen and competent actor in democratic life (Kellner, 2003, p. 55).

Paulo Freire, operating from Brazil in the 1960's, argued for emancipatory education. Emancipatory education proposed that the poor oppressed underclasses should educate themselves (Kellner, 2003):

> Freire perceived that education is often a form of indoctrination, of enforcing conformity to dominant values, and of social reproduction in which one is tutored into submission and accepting an oppressed and subordinate status. Therefore pedagogy of the oppressed must oppose dominate conceptions of education and schooling and develop more critical and emancipatory pedagogies aiming at radical social transformation (Kellner, 2003, p. 56).

Mary Wollstonecraft, a classical feminist, was a pioneer in education after the French revolution. She believed that society should be restructured to enable women to have the same privileges as men in the areas of education, business, politics, and cultural life (Kellner, 2003):

> Wollstonecraft argued that education is the only way for women to better themselves, that if women do not pursue education they cannot be emancipated, they cannot be participants in society, they cannot be equal to men and thus the Enlightenment project cannot be realized (Kellner, 2003, p. 56).

In conclusion of his review of critical theorists, Kellner (2003) made the interesting observation that all of the theorists he studied declared that education was the key to social enhancement and reform.

Critical Theory Conclusion

In this review of critical theory as a framework for this study, the history of the evolution of critical theory and its origin in the Frankfurt School was reviewed and summarized to discern what researchers have to say about critical theory and its practical application in the field of education today. Critical theory is all about changing societal attitudes, enacting social justice, and thus changing the world that we live in through awareness of problems and communication to foster needed change (Bennett deMarrais & LeCompte, 1999). A study by Theoharis (2007), which concentrated on the identification of social justice leaders in the public schools, was also reviewed. Theoharis (2007) was determined to uncover how principals achieved social justice, what type of struggles they confronted daily on the job, and how they persisted and endured in their quest for social justice on their respective campuses. A consecutive study was published by Theoharis in 2008. The intended goal of the second study was to recognize the leadership traits of seven principals committed to the quest for social justice in their schools. Critical theory, with an emphasis on social justice administrative leadership, relates specifically to the topic of this study, i.e., as the purpose of the study is to report on the 504 Program experiences of the parents of students with Type 1 insulin-dependent diabetes (T1D) and to give parents a voice. The subjects of this study were parents of a child with T1D, a minority and possibly a marginalized group in the public schools. Most of the parents were of Hispanic decent, a minority group in the United States, thus tying the study to Critical theory and a quest for social justice.

The well-educated and privileged members of American society may be more likely to speak up or demand their rights. Less educated or underprivileged individuals may not understand their rights or be hesitant to speak up (Lynn et al., 2006). The possibility was posed earlier in the introduction section of this research that individuals in positions of power in the public schools, (administrators, counselors, nurses, and teachers), may pay more attention to the needs of students with T1D who have parents that are well educated and come from a middle class to wealthy background than to those students who hail from a lower socio-economic background. There is a possibility that some students, because of their backgrounds, may be discounted or disregarded (Kim & Taylor, 2008). Again, such valuable feedback helped shed light on whether or not all of the parents interviewed in the study, no matter their socio-economic backgrounds, believed that their child with T1D was receiving appropriate school services and accommodations to facilitate successful learning outcomes in the classroom.

Chapter Two Summary

In Chapter Two, procedures for determining Section 504 accommodations were examined. Studies linked to communication between the parents of students with T1D and the schools were explored along with a report on recent studies, trends and priorities in diabetes care which have influenced the subpopulation of the current research study, the student with Type 1 diabetes. Finally, the practical and theoretical framework supporting the study, Critical Theory, with an emphasis on social justice leadership, was also reviewed.

CHAPTER III

DESIGN OF THE STUDY

The focus of this qualitative study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. Data collection consisted of a review of the Individualized Health Plan (IHP), which includes an Emergency Care Plan (ECP), for each student selected for the study. A review of students' IHPs revealed the types of accommodations agreed upon at each individual school within the district. Additionally, this study includes individual parent interviews that were audio-taped, transcribed, coded and analyzed, and a review of students' records to explore the research questions.

Research Questions

Several issues of concern to parents of students with Type 1 diabetes (T1D) constituted the research questions addressed in this study. The research questions were:

1. How do parents of students with Type 1 insulin-dependent diabetes describe their experiences and satisfaction with school services provided through the 504 program for their children and the quality of communications between and among the members of the 504 team?
2. What are the perceptions of parents of students with T1D about the best 504 practices and accommodations to help facilitate their child's learning in the classroom?

3. According to the perceptions of parents of students with T1D, what concerns and suggestions for improvement do they have regarding their student's overall care at school?

Methodology

Research Design

The study was qualitative, utilizing a descriptive research design that resulted in a multiple case study to answer the research questions. Qualitative research involves the accumulation, examination, and comprehension of an account and observable information with the purpose of procuring valuable awareness into a specific reality (Gay, Mills, & Airasian, 2006). In addition, these authors defined descriptive research as "research that determines or describes the way things are; involves collecting numerical data to test hypothesis or answer questions about the current subject of study" (p. 597). A case study, according to Creswell (2007), involves the researcher choosing "a site or sites to study, such as programs, events, processes, activities, individuals, or several individuals" (p. 122). A multiple case study is the study of numerous individuals that share some common criterion (Creswell, 2007). Similarly, Denzin and Lincoln (2005) described a multiple case study or collective case study as "a number of cases [which] may be studied jointly in order to investigate a phenomenon, population, or general condition" (p. 445).

After careful consideration of various research options, it was determined that the best way to uncover valuable information for the study would be to employ a descriptive research design resulting in a multiple case study. This design was selected because the study reports on the 504 Program experiences of parents of students with T1D in one South Texas public school district. Parents of students with T1D were interviewed and a case was written on each family based on the transcript of the interview. The researcher looked for common themes among the six cases and eventually reported the findings. The researcher is hopeful that when distributed to key personnel of the school districts, the information and feedback from the study, both positive and negative, will be used to enhance the quality of life and education of students with T1D and enhance leadership's response to the disease.

Population and Sample (Subjects)

The sample of parents for this study was drawn from parents of the total population of 30 kindergarten through 12th grade students with T1D who attend school in one large public school district located in south Texas, 15 miles north of the Mexican border. Purposeful sampling was used to select six sets of parent subjects from the population of 30 students with T1D in this single district. Creswell (2007) acknowledged that the concept of purposeful sampling is appropriate and common in qualitative research. Purposeful sampling "means that the inquirer selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study" (p. 125). Denzin and Lincoln (2005) noted that "…collective casework regularly requires cases to be chosen. Achieving the greatest understanding of the critical phenomena depends on choosing the case well" (p. 450).

Typology of sampling strategies in qualitative research is called maximum variation. Creswell (2007) stated that he prefers "to select unusual cases in collective case studies and employ maximum variation as a sampling strategy to represent diverse cases and to fully describe multiple perspectives about the cases" (p. 129). Such was the case in this research study. Maximum variation was the goal. The researcher strived to select sets of parents of students with T1D from different points on the spectrum based on six different criteria: 1) Income level, (low, middle to high), three from each category; 2) Primary Language Spoken, (three English speakers, three Spanish speakers); 3) Multiple Daily Injection (MDI) treatments or Continuous Subcutaneous Insulin Infusion (CSII) treatment, three of each (Battelino, 2006); 4) School Attendance, three 85 percent or lower and three 86 percent or higher; 5) grade levels 3rd, 5th, 7th, 8th, 9th, 12th (one from each grade listed); and 6) schools, one student with T1D from each of six different schools.

The researcher e-mailed the “Nurse-to-Parent Telephone Script Directions” form (Appendix A) and both the English and Spanish versions of the “Nurse-to-Parent Telephone Script” forms (Appendix B and C) to the district’s nurse coordinator. After contacting the nurses at the schools which house students with T1D, the nurse coordinator forwarded the “Nurse-to-Parent Telephone Script Directions” form and the “Nurse-to-Parent Telephone Script” forms to the school nurses at each identified campus. The school nurse at each campus contacted the parents by phone and explained the study using the “Nurse-to-Parent Telephone Script” verbatim. If the parent was in agreement to participate in the research study, the nurse obtained verbal permission to give the parent phone number to the researcher to facilitate setting up the interviews.

Six sets of parents were chosen for interviews from the original 30 sets of parents that agreed to be contacted by the researcher for an interview. Had the researcher not been able to generate at least 18 parent consent forms, of which six were chosen to participate in the study, the researcher would have worked with the school nurses to contact parents again requesting their participation. This back-up strategy was not needed since a sufficient number of parent consent forms were received.

Criterion One. Criterion one represents income levels of the participants chosen. The researcher chose three students that represent each of the categories of low or middle to high incomes.

Table 1

Sampling Criterion of Chosen Respondents: Income

Parent of T1D Pseudonyms	Income	Language	MDI or CSII	Attendance	Grade	School
Parent A	Low					
Parent B	Mid/High					
Parent C	Mid/High					
Parent D	Mid/High					
Parent E	Low					
Parent F	Low					

Criterion Two. Criterion two reflects the ethnicity and language spoken in the home. Every effort was made to ensure that three Spanish speaking parents and three English speaking parents were chosen.

Table 2

Sampling Criterion of Chosen Respondents: Language

Parent of T1D Pseudonyms	Income	Language	MDI or CSII	Attendance	Grade	School
Parent A	Low	English				
Parent B	Mid/High	English				
Parent C	Mid/High	English				
Parent D	Mid/High	Spanish				
Parent E	Low	Spanish				
Parent F	Low	Spanish				

Criterion Three. Criterion three designates the method of insulin treatment that was utilized by each student in the study. The researcher selected three students using the MDI treatment and three students using the CSII treatment.

Table 3

Sampling Criterion of Chosen Respondents: MDI or CSII

Parent of T1D Pseudonyms	Income	Language	MDI or CSII	Attendance	Grade	School
Parent A	Low	English	CSII			
Parent B	Mid/High	English	CSII			
Parent C	Mid/High	English	CSII			
Parent D	Mid/High	Spanish	MDI/CSII			
Parent E	Low	Spanish	MDI			
Parent F	Low	Spanish	MDI			

Criterion Four. Criterion four was the school attendance percentage of the student with T1D. The researcher made every effort to choose three students with an 85 percent or lower attendance percentage and three students with an 86 percent or higher attendance percentage.

Table 4

Sampling Criterion of Chosen Respondents: Attendance

Parent of T1D Pseudonyms	Income	Language	MDI or CSII	Attendance	Grade	School
Parent A	Low	English	CSII	< 86%		
Parent B	Mid/High	English	CSII	> 85%		
Parent C	Mid/High	English	CSII	< 86%		
Parent D	Mid/High	Spanish	MDI/CSII	> 85%		
Parent E	Low	Spanish	MDI	< 86%		
Parent F	Low	Spanish	MDI	> 85%		

Criterion Five. Criterion five reflects the expected grade levels for the sample. The researcher chose one student from the following grades: three, five, seven, eight, nine, and twelve.

Table 5

Sampling Criterion of Chosen Respondents: Grade

Parent of T1D Pseudonyms	Income	Language	MDI or CSII	Attendance	Grade	School
Parent A	Low	English	CSII	< 86%	7th	
Parent B	Mid/High	English	CSII	> 85%	9th	
Parent C	Mid/High	English	CSII	< 86%	12th	
Parent D	Mid/High	Spanish	MDI/CSII	> 85%	5th	
Parent E	Low	Spanish	MDI	< 86%	8th	
Parent F	Low	Spanish	MDI	> 85%	3rd	

Criterion Six. Criterion six reflects the different schools represented in the sample. The researcher chose one student from each of six different schools in the district.

Table 6

Sampling Criterion of Chosen Respondents: School

Parent of T1D Pseudonyms	Income	Language	MDI or CSII	Attendance	Grade	School
Parent A	Low	English	CSII	<86%	7th	Middle
Parent B	Mid/High	English	CSII	>85%	9th	High
Parent C	Mid/High	English	CSII	<86%	12th	High
Parent D	Mid/High	Spanish	MDI/CSII	>85%	5th	Elem.
Parent E	Low	Spanish	MDI	<86%	8th	Middle
Parent F	Low	Spanish	MDI	>85%	3rd	Elem.

The researcher attempted to approximate the maximum variation of sampling subjects. However, there were certain limitations to accomplish the goal of maximum variation dependent upon the criteria of the parent participants who ultimately agreed to join the study.

The Researcher’s Role

In order to gain entry to the research site, it was necessary to first gain approval from the superintendent of schools. Once approval was granted, the researcher met with select members of the district’s administrative team. This meeting included the superintendent of schools, the assistant superintendent for support services, the district’s nurse coordinator, and the district’s 504 coordinator. Once assembled, the researcher briefed the administrative team on the purpose of the proposed study, the role of each administrative member, and the timeline for the study. A question and answer session followed with the researcher answering questions demonstrating and establishing the level of integrity and credibility of both the researcher and the study. The researcher provided a copy of the proposed research, the interview protocol, the letter of consent and a copy of the IRB submitted to the university personnel. This is in accordance with the guidelines recommended by Gay et al. (2006), wherein the authors state, "In qualitative research, where the 'researcher is the instrument,' it is critical to the success of the study that the researcher establish his 'OKness' with the study's participants" (p. 87), and the ethical protocols at the UTPA.

Data Collection Procedures

In September 2011, permission was granted from the south Texas public school district through a letter sent to the superintendent of schools, followed by a meeting with the aforementioned administrative team. Approval was granted for the study by the superintendent of schools. The researcher sought approval from the Institutional Review Board (IRB) at the University of Texas-Pan American located in Edinburg, Texas, and was approved.

The subjects of this study were the parents of students with T1D. The school district nurse coordinator contacted the nurses at each campus that houses a student or students with T1D. The researcher e-mailed the "Nurse-to-Parent Telephone Script Direction" form (Appendix A) and both the English and Spanish versions of the "Nurse-to-Parent Telephone Script" forms (Appendix B and C) to the district's nurse coordinator. After contacting the nurses at the schools which house students with T1D, the nurse coordinator forwarded the "Nurse-to-Parent Telephone Script Direction" form and the "Nurse-to-Parent Telephone Script" forms to the school nurses at each identified campus. The school nurse at each campus contacted the parents by phone and explained the study using the "Nurse-to-Parent Telephone Script" verbatim. If the parent was in agreement to participate in the research study, the nurse secured verbal permission to give the parent phone number to the researcher to facilitate setting up the interviews. Along with the parent phone number, the nurse included information on each student with T1D as follows: whether or not the student was on Medicaid; the primary language, English or Spanish, spoken in the home; the method of insulin treatment, (MDI or CSII); the 2011-2012 student attendance record; the student's grade in school; and the name of the school that the student attended. This information helped to meet the six criteria to achieve maximum variation when selecting the subjects for the study.

Six sets of parents were chosen for interviews from the original 30 sets of parents who have a child with T1D in the south Texas school district. All 30 sets of parents verbally agreed to be contacted by the researcher for an interview. However, only 25 sets of parents followed through with the necessary contact information needed by the researcher to conduct the study. The nurse coordinator compiled a confidential list of the 25 sets of parents including parent and student information based on the six sample selection criteria of the study. The list, excluding names and phone numbers, was given to the researcher to expedite final selection of the six sets of parent participants for the study based on the six sample selection criteria to achieve maximum variation. After the researcher chose the six sets of parent participants for the research study, the nurse coordinator gave the researcher the names and phone numbers of the chosen participants and the researcher contacted all six to set up interviews during the month of December 2011.

A copy of the parent informed consent form in English may be found in Appendix D and the Spanish version may be found in Appendix E. The Spanish versions of the "Nurse-to-Parent Telephone Script" form, parent informed consent form, and the interview protocol were translated from English into Spanish through utilization of the translation option on Microsoft Office 2007. To ensure accuracy of the translations, a certified high school Spanish teacher read the translated documents twice, and the necessary corrections were made.

Six sets of parents were chosen for interviews from the original 30 sets of parents that were contacted by the school nurses. Parents were selected based on different combinations of the six criteria of the critical phenomena, students with T1D. The researcher strived to select parents of students with T1D who met the following criteria: 1) Income level, (low, middle to high), three from each category; 2) Primary Language Spoken, (three English speakers, three Spanish speakers); 3) Multiple Daily Injection (MDI) treatments or Continuous Subcutaneous Insulin Infusion (CSII) treatment, three of each (Battelino, 2006); 4) School Attendance, three 85 percent or lower and three 86 percent or higher; 5) grade levels 3rd, 5th, 7th, 8th, 9th, 12th (one from each grade listed); and 6) schools, one student with T1D from each of six different schools. The researcher was able to generate 25 parent consent forms, from which six were chosen to participate in the study to meet the selected criteria as closely as possible.

The following table reflects the six sample selection criteria of the parents of students with T1D who were ultimately chosen for the study.

Table 7

Final List of Chosen Respondents

Parent of T1D Pseudonyms	Income	Language	MDI or CSII	Attendance	Grade	School
Parent A	Low	English	CSII	30 %	7th	Middle
Parent B	Mid/High	English	CSII	79 %	9th	High
Parent C	Mid/High	English	CSII	74 %	12th	High
Parent D	Mid/High	Spanish	MDI/CSII	97 %	5th	Elem.
Parent E	Low	Spanish	MDI	82 %	8th	Middle
Parent F	Low	Spanish	MDI	81 %	3rd	Elem.

Before beginning each interview, the parent was asked to read and sign a consent form, a release for recording during the parent interview form, and a release of records form for the students with T1D for assurance of Human Subjects Protection. The parent consent forms were printed in English and Spanish (See Appendix D and E). The researcher went "…over the purpose of the study; the amount of time that was needed to complete the interview; and plans for using the results from the interview" (Creswell, 2007, p. 134).

Six individual, semi-structured, open-ended, one-on-one interviews, approximately one hour in duration were conducted with the parent subjects during the month of December 2011 (See Appendix F and G). Interviews were scheduled at the parents' convenience, preferably in their homes, which added valuable observable data to each case. If meeting in the home of a student with T1D, the parent(s) were asked to provide a low-traffic room to ensure privacy and a quiet locale free of interruptions, if possible. The parent interviews were audio-taped and, if warranted, an English-Spanish CITI certified translator was present, as the researcher is not fluent in Spanish. The English-Spanish CITI certified translator is an employee of UTPA. The English-Spanish CITI certified translator maintained complete confidentiality. Lapel mikes were used to better guarantee the intelligibility of the audio-taped interview. Creswell (2007) admonishes the interviewer to "…stay to the questions, complete the interview within the time specified, (if possible), be respectful and courteous, and offer few questions and advice" (p. 134).

As suggested by Creswell (2007), an interview protocol consisting of a header and ten open-ended queries on a ten page data sheet was utilized at each interview to record the researcher's notes of the parent responses (See Appendix F and G). This was in addition to the audio-recordings. Creswell (2007) suggested that the questions should be "a narrowing of the central question and sub questions in the research study" (p. 133). The header of the interview protocol consisted of a reminder to the researcher to repeat the purpose of the study and to encourage the interviewee(s), (parent(s)), to relax and talk freely in response to the open-ended interview questions, promising identity confidentiality. At the end of the interview protocol there was a reminder to the researcher to thank the parent(s) for participating in the interview (Creswell, 2007).

Data Analysis Procedures

Documents. Data was collected during the parent interviews, using the procedures described in the previous subsection. The interviews were audio-taped and transcribed verbatim. The researcher hired a CITI certified transcriber to complete the transcriptions. Special arrangements were made for the services of a CITI certified, native-speaking Spanish transcriber for transcriptions in Spanish. The transcriptions were then translated from Spanish into English through utilization of the translation option on Microsoft Office 2007. To ensure accuracy, the CITI certified Spanish transcriber, who also acted as the original English-Spanish CITI certified translator, read the original Spanish transcription twice and compared it to the English translation to guard precision.

Once the transcriptions were complete, the researcher analyzed the raw data of each set of parents into codes. The codes were then organized into the emerging themes of the parents' voices. "These themes can be and often are 'headings' used in a qualitative study" (Creswell, 2007, p. 169). Once the recurrent themes of the individual parent interviews were identified, the researcher searched for common themes between and among the different sets of parents. Then the parent interview data from the six sets of parents were examined and reexamined according to the emergent themes.

Validity (trustworthiness) and reliability (consistency and predictability) are key components of any research study. According to Gay et al. (2006), validity "is the degree to which qualitative data accurately gauge what the researcher is trying to measure" (p. 603). Gay et al. (2006) define reliability as "the degree to which a test (or qualitative research data) consistently measures whatever it measures" (p. 601). Creswell (2007) described eight validation strategies which have been used historically by qualitative researchers. He suggested that, "qualitative researchers engage in at least two of them in any given study" (p. 209).

Three validation strategies were utilized in this research study: rich, thick description; member checking; and peer review or debriefing. The first strategy, rich, thick description, "describes in detail the participants or setting under study. With such detailed description, the researcher enabled readers to transfer information to other settings and to determine whether the findings can be transferred …" (Creswell, 2007, p. 209).

Member checking, the second strategy, involved examining data, analytic categories and thematic conclusions with members of stakeholder groups from whom the data was originally collected (Creswell, 2007). According to Lincoln and Guba (1985), member checking is "the most critical technique for establishing credibility" (p. 314). For this study, the researcher let the parent interviewees know that after the researcher transcribed the taped interviews, analyzed the raw data into codes, and discerned the emerging themes of the various parent voices, the researcher, with consent from the interviewee, scheduled a second meeting with each interviewee at the interviewee's convenience "so that they can judge the accuracy and credibility of the account" (Creswell, 2007, p. 208).

The third strategy, peer review or debriefing, "provides an external check of the research process" (Creswell, 2007, p. 208). During the process of data analyses, coding, and determining emergent themes of the parents' voices, the researcher met with a peer de-briefer:

> an individual who keeps the researcher honest; asks hard questions about methods, meanings, and interpretations; and provides the researcher with the opportunity for catharsis by sympathetically listening to the researcher's feelings. This reviewer may be a peer, and both the peer and the researcher keep written accounts of the sessions, (Creswell, 2007, p. 208).

The peer was CITI certified and a member of the researcher's doctoral cohort.

Reliability was addressed in the study by giving careful thought and consideration to purchasing the best quality tapes for recordings and transcriptions of those recordings to ensure accuracy of parent responses during the interview process (Creswell, 2007). Creswell (2007) noted that “the tape needs to be transcribed to indicate the trivial, but often crucial, pauses and overlaps” (p. 209). Further, a codebook was developed to identify code names and match them to certain colors. The codebook included themes categorized under headings with passages and quotes identified under each of those headings (Creswell, 2007).

Auditability of the study was determined by the paper or “audit” trail amassed during the entire research process. The audit trail began with the superintendent research study approval, IRB paperwork and parent consent forms, and continued throughout the interview process and beyond by including interview protocols, (original interview notes), original tape recordings, transcriptions, color-coded transcriptions, codebook, and notes from member checks and peer debriefings. In short, a filing system was strictly maintained in order to preserve the raw data, which authenticates the research study. By analyzing and synthesizing the organized data with the help of rich, thick description, member checks, peer debriefings, quality tape recordings, transcriptions, and audit trails, the researcher successfully integrated the analyses in relation to the research questions. The findings of the qualitative research study were reported in dissertation writing.

Ethical Considerations

Gay et al. (2006) stated that “demonstrating sensitivity to possible ethical issues that may arise in conducting the study is critical to the success of the qualitative research plan” (p. 88). Therefore the researcher of this qualitative study realized the importance of presenting a condensed proposed study, the parent consent form, (See Appendix D and E), and the open-ended parent interview questions based on the research questions, (See Appendix F and G), respectively, to the IRB. Further, Denzin and Lincoln (2005) stated that:

> Case studies often deal with matters that are of public interest but for which there is neither public nor scholarly right to know. Funding, scholarly intent, or Institutional Review board authorization does not constitute license to invade the privacy of others (p. 459).

The identity of the school district from which parent participants were chosen was referred to as “one south Texas public school district.” The six identified parent subjects were given pseudonyms to assure anonymity. During the process of an individual interview or at any time during the course of the study, a parent participant had the opportunity to refuse to respond to any question or drop out of the study at any time without harm. No ethical dilemma arose, and the researcher adhered to strict ethical propriety.

Limitations of the Study

This study cannot be generalized to all parents of students with T1D because the study is designed to take place in one south Texas public school district located close to the Mexican border with the majority of the students of Hispanic descent. The results of the study may be different in other parts of the state or in other states depending on district or state interpretation of *Section 504 of the 1973 Rehabilitation Act* and the passing of Texas *House Bill (HB) 984* which directly benefits the student with T1D.

Timeline for Work

Permission was sought from the south Texas public school district through a letter sent to the superintendent of schools during the month of September 2011. Once the researcher had a signed letter from the superintendent, the researcher sought approval from the Institutional Review Board (IRB) at the University of Texas-Pan American located in Edinburg, Texas. Once the IRB granted approval of the proposed study, the researcher contacted the district’s nurse coordinator who, in turn, contacted the nurse at each campus which housed a student with T1D to seek the parent’s verbal approval for participation in the study. The researcher’s hope was to complete and defend the dissertation proposal as soon as possible, in order to be granted final certification by the Program Director and Associate Vice President for Graduate Studies and be considered “advanced to candidacy.”

The researcher’s timeline allowed for the parent interviews to be conducted during the month of December 2011. Interview transcriptions, coding, and emergent themes were analyzed and synthesized during the month of January 2012. Chapter Four, Chapter Five, and Chapter Six of the dissertation were written during February and March 2012. The final draft of the dissertation was submitted to the co-chairs by spring of 2012 with the hope of defending the final dissertation in early May 2012 in anticipation of a May 2012 graduation date.

CHAPTER IV

PRESENTATION OF DATA

The purpose of this qualitative study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. The study utilized a descriptive research design, resulting in a multiple case study to answer the research questions. The study included six individual parent interviews that were audio-taped, transcribed, coded and analyzed, and a review of students' records to address the research questions. The stories of the six families interviewed in the study needed to be told in order for the readers of this dissertation to understand the reality of each family's background and their living situation as they interact with the public schools. A pseudonym was used for the name of each child with Type 1 diabetes to maintain complete confidentiality.

Parent A

Magdalena Ledezma was born in 1998. She was diagnosed with Type 1 diabetes on March 5, 2009, when she was ten years old, during her fifth grade year in elementary school. She was suffering from a urinary tract infection and her mother took her to a health clinic. The doctor at the clinic ran a urine test. When he came back to the examination room to confer with Magdalena's mother, he told her, "She has a urinary tract infection. Oh, and by the way, she's a Type 1 diabetic." At that time, Magdalena's mother did not know what T1D was. The doctor said he was referring Magdalena to a hospital and his nurse would make the arrangements and then call her. The doctor gave Magdalena's mother antibiotics for the urinary tract infection, but did not give her any diabetic supplies such as a glucometer, blood glucose test strips, or insulin.

