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Sending Children Who Are Medically Fragile to School

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Sending Children Who Are Medically Fragile to School

Abstract

This study examined the decisions to send children who are medically fragile to school-based programming. A case study including parent interviews, as well as pediatrician surveys regarding the education of children who are medically fragile. Benefits, as well as problems, were discussed and were associated with children who are medically fragile attending school. Guidelines were presented for decisions to send children who are medically fragile to school. Also, conclusions were drawn from the literature and recommendations were made for the future of schooling for children who are medically fragile.

SENDING CHILDREN WHO ARE MEDICALLY FRAGILE TO SCHOOL

A Graduate Research Paper

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By

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ABSTRACT

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CHAPTER 1

INTRODUCTION

Background

Parents make difficult decisions about the education of their children. However, it becomes a much bigger task when children have special needs, especially medical needs. Although our society has changed its view of education for children with special needs, many of the options remain the same for parents. This has been true for over one hundred years in the United States, although it varies from state to state.

Samuel Howe and Edouard Seguin contributed to the education of children with special needs in the late 1800's. In 1839, Howe started the Perkins Institution for the Blind where Helen Keller became a student with interpreter Annie Sullivan (www.perkins.org). Seguin moved to the United States and "became a driving force in the education of individuals" with special needs (Biasini, Grupe, Huffman, & Bray, 1998, p. 2). In 1892, *residential training schools* were established in nearly every state. During the late 20th century, some individuals returned to their communities leading the transition of some educational residential training schools to residential custodial living centers (Biasini et al., 1998).

In the 1950's to the 1970's, parents and professionals advocated that the federal government should provide a *free and appropriate public education* (FAPE), to children with disabilities (www.cec.sped.org). In 1975, Congress passed Public Law 94-142 requiring that all children with disabilities receive FAPE.

Two Supreme Court cases that had implications for special education, specifically those who are medically fragile, were *Irvin Independent School District v. Tatro* in 1984

and in 1999, Cedar Rapids Community School District v. Garret F. (Katsiyannis & Yell, 2000). The rulings under the Individual with Disabilities Education Act (IDEA) of 1997 require school districts to provide *related health services* in order for a child to benefit from special education. However, if a physician provides the health procedure then it is a *medical service* not required of the school district.

“Advances in medical treatments” has led to growing survival rates of children who are medically fragile, and “increasingly, these medically fragile children are attending school along with the general population of their age-mates” (Rehm & Rohr, 2002, p. 345). Parents who influenced the educational legal decisions have been those who wanted their children included in the educational programming within the school. However, some parents choose homebound instruction and do not send their children who are medically fragile to school. Although federal and state laws govern homebound instruction, implementation may vary from state to state and district to district. The American Academy of Pediatrics has stated, “Federal and state legislation clearly dictate that the most appropriate setting for education is the school; this setting should provide the least restrictive environment possible so children can achieve their maximum potential” (AAPediatrics, 2000, p. 1154). This information is also defined in the Individuals with Disabilities Education Act (IDEA) of 1997 and Section 504 of the Rehabilitation Act of 1973.

Today, The Perkins School for the Blind provides residential and day programming for approximately 200 students a year. There are residential living centers and group homes that allow parents to place their children outside of the home to live in group settings. There are also residential schools that house children as well as teach

them. Parents can also choose to keep their children at home with some support and eventually decide to send their children to school-based public or specialized schools. Still, parents have the option of keeping their children at home with guidelines stating the amount the state will spend to support the children at home.

Purpose of the Study

The purpose of the study is to determine the benefits and the negative effects involved when parents send their children who are medically fragile to school. To accomplish this purpose, this paper will address the following questions:

1. How were children who were medically fragile educated in the past?
2. What are the benefits of sending students who are medically fragile to school?
3. What are the negative effects of sending students who are medically fragile to school?
4. What guidelines need to be developed for children who are medically fragile to be included in school?

Need for the Study

Parents need to make informed decisions about the education of their children who are medically fragile. Parents along with medical and educational professionals should be involved in the planning and decision-making from the beginning in order to prepare their child for each transition, which include the following: hospital to home, home to early intervention, early intervention to preschool, and preschool to school.

Limitations

The limited literature addressed the benefits and problems of including children with medical needs in school-based programming. There was limited research on

homebound instruction, residential schools, and guidelines for educational transitions. The laws regarding educational issues for children who are medically fragile are implemented differently from state to state and district to district. This arrangement makes it difficult to find universal procedures within the research. There were also limitations within the case study, which consisted of parent interviews and pediatrician surveys. Five of the 8 parent interviews were completed having only one parent who has never sent their child to school. Two of the 6 pediatrician surveys were completed, which limits the feedback from physicians.

Definitions

In the literature reviewed for this study, various terms were used interchangeably. Specifically, the terms chronic illness, children with specialized health care needs, and children who are medically fragile/technology-dependent will refer to children who are medically fragile for this study. These terms are defined to eliminate misunderstanding and ambiguity, as well as, aid in clarity.

Age-Appropriate: "...focuses on the knowledge of typical development in young children, the foundation on which teachers can plan appropriate, meaningful learning experiences" (Lillie & Vakil, 2002).

Care Coordination: Management of children's health care needs such as planning, monitoring, and ongoing reassessment that is provided by four areas including health care system, educational system, social service and public health system, and home setting (AAPediatrics, 1999).

Chronic Illness: Refers to medical conditions people live with including but not limited to cancer, diabetes, asthma, heart disease and spina bifida (Lynch, Lewis & Murphy, 1993).

Homebound Instruction: Instruction for acute or catastrophic health problems that confine a child or adolescent to home or hospital for a prolonged time which is governed by federal and state laws (AAPediatrics, 2000).

Individual Education Plan: Legal document which provides educational services to a child with a disability from 3-21 years of age (AAPediatrics, 1999).

Individual Family Services Plan: Early intervention services for infants and toddlers that is governed by law, and interpreted by each state (AAPediatrics, 1999).

Medically fragile: "...are a varied population that you cannot identify by a single set of characteristics. Their physical disabilities range from mild to severe, and their intellectual abilities range from below normal to above normal. Students might have a single impairment or a combination of impairments; they might have lived with a condition since birth or might have acquired it recently" (Essex, Schifani & Bowman, 1994, p.50).

Respite Care: Care offered to a person to relieve the primary care-giver of care (Rehm & Rohr, 2002).

School-based Programming: Includes a setting out of the home, to include preschool center and school-age building such as an elementary school (Rehm & Rohr, 2002).

Severe and profound disabilities: Refers to the degree of disability in cognition, and/or emotional disturbance as well as multiple disabilities (Hobbs & Westling, 1998).

Specialized Health Care Needs: Are those individuals who are at an increased risk of chronic conditions and require increased health services than others (AAPediatrics, 1999).

Technology-dependent: Medically fragile children who are also dependent on technology for support (Parette, Bartlett, & Holder-Brown, 1994).

CHAPTER 2

CASE STUDY

One limitation of this study includes the limited literature regarding parents' decisions for educational placement of their children who are medically fragile. Specifically, the decision to send their children to school or retain them within the home has to be decided. A case study was conducted within The Dubuque Community School District (DCDS) that serves a variety of children with special health related needs. The school district educates students who are medically fragile in various educational settings, including home/hospital, self-contained, self-contained with integration, and general education with support. I have been teaching for 10 years within the district's Personal Learning Program (PLP) at the Elementary level. This program is designed to meet the needs of children with severe and profound disabilities; some of whom are also medically fragile.

Using a case study approach, I interviewed 5 parents of children who are medically fragile. The questions used to guide the interviews are included in Appendix A. Four out of the 5 children also have a disability, and 3 of who are enrolled in the PLP. All parent interviews were audiotaped and then transcribed within Appendix B. In addition to the 5 parent interviews, two of the 6 Dubuque pediatricians returned surveys for this study that are included in Appendix D. In order to protect the identity of all participants, they have been given the label of Parent (1), and Child (1a), Parent (2) and Child (2b), etc. The pediatricians will be referred to as Pediatrician (1) and Pediatrician (2).

Parent Interviews

It is important to first establish the children's special health care needs to clearly label them for the purpose of this study as medically fragile. The following charts indicate some of these characteristics as well as special medical health care they require. Tables 1-4 describe the children's medical needs, which are grouped within 4 general categories or body systems, including respiratory, gastrointestinal (G-I), musculoskeletal, and neurological systems. Using interviews, Parent (1) reported that their Child (1a) has chronic lung disease, and tracheal malacia and a seizure disorder impacting her abilities in all areas. Parent (2b) reported that their Child (2b) does not have issues with her respiratory system, however, she had a series of strokes at the age of 2 years resulting in needs in the other 3 areas, G-I, musculoskeletal and neurological. Parent (3) shared that her Child (3c) has a severe seizure disorder that impacted her growth and development, which require medical care in all 4 areas, respiratory, G-I, musculoskeletal, and neurological. Parent (4) shared that Child (4d) has an unbalanced translocation of her fourth and fifth chromosome and she is missing her corpus colupsum that is a centerpiece of her brain. This requires medical care for Child (4d) in all 4 areas as well. Parent (5) indicated that her Child (5e) had lung failure and received a bilateral lung transplant at the age of 3 years 10 months. Currently, at age 11, he is in chronic lung rejection requiring medical support in respiratory and G-I. (Definitions of medical terms included in Appendix C).

Table 1: Respiratory System

	Suctioning	Trachea Care	Close Breathing Monitoring	Restricted Activity and Positioning	Treatments: oxygen, nebulizer, vest, etc.
Child (1a)	X		X		X
Child (2b)					
Child (3c)	X		X	X	X
Child (4d)	X	X	X	X	X
Child (5e)			X	X	X

Table 1, describes the respiratory needs that the children may have. Four out of 5 children require at least 3 out of the 5 needs. Three out of 5 children require suctioning and restricted activity level or positioning. Four out of 5 children require close monitoring of their breathing and some type of breathing treatment or therapy. Child (4d) was the only child who has a trachea requiring trachea care and Child (2b) doesn't have respiratory needs. Within the interviews, Parent (1), (3), (4), and (5) described using Vest therapy with their children on a daily basis at varying amounts with increased sessions at the onset and during an illness such as a cold. Parent (3) and (5) also reported the use of oxygen and nebulizer treatments for their child.