The clinic nurse never called and within a day or two, Magdalena's condition was rapidly deteriorating. "She was trembling, vomiting, pale, and had lost weight and was drinking a lot of water and urinating a lot," stated Magdalena's mother. She called for an ambulance and Magdalena was transported to the emergency room. At the hospital, Magdalena's sugar was over 500. The emergency room doctor began insulin therapy on Magdalena and then discharged her, referring her to a nutritionist who trained the mother on diabetic care. For the first year that Magdalena was a T1D she was given four or five injections a day. She was in and out of the hospital. The emergency room doctors accused Magdalena of sneaking food and her mother of preparing a poor diet for her daughter. In October of 2010, when Magdalena was in the sixth grade, her endocrinologist began insulin pump therapy on Magdalena. He trained both Magdalena and her mother. Magdalena caught on quickly to the mechanisms of her new insulin pump and completely operated the devise on her own. She preferred to wear the catheter of the insulin pump on her stomach. Magdalena was a 13 years old seventh grader at the time of the study. She lived with her single parent mother in a low income apartment complex and qualified for Medicaid. English was the primary language spoken in the home. She attended three schools in the same community since she began middle school as a 6th grader.

Magdalena answered the door when the researcher arrived at her modest home for the interview with her mother. She was of medium height and build with shoulder length, dark brown full hair, parted in the middle. Her hair was streaked with a dull red tint. Magdalena looked at the researcher with big brown eyes peering through her spectacles while sporting a huge friendly grin on her face. As she welcomed the researcher into her home, a little yappy dog began incessantly barking until Magdalena gently scooped him up and cradled him in her arms. She called to her mother, in the kitchen beyond, that the expected company had arrived.

Magdalena's mother, appearing to be in her early thirties, soon appeared, smiling and extending her hand in welcome to the researcher. It was hard not to notice the array of tattoos she was sporting on both arms and her upper chest. After introductions were made, the researcher was motioned to a seat on the small sofa. There were several boxes cluttering the messy dreary room devoid of Christmas decorations, as the interview was done in the month of December. The mother began to explain that the family had just recently moved to the apartment from a location in town farther north. The main attraction of the family room seemed to be a small 20 inch television set sitting on an entertainment stand which had already been assembled.

The mother situated herself on the couch next to the researcher and the two engaged in small talk for a short time. The mother volunteered that Magdalena suffered from several maladies in addition to T1D. She stated matter-of-factly that Magdalena had Attention Deficit-Hyperactive Disorder (ADHD) and was bi-polar and schizophrenic. She also suffered from recurrent urinary tract infections. Magdalena's mother said they were constantly at the doctor's office or emergency room for one ailment or another. When asked how many times Magdalena had been hospitalized in the last year, the mother stated that it must be "about 20 times." The researcher was inwardly a bit incredulous to the number of hospital or emergency room visits, but was not able to clarify those facts with the mother, as she insisted that, "yes, it must be around 20 times we've been to the hospital." Magdalena's mother also shared that Magdalena's cousin by marriage, who has a lot of mental problems, is promiscuous and is on drugs, had just entered the same school, and the two girls had gotten into an ugly verbal argument that almost got physical in the classroom. As a result, Magdalena's cousin had been moved to a different classroom and the mother was relieved with that outcome.

After going over the informed consent form, the permission for audio-taping the interview and requesting school records form, and obtaining the parent signature on both documents, the researcher explained the interview process with the parent. The interview promptly ensued. Earlier, while her mother and the researcher engaged in casual conversation, Magdalena had walked around the living room hugging and carrying her little dog, occasionally contributing a few words to the conversation. Once the interview questions began in earnest, however, Magdalena grew bored and scampered upstairs to “listen to her music,” a favorite pastime of hers, according to her mother.

When asked questions about the 504 program and the accommodations provided to her daughter in the public school, it became evident that Magdalena’s mother was unaware of many of the benefits of the 504 program. She knew her daughter received school health services, but was unfamiliar with what the program was called, how it worked, and only knew of three accommodations her daughter was given; the buddy system, (where a classmate walked the student with T1D to the nurse’s office when they are feeling the effects of a low or high blood sugar), snacks for low blood sugars, and insulin for high blood sugars in the nurse’s office. She stated:

> The plan there with the 504; it’s that she has a student, a friend of hers or a buddy that would take my daughter to the nurse and that’s when the nurse will do whatever she needs, like give her snacks or whatever she needs to do with her sugar.

She continued:

> I know that my daughter has the snacks with the nurses. She gets her snacks if her sugar is low or they take her there when her sugar is high, as well. Those are the only things that she has for my daughter right now.

When asked if the school principals were aware of her daughter's medical condition and if they were involved in her 504 diabetic management team, the mother acknowledged that the principals were aware of Magdalena's condition and did help look after her. It had previously been established that Magdalena had attended four schools since her initial T1D diagnosis at the end of the third grade. She was pleased with the care and attention her daughter was getting both in the classroom and the nurse's office in her current middle school. She said one of the teachers had called her to find out what symptoms Magdalena displayed when she had a high or a low blood sugar. She also stated that the nurse at Magdalena's current school was on top of things and had even spoken with her daughter's diabetic doctor to clarify patient care orders. Magdalena's mother, however, was not as satisfied with her daughter's care at the elementary school and first two middle schools Magdalena had attended. She stated:

> Well, actually, the only first school I noticed that they were on top of it was (name of third middle school) because the other schools, not even. They never realized what was going on. I explained to them what was going on and it was hard for me to get help through them.

When asked about the changes that were needed to help the 504 Program better determine and implement accommodations, Magdalena's mother said, "The other schools should first acknowledge or listen to the parents at their school and what the children are going through. I mean so they could better understand what's going on." She mentioned the nurse at the elementary school would not cooperate with her and would get mad when Magdalena had high or low blood sugars. The nurse would insist that the mother come and pick her daughter up from school to take her home. Magdalena's mother stated that her daughter's relationship with the nurse at the elementary and at her first middle school was "rocky," but her daughter's relationship with the nurse at the other two middle schools was excellent. When the question, “How has Type 1 Diabetes affected your child’s attendance record and grades in school?” was asked, the mother nervously replied with a laugh, “Do you really want to know?” She acknowledged that her daughter’s attendance and grades were severely affected by T1D. She stated:

> Yes, it has affected her. It has affected her attendance at school severely because she’s been out, you know. She’s been out of school for quite some time and she gets sick and here I go, taking her to the doctors and her grades; she was doing good, but now she is starting to pick them up. So it did affect her a lot.

She approximated that Magdalena had missed close to 45 days of school during her 7th grade year. Magdalena’s mother stated:

> She struggles during the night with low and high sugars or sometimes in the mornings she gets severe high sugars and she won’t control them or the insulin won’t be starting to kick in and that’s when I have to take her at least to the hospital and then she’ll be admitted there for at least two or three days until they know the sugar is already controlled again.

The final question of the interview was, “What concerns do you have regarding your student’s overall care at school.” Magdalena’s mother stated, “I do worry a little bit, but the thing is, overall, I know the nurses and everything and teachers are doing their best to take care of her.”

Parent B

Leo Maldonado was born in 1997. He was diagnosed with Type 1 diabetes when he was two and a half years old on December 20, 2000. The doctors at the hospital told his mother that his blood glucose or blood sugar reading was over 5000. They could not explain why Leo was still able to talk to them and was not in a ketoacidosis-induced coma. Leo was14 years old, on the insulin pump, (as of age nine), and did not qualify for Medicaid at the time of the study. Leo was a ninth grader and attended high school at the same school where his mother was a Business Computer Information Systems (BCIS) teacher and University Interscholastic League (U.I.L.) coordinator for many years. English was the primary language spoken in the home. Leo attended one elementary school, one middle school, and one high school during his ten years in the same public school district.

When making arrangements to meet for the interview, the parent was keen on meeting at a local popular coffeehouse rather than in her home. The researcher arrived at the coffeehouse about ten minutes prior to the designated meeting time. Leo's mother arrived right on time. She greeted the researcher with a warm friendly hug. She said she was fine with the table which was situated conveniently, out of the way, in the back corner of the coffeehouse. She was dressed in nice jeans, heels, and a fashionable blouse, and mentioned that after our interview, she had promised to pick Leo up to take him shopping at the mall for after-Christmas sales.

As Leo's mother made herself comfortable at the table and ordered herself iced tea from the waitress, the researcher and she began to engage in casual conversation. She stated:

> When Leo was first diagnosed, I was right in the middle of a divorce from his father. He never came to the hospital to visit Leo or showed any interest in learning how to care for his diabetes. That's why I decided to file for sole custody of Leo.

Therefore, Leo's mother has never received any child support from the father. As a result of not having a two parent income, the mother stated that she had never been able to afford a house for Leo and they had always lived in an apartment. She was optimistic that those circumstances might change as she had a banker friend who had recently called to let her know that his bank had repossessed a fairly new home in a nice neighborhood and the bank would sell it to her for well under market value. Her dream was for Leo to finally be in his own house with a backyard. She told the researcher that Leo was such a great son that she felt he really deserved to live in his own house, instead of an apartment.

After going over the informed consent form, the permission for audio-taping the interview and requesting school records form, and obtaining the parent signature on both documents, the researcher explained the interview process to the parent. The interview began thereafter by the parent describing the events that led to her son being diagnosed at age two and a half with Type 1 diabetes. Leo's mother recounted the events:

> I think the first time I realized that things were a little different with him were things that my mom would tell me, because she took care of him for me while I went to school and I worked as a teacher. She would tell me things like, 'Leo throws himself to the floor an awful lot.' He would get upset. She would also notice that he wouldn't want the normal, like daily routine of his lunch. He would zip it and wouldn't want to eat, and then later in the day crave for things that he wouldn't normally eat, like maybe cereals just out of the box in a bowl. Things that she wouldn't give him normally, you know, as a 2 year old she would give him healthy foods... She would always give him fruits, vegetables and plates of carrots and celery to the point where, after a while, you know it seemed like even within months, those kinds of foods he was just, like, shoving off to the side and would get upset. It almost seemed like he was craving sugar for a long time. It was during that time that I started noticing. He was already potty trained. He went back to wetting the bed because he would get up during the night and ask me for something to drink. So he was really, really thirsty…I would go and fill my water tank…I started noticing I was filling

> that water tank more than I normally did routinely because of the bed. So he was constantly drinking water even throughout the night which I didn't think was very normal.

After Leo started wetting the bed again, and continued to suffer from constant thirst, his mother took him to see his pediatrician. Unfortunately, his regular pediatrician was out of town and Leo had to see a pediatrician with whom he was unfamiliar. The pediatrician said that Leo probably had a viral infection that would run its course. Blood was drawn and sent to the lab, and Leo's mother was told that the lab results would be ready in a few days. After returning home from the doctor's, Leo ran over to play at the neighbor's house. Leo's mother stated:

> …she (the neighbor) was a little concerned. She said he was not playing or anything. He would always go over and go uncalled and walk into the door like he owned the house and he actually kept asking her for sugared drinks. He didn't want water and he (neighbor's husband) is a type-2 diabetic and she said, 'There's something wrong with Leo because his demeanor is different and he keeps asking me for sugary stuff.' And I don't know if that is a symptom or not of cravings of sugar but I noticed that as he got closer to getting really sick and he went into ketoacidosis, I noticed the sugar thing. If you gave it to him, he was going to take it. Whatever you hand to a 2 year old, of course, they're going to take. While mom was giving him a lot of water, other people didn't know what was going on with him, you know, except for Mrs. (neighbor's last name)… She did notice something because she was diabetic herself. She noticed the thirst and things like that and that he was very irritable and it seemed like his personality was a little bit different. It wasn't until, I believe, the night that he got really sick that I noticed his ribs. I could see through his shirt. I could see his little bones and I noticed that he lost

> a tremendous amount of weight in less than a week or two. You could tell in his face that he was a lot thinner and very pale; very pale in skin and kind of yellow pasty like. So the night that he got sick, he actually started vomiting, constant vomiting, vomiting, vomiting. That night I got really scared and I took him to a night clinic in (name of city). Then the doctor didn't even hesitate. He said, 'Mom, what does mom feel he has? Mom should feel something or been looking at things. What?' …He was amazing. He said, 'I'm going to do what they taught me, what a doctor, old doctor taught me; old medicine.' He said 'I'm going to test his urine.' The first thing that came out of my mouth when he said, 'What do you think he has?' was, 'I think he has diabetes. I just don't know what kind because he's not overweight. So I can't really figure out what it is but he has all the symptoms. I've been on the internet. I don't know what to look up.' Until he was like, 'Ok, that's what mom feels.' I was very scared at the time. I was going through a divorce so I was really… I went out of my mind.

Leo's mother waited while the doctor at the night clinic did a test on Leo's urine. The doctor came back a few minutes later and said, "I know that your son is going through a major stage. I'm going to call the hospital and you're going to be admitted as soon as you get there." Leo's grandparents drove them to the hospital. Leo's mother stated:

> …So I remember a visual of him on the emergency bed and he's crying away for me… It was just kind of like a blur, but they got it stable. He didn't go into a coma. You know the doctor said that the ticker readings were over 5,000. I have no idea how that's even possible, but he said that he was amazed that he was talking when he came in. He was amazed that he was coherent; that he knew who his grandparents were. That he was just looking around the room and that he was just as strong as he was.

Looking back on the entire sequence of events that led up to Leo’s T1D diagnosis, Leo’s mother reflected that:

> I think what triggered it, after talking to the doctor; he said it was all the sugar; that he was feeding himself and you were keeping him alive and not in a coma by giving him all the fluids, all the water. I was flushing out the ketones and he would refurnish them again. He’d give himself more sugar and I’d give him more water at night and then he’d give himself more sugar so it seemed like whatever we’re flushing, he’d take back in. So he (the doctor) said that me giving him all the water, the gallons of water that I would give him at night instead of letting him drink a soda or letting him drink juice; (Thank god I didn’t do that!) that somehow it could have helped from keeping him from going into the coma because he got his ketones working with water. And now that I see that, going back, every time the sugar is high, it’s simple. Give him water. You need to flush out your ketones, until your sugar goes down. Keep drinking water. Keep drinking water. They give him water all the time. They make sure that he’s got water, and that was one of the things that I had achieved at (name of current high school Leo is attending). Although his plan went with him, on his plan he didn’t say that he needed water to flush out any ketones or acidities he might develop. I hadn’t known of those things. I didn’t know that abscesses develop in their lungs. That’s why they have shallow breathing. And now that I see it and I go back to that, he says ‘You know you were filling him up with gallons and gallons of water at night. Yes, he’d be able to pee the bed, but you were saving his life.’

Leo’s mother stated that Leo’s kindergarten teacher suggested that he be placed in the 504 program, but that it wasn’t until the middle of his first grade year that Leo joined the program when she, the parent, suggested it to his teacher and to the nurse. Leo’s mother stated that at first she did not understand how the 504 program worked to benefit the health and education of her child, but that over the years she has come to a greater understanding of the process. When asked questions about the 504 program and the accommodations provided to her son in the public school, Leo's mother was well-versed about the benefits of the 504 program. The accommodations that Leo currently received, according to his mother, were the allowance of going to the nurse's office on a daily schedule to check his blood sugar levels or permission to go additionally whenever he felt he had a high or low blood sugar. The nurse also gave Leo snacks when his blood sugar was low and insulin and lots of water when his blood sugar was high. She stated:

> Ok, some of his Bible for accommodations right now are tests as needed, clean drinking water in the end when he has his highs. We just now did, in December, a new accommodation because of the new core testing. That's gonna be coming up in January where they take their four core exams. And they're timed tests. So when Leo was in elementary school, in 5th grade, he had the same accommodations as the water, the tests as needed; he'd go to the nurse.

Conversely, Leo's mother was concerned that a few very important accommodations were not being offered to her son at the high school level. She had requested that her son continue with the buddy system. However, the 504 diabetic management team did not list the buddy system as one of Leo's accommodations as they felt they could not ask other students to escort another student to the nurse's office because of liability and missed instructional time. Leo's mother was very worried that he could become disoriented on the way to the nurse's office from his class if he had a low or high blood sugar. He might wonder the hallways or fall and injure himself. She was afraid that campus security might not know of Leo's medical condition and mistake his disorientation as a signal that he was under the influence of an illegal substance. Since the high school has a second floor, she was also worried that Leo might fall down the stairs and had urged him on several occasions to take the elevator on his way to the nurse's office and avoid the stairs altogether. She stated that when Leo was in elementary and middle school:

> He had a little buddy that would walk him to the nurse most of the time, but what I see now; I don't see the buddy system very often in the high school level. I did see it in the junior high. They'd educate another student or a friend that was in the classroom with him on his symptoms and if he felt bad, he'd guide him to the nurse, such and such. I don't see that at the high school as much and that's probably one of the only implementations that I contest. I think it's, I don't wanna say frowned upon, but it seems to me that it's not looked up as high because class time now in high school is very important. Every student needs those 55 minutes of class time. So I can see why it's been watered down quite a bit. The only problem that bothers me is that if something does happen to a child with type 1, that being my son, and he's got either a high or a low depending if he isn't able to tell himself , he will wander the halls and he will get lost or he'll fall and hurt himself, one of the two. And then the district will be liable. That's the only part that worries me, is that he's going to end up hurting himself along the way and that has happened in just this year. He did wander, didn't get to the nurse for a while with a high because he was just kind of like "ugh," you know. He stopped at the water fountain, then maybe kind of stopped somewhere else; stumbled somewhere else. So by the time he got to the nurse it was like ten minutes later and then the nurse called me. "Leo's sugar is really, really high but he seems to wanna do everything really fast to get back to class." And he said, "No, you've got to wait a little bit. You've got to drink some

> water. Slow down.” Because he comes in and he says, “Ok, I need 20 units of insulin. I know my sugar’s high. Blah, blah, blah, blah, blah.” And he goes on and on and on and they’re just like, “Whoa!” So even though he wanders and another symptom kicks in, he’s like treating everything really fast because now he knows that he’s wasted time and he’s not coherent. He’s not thinking. And what worries me too, is that police, security, might think he’s on some kind of drug, which is very common because their eyes are watery. They’re moping. They’re just roaming. They’re roaming around and because he’s in a two story school, I tell him to use the elevator with a nurse’s pass but he needs to get a nurse’s excuse, you know, from the teacher. With Leo’s Type 1 it needs to be written on there so that security can know that the child is on the elevator for a reason. Because if he’s going down the stairs; forget that. I can see him going head first and not making it.
>
> So I tell him, “You need to go on the elevator. Mom says you need to go on the elevator.”

When asked if the use of the elevator and an elevator year-long pass were listed as a part of his 504 accommodations, she said no, she hadn’t thought to ask for those accommodations at the meeting but would ask for them to be added when she returned to school after the Christmas break. When asked why the buddy system was deleted from her son’s 504 accommodations, Leo’s mother stated:

> I don’t really know why it’s taken off. It might be because, then the other students… If it’s not a student that a teacher trusts, or whatever, maybe that kid won’t return back to class like they should. You know, back when they were small, they rushed back because they were afraid they’d get in trouble because they were little. And I can see why. I can see a lot of the pros and cons about sending a high school student with another student. But at the same time, I feel like we’ve got to find a solution, something that we can do. I

> don't know what to come up with to be honest with you. Because the teachers, they're looking at the class, and say, "Let's see who would I choose of everybody that's in my room…?" He has to meet all of the criteria in the class; someone that you trust as a student in the hall, not a trouble maker. I'm not saying that there are many, but any situation now that we have all this accountability in our classroom with our kids, it's hard to find that one student that's actually gonna return that has 90 percent of the criteria. It's just a short trip and back, but that's like 10 minutes, you know, of instruction, class instruction time, and I empathize with those teachers that have an issue… But at the same time, I feel like there's got to be something in place to protect the district as well and the teachers, because what if they don't (send a buddy) and something happens to that child on the way to the clinic?

Leo also has preferential seating in the front of the classroom to help him maintain focus on his lessons and has been given extra accommodations for the state's new STAAR End of Course (EOC) tests which will be given in each academic subject area; English Language Arts, math, science, and social studies. The state exams are timed for the first time in Texas state accountability testing history with four hours allotted to complete each test given on consecutive days. Leo's blood sugars tend to spike when he is under stress. High blood sugars lead to increased thirst and frequent urination. Therefore the test monitors will make sure Leo gets extra time to make up for when he has to leave the testing room for water, nurse, or restroom breaks. Leo's mother stated:

> Ok, the 504 plans and the core test is going to involve him being in a small group testing which was agreed upon by me, the counselor and the assistant principal in charge of 504. So he'll routinely be going to check his blood sugar levels and they won't take off that

time… They'll be able to say he left at this time. He continued testing here. He has 20 more minutes added to whatever he needs to finish his test, which I feel is going to be a positive. He did this in 5th grade. He did this in a small group because I wanted him to know at that time, he needed to pass the test in order to go to the 6th grade. I didn't want him to know that later on 6th graders would just get passed over. I wanted him to know that he actually had to earn it. So through that process I think it was a good lesson because he took extra time on the test. He said, 'Mom, I was the only one there till almost 6:00 p.m.' and I said, 'Yes, but at the same time, you did well on the test. You were able to review your questions. You were able to answer properly.' He said, 'Yes, I was and I feel better.' And I said, 'Ok, even though you had to go check your blood; even though you had to go to the bathroom, all because your sugars were high because you were so nervous about passing the test; that's certainly what's going to happen on the end of course. And I know you'd rather be in the classroom with all your friends, but think about all the times you're going to have to go out to the restroom; how many times that door shuts; how many times you're disturbing the other students who take this important exam, plus yourself. You're taking away the time that you need on that test to go to the restroom, to go check your blood with the nurse. If your blood's high, you have to stay in there until it drops. You're taking up a good hour away from that whole four hours, but you weren't allotted four hours like the other kids.' And so I tried to get it across to him that way; that that's why he's going to be tested in a small group. And I don't think he likes it, but, at this point, any procedure that he wants a good grade and he wants to pass. Fifteen percent of this test goes into your record, onto your record with the registrar; fifteen percent or ten percent, something like that. I said, 'And the teachers count the

> other part of their end of course exam as a grade for the class. If you don’t pass these tests you don’t graduate,’ and I’m trying to like make him get that in his head because, the poor freshmen, don’t know what hit them. They don’t know. So, that’s where we are with that.

Leo’s mother acknowledged that the quality of communication between the members of the 504 diabetic management team about what school accommodations were to be given to Leo was good. She stated that within the first three weeks at the high school, every teacher on Leo’s schedule knew about his 504 accommodations and were following through. The teachers had also been told to visit individually with the school nurse to go over the symptoms of high and low blood sugars and what to do in case of an emergency. She stated, “And the accommodations, though, are good. I feel comfortable with the water as needed. The teachers have all been notified.” She did not, however, believe that the 504 team members fully understood the chronic disease of T1D, other than the school nurse. She stated, “No, because they don’t have a child themselves, they don’t completely understand.” Leo’s mother felt the team had done a good job with the limited knowledge that they had. She felt that the 504 team members and Leo’s other teachers did not know the difference between Type 1 and Type 2 diabetes. Some of his teachers had stated to Leo’s mother that they could not understand why Leo had diabetes because he was a slender young man and was not obese as they thought you had to be to get diabetes. Teachers had also asked her why Leo needed insulin all day long and could not take care of his illness with diet and oral medications. As a result of such conversations with Leo’s teachers, his mother was convinced that the teachers and staff needed to be educated about Type 1 diabetes so that they could understand that it was a different disease than Type 2 diabetes. She stated:

> Except the only thing I don't know for sure, for a fact, is that a lot of teachers don't know. Until they get to know, a lot of teachers don't know the symptoms of Type 1. So they don't know what to look for. And as much as, even as a parent and as a teacher at (name of high school Leo attends), as much as I talk about it; until they see it for themselves, they're not going to know. They're not going to know what to expect. They have to get to know him first. He looks different.

Of all of the accommodations Leo receives, his mother thought regular blood sugar checks at the nurse's office to keep his glucose levels in the normal range were most important to best facilitate learning in the classroom. She maintained that Leo must have good blood sugar levels in the normal range to be able to stay focused on his lessons. She believed seating Leo in the front of the classroom helped him stay focused when his blood sugars were a little off. Leo's mother commended the school district overall when she stated:

> Another accommodation would be about her students sitting up in front of the class, especially in classes where they have difficulty. And a lot of times, they notice that the kids that are always sitting in front of the classroom are those with poor vision. And maybe that's not all the time. We're overlooking those that might have other issues. But other than that, I've seen a lot of credibility in the (name of school district that Leo attends) as far as accommodating my son. I don't see anything that I can say drastically has hurt him in any way. If anything, this 504 program has helped him.

When asked if the school administrators were actively involved as a part of Leo's diabetic management team, his mom stated that regardless of the fact that the high school where she works and Leo goes to school has a lot of students, the principals do know their 504 students and work with the teachers and parents to make sure that all 504 accommodations are provided to students in the program.

Leo's experience and relationship with the school nurses in elementary, middle school, and high school, according to his mother, have all been great. The nurses have all taken good care of him and have been very supportive. She noted that the middle school nurses worked to educate Leo about self-care for T1D and gave him advice on how to take care of his diabetes and on life in general. She stated, "They were very educated. They gave him advice on daily life issues and tests in general; advice on things that he was going through as a teenager." Whereas the high school nurses were focused on helping Leo to become self-sufficient and responsible for his own care, paving the way for college and adulthood. When asked how T1D had affected Leo's attendance and grades in school, his mother stated that his grades had not been adversely affected even though his attendance had always been an issue. She noted that:

> …elementary was the worst. That's when he was barely diagnosed and he missed school more when he was younger. When he had sick days, of course, he had to go home because of the high blood sugar or the very lows because of the diabetes management that's involved with those issues. It becomes a little bit more complicated attendance wise, though. The 504 program saves him from getting any type of attendance truancy type ticket, you know. So the 504 brought a help with that. His grades never really were affected. I want to say even up until now, (he does have some issues now in high school), but I think it's because subjects keep getting harder. His teachers were always very helpful, giving him his makeup work when he was out; things like that. Attendance is always going to be an issue, only because when they get sick, they really feel lousy, and it's like a double whammy. You know he has the diabetes to deal with and he's got this

> sick illness on top of that. So when he tells me that he really feels sick, he pretty much is telling me that he feels sick and he stays home. It could be two, three days in a row, just depending on what ailment he's gotten, whether it be the flu; flu being probably the worst. You know, one of his routine cares should be him actually getting a flu shot to prevent him being hospitalized. But he's never been hospitalized for diabetes or an illness, thank goodness. But they do tell me that that happens quite a lot with diabetes kids. I also think going into herbal remedies and possibly doing care without giving medication is also a very good reliable source of energy. I noticed that my son really takes time to talk to his chiropractor and loves natural medicine. I encourage that only because medications do take a toll on him and his every day issue with his body and he feels better when he feels he can take care of something without having to take a pill or taking other medications.