Table 2: Gastrointestinal (G-I) System

	Special Diet Oral	G-Tube/J-Tube Diet	Reflux	Suctioning
Child (1a)		X	X	X
Child (2b)	X			
Child (3c)	X	X	X	X
Child (4d)		X	X	X
Child (5e)	X			

Table 2, describes the G-I system or the area of nutritional needs for the children. All 5 children have needs within this area of nutrition. Three of the 5 require a special

diet. Child (1a), (3c), (4d) have reflux and aspiration requiring placement of a g-tube for nutrition. Child (3c) also has a J-Tube and receives a kietogenic diet to help prevent seizure activity. Child (2a) required a g-tube from age 2-5 until she relearned how to eat. She now eats orally a blended diet but she is completely dependent on others to feed her. Child (1a), (3a) and Child (4d) also require suctioning. Child (5e) requires a high caloric diet to help with weight gain.

Table 3: Musculoskeletal System

	Bone Concerns (scoliosis, hips)	Non-Ambulatory/ Position dependent	Tone and Range Concerns	Adaptive Orthotics (AFO's, body jacket)
Child (1a)	X	X	X	X
Child (2b)	X	X	X	X
Child (3c)	X	X	X	X
Child (4d)	X	X	X	X
Child (5e)				

Table 3 represents the medial needs in relation to the musculoskeletal system.

Child (5e) does not have any needs in this area. He is the only ambulatory child in the case study and his bones and muscles do not require specialized care. Four of the children have all 4 related issues including, bone concerns such as scoliosis or hip problem.. They are non-ambulatory and dependent on positioning; they have muscle tone and range concerns; and they wear at least one form of orthotics such as body jacket, and ankle foot orthotics (afo's).

Table 4: Neurological System

	Cognitive Disability	Seizure Disorder	Close Monitoring
Child (1a)	X	X	X
Child (2b)	X	X	
Child (3c)	X	X	X
Child (4d)	X	X	X
Child (5e)			

Table 4 describes the medical effect on the neurological system for each child. Child (5e) doesn't have any neurological needs. The other 4 children have a cognitive disability resulting from their medical condition, and they are all non-verbal. Child (1a)'s, (2b)'s, (3c)'s, and (4d)'s primary mode of communication is affect or their response to the environment, such as smiling, or crying. However, Child (2b) and (3c) are also able to use other means such as eye gaze and/or reaching for pictures and objects. All children except Child (5e) have a seizure disorder requiring medication and monitoring. Child (1a), (3c) and (4d) also require close monitoring and documentation for needed medication changes and/or possible emergency attention.

With medical needs established, Table 5 indicates the age of each child at the time of the interview, as well as the educational options they experienced.

Table 5: Age and Educational Options

	Age	Early Intervention	Preschool Center-based	School-based Programming	Homebound Instruction
Child (1a)	8	Birth to 5	NO	Age 8	Age 5 to 8
Child (2b)	12	NO	Age 3 to 5	Age 5 to 12	NO
Child (3c)	7	Birth to 3	Age 3 to 5	Age 5 to 7	NO
Child (4d)	4	Birth to 3	NO	NO	Age 3 to 4
Child (5e)	11	NO	NO	Age 6 to 11	Age 11

The children ranged in age from 4 years old to 12 years old. The educational services have varied for all of the participants. Three out of 5 children (1a,3c,4d)

wanted Child (3c) to stay home with her. Parent (3) shared, *They had taken care of her for so long that I didn't have a chance to be her mom. I wanted to be her mom and if she was in school I wasn't with her.* Now, Parent (1) and (3) have changed their choice to being an advocate for school attendance for their children along with Parent (2) and (5). However, Parent (4) remains completely against sending her child to school. Child (2b), (3c) and (5e) followed the general timeline for educational services offered, but Child (5e) started kindergarten at age 6 instead of 5.

Early intervention. Those children who received *early intervention* services include Child (1a), (3c) and (4d) and their parents reported positive experiences. Parent (1) reported that no one talked to them about early intervention educational options. They pressed the issue and their child began receiving services at age 6 months old. She received services 1 time per week for about 1 hour. Parent (2) shared that her daughter was in the hospital frequently, after the age of 2. The social worker and possible professionals from Iowa City Hospitals were the ones to suggest schooling. Keystone AEA personnel did come into the home and do an evaluation, but her services were from outside agencies. She was about preschool age when she started school. Parent (3) indicated that her daughter was in and out of the hospital most of the early intervention years. She would just get her home, and she would be back in the hospital. However, she did receive services 1-2 times per week for 1-2 hours when she was home. Parent (4) shared that she had services after the initial evaluation from Keystone AEA when she was born. They came into the home about 2 times per month and decreased to 1 time per month. During the winter months she did not receive services due to the flu and cold season. Those who received services reported being happy with them. Parent (3),

reported that the services were interesting. They provided her with ideas to implement with her daughter. Parent (1) was also pleased with services, but felt that they could've pushed her more. Child (1a) would con the service providers into giving her breaks that mom didn't feel were always needed. Parent (1) said, *She would take a break and sleep quite a bit of the time.* Parent (4) shared a concern about service providers. She wanted them to be more cautious when coming into her home with possible illness that could be passed on to her daughter. Although Child (2b) did not receive early intervention services, she did receive private therapy services. Parent (2) contributed her ability to care for Child (2b) more easily as well as helping her to relearn how to eat, due to these services.

Transition to preschool. Only 2 of the 5 children attended preschool center-based programming. In Dubuque, preschool programming consisted of a 4 day a week ½ day program that integrates children with varying disabilities and those without disabilities. According to Parent (2), preschool developed her daughter's ability to adapt to new environments, but it was the hardest year of school for her daughter. With the assistance from the Keystone AEA teacher, Parent (3) visited preschool and enrolled her daughter. She shared that it was the teachers who helped her a lot with the transition. Parent (3) reported that she stayed with her daughter at preschool for 3 weeks before leaving her there without her. Prior to attending, she was concerned about her being the only child in a wheelchair and requiring so much care. But she indicated that preschool did a lot for her daughter. Parent (3) stated, *She began to focus on things and experienced participated in all activities. She got really excited with finger-painting. Finger-painting was one of her biggest things there. So, she and I like it.* Neither parent reported any

concerns with preschool programming. Parent (1) was given a tour of preschool by a Keystone AEA consultant, but then shortly after Child (1a) became ill so they kept her home due to health issues. Child (1a) remained under early intervention services through Keystone AEA until the age of 5. The Keystone AEA teacher talked to Parent (4) about preschool services, but they did not send her. In addition to illness, Parent (4) continued to explain reasons for keeping her child home to include, limited time, and inadequate staff to children ratios, and other children's behaviors in dealing with germs. Child (4d) was switched to homebound instruction provided by DCSD at the age of 3.

Transition to school-based programming. Typically, children begin school-based programming at the age of 5 years old. In the DCSD, kindergarten is a full day five-day a week program with various special education programs available. Child (2b) and (3c) followed this timeline and began kindergarten at the age of 5. Parent (2) made the decision to send her daughter to school with the help of her husband, family, and physicians. All of these members felt school would be important for her once her medical condition was under control. Parent (2) explained that the school program helped maintain her Child (2b)'s mobility, and become more social and involved in the community. Parent (2) stated, *I really credit the school system a lot for her being as social and well functioning as she is now.* Parent (3) chose to have Child (3c) continue to attend only ½ days most of the year. However, she stayed longer days a few days per week at the end of the school year. Parent (3) attended the first 2 days of kindergarten with her child to help alleviate her fears. She reported being used to her previous classroom with her special needs friends, and in kindergarten she also had a regular classroom that she attended. As her teacher, I remember carrying my cell phone after she

left her at school. Parent (3) would have full access to updates on her daughter whenever she wanted to call, and she did call, often. This continues to be an available form of communication for Parent (3) even as Child (3c) enters 2nd grade in the fall. In addition, Parent (3) shared that her daughter really enjoys going to school making it an easier decision as well as the fact that she is learning. Parent (3) shared that her daughter now attends school for a full day, but it was really hard not having her at home. Parent (3) explained, *She is learning to do her switch and play the computer. You know. She is just. Gotten. She has grown up.* Parent (5) described keeping Child (5e) out of school until age 6 to build up his immune suppression after his lung transplant. She reported his transition to school to be completely normal, but she did talk to his new teacher each year. Parent (1) said that Child (1a) began homebound instruction from the DCSD at age 5. At that time, school-based programming was discussed with the director of special education, but they opted to keep her at home and secluded from other children. Occasionally, the homebound teacher would suggest school stating that when they were ready to let her know. However, they never felt pressured to send her to school. Parent (1) shared, *It was just really important for us to know that you know her health was most important. When her health was where we thought she was safe then we could send her to school.* Parent (1) shared that the doctor always supported their decision, but that it was their decision. At the time of this study, 4 out of 5 children had attended school-based programming. Child (1a) began school just this last year. What seemed to have changed their decision was the combination of Child (1a)'s health and a visit to see the educational program that she would attend. For the transition, Parent (1) came to school with Child (1a) for 2 hours each day until she worked up to half days and eventually full

days after 2 months. In addition, Child (1a) had a health plan and an IEP, which addressed precautions as she transitioned to school. Parent (1) insisted that she not participate in school assemblies and limit her time with other children. As her teacher, we also had an area just for Child (1a) with materials specifically for her, and we practiced extreme hand washing procedures with her. Initially, two 2nd grade peers came to read to Child (1a) daily, and they were monitored for hand washing as well as showing any symptoms of illness. Eventually, she started attending her general education 2nd grade classroom for 30-40 minutes per day while monitoring her health. As Child (1a) tolerated these activities more activities were added within her day to include, art, music and PE

Homebound instruction. Three out of 5 children received homebound instruction. Parent (1) shared that early intervention service transitioned to homebound when Child (1a) turned 5. The instructional time remained the same with the exception of a new teacher who was employed with the DCSD. Child (5e) had home nursing daily prior to school so that his mom could work. However, Parent (5) now works nights to accommodate for times when her son needs to stay home from school. In addition, Parent (5) took on the responsibility to complete make up work when Child (5e) missed school. It wasn't until this past school year that homebound instruction began. She reported that it was the school principal who arranged homebound instruction after her son began to miss more school. Parent (5) shared that the tutor for homebound instruction came in daily for an hour to an hour and a half until he was caught up on his schoolwork. Then she decreased her time to 3 days per week to maintain his place in his studies. Prior to the homebound tutor, Parent (5) was very frustrated by the amount of homework that

he was required to complete from the teachers. As a result, a 504 plan was written to address the accommodation for less homework while he does not attend school. Parent (5) shared, *It gives him no extracurricular activities, no shower time. It gives him no lets go shopping time. So that was our biggest problem. That is why the 504 came in.* Parent (4) reported that homebound instruction started when her daughter turned 3 years. She said she was happy with this service for the most part. Parent (4) stated, *They just basically talked to me and I was the one who did everything with her.*