Leo's mother was aware that his Emergency Care Plan (ECP) did entail the possibility of a glucagon shot being administered to Leo in the case of an extremely low blood sugar. She said she had also signed a permission form that an ambulance could be called in case of an emergency for her son. She stated:

> The emergency care is basically the glucagon shot which has to be updated every school year, has to have a recent date on the logo or emblem on there, and also cannot be expired. And then you sign a waiver or permission for the school to care for your son in case he needs an ambulance for any reason.

At the end of the interview, Leo's mom reiterated that her main concerns about Leo's overall care at the high school were the need for the reinstatement of the buddy system or a variation of the buddy system. She was adamant that it was not safe for Leo to go alone to the nurse’s office because of the possibility of him becoming disoriented along the way and wandering the hallways or falling. She also felt anxiety and fear for Leo about the state STAAR testing. She was worried that his blood sugar would go high due to stress and he would be out of the testing room too much for water and restroom breaks and to see the nurse, although she acknowledged that accommodations have been put in place to address STAAR testing concerns. Finally, she thought Leo was old enough to carry a glucometer in his pocket and check his blood sugar as needed, thus avoiding the need to leave class and miss valuable instruction to go to the nurse’s office for blood sugar tests. She stated:

> One more time being the buddy system, I think. I don’t think it was ever disregarded or not put into place. I think it just becomes something that isn’t seen. I think it needs to be implemented again into the high school and really focus on, only because of the student’s ability not to be able to focus on whether they’re high or low. He may not know what they’re doing or not doing so I think we need to come up with a new system. Also the end of course testing for the state of Texas; it’s difficult for Type 1 and Type 2 because they need to regularly go to the restroom. They may need to check their blood sugar levels to see how they feel and all the symptoms that go along with this may cause their end of course testing not to come out the way they would like their grades to be at the very end of that. And since it is a timed test, it takes away from the diabetes, Type 1, to be able to have the full amount of time that the other kids have... I also think that the glucometer should be carried by the students… But other than that, the overall care of the school has been great.

Parent C

Brittney Valdez was born in 1994. She developed Type 1 diabetes when she was in the third grade at the age of eight. She was a 17 year old senior in high school, on an insulin pump called the Omnipod which had a built in glucometer at the time of the study interview. She did not qualify for Medicaid. Brittney lived with both of her parents and her older sister in an affluent subdivision. Her father worked outside of the home and her mother was a homemaker. Brittney's father did not participate in the interview. English was the primary language spoken in the home. Brittney attended one elementary school, one middle school, and one high school during her thirteen years in the same public school district. Brittney was a soccer player at her high school. In addition, she regularly visited the gym to run on the treadmill and lift weights. Usually before a game, Brittney's sugar was high due to anxiety and anticipation for the game.

Brittney's mother answered the front door and greeted the researcher with a friendly smile. The researcher was guided through the expansive living room towards the big, sunny kitchen. One couldn't help but notice the beautiful grand piano, sitting center stage on a raised platform, just off to the right of the living room. Once in the kitchen, the researcher was waved into a chair at the table. Brittney's mother asked to be excused for a moment to attend to her older daughter who has Down's syndrome. The young lady was upset, crying, and clinging to her mother. The mother left the room and came back later by herself, saying that Brittney was keeping her sister company in the other room.

When asked to tell the story of how Brittney was diagnosed with T1D, her mother explained:

> She was very thirsty and hungry all the time. It was early February and we had gone to Houston for the weekend to see Mick Jagger and the Rolling Stones in concert. When we

were on the way to the concert, Brittney kept complaining that she was hungry and thirsty, wanting her dad to stop and get her something. He became annoyed with her and told her, ‘Brittney, everyone’s tired and thirsty; you’ll just have to wait like everybody else.’ Once we were at the concert she was after me every five minutes to take her to the restroom or get her something to drink. I couldn’t even watch the concert; we were up and down so much. I remember, though, that when I was with her in the restroom stall, there was a funny odor which I hadn’t noticed before. Then a few nights after we got home from Houston, she wet the bed. She continued to be tired and thirsty and just not feeling well for about a week after that. My husband is a Type 2 diabetic, so I knew what the symptoms of diabetes were. Plus, Brittany was chubby at the time. I thought, ‘Maybe she has diabetes.’ So we checked her blood sugar at home. I don’t remember what her reading was; I just know that it was a little high. I took her to her regular pediatrician the next day and told him what was going on with her. He checked her sugar and it was higher than before, when I had checked her at home. I can’t remember what it was. He told me she had all the signs of diabetes and I would need to take her to the Driscoll Children’s Hospital in Corpus and that I needed to leave now! I was a little taken aback by that because I am a stay at home mom and I’m in charge of my older daughter’s care. I had to leave her with my parents and take off with Brittney. Within the first hour that we were at the hospital they started giving her insulin. I kept telling them, ‘How do you know its Type 1. It could be Type 2 and maybe she’ll just need pills.’ The emergency room doctor told me that based on all the tests that had been run and how she was reacting to the insulin, it was Type1. It was then that I broke down. I was so upset. When I met with a nutritionist a few days later, she explained to me that the emergency room

> doctors are used to receiving Type 1 diabetics through the emergency room that are already in a coma with their sugars in the thousands. Parents are so scared that their child is going to die, that they are relieved and thankful when the doctors explain that it is Type 1 diabetes and it can be treated with insulin. She said that's why the doctors and nurses in the emergency room probably couldn't understand where I was coming from.

Brittney's mother went on to explain that she's not sure why Brittney got T1D. She said she knows it can be hereditary, and her husband has T2D, or it can be brought on by a virus. She stated:

> I remember that about a year and a half before Brittney was diagnosed, she was eating celery and somehow got a string from the celery caught in her throat. After that she would not eat solid food because she was afraid she was going to choke. All she would take in was liquids; milkshakes and stuff. Then one day I looked in her throat and her tonsils were huge. I took her to the doctor again and she had tonsillitis. The doctor scheduled her to have her tonsils out, but even after she was totally healed from the surgery, she still wouldn't eat solid foods. Finally, the doctor scheduled her for a GI test. Everything came out fine and, after she saw the results, she finally started eating. So, I don't know if all of that had anything to do with her getting diabetes or not.

When asked whether Brittney had lost weight prior to her T1D diagnosis, Brittney's mother stated that she had lost about seven pounds over a two month period before she was diagnosed.

Brittney's mother understood her daughter's rights under the 504 program and was well aware of the benefits of the program. She stated:

> She is allowed to take as many bathroom breaks as necessary. She's allowed to go to the nurse's office whenever she needs to. She gets extra time to complete work if she out of

> class. She goes to the nurse or to the restroom whenever and she's allowed extra time to complete class work. Teachers are supposed to repeat instructions or directives also if she's missed. If she is absent because of diabetes, she gets extra time. Let's say in the evening, if she has a low sugar or even a high sugar and she is not feeling well at all, then she's supposed to be allowed to have an extra evening to do her work. Sometimes it's successful; sometimes it's not, depending on the teacher and how much they understand; you know, what's going on with her.

Brittney's mother shared that devising a 504 plan and successfully following it was much easier during her daughter's elementary years than it was throughout middle school and high school primarily because she only had to communicate with the nurse and one teacher at the elementary level. She stated that:

> I think it's changed somewhat. I think it was much easier when she was in elementary merely for the fact that she only had one teacher. We only had to have one teacher to explain everything to and, you know, get extra time for assignments and things. So it was easier in elementary, the whole experience was easier when she was in elementary. But a lot of it depends on the teacher and just how much they are aware of her needs.

In regards to emergency care, Brittney's mother confided the following:

> Actually the instructions we have been given, have been contradicting at times because at one point they were saying she needed to have a buddy. If she needed to get out of class because her sugar was low, she could not go alone. The teachers had to send another student with her. Then, liability came in. No you can't give that responsibility to another student. What if she was to faint and the other student couldn't catch her and she hit her head or something? So then it was no, the teacher has to go. The teacher has to have

> somebody watch her class and escort Brittney to the nurse. Then it's you need to have the teacher call the office and have the nurse come after her with a wheelchair. We've been through that before. Now, I guess, because she's in high school, we're back to another student should be escorting her to the nurse. So as far as what's legal, I have no clue. I know that she shouldn't go alone when her sugar is low and it has happened where she's almost passing out and luckily a friend is there with her.

Brittney's mother went on to discuss the possibility of high school students with T1D being allowed to care for themselves outside of the nurse's clinic:

> You know, if her sugar is low and she knows it, she feels it; now that she's in high school, she has her sugar tester with her because she's on the Omnipod so she has her meter with her at all times. So now that she's in high school, if she needs to check it in class, I prefer her to check it in class than have to walk all the way to the nurse just to check her sugar when she knows it's low. It just doesn't make sense. But there again, they want stuff done in the clinic where it's documented. I know that she's not even supposed to have a meter, walking around, you know, campus with the meter. She's not supposed to be walking around class with syringes. She's not supposed to be walking around campus with the lab set, yet in an emergency, you know, these kids need to have them. They need to have these things with them… She's not supposed to have the lab set. When they start school at the beginning of the year, these things are supposed to be in the nurse's office, not carried around by the student and everything. Like I said, she's followed that rule up until she was a junior in high school because that's when she got the Omnipod. Her PDM which controls the Omnipod also is a sugar monitor. So it's all in one. So she has to have it with her. But if somebody was to stop her and let's say there

was a lab set, you know. And an officer, a security officer or somebody stopped her; they are gonna immediately say, ‘Why do you have this needle?’ That’s why they don’t want these kids walking around with these things. You know, I understand that. She’s not eighteen, you know. They’re just not supposed to have things like that walking around campus I guess. I don’t know, but not everybody understands that it’s pretty crucial that they be able to check their sugar right then and now, wherever they are. And I think that she should have been able to do that even in junior high, elementary not so much, but (name of middle school Brittney attended) is a large campus also… So that’s a concern too. I’ve heard stories where I think the lowest it’s been is maybe in the 40s, which is low enough usually. And I have heard just from Brittney talking to other students who have diabetes saying that that they collapsed somewhere at the high school and it’s just, it’s too large. They just need to be able to take care of their diabetes themselves. The high school students are old enough to do that; to manage their own at least to that extent; at least to know I have a low blood sugar. I’m gonna check it now so I can make sure that I can get myself something quickly. Like anything else, if a teacher, security, principal sees them mishandling something that she has for medical purposes, of course, they’re gonna be reprimanded. But you can’t assume that every child who has diabetes that has either syringes or lab sets with them; that they’re gonna use them inappropriately. You know most of them are not. They’ve realized; they know how important their health is and they know what these things are used for. So, and I understand that it can get in the hands of the wrong person, I understand that. But you need to make these kids accountable too. They need to be responsible for these things. They can’t wait to get to the nurse’s office from one end of the school to the other.

Of all of the accommodations provided through the 504 program for Brittney, her mother felt the one that was most beneficial to Brittney in high school was the provision for extended time to finish assignments.

When asked if the school administrators were actively involved as a part of Brittney's diabetic management team, her mom stated that since Brittney was diagnosed with T1D at eight years old during her early elementary school years, the elementary principal was very supportive and involved with her care. She stated:

> …In elementary, very much a part of it. There again, we're dealing with a smaller group of students overall. And it was just easier. It was also when she was diagnosed, so, of course, we immediately had to have the principal involved and at the time, my daughter was the only student with diabetes at the school, so we did get a lot of attention. We did get a lot of questions answered because I think the whole school kind of needed to know what was going on to some extent…The principal talked to the cafeteria staff and the coaches. We just had so many people involved and, if I remember correctly, the teacher and the nurse even spoke to the class. So that, of course, was much easier and the principal was very involved.

At the middle school, one of the assistant principal's also had a biological child, two years older than Brittney, with T1D. Brittney's mother was able to go to that assistant principal with questions and concerns in order to resolve problems. Brittney's mother stated that at the high school, the principal and assistant principals have not really been involved as a part of Brittney's diabetic management team. She said:

> I can't tell you that I've really spoken to a principal whose part of the team. I have spoken to one of the principals simply for the fact that she, (Brittney), had so many

> absences and tardies. We needed to take care of that. So last year, actually every year since she's been in high school, I've had to talk to a principal, the principal in charge of attendance. We've had to get things cleared up. So as far as principals go, that's the only reason I've talked to one at the high school, strictly because of absences.

Brittney's mother was adamant that several changes were in order to help the 504 program better determine and implement accommodations. She said, "I think the teachers need to be educated. I think a lot of these teachers don't have a clue as to exactly what these kids are going through!" She shared that Brittney had told her that too many people do not know there is a big difference between Type 1 and Type 2 diabetes:

> I think what my daughter has stressed to me is that too many people don't know the difference between Type I and Type II because we've actually had an incident in junior high when she was at (name of middle school), where a teacher pulled her aside in the line at the cafeteria; or actually, they, the officers, would allow Brittney to cut in line because of her sugar. Before she went to lunch, she would go check her sugar, of course, and the officers knew that she could go ahead of the line. Well, it just so happened one day that somebody else was there, not one of the security officers. Brittney does what she always does and goes ahead of the line because her sugar was low. I believe she was the secretary, I don't know, asked her what she was doing and she said, 'Well I'm diabetic and I'm supposed to go ahead of the line.' And she said, 'Well I'm diabetic too.' So I will never forget that. That has always been in mind. So I immediately went to (name of assistant principal), I believe at that point, and had a discussion with him. But you know, here is somebody; yes, she's diabetic, but she's the Type 2 diabetic. And I guess she didn't assume that or she wasn't aware either that there's a difference between the two.

> And as far as she was concerned, Brittney just needed to, you know, keep doing what everybody, all the other kids were doing, and she'd be fine. So I don't think she realized the severity of the low sugar.

The researcher asked Brittney's mother to describe the quality of communication between the members of the diabetic management team about the school accommodations given to Brittney. Her immediate response was:

> I commend the nurses. I have no problem with the nurses because they know what's going on. Her first period teacher this year knows that there's no point in marking her tardy. She is going to be tardy even if it's gonna be excused, so he doesn't even do it. He knows not to and that's because of the nurse; one of the nurses and so I have no problem with them.

She went on to say, however, that not all of the teachers on Brittney's schedule understand the severity of her condition and did not always follow Brittney's 504 accommodations. She told the story of Brittney as a freshman with a broken ankle. Brittney's first period teacher had intimidated her to the point where she didn't want to go to his class anymore. Brittney's mother said:

> And for example when she was a freshman, she had Health. He was a coach and she happened to, on top of diabetes; she had to have a broken ankle. So she was on crutches. This was first period and she was late every single day. The nurse told him, 'She is going to be late. She has diabetes; now she broke her ankle. She's going to be late.' And yet every time she walked in the door, he would make some kind of a comment. About two or three weeks, because this was after the Christmas vacation, I went to the counselor and said, 'We're changing her schedule. We're not gonna do this and she doesn't deserve to

> be treated like that. She has reasons why she's late.' But the nurses are great and they'll take care of things like that for me… She was a freshman. She was very intimidated by him and she didn't want to go to class and I don't blame her and then having to walk in late too. So she was stressing, just really stressed out over it and that's why we finally had to do something. Even having the nurse go over there wasn't enough. So we had to pull her out of that class.

Brittney's mother went on to explain that Brittney could be anywhere from five minutes to 45 minutes late to school in the morning. Sometimes she missed first period altogether and was late to second period. The time she arrived to school was dependent upon what her blood sugar readings were when she woke up or what her blood sugar readings were the night before. Brittney's mother shared that both low and high blood sugars affect the way that Brittney feels. She told Brittney that since her sugar was high, and not low that she should be able to get up and get to school on time. Brittney, however, argued with her mother saying, 'But Mom, I'm sick! I don't feel well. You don't understand.' Brittney's mother understood that regardless if Brittney's readings were high or low, they have to stop and take care of stabilizing her blood sugars, (drinking a sugary drink and eating a carbohydrate for a low blood sugar, or giving insulin and drinking lots of water for a high blood sugar). Both situations take time, but both Brittney's mother and Brittney agreed that Brittney's health must come first. Brittney's mother went on to explain that if:

> her sugar is high; she is up several times during the night, very thirsty, going to the restroom, again just not feeling well and doesn't sleep well. There have been times when she is low in the middle of the night and can't get up; doesn't want to get up; doesn't even have the strength to call me. I check it at 5:30 every morning. That's how I wake her

> up. Just recently it was like seventy something and I said, ‘Brittney, your sugar is low. You need to drink something,’ and she said, ‘Yeah, it’s been low for a long time but I just didn’t have the strength to call you.’ That’s why her cell phone is over by the bed. So days like that; she’s going to be late. There is no doubt about it because trying to get her up, get her sugar up, then having to get in the shower and she’s a girl. So, yeah, the hair and the make-up and you know it’s just real difficult, very difficult to get her to school on time.

Brittney’s mother confirmed that her daughter had accumulated a lot of absences and tardies to her first and second period classes. She mentioned that a truancy officer had pulled Brittany out of class. Brittney’s mother stated:

> …the truancy officer did pull her out of class, say maybe a month ago, and told her that she had excessive absences and that she was in jeopardy of losing credit. It hasn’t gone that far. It was a verbal warning. My understanding is that she did tell him that she was 504 and he looked at it and he said, ‘Well you don’t have that many absences, but you were tardy.’ So I think they were tardies because she’s tardy a lot to first period… She was angry. She was definitely angry. I know that we realized that not everybody can know what’s going on and the truancy officer, of course, didn’t. But she was angry. She, you know, of course, she takes it personally. Around that time, also, she had already been pulled out of class by a security officer prior to this and basically for the same reason. And absolutely she went to one of the principals. I can’t remember his name right now, one of the assistant principals. I think, maybe he’s in charge this year of attendance because he’s not one I had spoken to before. But anyway, she was really nervous about that. So she did what she’s not suppose to and got out her cell phone and sent me a text

> real quick and said, ‘The police and the assistant principal are going to call you and they pulled me out of class.’ So she was nervous, of course. So a few minutes later, of course, I get a call from him and he’s telling me does she have diabetes and that’s the reason she’s late to school? And I said yes and I think he just mainly wanted to verify everything that she was saying. But I’m assuming if he had looked at her folder or something, he would have seen it or contacted the nurse. She was telling the truth. But, I mean, I didn’t mind talking to him. It’s just that maybe he should have done his homework a little better before calling me.

When asked if the 504 team members fully understood the chronic disease of T1D, Brittney’s mother replied with an emphatic, “No.” She stated that, “I have all the confidence in the world in the nurses, but honestly can’t tell you about the others, if I really have confidence in them or not.” Brittney’s mother maintained that the relationship Brittney had with the nurse at the elementary school and the high school was excellent. At the middle school, however, there was not much stability. The nurse retired at the end of Brittney’s sixth grade year. A new nurse came in at the beginning of Brittney’s seventh grade year and only lasted about two weeks. After that there was a succession of substitute nurses until a permanent nurse was hired at the beginning of Brittney’s eighth grade year. Brittney’s mother said all of the different nurses did a good job and Brittney and she had confidence in them, but a middle school nurse-to-student relationship was never built during the middle school years as there was no stability of personnel in the nurse’s office:

> Elementary was great! There again she had just been diagnosed. She was the only student with diabetes there… So she got a lot of attention, so that was great. In middle school, it was fine too. There was an adjustment because we had a nurse and then she retired and

> then somebody came in just for a few weeks and then she was gone and somebody else came in. So it was kind of rocky there, but the nurses that were there I trusted. I can tell you that. It wasn’t their confidence, but it was the stability wasn’t quite there… I know I didn’t have the rapport that I have with these other nurses. Brittney, I don’t think she did as much either, but there again it’s just because they were switching them… But at the high school, wonderful, wonderful! I have the same two nurses the whole four years and that has been wonderful. They know Brittney very well and they know me and it’s just… I really appreciate them!

Brittney’s mother reiterated that T1D had taken a great toll on Brittney’s attendance. Brittney had a lot of absences, especially first period because of low or high sugars in the morning before school. Her high school credits had been blocked several times due to too many absences. Brittney had also struggled to get her permission form signed to start driver’s education by the school, because she had too many absences. Brittney’s mother shared the following thoughts about Brittney’s grades:

> If the teachers are not following the plan and they’re not giving her extra time, then, of course, her grades are going to suffer. There are times when she needs to study and she can’t because her sugar is low or high or whatever. She’s not feeling up to it and the mood swings, because the sugar is going up and down; so I think it has really affected her grades a lot. She’s a good student; not a straight A student. I can’t say that she’s even trying her best all the time because I think she gets very frustrated just because she has health issues. There’s a lot of frustration a lot of times.

Brittney’s mother stated that Brittney’s blood sugar is supposed to be between 80 and 180. If she feels low, a friend or buddy is supposed to escort her to the nurse’s office. If her blood sugar reading is below 80, Brittney is to eat a 15 gram carbohydrate snack, wait 15 minutes, and then recheck her blood sugar. Once her sugar has gone back up to the normal range, Brittney may go back to class. Sometimes Brittney's blood sugars don't go back to normal right away and she'll end up spending half the morning in the nurse's office or Brittney's mother will have to go pick her up. She told of a time when Brittney was on crutches due to soccer injuries:

> Somebody else was walking with her to help her with her books and she got really dizzy, and felt faint. She was sweating. It was an obvious low blood sugar. The student who was with her took off to the nurse. The nurses came with a wheelchair to get her. Had that student not been there with her, she could have fallen right there. But there again, I don't know what's legal. I don't know as far as liability responsibility if another student should even be doing that. I really don't know. I don't know how that should be handled. I just know that if it's that low, these students should not be walking by themselves to the nurse's office, and if you look at (name of high school Brittney attends), it's a huge campus. It takes a long time, especially out in the portables; then trying to get to the nurse's office. So it is a concern. It's a great concern and yet they're not supposed to be eating in the classroom.

Brittney is a member of the school's University Interscholastic League (U.I.L.) soccer team. Soccer involves a lot of conditioning and running which can cause blood sugar levels to drop. Brittney's mother described how playing soccer affects Brittney's T1D:

> Usually before a game, her sugar is high. Usually, I think, it's just the anxiety, the anticipation. So usually it's high. Occasionally, it's low, and she'll just have to sit out for a while. And then when she feels better; then she'll go back in. But usually we don't have so much of a problem actually during a game or during any kind of exercises until later.

> It is a delayed reaction as she will definitely have a low if she doesn't watch it; if she doesn't check her sugar throughout the evening and make sure that it's not dropping. But that happens a lot. That happens a lot where she does overdo it. And even if she'll do that, she'll go to school, run in soccer, and then she'll go to the gym in the evening and do something else you know, the treadmill and lifting weights or whatever and it will happen. She'll definitely have a low later that night and then, of course, we have issues in the middle of the night that she can't sleep or whatever. So yeah, the chances are, she'll be late in the mornings.

When asked what her main concerns were about Brittney's overall care in school, Brittney's mother stressed that there needs to be more communication between the diabetic management team and each student's teachers. She was also adamant that the diabetic management team and the teachers need to be fully educated about both Type I and Type II diabetes and the difference between the two chronic diseases. She felt that on large high school campuses, students should be allowed to carry a glucometer, check their blood sugar, and carry snacks to eat in case of a low blood sugar because the nurse's office is often too far away. One last area of concern for Brittney's mother was that it is rare that teachers who plan on being absent leave instructions for the substitute teacher about specific accommodations, which must be provided to students with special needs under the 504 umbrella. She stated:

> My first concern was with substitutes. When they have substitutes in a class, a substitute is not going to be aware of the students who fall under 504. In elementary, I know that the teacher would usually leave a note and tell the substitute, you know, here are the modifications, at least allow Brittney to go to the nurse five minutes before lunch or let her go the restroom whenever she wants to. And, of course, that was easier because there

> is only one teacher and one substitute. Once you get into the middle school and high school level, it's not as easy to do that. These teachers have 150 plus students to think of and Brittney is not always on their mind, but there have been cases where she's afraid to ask the substitute if she can get up and leave to go the restroom or the nurse; even her own teachers sometimes. They're in the middle of the lecture. She doesn't want to interrupt. Some teachers have told her in the beginning, once they realized that she has diabetes, "If you need to leave, just leave. Don't even tell me, just leave." I personally have told her over and over again, if she feels like she can't leave for whatever reason; if the teacher's gonna get upset or they're in the middle of the lecture, if she needs to get out of there to go to the restroom and she needs to get out because she feels her sugar dropping, I have told her just to leave; just walk out and we'll deal with it later… There are times where she just feels too intimidated to speak up. And you know that's more Brittney's personality. That's certainly not gonna be true of all kids with diabetes. But for my daughter and her personality, there are times where she just does not feel like she can interrupt the class and so she'd rather just walk out. So when the nurses even told her if she's somewhere and she feels like she can't get to the nurse's office, to use her cell phone and call the clinic. And that's something I would deal with later too. Use your cell phone at school if you have to. If it's an emergency and you need help right away, we'll deal with the consequences later. There shouldn't be. It's an emergency, but if it comes up, you know, we'll deal with it then if we have to.

Parent D

Ciro Rangel was born in 2000. He was diagnosed with Type 1 diabetes when he was ten years old in October of 2010. Ciro was 11 years old at the time of the study. His family did not qualify for Medicaid. He had been on four insulin injections a day since he was first diagnosed with T1D. Two days prior to the interview, however, Ciro received and was trained to use the insulin pump. His parents stated that he caught on quickly to the mechanics of the pump and was already operating it by himself under their supervision. When first using the pump, Ciro complained that the needle hurt and that the insulin pump felt weird, but his parents stated, he had already gotten used to it, and the needle was no longer hurting him. Ciro was a fifth grader. Spanish was the primary language spoken at home. His father, who worked outside the home, was also fluent in English, while his mother, a homemaker, spoke Spanish exclusively. Both parents participated in the interview. Ciro attended one elementary school during his four and a half years in the same public school district.