Parents' overall perceptions. Parent (1) shared that doctors wanted Child (1a) to be mobile to improve her health, but at home that was on the floor. At school, she was stimulated in many ways that Parent (1) felt it made a tremendous difference in her child. Parent (1) shared, *You can even tell in her disposition that she misses it on her days off. She doesn't get the same stimulation then she does at school...it helps her I think with her health.* Parent (2) believed it beneficial for her daughter to be with other children with similar disabilities as well as children without disabilities. She shared that her daughter was able to experience so much more by attending school. Child (2b) increased her skills, as well as her confidence and courage by belonging to a group. Parent (2) shared that she trusted the people caring for Child (2b), and she was confident in them. Parent (3) reported that school helps Child (3c) to learn, but at home, she doesn't push her. Parent (3) didn't have any concerns to share and believed all kids should try school. Parent (4) explained that some children may benefit from school. However, she doesn't believe school could benefit Child (4d) in her development more than at home. Parent (4) has felt pressured by Keystone AEA and school staff to send Child (4d) to school, and Parent (4) wanted school to respect their decision to keep Child (4d) at home. Parent (5) stated

that the benefits of school are individual, and parents need to make the decision. She shared that if Child (5e) were any other child, her decisions might be different. Child (5e) never gets mad at her decision to send him or keep him at home. Parent (5) reported that Child (5e) doesn't want to be sick either. Parent (5) shared, *He is the one sometimes that says, (may be I shouldn't go then.) You know, he doesn't want to be sick. He will say, (I want to live. I want to be here.) You know it breaks your heart .*

The Parents interviewed all had different experiences with their children that led to the decisions they made regarding their educational program. All parents valued the health of their child above education, however, they all indicated benefits of education. This case study will contribute to the further discussion in Chapter 3 and 4 of this study.

Pediatrician Surveys

Two local pediatricians returned surveys regarding the education of children who are medically fragile. Specifically, the decision-making roles to send children to school-based programming were addressed, as well as the benefits and concerns.

Both pediatricians shared that parents decide whether to send children who are medically fragile to school. Their role in the decision is to advise and consult on the medical condition of the child attending school. However, the parents are the primary decision-makers. Pediatrician (2) doesn't recall having a difference in opinion with parents, but Pediatrician (1) shared that he would *talk, talk, talk about differences, work toward a compromise or try something for a while, modify as needed, be flexible.*

In the surveys, the pediatricians reported that children who are medically fragile and/or who are disabled benefit socially and educationally from attending school. Pediatrician (1) also shared that when children attend school, the parents may benefit

from having a break or rest. However, both pediatricians were concerned with the high cost to schools when providing education in the school. Pediatrician (1) is also concerned that medical needs continue while at school. Both Pediatricians shared another concern of sending children who are medically fragile to school to include exposure to and potential for infections. In addition, Pediatrician (2) was concerned about the children's safety from teasing and belittling, as well as accessible facilities.

When asked about the role of school in the education and caring for children, who are medically fragile, Pediatrician (1) shared that school should *maximize educational experience, help with socialization, and maximize health needs*. Pediatrician (1) also asked whether educators were adequately trained for children who are medically fragile. Pediatrician (2) also reported schools *should appropriately teach/challenge*. However, he indicated that the school should *provide (within reasonable cost) a learning environment that does not threaten/worsen the child's medical condition*.

In the conclusion of the survey, Pediatrician (1) suggested a possible transition option for parents considering school. He suggested that the parents transition by attending school with their children and gradually fade their time to ½ days or every other day.

This information from the two returned surveys will also help with the discussions including in Chapter 3 and 4 of this study.

CHAPTER 3

REVIEW OF THE LITERATURE

Educational Decisions for Children who are Medically Fragile

There are a variety of educational options for children who have disabilities and/or are medically fragile. Within the law, the Least Restrictive Environment (LRE) was intended to provide educational settings on an individual basis to maximize the development of a child with a disability (Martin, 1997). Students may receive homebound or hospital instruction, residential or separate school instruction. There is also the option of school-based programming within self-contained instruction, self-contained with integration within the general education classroom, or full-inclusion within the general education classroom (Hobbs & Westling, 1998). "...The IDEA requires school districts to have a continuum of alternative placements available" (Yell, 1998, p. 71). The laws state that children with a disability receive services from birth to the age of 21, which are led by their Individualized Family Service Plan (IFSP), from birth to three years of age. Sometimes children as old as five years of age are included in the IFSP. The transition from IFSP to the Individual Education Plan (IEP) occurs at three years of age or sometimes five years of age until children are twenty-one years of age. "Participation in the public schools by children who are medically fragile and dependent on medical technology is also supported by Section 504 of the Rehabilitation Act of 1973" (Parette et al. 1994, p. 63). When a child is medically fragile the federal laws govern that each state provide services.

Within the case study, parents within the same community did not share similar experiences when faced with similar decisions. Some parents had the support of

Keystone AEA and/or the Dubuque Community School District professionals when making decisions but others utilized pediatricians and family members. Parents also reported having very little support or too much *pushing* regarding their decisions for educational placements. The pediatricians report that the ultimate decision falls on the parents. Consequently, unique experiences have led parents to their decisions for education. Parent (5) stated, *So, I think, they need to go with their gut instincts. They know their child better than anyone else.*

Although parent experiences and support was varied, the literature revealed that the multidisciplinary team should be utilized in the process of making educational decisions for children with specialized health care needs. It is essential that medical and educational professionals work together with the families, to ensure the best possible educational decisions are made (Levine, 1996). Given the benefits and negative effects of school-based programming, "...families may elect other educational settings" (p. 28).

Benefits of School-based Programming

School-based programming can be the most *natural* way for children to receive their education. "Given appropriate support, attending school can be particularly beneficial to children with chronic health conditions" (Mukherjee, Lightfoot & Sloper, 2000, p. 60). The study conducted by Rehm and Rohr (2002) indicated the benefits of attending school fell into three categories including, "education and skill attainment, socialization, and providing respite care for families" (p. 348). In addition, Parent (1) also felt that the stimulation and educational experiences Child (1a) received may have implications for improving her health. Quality experiences also seemed to be a

reoccurring theme within the case study parent interviews. Parent (1), (2), and (3) shared school experiences that have made a positive impact on their children (Appendix B).

“The companionship, stimulation, and adventure of going to school are particularly valuable to children who are medically fragile or technology dependent” (Wadsworth, Knight, & Balsler, 1993, p. 103-104). Students who were able to communicate thoughts regarding their chronic illness were interviewed in a study by Mukherjee et al. (2000). It revealed that they “...valued both academic and social life in school” (p.63). Using the case study interviews, Parent (5) reports,

He deserves the right to have dreams to grow up to be what he wants to be. And I am not ever going to take that right from him. So, he has dreams and if I pull him out of school and don't give him the education that he deserves, then he won't be able to fulfill his dreams. And what if that miracle does happen? ...No matter how sick he is he wants to talk to his friends. So. You know. Family is one thing but to have that social interaction is really important for his health. It gives him goals.

Pediatricians surveyed agreed that school could provide appropriate educational experiences with the benefit of social interaction with peers. Parent (2) shared that while her daughter was included with kids with and without disabilities, Child (2b) had a sense of belonging to a group. She also was able to learn social and cognitive skills through experiences, which *are things that she wouldn't otherwise have been apart of*. Parent (3) indicated she wouldn't have expected her Child (3c) to be able to learn what she has from attending school. She also shared that she was able to implement some of the instruction at home after observing Child (3c) at school. As the case study interviews suggest, there is limited instructional time when delivered within the home. Consequently, parents in a study by Lovett & Haring (2003) offered another advantage of school-based programming even at the preschool level to include the increased number of school hours their child would receive compared to earlier services. Parent (1) also identified the

benefits her daughter received by attending school more hours than she previously received.

“Parents want quality programs with high levels of service for their children” (Hobbs & Westlig, 1998, p. 12). The interview with Parent (2) indicated that having a child who is medically fragile is complicated and it is difficult to trust in the educational program. However, her experiences with staff, including teachers and nurses, within the educational environment have allowed her to become confident in the persons who care for her Child (2b). The teacher’s ability to implement additional support to an individual child within the classroom impacts the perception of others on accepting all children (Jones & Rapport, 1997). “Within the school context, teachers are a major sources of support for young people. Therefore, it is important that teachers feel well equipped to respond to the specific needs of this group of pupils” (Mukherjee et al., 2000, p. 60).

In addition to the educational and social benefits of attending school, Rehm and Rohr (2002) suggest it gives parents a break from the care their children require. Using the case study, the Pediatrician (1) also indicated that a benefit of school is the rest parents may receive. He added that school can help to *maximize health needs*. The parents within the case study also indicated that attendance has impacted their schedules. Parent (3) shared, *I have time for myself*. And Parent (5) shared that she had to switch her work schedule to accommodate for times when her son is not in school. The study by Rehm and Rohr (2002) explained that parents often arranged for one parent to be available to care for the child during the day. If a child attended school, it would offer the opportunity for parents to work or be free during those hours.

Negative Effects of School-based Programming

Although children who are medically fragile are eligible for school-based services, some parents choose homebound or home/hospital instruction. Lovett and Haring (2003) indicated that sending children to preschool center based programming is a major transition for parents. The decision-making process can become difficult to cope with especially when in conjunction with placement options for children who have a disability (Lovett & Haring, 2003). The research indicated three main reasons or risks associated with sending a child who is medically fragile to school-based programming.

The major risk noted by parents and educators in sending a child who is medically fragile to school-based programming is "...the increased susceptibility to infection" (Rehm, 2002, p. 79). Within the case study 4 out of 5 parents interviewed indicated at one point or another that germs and illness was a concern with sending their child to school. Parent (4) shared, *...between her doctor and myself and the fact that she would only be able to attend a short period of time, we just don't feel the benefits outweigh the risks.* (See additional information gathered within the transcripts in Appendix B) In addition, Parent (1) and (5) requested that school professionals inform them of school illnesses in order to make decisions to send their child to school on an on-going basis. Rehm (2002), shared that this strategy has varied success, if ongoing communication cannot be established to relieve fear of illness within the school and classroom. Then when parents were met with resistance from teachers, and teachers had difficulty adequately monitoring children for potential problems, "parents sometimes removed them from school during cold and flu season, usually the winter"(Rehm, 2002, p. 79). Parent (4) shared, *We value her being healthy more than her education. We live with the fact that*

one pneumonia could be... that's it! The case study pediatricians also shared this concern for children with immune suppression.