Ciro’s parents agreed to meet with the researcher at their home. The mother greeted the researcher and CITI certified translator at the door with a friendly, welcoming smile. Ciro’s father was standing behind her, and greeted both guests with a smile and a firm handshake. He motioned the researcher and translator to take seats on the couch. The researcher asked if they had a small table and a couple of extra chairs. The father obliged and set a small table and two folding chairs opposite the couch. The living room was small, but clean, tidy, and modern. A large flat screened television was located on the wall opposite the couch. Several religious pictures adorned the walls. After they situated themselves at the table across from Ciro’s parents, who were seated on the couch, the researcher and interpreter explained the interview process including the purpose of the informed consent form, the permission for audio-taping the interview and requesting school records form, and obtained the parent signature on both documents. Just then, Ciro and his five year old brother peeked around the corner. His father introduced both boys to the researcher and the interpreter. Ciro was thin with big brown sparkling eyes. He and his little brother smiled shyly at the guests and then ran back laughing down the hallway. The interview promptly ensued. The mother shared that they discovered that Ciro had T1D "…by the symptoms, which basically were urinating a lot and drinking a lot of water, and when we took him to the doctor he immediately said that it was diabetes."

When asked questions about the 504 program and the accommodations provided to their son in the public school, Ciro's parents informed the researcher that the elementary school was just going through the process of placing him in the 504 program and were working on the paperwork. After being diagnosed with T1D, the doctor sent Ciro and his parents to see a nutritionist. The nutritionist informed them about the 504 program in the schools and told them to inquire about the program at Ciro's school. When Ciro returned to school after being diagnosed with T1D, he began behaving badly. The principal and the counselor met with Ciro's parents and suggested that placing Ciro in the 504 program and giving him some accommodations would help Ciro to behave better. Therefore, Ciro's parents were not familiar with the way the program worked. They had met with the staff members who were going to be a part of the diabetic management team. The team included the nurse, a teacher who used to be a paramedic, the librarian, and the assistant librarian. Ciro's parents knew that a plan was in place in case their son felt shaky or was trembling and felt weak; he was to be escorted to the nurse's office by an adult. His blood sugar was to be checked and if low, he was to be given two ounces of juice, or Glucostat pills, or four cookies. In an hour the nurse was supposed to check his blood sugar again and send him back to class if it had stabilized.

When asked if the school principal was aware of their son's medical condition and if she was involved in his 504 diabetic management team, the parents acknowledged that the principal became aware of Ciro's condition after he started misbehaving and later complained of being bullied. However they did not think the principal was a part of the 504 diabetic management team. On the bullying issue, Ciro's father shared that Ciro:

> …would come home crying, in a sad mood. I mean he was pretty irritable; of course, that is something that we were told was going to happen. But when he started telling us that they were calling him names and teasing him, calling him 'stupid' and so on and so forth, that's when we started getting concerned. We brought it up to them; the principal, the counselor, the nurse, and nothing was done. We had to go a second time.

The principal questioned the students involved and informed Ciro's parents that the name calling was going back and forth. Ciro's father said "the biggest word was that he was lame; that he was stupid; that he was dumb because he had diabetes." Ciro's father went on to share that Ciro had fallen into a depression and was seeing a psychiatrist. Ciro's father stated that:

> I know he understands what happened to him as far as his condition. But I can see that he doesn't fully understand what it really is, as far as how he's going to live with that for the rest of his life. I know he understands what it is, but even me, myself; I still can't soak it in. I still can't accept it. He's gotten to the point where he's very irritated, I mean very irritable. Before he developed diabetes he used to be a real active student. Even at school he would always want to participate, always want to go play. Now it's been more of a no, no he doesn't want to do it. So it has taken its toll in his life. I have to say that.

In reference to the principal's involvement with Ciro's 504 diabetic management team, Ciro's mother stated:

> I haven't noticed or felt any interest on the part of the principal. In reality I haven't noticed or felt the slightest interest. She only said that she was going to implement her rules in the school. The word "her" is a word that I didn't like; that that is "her" school

> and that she would implement that; and that she suggested that we put our son in the plan, in that program. The one that did everything was the counselor. Since then I haven't seen the principal, not even to tell me, 'How else can we help you?' or nothing.

When asked about the changes that are needed to help the 504 Program better determine and implement accommodations, Ciro's father requested more training, not only for the nurse, but for the entire staff, including the coaches. He felt the staff did not know the difference between Type 1 diabetes and Type 2 diabetes. He stated:

> Well, I guess, more training, I would say, not only for nurses who deal with him directly, or any nurse for that matter at any school, not just specifically for here, but training would definitely be a big, big issue. We're surprised, I mean, how many people actually really know about it... Well, how many don't know about it. How few actually do know about that particular condition. Most here in the Valley, Latin, or... everybody hears about it, about Type 2; Type 1, of course, basically saying that it is a little different, in the sense that a little bit different care is involved. It is insulin dependent. It isn't something that you can just pass by; yeah, big, big issue. Here, again, just maybe training, I would say, training as far, not only with the teachers but coaches, other teachers, I mean, that don't necessarily have to be in direct contact but at least made aware, and basic training as to, in case of an emergency… That to me would be a big deal, or a big help as far as pretty much getting more teachers involved, maybe getting some of the assistants, whoever, again, not just specifically whoever deals directly with them, but people that normally don't.

Ciro’s mother agreed that the entire staff needed to be trained. She mentioned that the school secretaries supervise the students in the cafeteria during lunch and yet they have not been trained or given any education on the care of students with T1D. She said:

> They don’t supervise him to see if he ate all of his food. If they’re going to give him insulin, he needs to eat all of his food. His sugar goes down too much when he doesn’t eat his food. I would like a menu to be made for him where he will like his food every day so that he will eat it, because there are days when he doesn’t like his food; he doesn’t eat it and that day he goes to the infirmary with low blood sugar.

Ciro’s father added that Ciro likes to talk with his friends at lunch and sometimes ignores his meal because he’s having too much fun with his friends. He said:

> I’ve heard of several parents and the Youth Diabetic Association that were able to implement such a plan as far as getting with the school nutritionist, school cafeteria, and the principal and they have outlined a certain meal as far as certain types of foods that a particular student likes. Then they are sure that he’s going to eat. In other words, he will be able to fulfill his actual carb limits.

Ciro’s father shared that his wife and he had attended one meeting of a support group sponsored by the Youth Diabetic Association and found it to be a great experience. He also stated that Ciro’s fifth grade teacher was still putting limitations on his restroom breaks. He was hoping that would change once the 504 documentation was completed and given to Ciro’s teacher. Both parents felt that Ciro had not been given any accommodations in the classroom yet, and that his fifth grade teacher was not very understanding with Ciro. The mother stated:

> We even hope that after today that it may be a little different, because before, there were limitations for him going to the restroom, until we told them that one of the symptoms

> when he's got a high sugar is going to the bathroom a lot. But he was limited in that before, to not going so often to the bathroom, so I can't speak of accommodations, because there weren't any accommodations, or there weren't any until now. And before, the teacher he had in fourth grade, he was very understanding with him and he took good care of him, but with this other teacher it's not the same. She's very different and the excuse that she gives is that he's older now. Well I say, they may be older but he has that condition. So, no, I can't speak of accommodations.

Ciro's mother felt that the nurse and the teacher, who was an ex-paramedic, did have an understanding about what the chronic condition of T1D is and the difference between T1D and T2D. As for the other members of the 504 diabetic management team and the rest of the staff Ciro's mother stated:

> They don't know anything about that because they think that it's like Type 2 diabetes; that it can be managed with pills and everything is okay. But this is life or death. Many can die if their sugar goes up really high. They can die. It is very different. So that is what I think. They don't understand it.

Ciro's parents were pleased with the communication they had with the nurse, and felt she took good care of Ciro at school:

> The nurse has been very, from what I've seen, she has been understanding and she does know about it, although sometimes I've seen that she does have a few questions, but, of course, she does the right thing. First thing she does is she calls my wife, which is what was supposed to be done. The training that we had, or that I had personally from his doctor, his dietician was basically, real basic training, real basic education, but it was to the point where I could understand it. And again, the understanding that they have here; it

> is very, very different from what I've seen. In other words, they don't have much understanding.

Ciro's mother added that her son had developed a good relationship with the school nurse. She said:

> In my opinion, they get along very well. And the nurse helps him, and helps him see when he is wrong, because many times he is wrong. He thinks that he is going to eat more and he wants for her to give him more insulin, but she doesn't pay attention to him, because she knows how he is in his condition. She knows how each situation develops, and she already understands him; and that is an excellent relationship that they have.

However, they did not feel that the communication between the members of the 504 diabetic management team was good. For example, the counselor had shown Ciro a video about a young girl with T1D. The counselor did not discuss this with the nurse or Ciro's parents before showing the video to him. Ciro came home very upset and crying after seeing the video. The nurse agreed that the video should not have been shown to Ciro. Ciro's mother stated:

> It was the perception of a little girl. It was what the little girl thought, or rather, what she felt when she was diagnosed with diabetes. But it was her perception and not the perception of my son or another child. So for that reason it affected him a lot and the last thing that the little girl said in the video was, 'Insulin is not a cure.' My son got very upset and became anxious.

Ciro's father later watched the video and stated that, "It was overwhelming, even for me. It does send out a very, very, hard or powerful message." Both parents were in agreement that the nurse and Ciro had a great relationship. The two communicate well and she was good about following the doctor's orders and not giving in to Ciro's demands for extra food.

Despite Ciro's chronic condition, he still had good attendance, missing school only to go to his diabetic specialist appointments in San Antonio, 250 miles away. Ciro's grades were good, but slightly lower than the previous year, reflecting the increased rigor of the new STAAR test. Ciro's mom stated that:

> We haven't had to use his Glucagon, which is for once he has passed out. He hasn't had too many lows. The majority of them have been in school, but again, it's due to him not fully eating everything that's given to him; but absenteeism, as far as that sort of issue, no.

Both parents were aware of Ciro's emergency care plan. Ciro's mom stated that if he felt low and was shaky, trembling, or sweaty, an adult was to escort him to the infirmary where the nurse would immediately check his blood sugar. If low, Ciro would be given Glucostat. If Ciro lost consciousness, the nurse would check his sugar. If he was low he would be given the Glucagon shot and the nurse would call 911 for an ambulance. If he had a high sugar, he would be given insulin.

The final question of the interview was, "What concerns do you have regarding your student's overall care at school." Ciro's parents reiterated several points that they had already made over the course of the interview. They wanted Ciro to be allowed to use the restroom as needed. They wanted to see all of the staff trained to know about the care that students with T1D must have and to understand the difference between T1D and T2D. Ciro's mother stressed that it was important to educate and train the coaches because they hold class outside or in the gym which is a good distance away from the infirmary. Once trained, they wanted the staff to be able to effectively communicate about Ciro's care and well-being at school. Ciro's father was emphatic that, "Communication has been a big issue. It has caused some trouble or some problems. Basically that’s really one of the biggest issues, lack of communication and understanding.”

Parent E

Yesenia Ramirez was born in 1998. She was diagnosed with Type 1 diabetes when she was nine years old and in the third grade on February 3, 2008, a day her mother says she will never forget. Yesenia was 13 years old at the time of the study. Her family qualified for Medicaid. Yesenia’s mother gave her two insulin injections a day. Each injection included a mixture of long-acting and short acting insulin. Yesenia’s doctor asked her if she would like to be on the insulin pump, but Yesenia adamantly refused. Yesenia liked to wear fitted blouses and was concerned that the “bandage” of the pump would protrude and show through her clothing, regardless of whether she wore the “bandage” on her arm, stomach or leg. Yesenia’s mother spoke to the parents of another student at her daughter’s middle school that used the insulin pump. The parents claimed that their daughter liked using the insulin pump and was very happy with it. However, Yesenia was still not convinced and continued with insulin injections twice a day. Yesenia’s mother stated that Yesenia did not prick her own finger to conduct blood sugar checks with the glucometer. Yesenia was an eighth grader. Spanish was the primary language spoken at the home. Yesenia attended the same middle school since she began as a sixth grader. A new middle school opened at the beginning of Yesenia’s eighth grade year. Because of rezoning to relieve overcrowding at all of the district’s middle schools, Yesenia was sent a letter that she was zoned to the new middle school. Yesenia was resolute that she did not want to leave the middle school she had been at for two years. She was extremely close with the nurse at her school and did not want to leave her. Yesenia’s mother stated:

> I had to go to the administrators and I took a letter from her doctor. The doctor told me that the child couldn't move because she had diabetes. He wrote down this and that of things and they let me stay here in the school. But now she doesn't have a bus. I have to go and drop her off and I have to take her. I have this obligation, responsibility. That's why I can't work because I have this obligation to take her to school. I take her at eight and then I have to pick her up at four.

In short, Yesenia had a great relationship with the school nurse and felt close to her. She and her mother were pleased with the care and attention the school nurse gave to her.

On the day of the interview, Yesenia's mother answered the door of the government housing project apartment where the family lived with a serious face and a nod to the researcher and the interpreter. She was dressed in warm-up pants and a low cut strappy top, her hair pulled back in a ponytail. She waved her guests towards the couch in the cluttered, messy living room. When the researcher mentioned that the kitchen table might be more conducive to the interview, Yesenia's mother ignored the request and moved a folding chair across from the coffee table located in front of the couch. As the researcher and the interpreter situated themselves on the couch across from Yesenia's mother, she offered that Yesenia was in Mexico for the Christmas holidays staying with her mother-in-law and sister-in-law. She said Yesenia loves to be with her grandmother in Mexico. While in Mexico, Yesenia's aunt gives Yesenia her insulin injections and helps Yesenia to take care of her T1D. Yesenia's mother went on to say that her husband died about nine years ago. She has never remarried and is a single parent to her four children, two boys and two girls. After going over the informed consent form, the permission for audio-taping the interview and requesting school records form, and obtaining the parent signature on both documents, the researcher explained the interview process with the parent. The interview promptly ensued.

When asked questions about the 504 program and the accommodations provided to her daughter in the public school, Yesenia's mother was at a loss. The question was posed by the interpreter in several different ways, and Yesenia's mother kept repeating that she had never heard of the 504 program, did not know what it was, and had never been invited to a meeting with the nurse at school. Finally she volunteered that all communication between the nurse and her had taken place over the phone. She said Yesenia's doctor had sent the school nurse a special diet which was to be provided to her by the school. The nurse was not instructed to give her any injections at the school because Yesenia's mother gave Yesenia one injection in the morning before school and the other in the late afternoon before supper. She stated that the nurse called her when she had questions, needed medications, or to tell her of concerns for Yesenia's health at school. She said:

> Many foods, they don't give them to her because of her diet. But the child sometimes doesn't eat because she doesn't like what they give her there and her sugar goes down very often. Yes, her sugar does go down.

Although Yesenia's mother was not versed in the process and procedures of the 504 program, she was aware of procedures that were in place to stabilize her daughter's blood sugars during the course of the school day. She said if Yesenia's blood sugar is low, she goes to the nurse with a friend and her blood sugar is checked. If she is low, she is given orange juice each time, and sometimes given chocolate, or Skittles, which are her favorite candy. After ten minutes she is checked again. The lowest blood sugar reading she has had at school was a 40. The highest her blood sugar has been at school was a 300. When Yesenia's blood sugar is high they give her water which Yesenia's mother provides to the nurse. If Yesenia were to lose consciousness, the nurse has doctor's orders to give a Glucagon shot and transport Yesenia to the hospital by ambulance and notify the mother. She mentioned that Yesenia also suffers from asthma and has an asthma inhaler at the nurse's office. When she runs during PE she becomes agitated and has to use her inhaler.

Yesenia's mother stated that Yesenia was diagnosed with T1D while the family was living in Colorado Springs, Colorado, back in February of 2008. She shared that Yesenia:

> …had been drinking and drinking juice. She was drinking a lot of juice and I would give it to her but I didn't know she had diabetes, and neither did her teachers over in Colorado, or anybody. She would get very sleepy and feel like going to the bathroom all the time and everything. She'd drink a lot of water but didn't know because neither the teachers nor anybody ever told me about the symptoms that she had.

Since it was clear that she had lost weight and felt sick, Yesenia's mother took her to a clinic in Colorado. The doctor at the clinic did not do a blood or urine analysis and determined that Yesenia was suffering from a cold. The next day, Yesenia's mother traveled in her truck to her brother's a half hour away for a barbeque for her other daughter's birthday. Yesenia's uncle took one look at Yesenia and said, "Take her to the hospital because that little girl is going to die." Yesenia's mother put the emergency lights on the truck and drove her immediately to the hospital. At that time Yesenia was not covered by Medicaid. Yesenia's mother stated:

> I didn't have it and they did not want to attend her. I told them that that month it had expired. They didn't want to see her or help her. I told them to please help her and they put her in the emergency room. Then a day or two later, I went over there to talk to them about the Medicaid, there at the stamps office, the office where they have food stamps.

At the emergency room, the staff checked Yesenia's blood sugar and it was a 2000. They immediately gave her insulin to bring her sugar down and kept her hospitalized for five days in order to regulate her blood sugar and to educate her mother about how to check blood sugars, give injections, and prepare Yesenia's food.

Yesenia's mother shared that when they were living in Colorado after Yesenia was diagnosed with T1D; her blood sugar was very well controlled. Yesenia loves Mexican candy and food. Since the family moved to the Rio Grande Valley of South Texas, Mexican food and Mexican candy are plentiful. As a result, Yesenia has gained weight to the point her clothes don't fit her anymore. Yesenia's mother states that:

> She eats lots of candy, bread, chips, candies; everything, everything she finds, and if I don't buy it for her, and I buy it for the other children, she goes anyway and gets it in the store. Or, that is, I'm saying, well, she's a child, and she's difficult.

Her doctor warned Yesenia that her blood sugars had been at a high level and that she must get control, but she would not listen to the doctor's orders. Her blood sugars continued to be up and down. Yesenia's mother went on to say, "She doesn't understand. Well, she does understand but she doesn't do it. That is, she says she doesn't care anymore. She says that anyway she's still going to die." Yesenia's mother mentioned that a few years ago Yesenia refused to eat her supper after she had already been given her evening insulin injection. As a result, Yesenia had a hypoglycemic reaction and seizure in the middle of the night. Yesenia sleeps with her mother every night and she felt Yesenia moving in the night as she began seizing. Yesenia's mother stated that:

> Once the ambulance came here, she had fainted. She felt like… It went down a lot, like about 20, I think, like about two years ago or so. It came out like, like, like… It's called

> like an attack, like shock, and it went down and then she has a special injection to check her but I can't do it. I can't inject her because I get nervous and then, the little jar where…I bent the… I took the cover off the top and I bent the needle and I couldn't inject her. Then I gave her juice from the refrigerator that has a straw and I put it in over here through the side of the mouth and that's how she revived. Just a little bit, right, and that was enough and she returned, revived that way. God returned her to me. Yes, I got very frightened and I called an ambulance and everything. I think that she had already died. I got very frightened, yes.

Yesenia's mother stated that Yesenia has been hospitalized for her T1D two or three times since the family moved from Colorado to the Rio Grande Valley of South Texas.

When asked if the school principal and assistant principals were aware of her daughter's medical condition, Yesenia's mother thought they were, but was not sure. She had never discussed Yesenia's medical condition with administrators at her daughter's middle school. When asked, she also said the teachers have never called her about her daughter's condition, but have called her about Yesenia's low grades and poor behavior. Yesenia's mother stated that Yesenia has a tendency to fight in school and says:

> I think it's for the same reason because the child also gets angry and starts fights. It's for the same reason, the diabetes. I say that it's because her sugar gets her that way. I have a really hard time with her. I am taking her to therapy because she got a knife and said that she wanted to kill herself. She would go into her room and lock herself in. Yes, I had a really hard time with her.

It was after that episode that Yesenia's mother began taking Yesenia to a therapist. According to Yesenia's mother, Yesenia still fights frequently with her brothers and sisters, complaining that she is the only one of the siblings that has T1D.

When asked the question, "How has Type 1 Diabetes affected your child's attendance record and grades in school? Yesenia's mother replied:

> Yes, yes, she does miss a lot because she has doctor appointments with the one for the blood, the diabetes doctor, and with the dentist because she got braces and now she has some springs because she bites more, and there I go because they fall and then, well, because something comes unhooked, undone and I have to take her to the dentist as an emergency. Yes, she misses school a lot, but they say her grades are low. They say, Mrs. Ramirez, I understand that the child has to go to the doctor, but she says that she has very low grades. I don't know if it's because she doesn't pay attention or because she's absent, or… I don't know.

Finally, Yesenia's mother shared her concerns about Yesenia's general care at her middle school. She stated:

> What only worries me is that she doesn't eat because she says that she doesn't like the food that they give her. Or if they give her a hamburger, they take off the bread. They only give her the meat and they give it to her with bread mixed in. I don't know. They give her another thing and she says she doesn't like it. In Colorado they used to give her everything. Over there they gave her pizza. They gave her hamburgers. Here they don't do that and they should do that.

Yesenia's mother was encouraged by an employee in the school cafeteria in Colorado to have Yesenia eat regular ice cream before going to bed every night. After eating ice cream before bed, Yesenia would wake up with an 80 or 100 blood sugar. “But not here.” she stated. “Here she has it very out of control.”

Parent F

Yasmina Vasquez was born in 2003. She developed Type 1 diabetes when she was four years old. She was eight years old, on insulin injections, and qualified for Medicaid at the time of the study. Yasmina was in the third grade and lived with both parents in a trailer park on the outskirts of town. Her father worked outside the home and her mother was a homemaker. Spanish was the primary language spoken in the home; however, Yasmina’s father was also fluent in English. Yasmina attended one elementary school since beginning kindergarten.

The researcher cautiously approached the trailer as two small dogs barked incessantly at her feet. The interpreter watched from the safety of the van in the street. As the researcher started to climb the rickety steps up to the trailer door, the door opened and two petite little girls peeked out to see what or who had caused the dogs to get all excited. When they saw who it was, they called out to their mother who opened the door wide with a friendly smile. Just as the researcher waved to the interpreter in the car that it was safe to get down, a truck pulled up in the driveway and Yasmina’s father joined the group. Once inside the tidy, but sparsely furnished trailer, introductions were made and the researcher and interpreter were given seats on the couch. Yasmina’s parents pulled up kitchen chairs across from the couch. The researcher took note of a cute diminutive Christmas tree to her right which already had several presents under it. As introductions and seating arrangements were made, Yasmina and her sister had been chasing each other back and forth through the length of the trailer. Yasmina and her sister were beautiful, lively little girls with big brown eyes and long brown hair. Yasmina’s father asked the girls to stop running and go to their room. They swiftly obeyed.

After going over the informed consent form, the permission for audio-taping the interview and requesting school records form, and obtaining the parent signature on both documents, the researcher explained the interview process with the parents. The interview promptly ensued. The researcher first asked Yasmina's parents to describe how they found out that their daughter had T1D. Yasmina's father shared that for a week and a half prior to her T1D diagnosis, Yasmina had been urinating a great deal. He stated:

> She had begun to urinate a lot. She couldn't control it and she already knew how to go to the bathroom by then. She began to urinate without knowing it and we would scold her. We'd ask her why she peed and she didn't know. She'd say she couldn't control it. Then in school they also discovered that she was peeing a lot, but they didn't tell us anything. The school nurse never told us, 'You know what? She probably has diabetes. Go and get her checked.' Nothing! There I saw somewhat that they were not well prepared or educated to know; to look after a child that possibly had diabetes. We didn't find out until she had high levels of sugar in her body. Well…well, it was very hard because we almost…we almost lost her.

Yasmina's mother added:

> One night she got up at around two in the morning and she began to ask for water, that she was very thirsty. I gave her water and later she got up again and she drank milk and she drank water and then she fainted. Then we ran to the hospital and there we found out that our daughter had diabetes and that she was at an 1100 sugar reading. It had a huge impact on us because we didn't know anything about that illness.

When asked questions about the 504 program and the accommodations provided to their daughter in the public school, Yasmina's parents were cognizant of 504 program procedures.

Yasmina’s father believed that things had been going well at the school in terms of the care of Yasmina’s diabetes, but he felt that more staff members other than the nurse, specifically the teachers, should be educated about the care of students with T1D. Yasmina’s mother stated that, “I would like the nurse to be better educated so that I can be more at ease here at home.”

Both parents agreed that Yasmina’s most important accommodation of the 504 Program that facilitates her classroom learning is her school meals; breakfast, lunch, and her two snacks. However concerns were raised because Yasmina’s parents feel that the portion sizes are too small. Yasmina’s mother described her as “thin but very sturdy. She’s got muscles. She likes to play. She likes to run. She’s very active.” Yasmina’s mother continued:

> Well, she is well attended to with her lunch, her breakfast, her food. They also give her a snack. But since diabetic children are big eaters, I would love to see that they are always aware and on the lookout for that, because she says that it is very little food, or that she needs to eat a little more. All that worries me, because I know that it is because of the illness that she would like to eat everything.

Yasmina’s father stated:

> Well, my comment would be similar to that of my wife’s; above all in nutrition. Since I believe that she needs a little more variety in her food since they repeat quite often the same menu. Even though she likes it, she gets tired of eating the same thing. They give her very little. I think that she needs a little more variety in the food that they give her, in her nutrition. Every day I’m with her in the morning. I sit down with her for her breakfast and I see that almost always it’s the same. It’s always two or three things and they don’t change it. I believe that they need a different menu.

When asked if the school principal was aware of their daughter’s medical condition and if she was involved in her 504 diabetic management team, the mother acknowledged that the principal was aware of Yasmina’s condition and did help look after her. Yasmina’s mother answered:

> Yes, everyone there at school is informed about Yasmina’s illness. The principal calls us to have meetings, and tells us about anything that she sees different; sometimes about whether we have a question or anything that we might want her to do. She always has meetings with us, but, well, I would say that it’s more often when they send some paper or some letter that has to be signed. But I’d say it’s probably more for that. But, no, no; when we’re no longer there, they probably just treat her like any other child. Well, I’m not there; and I can ask myself lots of questions. But God willing that yes, they are looking out for my daughter, as I would wish them to.

Yasmina’s father agreed that:

> That’s right, from the principal to the teachers and the nurse; I see that they are very concerned about my daughter. They call us at home daily. They send us letters. When the girls, for whatever reason, are absent, they are worried and they call and ask if the child is fine, or ask what is wrong with her; and I believe that yes, it’s because they are very concerned about her.