Absenteeism became the second reason for negative effects for attending school. Absenteeism affects the success and failure of students who are medically fragile. Colds are reported as the main reason for absenteeism within this group. When students fall behind academically due to illness, they are faced with catching up instead of keeping up. This contributed to poor academic performance and a decrease in liking school (Thies, 1999). However, missing school does not only affect academic performance but social interactions. After her son missed school for the entire winter Parent (5) reported,

...he doesn't realize that when he goes back to school, it doesn't pick up where he left off. Your friends have moved on, things have happened in school that you have no clue about. So probably the first 2 weeks are really hard for him. But then once he got back in with his friends and with the groove with what is going on, then it became fun again. Even though they talk on the phone and stuff like that, things happen in school that you're not apart of. ...So it was hard for him but he bounces back so quickly. Within 2 weeks, he couldn't wait to go to school again..

The third reason, in addition to illness and absenteeism, quality-of-care standards were questioned when performed by non-health care professionals in school settings (Rehm, 2002). Teachers do not typically receive the adequate preparation to meet the needs of students who are medically fragile (Parette et al., 1994). In a study by MrCarthy, Williams, & Eidahl (1996) educators reported the major concerns when teaching children with chronic conditions is the fear of medical emergencies. Within the case study, Pediatrician (1) shared his concern of lack of adequate training. The cost to the school district was a concern shared by both Pediatrician (1) and (2) when providing school-based programming (Further information found in Appendix D).

“...educators, physicians, and school nurses often do not discuss the impact of children’s health conditions on their ability to learn” (Thies, 1999, p.392) Therefore, there is an unequal integration between academic or educational goals and health needs. Becoming aware of these risks from the beginning can promote better decision-making for educational plans for children who are medically fragile.

CHAPTER 4

GUIDELINES AND STRATEGIES FOR EDUCATING CHILDREN WHO ARE MEDICALLY FRAGILE IN SCHOOL-BASED PROGRAMMING

Educational decisions for children who are medically fragile are unique to each family. In order for parents to make informed decisions to send their child to school-based programming, a set of guidelines is necessary. The following guidelines will aid parents and professionals in educating children with complex medical needs in school-based programming.

1. Communication between professionals and parents is essential to provide the best learning situation for all children.

“Teachers with good communication skills enhance collaboration through relaying and receiving information from a variety of sources supporting the child and the educational program” (Jones & Rapport, 1997, p. 26). Once a child begins an educational service, it is important to set up clear methods of communicating in order to meet the ongoing needs of the child. Parents become the main source of medical and health related information regarding their child (Rehm, 2002). Especially, when children are non-verbal it is important to have a communication between caregivers and parents (Durham, 2000). For example, a clipboard (Dunham, 2000), or other communication devices could aid in the ongoing communication to enhance the school experience. The case study indicated that phones can bring instant access to the parent and teacher, which also provides ongoing communication. The more complete the information is from parents “the better care and education the school can provide” (Wadsworth et al., 1993, p.103).

2. Transitions to the next education setting need to be anticipated, explained and facilitated.

“Communication is particularly important in facilitating a smooth transition to the next educational setting” (Jones & Rapport, 1997, p. 26). Parents need clear explanations and guidelines for their educational options. A partnership between medical professionals, and Keystone AEA and Public school professionals becomes essential. In addition, children requiring hospitalization need a plan for transitioning from the medical setting (Parette et al., 1994). Parents’ perspectives need to be validated by educators when they enter school (Lynch et al., 1993), especially during each educational transition.

Generally, early intervention services and homebound instruction were limited to a few hours a week, and parents were present during the instruction. Parental fears become much more present with the discussion of preschool and school-based programming when the child would actually leave the home (Rehm, 2002). Advanced communication of the next educational option may alleviate concerns of parents. “There is a year of preparation that goes into a child entering the classroom as a rule” (Rehm, 2002, p.77). Parents should be a part of this preparation and should be allowed to have “parent protective strategies” (Rehm, 2002, p. 79). These strategies offer additional preparation when transitioning to the next educational setting. Rehm (2002) suggested parents meet both formally and informally with the appropriate people, observe the setting, and even ride the bus with their child. The case studies also revealed strategies to include: attending with their child until they are confident in the placement, gradually increasing the amount of time the student attends, and make some limitations and

compromises until all parties are comfortable with activities involving the child. “Parents and professionals need to be cognizant of the nature of transition as a process rather than a product in order to adapt each transition to the specific needs of the child” (Lillie & Vakil, 2002, p. 54).

3. Develop integration of health care and education so that each child can achieve his or her potential.

Care coordination allows families’ access to public and private support for their child who is medically fragile. “Generally, the goals of care coordination are the following: 1) gain access to and integrate services and resources, 2) link service systems with family, 3) avoid duplication and unnecessary cost, and 4) advocate for improved individual outcomes” (AAPediatrics, 1999, p. 981). American Academy of Pediatrics (1999) suggested that the most beneficial care coordination result when the family assumes the leadership role. However, professionals support the families when they work together in the planning for the child, especially in the area of anticipated emergency problems. Working collaboratively with parents and medical professionals, schools need to think creatively in order to integrate the educational and health needs of students (Thies, 1999).

Rehm (2002) reported that parents felt much more comfortable in sending their child to school when they had an advocate they could count on such as a teacher, administrator or school nurse. This person can be instrumental in supporting the parents and assisting with the development of the IEP, 504, and/or Individual Health Care Plan. When children receive school-based programming it may be important to include the option for homebound instruction within the IEP (Rehm, 2002) or 504; this action reassures parents

that supports are in place. It becomes an appropriate back up plan when school-based instruction falls short of their expectations or when the concern of illness weighs too heavily on their decision to continue to send them to school.