Yasmina’s parents, when asked about the changes that are needed to help the 504 Program better determine and implement accommodations, again stressed more T1D training for all teachers and staff, including the school nurse, larger portion sizes for school breakfast and lunch, and more variety of foods in the school menu. They also were encouraged because they were recently sent papers to approve that trained teachers and other trained staff members may do blood sugar tests and give insulin shots to Yasmina when the nurse is away from the school. Yasmina's parents were pleased that more staff members were being trained in the care of students with T1D. One of the biggest changes that Yasmina's mother and father would like to see is flexibility in giving insulin injections when Yasmina's blood sugar is high. Yasmina's father stated:

> When she is high; when they have called us; many times I have become upset. I tell them, 'You know what? You have it. Give her insulin.' They tell us, 'It's because I can't give her any, because the orders that I have from the doctor say that I can only give her insulin at certain times.' So then realize this, that if the child has her sugar high at ten in the morning, the nurse can't give her insulin until eleven forty-five when she's due for her food. I tell them that they cannot wait. They can't wait until it goes up or it goes down. At that time they have to give her insulin so that it will go down even if there is no permission. I don't know. There has to be permission so that at any time they can give her insulin so that her sugar will go down. Many times, even though she doesn't want me to measure her, she's on irregular levels. Many times, any little thing, and her sugar goes up and the insulin that she was given wasn't enough. She cannot go around with her sugar high two or three hours to wait until the time comes that the doctor said. But I say that they should act quickly and give her the insulin. Many times, when they have called me and they tell me that they cannot give her insulin, I leave work. I go, and I bring her home and here I give her the insulin.

Yasmina's mother agreed with her husband stating:

> That happened about two weeks ago; what my husband said. The child said, 'Mommy, I get a pain in my stomach at school,' and I tell her, 'But what is it that happens,

> daughter?' In the morning she wasn't going to go to school and then we checked her and she had it at 500 without having eaten or anything. She had it at 500 and had a stomachache. Then she told me, 'Mommy, this same pain in my stomach that I have now is the pain I get at school.' It's because they let too much time go by with her sugar high because they're waiting until it's time for her snack to be able to give her insulin, because they go by the doctor's recommendation, what the doctor tells them. That's all right because they have to go with what the doctor tells them, but the child has high blood sugar. If they could at least give her one unit of insulin, or a little, so that they can try to lower it as quickly as possible. That is what we would like for them to help us with in that aspect. That is what we are currently struggling with, but it's with the nurse. Because in the case of the nurse, I'm saying, well, if she could support us, right, she could put a little more of her heart into it than of her work. You understand?

Yasmina's mother went on to say:

> What happens is that we have to understand that the doctor doesn't know at what time the nurse is going to mark it down. That's why the order has to be made out, so that the nurse will know. The nurse, Bobbie, she used to give her the insulin. She didn't know if the doctor had given permission or not, but she already knew the child's body; she had built a relationship with her. So then she would see that Yasmina was at 500 and they had already given her three units. She didn't expect it to go down. Then what she did was to give her one unit more and then it would go down more quickly. Then that is what we need, a signed order from the doctor, or for the nurse to become more involved with that illness because that illness is a matter of life and death. In an instant it can go up or it can go down and that is the fear that we have. That's why we need a nurse that is there 100

> percent, that can be with her. That is what we had with the previous nurse. The school nurses need to have it explained to them that when the sugar is high, it affects the lungs, the eyesight. There are many faults, breakdowns, things that stop working when the sugar is always, always high. So that is what has to be explained to them. That it is necessary that they always maintain the sugar at a normal level because it affects her. It affects the child. Every little while she asks permission to go to the bathroom, and it's because her sugar is high. They need to have it explained to them.

Yasmina's parents agreed that the school nurse did her job, but they did not agree with her rigidity to the rules. They knew the new nurse was just following orders, however, they felt she had not tried to build a relationship or bond with their child. It was clear that Yasmina and her parents preferred the previous nurse, and were finding fault with the new nurse in comparison.

Both of Yasmina's parents felt that the members of the 504 team did communicate with each other about Yasmina's care, were aware of the difference between T1D and T2D, and were familiar with the symptoms of low and high blood sugars. They are relieved, however, that Yasmina is starting to recognize when her own blood sugar feels low or high and communicates the information to school personnel and to her parents so they can help her stabilize her blood sugars. When the question, "How has Type 1 Diabetes affected your child's attendance record and grades in school?" was asked, Yasmina's father confided that:

> …regarding her attendance, yes, it has been affected. Many times, if I see that the child is struggling to control her sugar, I prefer to have her at home than to send her. At school, if, for example, she is high or whatever, they're always calling and calling and don't do anything because they can't give her any insulin. If she's high, then one has to leave work, go for her, and bring her home. In that case, I prefer for her to stay at home. I know

> that my wife is going to be taking care of her, and is going to be checking her every little while, and if she needs insulin, she will give it to her. It's for that reason that sometimes we don't send her to school, so that we can better take care of her, ourselves, here at home. And many times they have called us from school. That's why, if she's high, they can't give her insulin. They want us to go for her, and well, and then I have to miss work too. So yes, it has affected us somewhat in that. But in her learning, she is doing very well.

Yasmina's mother added that:

> Yes, in her schooling, she is learning a lot. I see that she has been given very capable teachers and we see the progress that she has had this year. Yes, as my husband says, sometimes when she is struggling with her sugar and it is out of control, she has to stay home and miss school. And they do call us from school and ask, 'Why didn't Yasmina go to school?' We tell them and they understand why, right. They don't pressure us too much. But in her schooling the child is doing very well, and she is doing excellent now with the teachers she has.

Yasmina's father described her individualized medical care plan in detail. He made it a practice to give Yasmina her morning injection and eat breakfast with her at school every morning. Two hours later she goes back to the nurse's office to check her sugar and eat her snack. She goes back to class and gets another blood sugar reading and insulin injection two hours later right before lunch. Yasmina gets her last snack two hours after lunch in the middle of the afternoon, regardless of whether her sugar is high or low. Yasmina's parents are not in agreement with the snack policy. Yasmina's mother states, "We are not in agreement with that, because if she has it high, it’s going to go up higher. So then its little things but which, at the same time, for her body are big things, right?”

The final question of the interview was, “What concerns do you have regarding your student’s overall care at school.” Yasmina’s mother poignantly stated the plight of all children with Type 1 Diabetes when she replied:

> I, as a mother, wish that there would be more progress in the study of the illness of Type 1 diabetes. More than anything, for the sake of the children, because they do suffer; they do struggle a lot. It is a very ugly disease. It is difficult to see as a parent, to see one’s child with low sugar and having convulsions. It is a terrible thing that I don’t wish on anybody! That’s why, I beg you, I ask you, to put forth a little more effort, more interest in finding, if not a cure, then something that can control diabetes in children, because Type 2 diabetes, in adults, at least they are already adults, but the children suffer so much.

Chapter Four Summary

In order to answer the research questions, a multiple case study, including six individual parent interviews, was conducted. The interviews were audio-taped, and later transcribed, coded and analyzed along with a review of students’ records. A descriptive research design was utilized in Chapter Four to present the data from the six individual parent interviews and to tell the stories of the six families. A pseudonym was used for the name of each child with Type 1 diabetes to maintain complete confidentiality. The data was presented in Chapter Four with rich, thick description and assisted the reader in understanding the reality of each family’s circumstances and living conditions as they interacted with the public schools.

CHAPTER V

FINDINGS AND ANALYSIS

The purpose of this qualitative study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. Students with T1D automatically qualify for Section 504 services (Brady, 2004). Getch et al. (2007) noted:

> …that children with diabetes are protected under *Section 504 of the Rehabilitation Act* (1973), *Individuals with Disabilities Education Act* (1990), and *the Americans with Disabilities Act* (1990). Under those laws, diabetes has been determined to be a disability, making it illegal for public schools to discriminate against children with diabetes (p. 48).

Subpart D of *Section 504 of the Rehabilitation Act of 1973* calls for an individualized accommodation plan (IAP), centered on educational necessity, for each entitled student. The 504 team may consist of the classroom teacher or teachers, the school principal or assistant principal, the school counselor, the school nurse if applicable, and the parents (Conderman & Katsiyannis, 1995). After interviewing all six parents or sets of parents with a child with T1D and perusing school records of all six students with T1D, the researcher noted that all students were in the 504 program at their school and each student had both an updated, detailed Individual Health Plan (IHP) and an Individual Emergency Plan (IEP). Such individualized accommodation plans are intended to extend educational assistance to students with disabilities defined under *Section 504 of the Rehabilitation Act of 1973* (Conderman & Katsiyannis, 1995), to help equalize a student's access to public education. One of the reasons that students with disabilities such as the chronic disease of Type 1 diabetes fall under the 504 umbrella is that fluctuation of blood glucose levels and the daily management regiment of T1D may lead to excessive school absences or extended trips to the nurse’s office. Even with sufficient access to treatment, students with T1D may still experience hypoglycemia or hyperglycemia. Existing treatments for diabetes do not entirely replicate the body’s natural utilization of insulin. As a result, a student’s blood glucose levels may rise and fall through no fault that may be attributed to the student. The diabetic management team should be mindful of this fact and work with the student in an optimistic, encouraging manner to help monitor diabetic control (Getch et al., 2007). Excessive school absences or daily extended trips to the nurse’s office for students with T1D result in a loss of face-to-face, student-to-teacher instructional time that can never be regained. Over the course of years, the cost of such loss of student-to-teacher instructional time for the student with T1D, may, at the very least, put them at a disadvantage to students who do not have a disability.

Critical theory, with an emphasis on social justice leadership, was utilized as the theoretical framework for the dissertation topic chosen for the study. Theories, in general, attempt to explain how society is structured and how society operates. According to Lynn et al. (2006), “not only do critical theorists attempt to discover why oppressive structures exist and offer criticisms of their effects; they also explore the ways in which we can transform our society” (p. 18). In just such a way, the qualitative study was designed to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. The interview questions were developed with the intention of querying parents to discover if social justice had been served for students with chronic illnesses such as T1D in one south Texas public school district. Critical theory, with an accent on social justice leadership, relates distinctively to the chosen topic for the study as the purpose of the qualitative study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district and to give parents a voice.

The parent interview questions of the study were geared towards identifying the quality of communication between school staff members of the 504 diabetic management team and the parents of students with T1D, positive and negative aspects of 504 program services, and parent of students with T1D concerns and suggestions for improvement. The study included six individual parent interviews, which were audio-taped, transcribed, coded and analyzed, and a review of students' records to explore the research questions. A pseudonym was used for the name of each child with T1D and their parent or parents to maintain complete confidentiality. Several issues of concern to parents of students with T1D constituted the research questions addressed in the study. The research questions were:

1. How do parents of students with Type 1 insulin-dependent diabetes describe their experiences and satisfaction with school services provided through the 504 program for their children and the quality of communications between and among the members of the 504 team?
2. What are the perceptions of parents of students with T1D about the best 504 practices and accommodations to help facilitate their child's learning in the classroom?
3. According to the perceptions of parents of students with T1D, what concerns and suggestions for improvement do they have regarding their student's overall care at school?

It was anticipated that the study would provide useful information on how to improve services and/or accommodations for students with T1D in order to level the educational playing field with students who are not afflicted with a chronic disease such as T1D. The aim was that new research findings of the study would add to findings of previous studies which were reviewed in Chapter Two. The hope was that new light would be shed on the 504 program experiences of parents of students with T1D in one south Texas public school district.

After coding and analyzing the transcriptions of the six audio-taped individual parent interviews and reviewing students' records, the researcher found five commonalties, or common themes, among the six cases. The themes were: 1) Administrative Awareness and Involvement; 2) 504 T1D Management Team Communications; 3) School Nurse-to-Student with T1D Relationship; 4) Best T1D 504 Accommodations; and 5) Parents of Students with T1D Concerns and Suggestions for Improvements.

Administrative Awareness and Involvement

The first theme, Administrative Awareness and Involvement, refers to the campus administrator's awareness of the implementation of 504 services for students with T1D and the administrator's involvement with the 504 diabetic management team. The lead campus administrator sets the tone for the level of importance of equal access to education for all students, including students who are serviced as a part of a special population of students. The theme, Administrative Awareness and Involvement, took precedence in the study because administrators, as educational leaders, supervise and are responsible for all aspects and elements of a public school campus. First and foremost, public school administrators are ultimately in charge of and must maintain student safety. In the Chapter Two Review of Literature of the dissertation study, it was reported that legislation called "Safe at School" was put in place to guarantee that all "students with diabetes are medically safe and have access to the same educational opportunities as peers without diabetes" (American Diabetes Association, 2011a, p.

2). The vital point of such legislation is to permit students with diabetes to self-manage their care, to make sure that school employees are taught to perform standard and emergency diabetic care functions, and to prevent segregation of student with diabetes (American Diabetes Association, 2011a).

Also in Chapter Two, The Review of Literature, a study conducted by George Theoharis (2007) of a subgroup of principals who were social justice activists was examined. Theoharis (2007) established his study primarily upon critical theory. The researcher specified that, for his study, social justice leadership was defined:

> … to mean that these principals make issues of race, class, gender, disability, sexual orientation, and other historically and currently marginalizing conditions in the United States central to their advocacy, leadership practice, and vision. This definition centers on addressing and eliminating marginalization in schools. Thus, inclusive schooling practices for students with disabilities, English Language Learners (ELLs), and other students traditionally segregated in schools are also necessitated by this definition (p. 223).

In another study examined in Chapter Two, The Review of Literature, Getch et al. overall encouraged team work by administration, teachers, counselors, and the nurse in providing each child with diabetes an individualized diabetes management plan. The researchers determined that such a plan would enhance the educational well-being of the child with T1D.

One of the parent interview questions of the dissertation study inquired, “How are the school administrators actively involved as a part of your student’s diabetic management team?” The question was intended to measure, through codes and themes developed after analyzing the interview transcriptions, if the educational leaders of a campus were actively involved as a part of a student’s diabetic management team and empathized with the plight and special needs of students with T1D. If so, social justice leadership would, indeed, be served on that campus as the administrator would then strive to make sure that all necessary accommodations for the student with T1D are implemented to better serve students’ needs.

The six parents or sets of parents answered accordingly to the aforementioned question:

Parent A

Parent A, whose child was a seventh grader at a middle school, stated that the principals were aware of her daughter’s condition and did look after her. Parent A said, “They are involved in knowing what are her changes in moods or changes in her; the way she acts. They’re always, like for example, looking after her.”

Parent B

Parent B, whose son was a freshman in high school, stated that despite the fact that the school had so many students, the principals did know their 504 students and followed up with students and parents to make sure all 504 accommodations were provided to students. She stated:

> Well, you know I want it to be that I think they get involved by just knowing who they are; they know who their 504s are. I know that just because I’m a teacher and 504 and even Special Ed. aren’t the key representatives I have to fit in. So I’ve been able to see from the administrator’s perspective what they have to do in order to figure out what accommodations they need to put in place for these kids. Whether they need wheel chairs; whether it’s a fire drill and the kid’s upstairs; and how are they going to get down? All these new things and where the wheel chairs are placed and for my son I think just the fact that they know who their 504 kids are is a big deal; that they know that. They just know who they are by saying, by their names. It’s a repetitive thing. Our

> administrators at (name of high school) even know those kids that still have not passed their test. They have pictures of them and they call them their "faith." That bulletin board in the main office right next to the principal that says "our top faith" and then pictures of those kids. It could be 20 of them; it could be 50 of them. Next year it could be 65 to 150. They're all on her wall. And they're in color. That's the mentality of the main principal, so she knows each and every single one. She sees their face daily. She calls them by their name and they're labeled like that and they're all taking pictures, Polaroid's, really pretty on colored paper. They're really nice, but not necessarily are they 504; but most of them, some of them, 80 percent, maybe 60 to 80 percent aren't. A lot of them are not, but, nevertheless, there's a big percentage that are 504 and Special Ed., you know. So I think they take a good percent amount of their daily time to know who these kids are. So that's how I see that they're active and involving themselves in their lives just by recognizing who they are and making sure that they are imbedded in their brains, you could say. Every day she walks into her office, she has to go across that bulletin board. So if she sees one more or another one, she knows who her faiths are, and that's what she calls them. That's the way she labels them. So I like that.

Parent C

Parent C, whose daughter was a senior in high school, divided her answer to the question into three levels, administrator's awareness of the implementation of 504 services for students with T1D and the administrator's involvement with the 504 diabetic management team in elementary school, middle school, and high school. She stated:

> …in elementary, very much a part of it. There again, we're dealing with a smaller group of students overall. And it was just easier. It was also when she was diagnosed, so, of

> course, we immediately had to have the principal involved and at the time, my daughter was the only student with diabetes at the school, so we did get a lot of attention. We did get a lot of questions answered because I think the whole school kind of needed to know what was going on to some extent…The principal talked to the cafeteria staff and the coaches. We just had so many people involved and, if I remember correctly, the teacher and the nurse even spoke to the class. So that, of course, was much easier and the principal was very involved.

Parent C stated that the assistant principal at her daughter's middle school also had a child with T1D and therefore was aware of her daughter's condition and was helpful in resolving problems. Parent C, however, was not as satisfied with the administrator's awareness at the high school level. She felt that the high school principals were uninvolved with her daughter's 504 diabetic management team. She had sought their assistance several times over a four year period to unblock her daughter's credits due to excessive absences. She stated, "So as far as principals go, that's the only reason I've talked to one at the high school, strictly because of absences."

Parents D

Parents D, which included both the mother and father of the student with T1D who was in elementary school, agreed that the principal became aware of their son's medical condition after he began misbehaving and later complained of being bullied and ridiculed by other students for having T1D. However they did not think the principal was a part of the 504 diabetic management team. The mother stated:

> I haven't noticed or felt any interest on the part of the principal. In reality I haven't noticed or felt the slightest interest. She only said that she was going to implement her rules in the school. The word 'her' is a word that I didn't like; that that is 'her' school and

> that she would implement that; and that she suggested that we put our son in the plan, in that program. The one that did everything was the counselor. Since then I haven't seen the principal, not even to tell me, 'How else can we help you?' or nothing.

Parent E

Parent E was unsure whether the principals at her daughter's middle school were aware and involved in the decision making process of her 504 team. She answered, "I imagine that they do."

Parents F

Parents F, which included both the mother and father of the student with T1D acknowledged that the principal at their daughter's elementary school was very much aware and involved in her 504 plan. The mother stated, "The principal calls us to have meetings, and tells us about anything that she sees different; sometimes about whether we have a question or anything that we might want her to do." The father agreed and responded, "That's right, from the principal to the teachers and the nurse; I see that they are very concerned about my daughter. They call us at home daily. They send us letters."

504 T1D Management Team Communications

The second theme, 504 T1D Management Team Communications, refers to the verbal interaction between the members of the 504 T1D Management Team, the teachers of the student with T1D, and the parents of the student with T1D. In the study by Theoharis (2007) each principal worked conscientiously to create a positive, hospitable school climate by developing cordial relations with staff, students, parents, and the community encasing the school. The principals in the study also employed an effective toolbox of proactive tactics to further their quest for social justice in their schools. "These strategies included communicating purposefully and authentically, developing a supportive administrative network, working together for change, keeping their eyes on the prize, prioritizing their work, engaging in professional learning, and building relationships" (Theoharis, 2007, p. 244). Amillategui et al. (2007) examined parents who were enlisted to answer questionnaires designed "to identify the special needs of children with Type 1 diabetes in schools from the parents' point of view and the difficulties experienced with full integration, and to define a series of interventions which may improve the situation" (p. 1073). Based on the data analysis from the study, training sessions on T1D and better communication between administration, teachers, and parents were two of the "key factors that may improve the full integration of the diabetic child in this setting" (p. 1073).

The six parents or sets of parents addressed 504 T1D Management Team Communications as follows:

Parent A

Parent A, whose child was a seventh grader, shared that she was pleased when one of the teachers had called her to clarify what symptoms her daughter displayed when she had a high or a low blood sugar. The parent complained, however, about her daughter's care in elementary school and the first two middle schools she attended stating, "They never realized what was going on. I explained to them what was going on and it was hard to get through to them."

When asked to describe the quality of communication between the members of the Diabetic Management Team about the school accommodations given to her child with T1D, Parent A answered:

> Like, for example, on (name of elementary) it was hard because, I mean, the nurse would not cooperate with us. When Magdalena would get sick, she would get mad. The nurse would get mad because she would have to go pick her up because of her sugars or her

> being sick. And (name of middle school), there was another nurse there that was always helping me out but not to the extent where my daughter would meet her needs. And then (name of second middle school), the nurse there, she was real good. She was real good there. And now (name of third middle school), the nurses there are excellent; I mean they're meeting her needs and talking to her doctor, as well. So they're meeting her needs of what she needs.

Parent B

Parent B, whose son was a freshman at the high school campus where she worked, was quite content with the quality of communication between the members of the 504 diabetic management team. In addition, each teacher had visited with the school nurse individually to go over the symptoms of high and low blood sugars, emergency care and procedures. Parent B stated that:

> …all of his teachers received his 504 accommodations within the first three weeks of school. Every teacher knew he was a 504 with accommodations. They also were told to visit with the nurse so she could go over his symptoms for high and low blood sugars. The expectations and communication are there.

Parent B felt sure that each teacher understood the importance of following her son's accommodations.

Parent C

Parent C, whose daughter was a senior in high school, stressed that communication between the members of the 504 diabetic management team was much easier in elementary school, where she only had to communicate with the nurse and one teacher. She said:

> I can't tell you who the 504 team consists of at the high school. I think I know who the assistant principal is, who's in charge of it. I've maybe spoken to her once over the phone after I had already taken care of an attendance problem. I had tried to contact her and she did not return my call. But at the time, Mr. ________ was in charge of attendance and he did call me back before she did. I'm pretty sure I know who it is, but I haven't really spoken to her personally, not too much. Then other than the nurses, I really don't know… Actually, I can say it very simply. Aside from the nurses, I'm really not sure how competent the other ones are or how capable they are in understanding the disease. I have all the confidence in the world in the nurses, but honestly can't tell you about the others if I really have the confidence in them or not.

Parent C felt that many of her daughter's teachers at the high school level did not fully understand what Type 1 diabetes was and the severity of the disease. As a result, Parent C stated that her daughter's teachers did not always follow all of her 504 accommodations as they should. She stated:

> …Yes, definitely communication and education – educating the teachers, not all of them. Maybe even the diabetes team needs to make sure that all the teachers for the students that year are in sync and realize what's important. I don't know how many times actually the teachers are pulled aside. You know, if my daughter has five or six teachers, maybe those five or six teachers need to meet with the diabetes team and discuss exactly what's allowed and what's not allowed. With the tardy incident a few weeks ago, like I said, it was one of those teachers who was suppose to be the "go to person" for diabetes and I requested a meeting with her through the counselor because I felt like Brittney was not being allowed time. Well, sure enough, when we got to that meeting, then after the

> teacher realized that Brittney was 504, she admitted to us, and this was just a few weeks ago, you know this is already November, and she admitted that she had not looked at the 504 accommodations; that she didn't know. I was surprised because I did go to "Meet the Teacher Night" and we did have a conversation about Brittney and the diabetes. And yet she still was not aware of and she had forgotten. So that was upsetting.

When asked if she felt her daughter's grades had suffered because she was not given her accommodations such as extra time to complete assignments, Parent C replied:

> She wasn't allowed the extra time and we couldn't go back and change the first six weeks and the second six weeks, but you better believe the third six weeks, since it had just begun, she was able to change a couple of grades... Yes the first and second six weeks were lower; the grades were lower, than they should have been.

Parents D

Parents D, although pleased with their communication with the school nurse, were dissatisfied with the communication between the 504 diabetic management team and themselves. Their son, a T1D for a little over one year, was in elementary school and had just been placed in the 504 program. The father stated:

> The way I found out about that program is because of our doctor, not the school. So we were the ones who actually started up, because the doctor, his nutritionist is the one that said, 'Ask about the 504,' or 'Have you been offered it?' And no, we had not been offered it. So when we got here, that's when they started saying, 'Whoa, we need to put him in, but we need to go through all the paperwork and all.' So, we found out because of his nutritionist.

The school counselor had recently shown their son a video about a little girl who had T1D. The video had a powerful message that scared and upset their son who came home crying. Parents D felt they should have been consulted first to see if they felt their son was emotionally ready to view the video. The father stated, “Communication has been a big issue. It has caused some trouble or some problems. Basically that’s really one of the biggest issues, lack of communication and understanding.”

Parent E

Parent E whose daughter was in middle school, had never heard of the 504 program. The only communication she had about her daughter’s diabetic condition was with the school nurse, over the telephone. School records documented that Yesenia was in the 504 program and did have an Individual Health Accommodation Plan and an Emergency Health Accommodation Plan.

Parents F

Parents F, whose daughter was a third grader, both agreed that the members of the 504 team did communicate with each other about their daughter’s care, were aware of the difference between T1D and T2D, and were familiar with the symptoms of high and low blood sugars. The mother stated:

> About fifteen days ago, they told us that they had… taken training on diabetes regarding checking Yasmina. They are becoming more concerned. You can see more interest; that when the nurse is not there, even the teacher can check her (blood sugar levels), something that did not happen last year. Now everyone is informed there at school; what Yasmina’s sugar levels should be, what it is that they can do when something bad can happen...and well, that is something more interesting...

The father agreed:

> Okay, for this question; above all, consider the changes they have made, because last year, the teachers couldn't check her (blood sugar levels), nor could they give her insulin. And now, her teacher already went to some special classes that the school sent him to; special classes about Type 1 diabetes and they showed him how to check her, how to give her insulin, and as a matter of fact, they have a paper which says how many units they have to give her, how many levels of sugar. There it shows them how many insulin units the child should receive. Her own teacher, as well as other teachers that know her, have already been prepared for those kinds of occasions, when the nurse is not there. They also have the permission and the knowledge to be able to help her.

School Nurse-to-Student with T1D Relationship

The third theme, School Nurse-to-Student with T1D Relationship, analyzed the quality and importance of the relationship between the nurse and the student with T1D. Conderman and Katsiyannis (1995) reported that the 504 team, in addition to its other members, may include the school nurse if applicable. In the dissertation study, all six schools from one south Texas public school district did house their own school nurse who was a member of the T1D 504 management team. *Section 504 of the Rehabilitation Act of 1973* mandates that an individualized accommodation plan (IAP) based on educational necessity must be put in place for each entitled student. The IAP, according to the *American Diabetes Association*, should be developed by the diabetic management team comprised of the parent or guardian, the student's diabetes doctors, and school personnel. The chief aim of the diabetes management team is to maintain target blood glucose levels through "blood glucose monitoring, insulin administration, insulin pump management, meals and snack provision, and symptoms and treatment of hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar)" (Getch et al., 2007, p. 48). Specific instructions for each of these diabetes care interventions should be written clearly in the IAP. During school hours students with T1D:

> …need to have (a) access to the tools for diabetes management (blood glucose testing equipment; insulin delivery systems; and oral, fast-acting carbohydrates and glucagons) (b) sufficient time to adhere to their nutrition plan; and (c) access to personnel who are knowledgeable about diabetes and are able to assist when needed (Getch et al., p. 47).

In all six schools from one south Texas public school district included in the dissertation study, the role of the school nurse was critical to the development and implementation of the IAP.

Three of the studies examined in Chapter Two, The Review of Literature, were related to the school nurse's role as a part of the T1D 504 Management Team. In the first study, Clay, Farris, McCarthy, Kelly, and Howarth (2008) recount the medication regimen from the child and parent's frame of reference after conducting their study. Medication mismanagement and the effects of such mistakes on student academic success and school friendships were scrutinized. Children between eight to eighteen years who were patients at Midwestern Children's Hospital were encouraged to participate in the study. The children, young adults, and their parents were interviewed using a survey called *Child/Parent Perceptions of Medication Administration in the School Setting*. The findings of the study recognized that missing a dose or running out of medication was the number one concern of parents. Clay et al. (2008) noted that skipping doses of medication could lead to academic, psychosocial, and physical problems for youth. The suggestion was that more research was needed on nurse's medication distribution best practice, and self-management of care for children.

The second study focused on the parental decision of which method of insulin treatment their child with T1D should receive, multiple daily insulin injections (MDI) or continuous subcutaneous insulin infusion (CSII) treatment, more commonly known as insulin pump therapy. The goal would certainly be a balance of the tightest blood glucose control possible, while avoiding episodes of hypoglycemia. “A near-normal hemoglobin A1c (HbA1c) serves as a major goal of insulin therapy in the pediatric age group” (Danne, von Schütz, Lange, Nestoris, Datz, & Kordonouri, 2006, p. 25). According to Battelino (2006), the insulin pump has been in use and continued development for over 25 years. The expediency and popularity of the latest technology in terms of diabetic care is tempered by parent and child fears of the unknown and, also, the cost of the new technology. While the 504 diabetic management team must leave the treatment selection, MDI versus CSII, up to the parent, endocrinologist, and the child with T1D, the team members must be supportive and educated about both insulin treatment methods so as to be of assistance to students (Getch et al., 2007).

The third study was an observational study conducted by Amillategui et al. (2007). Parents answered questionnaires designed “to identify the special needs of children with Type 1 diabetes in schools from the parents’ point of view and the difficulties experienced with full integration, and to define a series of interventions which may improve the situation” (p. 1073). Based on data analysis from the study, training sessions on T1D and more nurses in the school setting, were two of the “key factors that may improve the full integration of the diabetic child in this setting” (p. 1073).

The six parents or sets of parents addressed the School Nurse-to-Student with T1D Relationship as follows:

Parent A

Parent A, whose daughter was a seventh grader, was happy with the care and medical attention given to her daughter at her current middle school. She also stated that the nurse at her daughter's current school was on top of things and had even spoken with her daughter's diabetic doctor to clarify patient care orders. She mentioned the nurse at the elementary school would not cooperate with her and would get mad when her daughter had high or low blood sugars. The nurse would insist that the mother come and pick her daughter up from school to take her home. Parent A stated that her daughter's relationship with the nurse at the elementary and at her first middle school was "rocky," but her daughter's relationship with the nurse at the other two middle schools was excellent. When asked to describe her daughter's relationship with the school nurse, Parent A answered:

> The relationship with the nurse at (name of elementary school) wasn't that well. It was in a rocky side and (name of first middle school) the same thing. (Name of second middle school), she was a good nurse. She did accommodate her (child with T1D) needs. (Name of second middle school) and now here in (name of third middle school), she's (the nurse) been doing an excellent job.

Parent B

Parent B, whose son was a freshman in high school, stated that her son had a great experience and relationship with the school nurses in elementary, middle school, and high school. The nurses all took good care of him and were very supportive. She noted that the middle school nurses worked to educate her son about self-care for T1D and gave him advice on how to take care of his diabetes and about life in general. The high school nurses were more focused on helping her son to become self-sufficient and responsible for his own care, paving the way for college and adulthood. Parent B stated:

> Once he's at (name of middle school) the relationship he had with them was wonderful. They were very educated. They gave him advice on daily life issues and tests in general. Advice on going through things that he was going through; the things he was going through as a young teenager; very different from that to high school. The two high schools nurses are a married couple and they seem more about holding the student responsible for their diabetes management and so this is a big change. I guess giving them the road into dealing with their diabetes management into college and their everyday lives. So this has been a transition from elementary all the way to high school.

Parent C

Parent C, whose daughter was a senior in high school, maintained that the relationship her daughter had with the nurse at the elementary school and the high school was excellent. She stated, "I have all the confidence in the world in the nurses..." She continued, "…at the high school, wonderful, wonderful! I have the same two nurses the whole four years and that has been wonderful. They know Brittney very well and they know me and it's just… I really appreciate them!" At the middle school, however, there was not much stability. The nurse retired at the end of her daughter's sixth grade year. A new nurse came in at the beginning of her seventh grade year and only lasted about two weeks. After that there was a succession of substitute nurses until a permanent nurse was hired at the beginning of her daughter's eighth grade year. Parent C said all of the different nurses did a good job and her daughter and she had confidence in them, but a middle school nurse-to-student relationship was never built as there was no stability of personnel in the nurse's office.

Parents D

Parents D, whose son was in elementary school, felt that the school nurse did understand about the chronic condition of T1D and knew the difference between T1D and T2D. They were pleased with the communication they had with the nurse and felt she took good care of their son at school. Both parents were in agreement that the nurse and their son had a great relationship. The two communicated well and the nurse was good about following the doctor's orders and not giving in to their son's demands for extra food. The father stated:

> He has a pretty good relationship with her… She knows his character… Because well, basically, he deals more with her during the day than with anybody else. Because most of the time she's the one who's there, she's the one who takes care of his insulin, so he is, I believe, pretty happy; pretty much has a good relationship with her as far as with good communication.

The mother agreed when she answered:

> In my opinion, they get along very well. And the nurse helps him, and helps him see when he is wrong, because many times he is wrong. He thinks that he is going to eat more and he wants for her to give him more insulin, but she doesn't pay attention to him, because she knows how he is in his condition. She knows how each situation develops, and she already understands him; and that is an excellent relationship that they have.

Parent E

Parent E, whose daughter was in middle school, volunteered that all communication between the nurse and her had taken place over the phone. She stated that the nurse called her when she had questions, needed medications, or to tell her of concerns for her daughter's health at school. She stated:

> I talk with her and she tells me that the child has been all right and she calls me when something is needed. She says, ‘Mrs. Ramirez, the child is doing very well. I have her here because her sugar is down. But don’t be worried. We’re here and we’re watching over her and she’s all right now.’

Parent E was very pleased with the care and attention the school nurse gave to her daughter. She stated that, although her daughter was affected by district rezoning, she applied for a transfer to allow for her daughter to remain at the middle school she had attended for two years. Her daughter did not want to leave because she was extremely close with the nurse at her school. When asked to describe her daughter’s relationship with the school nurse, she said, “She likes her a lot.” Parent E acknowledged that her daughter had a great relationship with the school nurse and felt close to her.

Parents F

Parents F, whose daughter was a third grader, were the only parents interviewed who were not pleased with the nurse at their child’s school. The mother was emphatic that, “I would like the nurse to be better educated so that I can be more at ease here at home.” Parents F agreed that the school nurse did her job, but they did not agree with her rigidity to the rules. They knew the new nurse was just following orders, however, they felt she had not tried to build a relationship or bond with their child. It was clear that Parents F and their daughter preferred the previous nurse, and were finding fault with the new nurse in comparison. Parents F were at odds with the present nurse at their daughter’s school because when her blood sugar was high, the nurse refused to give extra insulin unless it was directly prescribed by the doctor. The mother stated:

> If they could at least give her one unit of insulin, or a little, so that they can try to lower it as quickly as possible. That is what we would like for them to help us with in that aspect. That is what we are currently struggling with, but it’s with the nurse. Because in the case of the nurse, I’m saying, well, if she could support us, right, she could put a little more of her heart into it than of her work. You understand? … We need a nurse that is there 100 percent, that can be with her. That is what we had with the previous nurse.

The father stated:

> Okay, with the nurse that she has now, I see that she tries to help her a lot, but in view of the fact that my child doesn’t feel very sure with her, she’s a little more distant. She doesn’t have as much trust in her. On the contrary was the case with the previous nurse that she had. It was a relationship not only as with any other child at school, but a very close friendship, a very great friendship. The child felt very sure, secure with her. She took care of her a lot. You could see the difference. My child, when she was in the office, she would play, smile and laugh with her; very comfortable. And I think that that helps the children with diabetes to have a better time at school because it’s very hard on them to be injecting them and checking them (their blood sugar levels) and all that. And I believe that when they find a nurse that is really concerned about them and that doesn’t just behave like the school nurse, but that apart from being a nurse is a friend, being that she helps her and all that, the child feels better.

Best T1D 504 Accommodations

The fourth theme, Best T1D 504 Accommodations, refers to the accommodation or accommodations which each parent interviewed thought were most beneficial to their child.

One of the studies examined in Chapter Two, The Review of Literature, related to the determination of best T1D 504 accommodations. Best accommodations were addressed by Getch et al. (2007) when the researchers concluded in their study that the main goal of the diabetes management team is to maintain target blood glucose levels through “blood glucose monitoring, insulin administration, insulin pump management, meals and snack provision, and symptoms and treatment of hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar)” (p. 48). The researchers went on to note that during school hours students with T1D:

> …need to have (a) access to the tools for diabetes management (blood glucose testing equipment; insulin delivery systems; and oral, fast-acting carbohydrates and glucagons) (b) sufficient time to adhere to their nutrition plan; and (c) access to personnel who are knowledgeable about diabetes and are able to assist when needed (p. 47).

Parent A

Parent A, whose child was a seventh grader, was not cognizant of the 504 program and the benefits provided through the program, but did state that she was pleased with the care and attention that her daughter was getting both in the classroom and the nurse’s office. She was aware that her daughter received three important accommodations; the buddy system, (where a classmate walked the student with T1D to the nurse’s office when they were feeling the effects of a low or high blood sugar), snacks for low blood sugars, and insulin for high blood sugars in the nurse’s office. She stated:

> I feel that they are following through with everything they had told me. Like for example, with her classes, she has a follower and she has already contacted me, as well, to see what are the signs that my daughter gets when she is with her low, bad, low sugar. She has called me and asked me what were her reactions or what were the mood swings.

When asked to describe the 504 practice and accommodations that best help facilitate learning to meet the needs of her daughter in the classroom, she answered, “I guess when the follower sits beside her and instructs her how to; what’s going on in the class, like for the materials that she needs or the reading that she has to do.”

Parent B

Parent B, whose son was a freshman at the high school campus where she worked, thought that of all of the accommodations her son received, his regular blood sugar checks at the nurse’s office to keep his glucose levels in the normal range were the most important to best facilitate learning in the classroom. She maintained that Leo must have good blood sugar levels in the normal range to be able to stay focused on his lessons. She believed preferential seating in the front of the classroom helped him stay focused when his blood sugars were a little off. She stated:

> Ok, I think actually going to the nurse to check his blood. Because if he’s got a good blood sugar; he’s going to be responsive. He’s going to learn. Something else I think, even as parents and as teachers we might not notice it, but I noticed it this year because the counselor suggested it to me. She said, ‘Leo may not need this accommodation, but ask him in any one of his chosen classes that he feels that he’s having more difficulty in; ask him to sit up front if there’s not a seating chart in place.’ He did do that for his Algebra I class which was with a very good teacher that I recommended he change to, Mr. (teacher’s name). He was commended at (name of university) and has a Promethium board. All of the technology is in place in his room. So he has the Promethium board in the classroom for the kids to learn and I thought, ‘Why is my son not understanding these math equations?’ I mean the tools are there. The technology is there for them wanting to

> learn. There’s got to be something else wrong, you know? That he’s either with his blood high during that period, and it was second period. So it’s early morning. So the last week of school he got seated up in the front and Mr. (teacher’s name) he came up to me during that week and said ‘Leo sat up in the front his whole week and finished all his work, he even helped other students in class. I am so proud of him!’ I didn’t know what to say. I mean I was freaked out. I just, like, oh my God, to get a compliment from a teacher of that; I mean because he’s a super intelligent man. He’s a retired engineer and he decided to come back, a retired engineer, and teach. So all his technology background and his intelligence just in the classroom alone and the way he’s sincere with the kids, you can tell, you know, that he really likes children. I just felt that this would be a great experience for my son and there’s just no way he can’t learn from this man. He’s excellent and even I want to go in there and learn. That would be something. So that was something that I thought would be a good accommodation; getting our kids, Type 1 kids, to be in the front because they might be going through a low or a high and in between they’re kind of like, ‘ugh’ you know. There and just sitting in the front row might be like, being in the front row of a movie theatre. You’re right there where nothing can distract you. There’s nothing else to look at except for the teacher and the screen.

Parent C

Parent C, whose daughter was a senior in high school, stated that of all of the accommodations provided through the 504 program for her daughter, the one that was most beneficial to her in high school was the provision for “extended time to finish assignments.”

Parents D

Parents D, whose son was in elementary school, did not fully answer the question, as to which 504 accommodation was most beneficial to their son in the school setting as the school was just going through the process of placing him in the program. However, Parents D were aware and were relieved that the school did have an emergency care plan in place. The mother stated:

> Okay, the only plan that there is, is that if the child feels shaky, like he's trembling, or if he feels very weak or whatever... With a person from his classroom, an adult, he should go to the infirmary (nurse's office), and he is immediately checked. If he is high, of course, only to observe him, because he can't be given... actually, now he can be given some because we had the insulin pump put on him; but before, only to watch him, more than anything. But if it was low, to give him one or two ounces of juice, or the pills, the Glucostat, or some cookies, some four cookies and that's all. And in an hour, check him again. If he is already stabilized, he can be sent on to class again.

The father added, "They are also aware about the glucagon, which is once he has passed out. That is pretty much the only thing to do and of course, immediately call 911." Both parents were adamant that their son is allowed to go to the restroom as needed and were concerned because his fifth grade teacher had been limiting the number of times he was allowed to go.

Parent E

Parent E, whose daughter was in middle school, although not versed in the process and procedures of the 504 program, was aware of procedures that were in place to stabilize her daughter's blood sugars during the course of the school day. She stated that if her daughter's blood sugar was low, she was sent to the nurse with a friend, her blood sugar was checked, and she was given orange juice. Sometimes she was given chocolate, or Skittles, her favorite candy. After ten minutes she was checked again. When her blood sugar was high, the nurse gave her water. If her daughter were to lose consciousness, the nurse had doctor's orders to give a Glucagon shot and transport her to the hospital by ambulance and notify the mother. Parent E stated:

> In class, it has gone down several times, but they take her to the infirmary and they give her the juice and then they check her to see how she has it first… They let some ten minutes go by and then they check her again. They give her orange juice pretty much every time. They… send her with…with a friend. Yes, because, that is, it even goes down to 40 sometimes. When she has it very high, then they have to give her water.

Parents F

Parents F, whose daughter was a third grader, both agreed that their daughter's most important accommodation of the 504 Program that facilitates her classroom learning was her school meals: breakfast, lunch, and her two snacks. The mother stated:

> She likes to eat a lot. That's why she says, 'I'm happy when I get home,' because she's very hungry, but very strong. She's thin but very sturdy. She's got muscles. She likes to play. She likes to run. She's very active. Well, she is well attended to with her lunch, her breakfast, her food. They also give her a snack. But since diabetic children are big eaters, then I would love to see that they are always aware and on the look out for that, because she says that it is very little food, or that she needs to eat a little more. And all that worries me because I know that it is because of the illness that she would like to eat everything. Therefore I would like for them to pay a little more attention to her food; nutrition.

The father agreed:

> Well, my comment would be similar to that of my wife's; above all in nutrition, since I believe that she needs a little more variety in her food, since they repeat quite often the menu. And often, even though she likes it, she gets tired of eating the same thing. They give her very little. I think that she needs a little more variety in the food that they give her, in her nutrition, Because every day I'm with her in the morning, I sit down with her for her breakfast and I see that almost always it's the same. It's always two or three things and they don't change it. I believe that they need a different menu.

Parents of Students with T1D Concerns and Suggestions for Improvements

The fifth theme, Parents of Students with T1D Concerns and Suggestions for Improvements, was an important theme, as, with any study, the critical phenomena was scrutinized in order to improve a situation or condition for the subject or group of subjects included, the student with T1D. Three main concerns were detected after analyzing the parent interview transcriptions; staff diabetic education and care training, the absences of the student with T1D, and cafeteria food. Information included in Chapter Two, Review of Literature, was a law called the *Healthy, Hunger-Free Kids Act* which was passed by the House and was awaiting President Obama's signature. "The new law reauthorizes federal child nutrition programs, removes junk food from school cafeterias and vending machines, promotes healthy lifestyles and allows schools more flexibility to provide healthy food choices" (American Diabetes Association, 2010a, p. 1). With the increase of children diagnosed with T1D or T2D, it is crucial that schools be held responsible for serving wholesome meals to help confront the dilemma rather than contribute to it. Christine Tobin, a certified diabetes educator and president of Healthcare and Education for the American Diabetes Association, reported that according to the

American Diabetes Association, the top ten super foods for non-diabetics and type 1 and 2 diabetics alike are: beans; dark, leafy green vegetables; citrus fruits; sweet potatoes; berries; tomatoes; fish high in omega 3 fatty acids, (to include herring, halibut, mackerel, albacore tuna, and salmon); whole grains; nuts; and fat-free milk and yogurt. Tobin advises anyone intent upon overindulging to choose snacks from one of the ten super foods groups (Noonan, 2010). Food and nutrition directors for American schools would be well-advised to plan school menus with an abundance of the “super foods” recommended by the American Diabetes Association; as such foods are good for all children.

Three of the studies examined in Chapter Two, The Review of Literature, were related to the determining of concerns and suggestions for improvements by parents of students with T1D. In the first study, Getch et al. (2007) gathered significant research to report on the care of students with T1D in schools. The authors noted that students with T1D needed vigilance on the part of the classroom teacher. Teachers should be acquainted with the symptoms of both low and high blood sugars such as “increased thirst, increased urination, constant hunger, confusion, inattention, blurred vision, headache, and fatigue” (p. 46). In the second study, Hayes-Bohn et al., reported that both students with T1D and their parents were displeased with numerous aspects of care within the school; teacher lack of knowledge about diabetes and care of individuals with the chronic disease; unhealthy food selections in the school café and snack machines; and strict school rules and schedules that hindered diabetic self-care. The authors suggested that future research studies be conducted linked to diabetic care training for school personnel; diabetic care management team strategies; studies to change school rules that negatively affect students with T1D; and changing policies on café and snack machine food choices. The third study was an observational study conducted by Amillategui et al. (2007) with a similar objective as the dissertation research study. Parents answered questionnaires devised "to identify the special needs of children with Type 1 diabetes in schools from the parents' point of view and the difficulties experienced with full integration, and to define a series of interventions which may improve the situation" (p. 1073). The intent of Amillategui et al. (2007) was to develop interventions to accommodate students and parents as they traverse the school system. Based on data analysis from the study, training sessions on T1D, additional nurses in the school setting, and improved communication among administration, teachers, and parents are "key factors that may improve the full integration of the diabetic child in this setting" (p. 1073).

Parent A

Parent A, whose child was a seventh grader, stated, "The other schools should first acknowledge or listen to the parents at their school and what the children are going through. I mean so they could better understand what's going on." She also confided that:

> She's gone to the hospital like around, probably almost the beginning of the year till, let's see, we're December; probably till July; the beginning of this year till July. She's been in and out of the hospital quite a few times. Probably around 20 times, she's been in there.

In a second interview, the researcher was able to clarify that statement with the parent. She stated that her daughter was prone to low blood sugars, and as she, the parent, was not willing to give her daughter the glucagon emergency shot, she took her to the emergency room every time she had a low sugar. Since the family is on Medicaid, all of the hospital visits were free of charge to this family and did not pose an economical strain on the family finances. However, these frequent hospital stays had negatively affected her daughter's school attendance. When the question, "How has Type 1 Diabetes affected your child's attendance record and grades in school?" was asked, the mother nervously replied with a laugh, "Do you really want to know?"

She stated that her daughter's attendance and grades were severely affected by T1D. She approximated that her daughter had missed close to 45 days of school during her 7th grade year. In addition:

> She struggles during the night with low and high sugars or sometimes in the mornings she gets severe high sugars and she won't control them or the insulin won't be starting to kick in and that's when I have to take her at least to the hospital and then she'll be admitted there for at least two or three days until they know the sugar is already controlled again.

After examining school cumulative attendance records, the researcher documented that the student had missed 62 total days of school. She was also assigned Homebound from October 11th through December 2nd, 2011 for a total of 36 school days. Her report card revealed that her first semester final grades included two "A's" in Physical Education and Texas History; a "C" in Math; a "D" in Science; an Incomplete in English Language Arts/Reading; and no grade assigned in Intervention Math Lab.

Parent B

Parent B, whose son was a freshman in high school, stated that her main concerns about her son's overall care at the high school were the need for the reinstatement of the buddy system or a variation of the buddy system. She was adamant that it was not safe for her son to go alone to the nurse's office because of the possibility of him becoming disoriented along the way, wandering the hallways or falling. Parent B stated:

> One more time being the buddy system, I think. I don't think it was ever disregarded or not put into place. I think it just becomes something that isn't seen. I think it needs to be implemented again into the high school because of the student's ability not to be able to

> focus on whether they're high or low. He may not know what they're doing or not doing. So I think we need to come up with a new system.

Parent B also felt anxiety and fear for her son about the state STAAR testing. She was worried that his blood sugar would rise due to stress and that he would be out of the testing room too much because of nurse visits or water and restroom breaks. She stated:

> Also the end of course testing for the state of Texas; it's difficult for Type 1 and Type 2 because they need to regularly go to the restroom. They may need to check their blood sugar levels to see how they feel and all the symptoms that go along with this may cause their end of course testing not to come out the way they would like their grades to be at the very end of that. And since it is a timed test, it takes away from the diabetes, Type 1, to be able to have the full amount of time that the other kids have. So I believe that it's also an important thing that the school needs to look at and care for overall for the students.

Parent B was adamant that students with T1D should be allowed to carry their glucometers with them and use the machines to check their blood sugars as needed throughout the school day. She said:

> I also think that the glucometer should be carried by the students. I also think someone else should carry a glucometer, whether it is the nurse or a coach. It's just blood sugar levels. Just because they're on school property, basically, a student may or may not let a nurse or individual person that's taking care of them know what they're reading is unless the meter directly sends that reading to the pump. If they're wearing a pump and they're on insulin shots, there's no way of knowing what their readings are unless you check their glucometer and look at the last reading. I know that that was always a question

> asked by me from elementary level before I got the glucometer that sends the reading directly to the pump. They would always have to look at his reading on his glucometer to make sure that the readings were exactly what he said they were. If it was a 60; if it was 100; if it was a 200, they'd have to go back and look at the readings. So I think it's imperative that there be other glucometers set up on campus and not just by one nurse, not by one caregiver on campus but maybe by another individual, just in case one can't get access to one during the fire drill during a; oh goodness, during, God forbid a lock down procedure. But those are the times we should be able to carry their glucometer, during those times. But other than that, the overall care of the school has been great.

With the exception of the school nurse, Parent B did not believe that the 504 team members fully understood the chronic disease of T1D. She stated, "No, because they don't have a child themselves, they don't completely understand." Parent B was convinced that the teachers and staff needed to be educated about Type 1 diabetes so that they could understand that it was a different disease than Type 2 diabetes. Attendance was also a concern. Parent B stated that:

> attendance is always going to be an issue, though, because when they get sick, they feel really lousy and it's like a double whammy. You know he has diabetes to deal with and then he gets an illness on top of that. So when he tells me that he really feels sick, he stays home. It could be two to three days in a row depending on what ailment he's got, flu being probably the worst.

After examining school cumulative attendance records, the researcher documented that the student had missed 19 total days of school. His report card revealed that his first semester final grades included four "A's" in English I PAP (Pre-Advanced Placement), Spanish I Monolingual, Business Information Management I, and Golf Team I; a "B" in World Geography PAP; a "C" in

Biology PAP; and a “D” in Algebra I. Finally, Parent B thought her son was old enough to carry a glucometer in his pocket and check his blood sugar as needed, thus avoiding the need to leave class and miss valuable instruction to go to the nurse’s office for blood sugar tests.

Parent C

Parent C, whose daughter was a senior in high school, was adamant that several changes were in order to help the 504 program better determine and implement accommodations. She said:

> I think the teachers need to be educated. I think a lot of these teachers don’t have a clue as to exactly what these kids are going through. I know when Brittney was a freshman; I had to deal with the teacher who had just come on board, like in middle of year. And we had to start over, of course, explaining everything. She told me that she had never heard of diabetes; didn’t know what it was. And my immediate thought was; you’re from the Valley. How can you not know? So yeah we just assumed that everybody knows what it is and what to expect.

She shared that her daughter had told her that too many people do not know there is a big difference between Type 1 and Type 2 diabetes. Parent C stressed that there needed to be more communication between the diabetic management team and her daughter’s teachers. She felt that on large high school campuses, students should be allowed to carry a glucometer, check their blood sugar, and carry snacks to eat in case of a low blood sugar because the nurse’s office was often too far away. Absences and tardies were a major concern for Parent C and her daughter. Parent C stated that T1D had taken a great toll on her daughter’s attendance. She had a lot of absences, especially first and second period because of low or high sugars in the morning before school. Her high school credits had been blocked several times due to too many absences. It took time and was a worry and a hassle for the parent to get the credits unblocked by enlisting the help of administrators and the attendance office.

After examining school cumulative attendance records, the researcher documented that the student had missed 17 full days of school. She had 44 absences from first period and 23 absences from second period. Her report card revealed that her first semester final grades included four “A’s” in Career Preparation I, Economics, College Readiness, and Women’s Soccer 4; and one “B” in Food Science.

One last area of concern for Parent C was that it was rare that teachers who planned on being absent left instructions for the substitute teacher about specific accommodations which must be provided to students with special needs under the 504 umbrella. As a result, when substitutes were present in the classroom, her daughter was questioned and had to explain about her condition and needs. This was uncomfortable for her daughter and many times she stayed silent and suffered through class.

Parents D

Parents D, whose son was in elementary school, wanted him to be allowed to use the restroom as needed. They wanted to see all of the staff trained to know about the care that students with T1D must have and to understand the difference between T1D and T2D. The mother stated:

> They don’t know anything about that because they think that it’s like Type 2 Diabetes; that it can be managed with pills and everything is okay. But this is life or death. Many can die if their sugar goes up really high. They can die. It is very different. So that is what I think. They don’t understand it.

She stressed that it was important to educate and train the coaches because they hold class outside or in the gym which is a good distance away from the infirmary. In addition, she mentioned that the school secretaries supervise the students in the cafeteria during lunch and yet they have not been trained or given any education on the care of students with T1D. She said:

> They don’t supervise him to see if he ate all of his food. If they’re going to give him insulin, he needs to eat all of his food. His sugar goes down too much when he doesn’t eat his food. I would like a menu to be made for him where he will like his food every day so that he will eat it, because there are days when he doesn’t like his food; he doesn’t eat it and that day he goes to the infirmary with low blood sugar.

The father added that his son likes to talk with his friends at lunch and sometimes ignores his meal because he’s having too much fun with his friends. He said:

> I’ve heard of several parents and the Youth Diabetic Association that were able to implement such a plan as far as getting with the school nutritionist, school cafeteria, and the principal and they have outlined a certain meal as far as certain types of foods that a particular student likes. Then they are sure that he’s going to eat. In other words, he will be able to fulfill his actual carb limits.

Once trained, they wanted the staff to be able to effectively communicate about their son’s care and well-being at school. The father was emphatic that, “Communication has been a big issue. It has caused some trouble or some problems. Basically that’s really one of the biggest issues, lack of communication and understanding.” Parent D reported that his son’s attendance had been good, regardless of the fact that he had T1D.

After examining school cumulative attendance records, the researcher documented that the student had only missed three days of school. His report card revealed that his first semester final grades included an “A” in English Language Arts; and four “B’s” in Reading, Math, Science, and Social Studies.

Parent E

Parent E, whose daughter was in middle school, was most concerned about her daughter’s attendance and eating habits at school. When asked the question, “How has Type 1 Diabetes affected your child’s attendance record and grades in school? Parent E replied:

> Yes, yes, she does miss a lot because she has doctor appointments with the one for the blood, the diabetes doctor, and with the dentist because she got braces and now she has some springs because she bites more, and there I go because they fall and then, well, because something comes unhooked, undone and I have to take her to the dentist as an emergency. Yes, she misses school a lot, but they say her grades are low. They say, Mrs. Ramirez, I understand that the child has to go to the doctor, but she says that she has very low grades. I don’t know if it’s because she doesn’t pay attention or because she’s absent, or… I don’t know.

After examining school cumulative attendance records, the researcher documented that the student had missed 16 days of school. Her report card revealed that her first semester final grades included an “A” in Girl’s Athletics; two “C’s” in Science and Intervention Math; one “D” in Pre-Algebra; and an “F” in English Language Arts/Reading GT (Gifted and Talented). The student was scheduled into the same English Language Arts/Reading GT class that she had failed first semester during the second semester. Parent E acknowledged that her daughter’s eating habits at school were also a concern. She stated:

> Many foods, they don’t give them to her because of her diet. But the child sometimes doesn’t eat because she doesn’t like what they give her there and her sugar goes down very often. Yes, her sugar does go down.

Parents F

Parents F, whose daughter was a third grader, stressed the need for larger portion sizes for school breakfast, lunch, and snacks, along with more variety of foods in the school menu, as their slender daughter was coming home daily complaining of being hungry. Parents F requested more T1D training for all teachers and staff, including the school nurse. Parents F complained that the school nurse was very rigid in her care of their daughter, and was not taking the time to try to bond with the little girl. If her sugar was high and she was due for a snack, the nurse gave her the snack even though it would make the blood sugar go higher. If her blood sugar was high, but the doctor’s orders did not allow for an insulin injection at that time, the nurse would refuse to give an injection, even if the parents gave her permission to do so which frustrated both parents.

Parents F shared that they were concerned with their daughter’s attendance. After examining school cumulative attendance records, the researcher documented that the student had missed 17 days of school. Her report card revealed that her first semester final grades included three “C’s” in English Language Arts, Reading, and Social Studies; and two “D’s” in Math and Science.

Chapter Five Summary

Five commonalties, or common themes were gleaned from an analysis of the six interview transcriptions and review of students’ records of the study and were revealed and analyzed in Chapter Five. The themes were: 1) Administrative Awareness and Involvement; 2)

504 T1D Management Team Communications; 3) School Nurse-to-Student with T1D Relationship; 4) Best T1D 504 Accommodations; and 5) Parents of Students with T1D Concerns and Suggestions for Improvements. The aim of the study was to add to findings of previous studies which were reviewed in Chapter Two and again in Chapter Five. The hope was that new light would be shed on the 504 program experiences of parents of students with T1D in one south Texas public school district and that the study would provide useful information on how to improve services and/or accommodations for students with T1D in order to level the educational playing field with students who are not afflicted with a chronic disease such as T1D.

CHAPTER VI

DISCUSSION AND RESULTS

The purpose of this qualitative study was to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district. Critical theory, with an emphasis on social justice leadership, was utilized as the theoretical framework for the dissertation topic chosen for the study. The study included six individual parent interviews which were audio-taped, transcribed, coded and analyzed, and a review of students' records to explore the research questions. A pseudonym was used for the name of each child with T1D and their parent or parents to maintain complete confidentiality. Several issues of concern to parents of students with T1D constituted the research questions which were addressed in the study. The research questions were:

1. How do parents of students with Type 1 insulin-dependent diabetes describe their experiences and satisfaction with school services provided through the 504 program for their children and the quality of communications between and among the members of the 504 team?
2. What are the perceptions of parents of students with T1D about the best 504 practices and accommodations to help facilitate their child's learning in the classroom?
3. According to the perceptions of parents of students with T1D, what concerns and suggestions for improvement do they have regarding their student's overall care at school?

The parent interview questions of the study were geared towards identifying the quality of communication between school staff members of the 504 diabetic management team and the parents of students with T1D, positive and negative aspects of 504 program services, and parent of students with T1D concerns and suggestions for improvement. It was anticipated that the study would provide useful information on how to improve services and/or accommodations for students with T1D in order to level the educational playing field with students who are not afflicted with a chronic disease such as T1D. The aim of the study was to add to findings of previous studies which were reviewed in Chapter Two. The hope was that new light would be shed on the 504 program experiences of parents of students with T1D in one south Texas public school district by giving parents a voice.

After coding and analyzing the transcriptions of the six audio-taped individual parent interviews and reviewing students' records, the researcher found five commonalties, or common themes, among the six cases. The themes were 1) Administrative Awareness and Involvement; 2) 504 T1D Management Team Communications; 3) School Nurse-to-Student with T1D Relationship; 4) Best T1D 504 Accommodations; and 5) Parents of Students with T1D Concerns and Suggestions for Improvements. The details within each of these five themes answer the research questions of the study. The findings of the study, categorized by the five themes, will be addressed as they relate to the three research questions during the discussion of the results.

After reviewing and analyzing the parent responses from the first theme, Administrative Awareness and Involvement, the researcher noticed a pattern. Only one of the six parents or sets of parents interviewed stated that an administrator was actively involved as a part of the 504 diabetic management team for their child with T1D. Most of the parents stated that the school principal or assistant principals knew of their child's medical condition, but were not sure what role administrators played within the 504 diabetic management team. Each campus in the public school district participating in the study had either a principal or an assistant principal assigned as the campus 504 coordinator. As the 504 campus coordinator of this particular school district, the administrator, must attend and lead a 504 annual meeting which parents of students of T1D are required to attend. It is surprising and alarming that five of the six parents of students with T1D report little administrative involvement and attention to their child’s care in schools. Therefore, a suggestion would be that the 504 campus coordinator should follow-up with students with T1D and their parents periodically over the course of the school year to make sure all school staff are following the students’ accommodations and the students’ needs are being met at school. As was mentioned in Chapter Four, the lead campus administrator sets the tone for the significance of equal access to education for all students, including students who are serviced as a part of a special population of students such as students with T1D. The theme, Administrative Awareness and Involvement, is addressed first in the study because administrators, as educational leaders, oversee and are accountable for all facets and building blocks of a public school campus.

The ultimate charge of a public school administrator is to maintain the safety of all students and staff. It is clear that the two high schools mentioned in this study have not made the safety of all students a priority. According to Parent B, it appears that administrators and teachers are more concerned that students may miss five to ten minutes of classroom instructional time in preparation for the state STAAR End of Course (EOC) exams, than to ensure the student with T1D arrives safely at the nurse’s office. The main emergency situation for a student with T1D is hypoglycemia, or low blood sugar. The parents of the two students with T1D at two separate high schools were legitimately concerned about how their teenager was to make it from the classroom to the nurse’s clinic if their blood sugar was low. The buddy system was available when the students were in elementary and middle school, but was not offered to them as an accommodation at the high school. Both parents felt the buddy system had worked well for their children when they were younger and were worried that if suffering from a low blood sugar, their children would fall or pass out on the way to the clinic and be severely injured. High school campus administrators should be aware of this safety discrepancy and hasten to remedy the situation at their school. A practical solution may vary dependent upon the layout of the building. However, it was clear after interviewing the two high school parents, that their teenager walking to the nurse’s office by themselves with a low blood sugar was a disaster waiting to happen. One parent clearly stated that, in the event of her son collapsing or falling while on the way to the nurse’s office by himself, she would hold the school responsible.

Two other parent concerns also affect the safety of students with T1D at school. The first is the fact that school secretaries and paraprofessionals often supervise students with T1D at lunch and yet, have had no training or instructions for their care. The parents of a young boy in elementary school complained that their son sometimes became engaged in conversation with his friends at lunch, and disregarded his meal. This resulted in a low blood sugar in the middle of the afternoon and missed instructional time spent in the nurse’s office on several occasions. A scenario such as this may be more common at the elementary level when students may be immature and less involved in self-management of the care of their T1D. School secretaries and paraprofessionals should be included in teacher and staff training on the care of students with T1D, the difference between T1D and T2D, and should know which students have T1D so that they can monitor their food intake and report back to the nurse after the lunch period.

The second safety issue involves procedures in case of a substitute. It should be standard practice that all teachers leave accommodation information for special needs children in a substitute folder as a necessary preparation for the event of the teacher's absence. In order to ensure that all folders are completed, the folders should be checked by administrators at the beginning of the year and housed in the front office in a central, secure location. Information and instructions about accommodations for special needs students would be placed in the front of the substitute folder; folders would be given out to substitutes at the beginning of the day by the front office secretary and returned at the end of the day. It would be the teacher's responsibility to update the folder whenever they received new students with accommodations, or when there was a change in accommodations.

Administrators are typically in charge of staff development. One of the concerns and suggestions for improvement was teacher and staff training on the care of students with T1D and education on the difference between T1D and T2D. A goal of many administrators is to be a social justice leader and strive for equal access to education for all students. As an advocate for all students, administrators may consider including the school nurse as one of the strands for staff development days in order to educate teachers and staff members about the care of students with T1D; the difference between T1D and T2D; and how other chronic illnesses or conditions, such as asthma, cerebral palsy, spina bifida, Attention Deficit-Hyperactive Disorder (ADHD), Attention Deficit Disorder (ADD), and Bi-Polar, may affect students in the classroom. By acquiring a better understanding of the natural symptoms of different chronic illnesses and conditions, teachers and staff members, who are responsible for the daily supervision of students with such ailments, may become more empathic, compassionate, and accommodating. As a result, students' needs will be better met, student learning will be enhanced, and social justice will be served. In addition, the study indicated that parents with little education and from low socio-economic backgrounds were in need of T1D care training and support in order to establish stability of their child's care while at home. Such training and support could be offered to parents of students with T1D through the district nurse coordinator's office yearly and as needed.

After reviewing and analyzing the parent responses from the second theme, 504 T1D Management Team Communications, it was apparent to the researcher that the parents of students with T1D largely felt that the 504 T1D Management Team needed to have better communication amongst team members and between the 504 T1D Management Team and the teachers of record of students with T1D. Parent C shared her concern about two of her daughter's teachers: one who made comments to her daughter on a daily basis when she walked into first period late, and another teacher who had forgotten that her daughter was a 504 student with T1D and had not given her daughter her accommodation for extended time to turn in assignments. Such communication problems could easily be avoided if the 504 T1D management team, with the school nurse taking the lead, scheduled a mandatory meeting with the parents of the student with T1D and all of the student's teachers at the beginning of each new semester. The teachers could be briefed by both the nurse and the parents about the symptoms and signs of low blood sugars and procedures to follow in the case of a low blood sugar. During the meeting, it would be important to pass out the 504 accommodations and discuss implementation of those accommodations with the teachers. All questions could be answered, parent and teacher contact information could be exchanged, and the door to better communication throughout the school year would open a little wider. Ogawa and Bossert (1995) encouraged educators to explore "new dimensions of leadership" (p. 54). The authors challenged those in positions of power to recognize leadership across the school organization, emphasizing that leadership is “institutional” and may be found in many strong individuals in a variety of positions within a school. The school nurse is a medical expert, queried, by staff and students, for medical advice. As a medical expert, the school nurse can act as an advocate for students with chronic illnesses such as T1D in the public schools and remind administrators and teachers of policies that need to be put in place or enforced to meet students’ needs and ensure students’ safety.

The third theme, School Nurse-to-Student with T1D Relationship, answers research question one: How do parents of students with Type 1 insulin-dependent diabetes describe their experiences and satisfaction with school services provided through the 504 program for their children and the quality of communications between and among the members of the 504 team? The third theme, School Nurse-to-Student with T1D Relationship, had an overall favorable response from the parents of students with T1D. All but one of the parents or sets of parents stated that their child with T1D had a positive and close relationship with the school nurse. They were in agreement that the school nurse took good care of their child while the child was at school. Even the set of parents that were not pleased with the school nurse and stated that the school nurse was too rigid in her rules and had not made an effort to form a nurse-to-student relationship or bond with their child with T1D stated that the school nurse did take good care of their daughter as dictated by the doctor’s orders. Overall, all of the parents interviewed agreed that their children’s basic accommodations to facilitate T1D care were implemented in the school setting and that the school nurses followed the diabetic care plan prescribed by their child’s doctor.

Parents F indicated concern because they thought the school nurse was too rigid in following the doctor’s written orders. They were upset because the nurse would not deviate from a time schedule, devised by the doctor, to give insulin doses. If their daughter’s sugar was high, she was not given insulin by the nurse until it was the scheduled time. Also, their daughter was given her snack at snack time, even if she had a high sugar. The parents did not believe in either of those practices as they felt letting their daughter's blood glucose level remain high, or deliberately increasing an already high blood sugar by giving a snack was damaging to the health of their daughter. A practical solution would be for the nurse to be proactive by contacting the student's endocrinologist and sharing the concerns of the parents along with her own concerns. A sliding scale for the administration of insulin in the nurse's office could be requested from the endocrinologist, and as a result, parent's fears of damage to their child's health due to prolonged bouts of high blood sugar could be alleviated. As a result of this study, Parents F were given a voice to express their frustration with policies and procedures in the nurse's office that seemingly made no sense to them and might have actually harmed the overall health of their elementary school daughter. The researcher will have the opportunity to share these results with both the superintendent of schools and the district nurse coordinator who will have the opportunity to work together to change policies and procedures which are outdated, unreasonable, and harmful to students' health.

The fourth theme, Best T1D 504 Accommodations, answers research question two: What are the perceptions of parents of students with T1D about the best 504 practices and accommodations to help facilitate their child's learning in the classroom? The fourth theme, Best T1D 504 Accommodations, was the parents of students with T1D acknowledgement of 504 accommodations given to their child that best fit their needs and helped to facilitate their classroom learning. The various answers by the six parents or sets of parents were:

1. Parent A: The buddy system; snacks for low blood sugars; and insulin for high blood sugars in the nurse's office.

2. Parent B: Regular blood sugar checks at the nurse’s office to keep glucose levels in the normal range; preferential seating in the front of the classroom to help maintain focus when blood sugars are askew.
3. Parent C: Extended time to finish assignments.
4. Parent D: Hypoglycemic episode emergency care plan; the use of the restroom as needed.
5. Parent E: The daily schedule and procedures that were in place to stabilize the blood glucose levels.
6. Parent F: School meals; breakfast, lunch, and snacks.

The fifth theme, Parents of Students with T1D Concerns and Suggestions for Improvements, answers research question two: According to the perceptions of parents of students with T1D, what concerns and suggestions for improvement do they have regarding their student’s overall care at school? The fifth theme, Parents of Students with T1D Concerns and Suggestions for Improvements, should be of interest to administrators who strive to achieve social justice for all students at their campus, nurse coordinators, and 504 district and campus coordinators who want to improve services for student with T1D in the public school system. Student cumulative absences, a parental concern, were also listed.

1. Parent A: Acknowledge or listen to parents and what their children with T1D are going through; cumulative attendance: absent 62 school days /Homebound 36 school days.
2. Parent B: Reinstatement of the buddy system or a variation of the buddy system; high school students with T1D should be allowed to carry their glucometers with them and check their blood sugars as needed throughout the school day; staff

education about T1D to include information on the difference between T1D and T2D; cumulative attendance: absent 19 school days.

3. Parent C: Teacher education about T1D to include knowledge about the difference between T1D and T2D; more communication between the diabetic management team and the teachers of students with T1D; high school students with T1D should be allowed to carry a glucometer, check blood sugar, and carry snacks; instructions left for substitute teachers about specific 504 accommodations for students with special needs; cumulative attendance: absent 17 school days, (44 absences from first period and 23 absences from second period).
4. Parents D: Unlimited restroom breaks; staff training, (teachers, coaches, secretaries and paraprofessionals), on T1D to include education about the difference between T1D and T2D; effective communication between the T1D 504 diabetic management team, teachers, and parents about the care and well-being of students with T1D at school; cumulative attendance: absent 3 school days.
5. Parents E: Eating habits at school, (school cafeteria menu not to child's liking); cumulative attendance: absent 16 school days.
6. Parents F: Need for larger portion sizes for school breakfast, lunch, and snacks, along with more variety of foods in the school menu; more T1D training for teachers, staff, and school nurse; flexible insulin injection and snack schedule; attendance: absent 17 school days.

Although each parent had a different main concern or suggestion that they were eager to share with the researcher, the overall list of suggestions and concerns were similar in each interview. All parents felt that school personnel were in need of more basic education about

T1D, symptoms of the disease, and care for the disease. They wanted patience, kindness, understanding, and flexibility from all school staff members. All but one of the six students had a school attendance problem related to their chronic illness. Parents of elementary and middle school students with T1D stated that the schools did not pressure them too much about absences. However, one of the parents of a high school student with T1D stated that her daughter had been taken out of class by a truancy officer and both the parent and young lady were upset by the incident.

As mentioned before in Chapter Five of this study, the chief aim of the 504 diabetes management team is to maintain target blood glucose levels through “blood glucose monitoring, insulin administration, insulin pump management, meals and snack provision, and symptoms and treatment of hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar)” (Getch et al., 2007, p. 48). Specific instructions for each of these diabetes care interventions should be written clearly in the IAP. During school hours students with T1D:

> …need to have (a) access to the tools for diabetes management (blood glucose testing equipment; insulin delivery systems; and oral, fast-acting carbohydrates and glucagons) (b) sufficient time to adhere to their nutrition plan; and (c) access to personnel who are knowledgeable about diabetes and are able to assist when needed (Getch et al., p. 47).

Overall, according to the parents of students with T1D in one south Texas public school district, their children’s basic needs, as outlined by Getch et al., were being met by their child receiving accommodations through the 504 program at the different district campuses. All but one of the six sets of parents praised the school nurse at their child’s campus, and even the complaining parent admitted that the nurse had taken good care of their child based on the doctor’s orders she had received.

This study has been helpful in discovering some positive and negative aspects of the care and accommodations given to students with T1D at six different campuses within one south Texas public school district, according to their parents. It is quite possible that the 504 program experiences of the six sets of parents of students with T1D in this study may also be true for parents of students with T1D in other schools across the district and other public school districts in Texas and across the country.

After interviewing all of the parents and following up with a second interview, it became clear to the researcher that T1D is a chronic illness that affects all aspects of schooling and family life. Only one person in each family had the disease, yet parents and siblings of that child were affected emotionally and physically by their love for the child with T1D and their need to help the child survive day to day with the T1D regimen. Each family was deprived of the luxury of sending their children off to school with no worries. Instead, the parents of students with T1D interviewed in this study worried on a daily basis that their child’s sugar might become too high or too low. The parents never knew when they might get an emergency call from the school informing them that their child had a hypoglycemic reaction and was on the way to the hospital in an ambulance. While school personnel cannot totally eliminate the worries of these parents, they can provide the support necessary to alleviate some or most of their worries.

A recurring irritant for students with T1D and their families was the fact that bystanders looking on with little knowledge about T1D, may assume and comment that T1D is the same as T2D, not understanding that a person with T1D requires insulin immediately upon diagnosis and for the rest of their life in order to stay alive. If insulin is not continuously delivered, after the course of a few days, the person with T1D will fall into a ketoacidosis coma and die if insulin treatment is not resumed. T1D is not brought about by being overweight or having a poor diet.

Persons with T1D bristle at the accusation that they may have contracted the disease for those reasons. Scientists are not certain why an individual develops T1D, but suspect it may be caused by heredity through certain genes or brought on by a viral infection (Betschart Roemer, 2011).

Education is the key to better communication between school personnel, students with T1D, and the parents of students with T1D. When school personnel have been educated about the chronic disease of T1D, the symptoms of the disease, the treatment of the disease, and the human factors of the disease, communication will improve. Once effective communication has been established, students with T1D and their parents will not only be assisted in maintaining good blood glucose levels while at school, but will form strong alliances with school personnel based on trust, understanding, compassion, and respect.

The next recurring theme was, in fact, effective communication. The parents of students with T1D wanted all school staff members to be aware of their child’s chronic illness. They expected school staff members to understand emergency care for hypoglycemic episodes in order to keep their child safe at school and to understand prolonged, day to day care to control blood sugar levels in order to avoid the complications of diabetes which may be brought on by hyperglycemia or high blood sugars over time. The parents of students with T1D wanted to be able to communicate with the school nurse, administrator, teachers, coaches, cafeteria workers, secretaries and paraprofessionals about their child’s condition and care in an intelligent, respectful manner. They also wanted staff members, including the teachers and the school nurse, to be understanding of what their child was going through having to live with the chronic illness of T1D 24 hours a day, seven days a week. Of the six students with T1D whose parents were interviewed for this study, five had school attendance problems. Parents of the five students with attendance problems stated that the negative effects of low and high blood sugars affected how their child felt from day to day and determined whether the child arrived late to school or missed school entirely. Students with T1D and their parents should be encouraged like any other student to meet state attendance requirements by attending school regularly and avoiding unnecessary absences. However, school staff in charge of monitoring student attendance and maintaining student attendance records, such as administrators, teachers, truancy officers and attendance clerks, should keep in mind that T1D is a chronic illness that is difficult to control even when meal plans, insulin treatment, and exercise are strictly followed. As previously stated in Chapter Five, despite satisfactory access to treatment, students with T1D may still suffer from hypoglycemia or hyperglycemia. Current treatments for diabetes do not fully duplicate the body's normal utilization of insulin. As a result, a student's blood glucose levels may increase and decrease through no lapse of treatment or care that may be ascribed to the student. The diabetic management team should be aware of this reality and work with the student in an optimistic, encouraging manner to help monitor diabetic control (Getch et al., 2007). Flexibility on the part of the entire school staff is essential to provide equal access to a quality education for the student with T1D. Students with T1D and their parents should not be made to feel like truants or negligent parents because the student with T1D has more absences than other children in the public school system that do not have a chronic illness.

The school nurse is a key member, and often the lead member of the 504 diabetic management team. T1D is a chronic medical condition and the school nurse has basic medical training in how to care for students that suffer from the disease. It only stands to reason that the school nurse can act, according to Ogawa and Bossert (1995), as an institutional leader and a student advocate across the school organization for 504 students with chronic illnesses under her care. Therefore, it is important that when a parent notifies the school nurse that their child has

T1D or T2D, the school nurse should be the first school official to inform the parent about the 504 program. Once the parent is in agreement to enroll their child in the program, the nurse can inform the administrator in charge of 504 to initiate the paperwork and begin the proceedings to provide service to the student through the 504 program. The school nurse or administrator should not wait for the parents to inquire about the 504 program because not all parents are aware of the 504 program's existence. School nurses should also be proactive. If doctor's orders for insulin doses and snacks do not meet the needs of the student with T1D at school, the nurse should contact the doctor, explain the dilemma, and make suggestions for adjustments in the student's insulin treatment schedule or meal plan to benefit the health of the student.

If a student with T1D seems depressed or is having trouble coping with the everyday stress of living with T1D, the nurse may refer the student to the school counselor or encourage the parent of the student with T1D to talk to their medical doctor for a referral to a counselor, psychologist, or a psychiatrist outside the realm of the school.

Future studies could be beneficial to research on the critical phenomena, students with T1D, by interviewing other members of the 504 diabetic management team such as administrators in charge of the 504 program, students with T1D, school nurses or teachers to analyze and compare the different perceptions of the strengths and weaknesses of the 504 program as it pertains to meeting the needs in school of students with T1D and ensuring social justice among all students in the public schools, including special populations of students such as those with chronic illnesses.

Chapter Six Summary

In conclusion, the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes (T1D) in one south Texas public school district were reported. All of the parents interviewed in this study were in agreement that the school nurses followed the diabetic care plan prescribed by their child’s doctor and basic necessary accommodations to facilitate the care of students with T1D were implemented in the school setting. Parents of students with T1D identified accommodations which they felt best met their child’s needs such as the buddy system; the use of the restroom as needed; school meals and snacks for low blood sugars; regular blood sugar checks to keep glucose levels in the normal range and insulin for high blood sugars; preferential seating in the front of the classroom to help maintain focus when blood sugars were askew; and extended time to finish assignments. Parents of students with T1D also gave suggestions and identified areas of concern for improved care for their child. Among the suggestions and concerns were: 1) school acknowledgement and attention to parents concerns; 2) reinstatement of the buddy system or a variation of the buddy system at the high school level; 3) permission for high school students with T1D to carry a glucometer, check blood sugar, and carry snacks throughout the school day away from the nurse’s office; 4) staff education and training, (administrators, teachers, coaches, secretaries and paraprofessionals), on T1D to include education about the difference between T1D and T2D; 5) instructions left for substitute teachers about specific 504 accommodations for students with special needs; 6) unlimited restroom breaks; 7) effective communication between the T1D 504 diabetic management team, teachers, and parents about the care and well-being of students with T1D at school; 8) the need for larger portion sizes for school breakfast, lunch, and snacks, along with more variety of foods in the school menu; and 9) more flexible insulin injection and snack schedules.

The researcher’s aim for this study was that new light would be shed on the 504 program experiences of parents of students with T1D in one south Texas public school district. It was anticipated that this study would provide useful information on how to improve services and/or accommodations for students with T1D in order to level the educational playing field with students who are not afflicted with a chronic disease such as T1D. The researcher was intent upon sharing the findings of the study with the superintendent and the nurse coordinator of the district from which the population and sample subjects were chosen. The researcher also planned to offer her services to the Texas Region One Education Service Center as a speaker for principal and superintendent staff development. As a final result of this study, parents of students with T1D were given a voice. Parents with little education and from low socio-economic backgrounds were in need of T1D care training and support in order to establish stability of their child's care while at home. In addition, the possibility of the continued integration of social justice in the public school setting through the leadership of committed administrators and other institutional leaders for students with chronic illnesses such as Type 1 diabetes was explored and found present but not complete. The findings of the study indicated a need for administrators to be more involved in 504 processes and services for students with chronic illness such as T1D in the public school system.

Reflections

The journey that has led to the final thoughts of this scholarly research titled, "The 504 Program Experiences of Parents of Students with Type 1 Insulin-Dependent Diabetes in One South Texas Public School District," began eighteen years ago on December 1, 1993. It was on that day that my two-year old son, Brian Michael Garza, was diagnosed with Type 1 Insulin-dependent diabetes. On the very first day he was diagnosed, I had to give him an insulin shot and listen to his cries of fear and pain. As the days progressed, we gave him four and five shots a day and pricked his little fingers to check his blood sugar. I felt so helpless, overwhelmed, and sad. I never had a desire to be a nurse because I was afraid of blood and needles. That disappeared quickly as I worked to keep my son healthy.

Brian Michael Garza, (far right), December 1993, after recent diagnosis of T1D

During the course of that first year when I was trying to educate myself on his care and general health, the endocrinologist recommended that I attend a juvenile diabetic support group. As I sat in the circle listening to the other parents discuss what their children incurred in the public school system and the horrifying experiences of the schools' ignorances, I became hysterical and started crying. I realized that I did not belong there. I was still grieving for the health of my child and was not ready to attend a diabetic support group. I cried myself to sleep every night for a year.

Then, about a year after my son was diagnosed with T1D, while at church, I heard an elderly lady talk about her multitude of health problems. Her final statement impacted my life forever. She said, “I just do the best that I can everyday and leave the rest up to the Lord.” And that was the last day that I questioned why. I woke up the next day and the sun was shining again. I made the choice to be positive and enjoy life with my son and the rest of my family, and that’s what we have done from that day forward.

When my son went into the public school system, our experience was totally the opposite of those parents’ experiences in the support group. Instead, for thirteen years, my son, Brian, and our family were treated with the utmost kindness and respect by everyone that we ever encountered in the public school system. From the nurses to teachers and principals, Brian was treated with love and care. Still, as a parent, I did have some serious concerns. As an educator, I was able to speak up, share my concerns with school personnel, and make my wishes known. However, I worried about other parents of children with T1D who were uneducated and would have difficulty navigating the system. Hence, this dissertation was born...

So now, let me show you my boy, Brian Michael Garza, as he is today.

Diabetes, football a huge part of Garza's life at Edinburg

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Eladio Jaimez
RGVSports.com

EDINBURG — Don't let his nickname fool you. Sugar Bear is about as tough as they come.

His birth name is Brian Garza. He's 6-foot-1, 260 pounds and loves to play football. The Edinburg Bobcats' defensive tackle even picked off his first career interception last week in a win against the PSJA Memorial Wolverines. Garza might seem as normal as the rest of the Bobcats. He's not. Garza wakes up every morning around 7:30 a.m. and checks his blood sugar levels. That's right, Garza is diabetic. He then takes insulin via a pump before having breakfast at around 9 a.m. Garza checks his blood sugar levels again at around 10:30 a.m. and again before noon. He gets one last read of his blood sugar before heading out for practice at around 3 p.m. and then checks it every 20 minutes or so during practice, hence the name, "Sugar Bear." "After that it's every hour and a half until I go to sleep," Garza said very nonchalantly.

After 15 years, the daily pricking of the skin to check blood sugar levels and the injection of insulin by syringe or pump becomes a way of life. "I've been doing this since I was two-years old," Garza said. "All my life I've grown up knowing there are certain things I can and can't do because of this. I'm used to it now. This is normal for me. I wouldn't know what it feels like to not have it (diabetes)."

Garza runs all the same drills and practices just as hard as anyone else on the team. Edinburg head coach Joey Caceres said Garza is something of an inspiration to the team and the coaching staff as well. Aside from the fact that trainers might have to check his blood sugar levels during practice and that they have snacks handy just in case Garza's sugar levels drop, the lineman isn't treated any different than any other player."Ever since he was a young kid, he's dreamed of being a Bobcat," Caceres said. "He's a leader for us. When he speaks, the guys listen. He motivates us too. He has to deal with this every day and still comes out and makes sacrifices. He's an inspiration to all of us." Garza doesn't quite see it that way. He plays football because he loves it. His older brother, M. J., played linebacker for the Bobcats and was one of the Valley's top defenders a few years ago. "I love football," Garza said. "My whole family has played and that's all I've ever wanted to do."

Garza and the Bobcats have a tall task at hand this week as they face off with the Harlingen Cardinals in the Valley Morning Star's Game of the Week. The Cardinals are ranked No. 1 in the Valley and are fresh off a 61-17 spanking of the Edinburg North Cougars. Still Garza isn't scared. He's faced plenty of adversity in his life. The Harlingen Cardinals aren't anything he or the Edinburg Bobcats can't handle, he said. "I know everyone thinks this will be a blowout," Garza said. "This is the best team we've had since I was a freshman. And Harlingen is a team like any other team. They're just a bunch of 17-year old kids just like us. They're not Gods. We're going to take it to them and give it our best."

Eladio Jaimez covers District 31-5A for Valley Freedom Newspapers

"Sugar Bear"

Brian Garza, being congratulated by his teammates, immediately after making an interception in a 2009 5A Texas public school district interscholastic football game.

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APPENDIX A

APPENDIX A

NURSE-TO-PARENT TELEPHONE SCRIPT DIRECTIONS

Dear Edinburg CISD Nurse:

I am Mrs. Mary F. Garza, a doctoral student in the Educational Leadership program at the University of Texas-Pan American (UTPA), and an assistant principal at South Middle School in the Edinburg CISD. I am conducting a dissertation study entitled “The 504 Program Experiences of Parents of Students with Type 1 Insulin-Dependent Diabetes in One South Texas Public School District.” I am working under the supervision of Dr. Shirley Mills and Dr. Anita Pankake, both faculty members at UTPA.

The purpose of the study is to report on the 504 experiences of parents of students with Type 1 insulin-dependent diabetes in one South Texas public school district. The story of these experiences will help families with children with Type 1 diabetes navigate the public school system and offer valuable feedback to the school district about what is and what is not working. The superintendent of Edinburg CISD, Dr. Rene Gutierrez, has reviewed this research study and determined it is a worthwhile endeavor for the parents of students with Type 1 diabetes. Findings from the study may provide valuable information to enhance the health, safety, and education of students with Type 1 diabetes in the Edinburg CISD.

Mr. Albert Lopez, ECISD Nurse Coordinator, has most graciously agreed to contact the nurses at ECISD schools which house students with Type 1 insulin-dependent diabetes (T1D) and distribute this letter and the Nurse-to-Parent Script, which is provided in English and Spanish. Mr. Lopez, on my behalf, will be asking you to call each family of your student or students with T1D and read them the Nurse-to-Parent Script exactly as it is written. Please note the date and time of all calls to families on the Nurse-to-Parent Script form for that family. If you are unable to make contact with your first call to a household, please note the date and time on the Nurse-to-Parent Script form for that family, and try phoning them again later. I will collect the Nurse-to-Parent Script forms as a part of the documentation for the study.

If you have any questions or concerns, please do not hesitate to contact me by phone at © (956) 537-7722 or (w) (956)289-2415; or by e-mail at ma.garza@ecisd.us
I would like to thank you in advance for assisting me with this endeavor.

Sincerely,
Mary F. Garza
UTPA Doctoral Student
SMS Assistant Principal

APPENDIX B

APPENDIX B

NURSE-TO-PARENT TELEPHONE SCRIPT

Hello Mr. / Mrs. ___________,

This is Nurse __________, from ___________ School. I am calling to invite you to participate in a research study involving interviews with parents of children with Type 1 diabetes. The study is being conducted by Mrs. Mary F. Garza, a doctoral student in the Educational Leadership program at the University of Texas-Pan American.

Mrs. Garza's research involves a report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes our school district with the aim of helping such families navigate the public school system and offering feedback to the school district about what is and what is not working.

The superintendent of Edinburg CISD, Dr. Rene Gutierrez, has reviewed and approved this research study. Rather than provide Mrs. Garza with a list of all parents meeting the research criteria, however, we are contacting parents ourselves to see if they are willing to be interviewed by Mrs. Garza. If you are willing to participate, I will forward your contact information on to Mrs. Garza so that she can contact you to provide more details and set up a 1-hour interview with you. The interviews are confidential and participation is completely voluntary; this is an independent research study and there are no penalties for not participating.

Would you be interested in participating in this research study and can I pass your contact information on to Mrs. Garza so she may contact you?

(If parent says "yes")

__________Mrs. Garza will be contacting you very soon. Thank you for your time and attention to this manner.

(If parent says "no")

___________Thank you for your time and attention to this matter.

APPENDIX C

APPENDIX C

ENFERMA PARA PADRE-ESCRITURA TELEFÓNICA

Hola Sr. / Sra. ___________,

Soy la enfermera __________, de la escuela ___________. Le estoy llamando para invitarle a participar en un estudio de investigación en el que se llevaran a cabo entrevistas a padres de niños con diabetes del tipo 1. El estudio será conducido por la Sra. Mary F. Garza, estudiante en el programa doctoral de liderazgo educacional en la Universidad de Texas Pan-American.

La investigación de la Sra. Garza es un informe sobre el programa 504 y las experiencias de los padres de los alumnos con diabetes tipo 1 dependientes de la insulina en nuestro distrito escolar y tiene como propósito el de ayudar a esas familias a navegar el sistema educativo público y ofrecer información al distrito escolar acerca de lo que funciona y lo que no funciona.

El Superintendente del distrito escolar de Edinburg, Dr. René Gutiérrez, ha revisado y ha aprobado este estudio de investigación. En lugar de proveer una lista con los nombres de los padres que califican para esta investigación a la Sra. Garza, nosotros estaremos contactando a los padres para ver si están dispuestos a ser entrevistados por la Sra. Garza. Si usted desea participar le proporcionaremos su información a la Sra. Garza para que ella se ponga en contacto con usted para proveerle en detalle acerca de la entrevista y para darle una cita para la entrevista que tomará una ahora. Las entrevistas son confidenciales y su participación es completamente voluntaria; este es un estudio de investigación independiente y no hay sanción por no participar.

¿Estaría interesado en participar en este estudio de investigación?

(Si el padre dice "sí")

__________Muy pronto la Sra. Garza se pondrá en contacto con usted. Gracias por su tiempo y atención a este asunto.

(Si el padre dice "no")

___________Gracias por su tiempo y atención a este asunto.

APPENDIX D

APPENDIX D

THE UNIVERSITY OF TEXAS-PAN AMERICAN
INFORMED CONSENT FORM

Study Title: The 504 Program Experiences of Parents of Students with Type 1 Insulin-Dependent Diabetes in One South Texas Public School District

This research survey is being conducted by Mrs. Mary F. Garza from the University of Texas-Pan American/UTPA, under the supervision of Dr. Shirley Mills and Dr. Anita Pankake. We are conducting a research study to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes in one South Texas public school district. We hope that the story of these experiences will help families with children with Type 1 diabetes to navigate the public school system and offer valuable feedback to the school district about what is and what is not working. As part of this study, we are interested in the views of parents of students with Type 1 insulin-dependent diabetes.

We have invited you here today so that we can conduct an interview about issues related to this topic. The interview is expected to last approximately 60 minutes. Your individual responses will be treated confidentially. Your participation is completely voluntary; although you have shown interest in participating in this study, you are free to withdraw from the interview at any time and can choose not to answer specific questions.

In order to ensure the accuracy of recorded statements, we will be recording the session on audiotape and later transcribing the tapes. The tapes will not be marked with your names and will be securely stored at UTPA. The recordings themselves will only be used for research purposes and will not be given to anyone not directly involved in the research. After five years, the tapes will be destroyed or erased.

Your responses may be quoted in whole or in part in publications or presentations based on this research. If quotes are used, your real name will be replaced by a made up name (pseudonym) and any additional information that might directly identify you will be excluded.

You must be at least 18 years old to participate in this research. If you are under 18, please let the researcher know before the session begins.

Researcher contact information:	Name: Mary F. Garza Dept: Educational Leadership The University of Texas-Pan American Phone: (956) 537-7722 Email: ma.garza@ecisd.us

Faculty Advisor contact information:	Name: Dr. Shirley Mills	Name: Dr. Anita Pankake
	Dept: Educational Leadership	Dept: Educational Leadership
	University of Texas-Pan American	University of Texas-Pan American
	Phone: (956)566-2321	Phone: (210)757-3211
	Email: millssj@utpa.edu	Email: pankake@sbcglobal.netour

This research has been reviewed and approved by UTPA's Institutional Review Board for Human Subjects Protection (IRB) and by Dr. Rene Gutierrez, Superintendent of ECISD. If you have any questions about your rights as a participant, or if you feel that your rights as a participant were not adequately met by the researcher, please contact the IRB at (956) 665-2889 or irb@utpa.edu. You are also invited to provide anonymous feedback to the IRB by visiting www.utpa.edu/IRBfeedback.

APPENDIX E

APPENDIX E

LA UNIVERSIDAD DE TEXAS-PAN AMERICAN
FORMULARIO DE CONSENTIMIENTO: ENTREVISTA

Título de estudio: Las experiencias del programa 504 para padres de estudiantes con Diabetes del tipo 1 insulina – diabéticos dependientes en un distrito escolar público en el sur de Texas

Este estudio de investigación está siendo conducido por la Sra. Mary F. Garza de la Universidad de Texas-Pan American/UTPA, bajo la supervisión de el Dr. Shirley Mills y la Dr. Anita Pankake. Estamos llevando a cabo un estudio de investigación que informe sobre las experiencias de padres de estudiantes con diabetes tipo 1 dependientes de insulina en una escuela pública de el Sur de Texas. Deseamos que estas anécdotas y experiencias ayuden a las familias de niños con diabetes del tipo 1 a desplazarse por el sistema de escuelas públicas y ofrecer información valiosa para el distrito escolar acerca de lo que funciona y lo que no funciona. Como parte de este estudio, nos interesa la opinión de los padres de los estudiantes con diabetes insulina-dependiente del tipo 1.

Le estamos invitando a venir hoy para poder realizar una entrevista sobre asuntos relacionados con este tema. Se espera que la entrevista dure aproximadamente 60 minutos. Sus respuestas individuales se tratarán de forma confidencial. Su participación es completamente voluntaria; Aunque haya mostrado interés en participar en este estudio, es libre de retirarse de la entrevista en cualquier momento y puede decidir no responder a preguntas específicas a este tema.

Con el fin de garantizar la exactitud de las declaraciones grabadas, la sesión será grabada en audio y más tarde se harán las transcripciones de las cintas. Las cintas no se marcarán con sus nombres y se almacenarán de forma segura en la universidad UTPA. Las grabaciones se utilizarán sólo con el fin de investigación y no se compartirán con ningún individuo que no participe directamente en la investigación. Después de cinco años, las cintas serán destruidas o borradas.

Sus respuestas pueden ser reproducidas en su totalidad o en parte en publicaciones o presentaciones basadas en esta investigación. Si se usan cotizaciones, su nombre real será sustituido por un nombre compuesto (seudónimo) y se excluirá cualquier información adicional que pueda identificarle directamente.

Usted debe tener por lo menos 18 años de edad para poder participar en esta investigación. Si usted es menor de 18 años, por favor déjele saber al investigador antes de que comience la sesión.

Investigador: Mary F. Garza
Departamento: Liderazgo educativo
La Universidad de Texas-Pan American
Teléfono: (956) 537-7722,
Correo electrónico: ma.garza@ecisd.us

Asesor: Dr. Shirley Mills
Departamento: Liderazgo educativo
La Universidad de Texas-Pan American
Teléfono: (956) 566-2321
Correo electrónico: millssj@utpa.edu

Asesor: Dr. Anita Pankake
Departamento: Liderazgo educativo
La Universidad de Texas-Pan American
Teléfono: (956) 757-3211
Correo electrónico: pankake@sbcglobal.netour

Esta investigación ha sido revisada y aprobada por la junta de revisión institucional para protección de sujetos humanos (IRB) y por el Dr. René Gutiérrez, Superintendente del distrito escolar de Edinburg. Si usted tiene alguna pregunta acerca de sus derechos como participante, o si siente que sus derechos como participante no fueron adecuadamente satisfechas por el investigador, comuníquese con IRB, al teléfono (956)665-2889 o por medio del correo electrónico irb@utpa.edu. Al igual, queda usted invitada para compartir anónimamente su punto de vista en alguna área dudosa visitando el sitio electrónico www.utpa.edu/IRBfeedback.

APPENDIX F

APPENDIX F

THE 504 PROGRAM EXPERIENCES OF PARENTS OF STUDENTS WITH TYPE 1 INSULIN-DEPENDENT DIABETES IN ONE SOUTH TEXAS PUBLIC SCHOOL DISTRICT

INTERVIEW PROTOCOL

NAME: ____________________________ DATE: ________________

Hello, my name is Mary Garza. I am married and have three sons, aged 23, 20, and 14; no grandchildren yet.☺ I am a doctoral student from the University of Texas-Pan American/UTPA, under the supervision of Dr. Shirley Mills and Dr. Anita Pankake. I work for the Edinburg Consolidated Independent School District at South Middle School.

We are conducting a research study to report on the 504 Program experiences of parents of students with Type 1 insulin-dependent diabetes in one South Texas public school district. As part of this study, we are interested in exploring how parents of students with Type 1 insulin-dependent diabetes (T1D) describe their experiences and satisfaction with school services provided through the 504 program for their child and the quality of communications between and among the members of the 504 team. We hope that the story of these experiences will help families with children with Type 1 diabetes to navigate the public school system and offer valuable feedback to school district administrators about what is and what is not working.

We have invited you here today so that we can conduct an interview about issues related to this topic. The interview is expected to last approximately 60 minutes. Your individual responses will be treated confidentially. Your participation is completely voluntary; although you have shown interest in participating in this study, you are free to withdraw from the interview at any time and can choose not to answer specific questions.

In order to ensure the accuracy of recorded statements, we will be recording the session on audiotape and later transcribing the tapes. The tapes will not be marked with your names and will be securely stored at UTPA. The recordings themselves will only be used for research purposes and will not be given to anyone not directly involved in the research. After five years, the tapes will be destroyed or erased.

Your responses may be quoted in whole or in part in publications or presentations based on this research. If quotes are used, your real name will be replaced by a made up name (pseudonym) and any additional information that might directly identify you will be excluded. Please relax and speak freely in response to the interview questions. Be assured that your identity will remain completely confidential.

PARENT INTERVIEW QUESTIONS

1) At what age did your child develop Type 1 diabetes?
2) Tell me about the 504 practices and accommodations used for your child with T1D. How do you feel about the implementation?
3) Describe the 504 practices and accommodations that best help facilitate learning to meet the needs of your student in the classroom.
4) How are the school administrators actively involved as a part of your student’s diabetic management team?
5) Tell me about the changes you believe are needed to help the 504 system better determine and implement accommodations.
6) Describe the quality of communication between the members of the diabetic management team about the school accommodations given to your student with T1D.
7) How do you feel about the diabetic management team? How do you feel about the team’s ability to fully understand the chronic disease of T1D?
8) Describe your child’s relationship with the school nurse.
9) How has T1D affected your child’s attendance record and grades in school?
10) Describe your student’s Individualized Health Care Plan (IHP) including their Emergency Care Plan (ECP) for low blood sugars.
11) What concerns do you have regarding your student’s overall care at school?

That is the last of the questions I have for you today. Thank you so much for participating in the interview!

APPENDIX G

APPENDIX G

APÉNDICE C DEL PROGRAMA 504 EXPERIENCIAS DE PADRES DE ESTUDIANTES CON DIABETES DE TIPO 1 INSULINA-DEPENDIENTE EN UN DISTRITO PÚBLICO DEL SUR DE TEXAS

PROTOCOLO DE ENTREVISTA

NOMBRE: ______________________ FECHA: _______________

Hola, mi nombre es Mary Garza. Yo estoy casada y tengo tres hijos de 23, 20 y 14 años de edad; todavía no tengo nietos. Yo estoy una estudiante de doctorado de la Universidad de Texas-Pan American/UTPA, bajo la supervisión de la Dr. Shirley Mills y la Dr. Anita Pankake. Trabajo en la escuela South Middle School para el distrito de escuelas en Edinburg.

Estamos llevando a cabo un estudio de investigación que informe sobre las experiencias de padres de estudiantes con diabetes tipo 1 dependientes de insulina en una escuela pública de el Sur de Texas. Como parte de este estudio, estamos interesados en explorar cómo los padres de los alumnos con 1 tipo insulina – dependiente de la diabetes (o) describen sus experiencias y satisfacción con la escuela de servicios prestados a través del programa 504 para su hijo y la calidad de las comunicaciones entre los miembros del equipo 504 y. Deseamos que estas anécdotas y experiencias ayuden a las familias de niños con diabetes del tipo 1 a desplazarse por el sistema de escuelas públicas y ofrecer información valiosa para el distrito escolar acerca de lo que funciona y lo que no funciona.

Le estamos invitando a venir hoy para poder realizar una entrevista sobre asuntos relacionados con este tema. Se espera que la entrevista dure aproximadamente 60 minutos. Sus respuestas individuales se tratarán de forma confidencial. Su participación es completamente voluntaria; Aunque haya mostrado interés en participar en este estudio, es libre de retirarse de la entrevista en cualquier momento y puede decidir no responder a preguntas específicas a este tema.

Con el fin de garantizar la exactitud de las declaraciones grabadas, la sesión será grabada en audio y más tarde se harán las transcripciones de las cintas. Las cintas no se marcarán con sus nombres y se almacenarán de forma segura en la universidad UTPA. Las grabaciones se utilizarán sólo con el fin de investigación y no se compartirán con ningún individuo que no participe directamente en la investigación. Después de cinco años, las cintas serán destruidas o borradas.

Sus respuestas pueden ser reproducidas en su totalidad o en parte en publicaciones o presentaciones basadas en esta investigación. Si se usan cotizaciones, su nombre real será sustituido por un nombre compuesto (seudónimo) y se excluirá cualquier información adicional que pueda identificarle directamente. Por favor, relájese y hable libremente al responder las preguntas de la entrevista. Puede estar seguro(a) de que su identidad será completamente confidencial.

PREGUNTAS EN LA ENTREVISTA PARA LOS PADRES

1) ¿A qué edad su hijo desarrollo diabetes de tipo 1?
2) Dígame acerca de las prácticas y comodidades utilizadas por el programa 504 para su hijo/hija con diabetes tipo uno. ¿Cómo se siente acerca de las implementaciones puestas en prácticas?
3) Describa las prácticas y comodidades del programa 504 que mejor ayudan a facilitar el aprendizaje y satisfacen las necesidades de su hijo/hija en el salón.
4) ¿Cómo son los administradores de la escuela? ¿Participan activamente como parte del equipo para ayudar a su hijo/hija diabético(a)?
5) Dígame acerca de los cambios que usted cree son necesarios para ayudar a mejorar el programa 504.
6) Describa la calidad de comunicación entre los miembros del equipo directivo sobre las comodidades de la escuela a los estudiantes con diabetes tipo uno.
7) ¿Cómo se siente con el equipo de administración diabética? ¿Cómo se siente sobre la capacidad del equipo para entender esta enfermedad crónica que es la diabetes tipo uno?
8) Describa la relación de su hijo/hija con la enfermera de la escuela.
9) ¿Cómo ha afectado esta enfermedad la asistencia escolar y las calificaciones en la escuela de su hijo/hija?
10) Describa el plano de cuidado médico individualizado de su hijo/hija incluyendo su plan de emergencia para la atención de niveles bajos de azúcar en la sangre.
11) ¿Qué preocupaciones tienen sobre el cuidado general de su hijo/hija en la escuela?

Esta es la última de las preguntas que tengo para usted hoy. Muchas gracias por participar en la entrevista.

BIOGRAPHICAL SKETCH

Mary Frances Cornwell-Garza is the third child born to Rhea Ann Appenzeller-Cornwell and James Cornwell in Peoria, Illinois in 1959. She graduated first in her class from Deer Creek-Mackinaw High School in Mackinaw, Illinois in 1978. She attended Illinois Wesleyan University in Bloomington, Illinois, where she played intercollegiate softball and volleyball. She transferred to Drake University in Des Moines, Iowa and graduated with a Bachelor of Science (BS) degree in Education with a major in Physical Education and a minor in Health in 1982. In 1994, Mary Frances earned a Master of Education degree in Counseling and Guidance from the University of Texas-Pan American (UTPA) in Edinburg, Texas. Respectively, in 2006 and 2010, she received her Principal and Superintendent Certification from UTPA. Mary Frances was accepted into Cohort V of the UTPA Educational Leadership Doctoral Program in 2007 and earned a Doctorate in Education (Ed. D.) degree in May of 2012.

Mary Frances moved from Illinois to Texas in the fall of 1982 after accepting her first teaching job at Brown Junior High in McAllen, Texas. Since then her career in Texas public education spans 30 years, including 12 years as a teacher and coach for McAllen Independent School District, 11 years as a middle and high school counselor for La Joya Independent School District and Edinburg Consolidated Independent School District (Edinburg CISD), and seven years as an assistant principal at South Middle School in the Edinburg CISD.

Mary Frances resides with her husband of 25 years, Manuel C. Garza, and three fine sons, Manuel James, Brian Michael, and Jacob Matthew at 1010 McKee Drive, Edinburg, Texas. Her e-mail address is marygarza3@hotmail.com.