When coordinating education and health, discussing scheduling of specialized health care needs and accommodations can be included in the development of the child's plan. Black (1994) suggests that scheduling of routine health care with limited disruptions from educational activities is optimal for instruction. Using the case study, the Pediatricians shared that school should maximize the health needs as well as provide educational and social experiences. Parent (5) indicated that the 504 plan was instrumental in making accommodations for her son. One potential problem may be the need to provide parents with notice of illness within the school and classroom (Rehm, 2002). The development of the plan, and specific needs of the child should be addressed with ongoing communication to modify as needed.

4. Providing adequate medical support is needed.

“Inclusion in safe school environments that facilitate effective learning can be accomplished with appropriate health-related service delivery that is provided through the careful planning” (Parette et al., 1994, p. 64). The team can discuss the varied medical needs required for school-based programming. From the time the child leaves for school and returns home, specific needs should be determined on an individual basis.

...the team members must collaboratively address the following planning issues related to each setting: (a) services needed, (b) personnel involved, (c) training of personnel, (d) equipment needs, (e) potential problems and emergencies, (f) emergency plans for personnel, (g) backup plans during staff absences, and (h) plans for contacting emergency personnel. (Parette et al., 1994, p. 67)

The health care plan documents these specialized health care needs within school-based programming (Parette et al., 1994). Nurses were able to train staff and supervise staff in procedures to be administered while at school such as, g-tube feedings, nebulizers and tracheostomy care (Rehm, 2002). In turn, the educational system needs to prioritize health care professionals in the schools as well as establish criteria for training other educators including paraprofessionals and teachers (Krier, 1993).

4. Problem-solving planning is needed to avoid medical problems and to help the children to learn most affectively.

Professionals and parents need to work together to identify possible educational concerns in order to develop solutions. Hobbs & Westling (1998) describe collaborative problem-solving (CPS) as one-way to effectively work together with professionals. The problem-solving process included the following 5 steps. "They are: (a) defining the problem, (b) assessing possible antecedents or "causes," (c) setting goals or objectives, (d) carrying out actions or interventions, and (e) evaluating success" (p. 16). This strategy can be used in the implementation of health care needs of the children included in school-based programming, as well as evaluating the outcome. Parents and professionals could then document the successful and unsuccessful strategies.

CHAPTER 5

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary

The purpose of this study was to examine the education of children who are medically fragile and to present guidelines for school-based programming. The paper addressed four questions to accomplish this purpose:

1. How were children who were medically fragile educated in the past?

Prior to the 1970's, educational options were limited for parents, and many children with disabilities were institutionalized and/or placed in residential schools. In 1975, Congress passed Public Law 94-142 requiring that all children with disabilities receive free and appropriate education. This contributed to the education of children with disabilities some of whom also have medical conditions. However, "advances in medical treatments" has led to increased survival of children who are medically fragile and has contributed to their capabilities of attending school" (Rehm & Rohr, 2002, p. 345). Therefore, in 1999, Cedar Rapids Community School District v. Garret F. (Katsiyannis & Yell, 2000) ruling requires school districts to provide *related health services* in order for a child to benefit from special education. Currently, federal law mandates that each state provides services but the services vary from state to state (Parette et al. 1994).

"Participation in the public schools by children who are medically fragile and dependent on medical technology is also supported by Section 504 of the Rehabilitation Act of 1973", p. 63). When a child is medically fragile the federal laws govern that each state provide services.

2. What are the benefits of sending students who are medically fragile to school?

Attending school-based programming has several benefits for children who are medically fragile. As Rehm and Rohr (2002) suggested there are educational and social benefits of attending school, as well as providing respite to the family. Pediatrician (1) and Parent (3) also implied the break school could give. Parent (1), (2), and (3) also shared that their children have had more opportunities to experience things while at school as opposed to being at home. Parent (1) suggested that the increased amount of stimulation and activity has made a tremendous difference in Child (1a) that may improve her health.

3. What are the negative effects of sending students who are medically fragile to school?

Using the case study interview, parents all value their children's health over their education. The exposure to illness and germs is the greatest negative effect of school attendance because it may compromise the health of a child who is medically fragile. Consequently, absenteeism is common with children who are medically fragile resulting in decrease in academic studies and social relationships (Thies, 1999). As Rehm (2002) study found that quality-of-care with adequate training could become a concern impacting negatively on the school setting. Pediatricians within the case study were also concerned with the cost of providing service to children who are medically fragile in school.

4. What guidelines need to be developed for children who are medically fragile to be included in school?

Guidelines are necessary when attempting to educate children who are medically fragile in a school-based program. Building communication between professionals and parents becomes the first step. As Wadsworth et al. (1993) explained, school is able to provide a better education to children when parents are thorough with the information they share. In addition, Dunham (2000) reported that communication should be clear and ongoing. The communication method may vary to meet the necessity of the information to enhance education. Next, communication can be used to transition to the next educational setting. Educators should value the parent perspective and offer strategies to assist with each transition (Rehm, 2002). As Lillie and Vakil (2002) stated parents and professionals need to view “transitions as a process rather than a product” (p. 54). The third and fourth steps include coordinating health needs and education as well as providing adequate medical support. Parette et al. (1994) suggested that planning could contribute to the successful inclusion of children who are medically fragile in school. Care coordination, in addition to parents assuming the leadership role can access support needed for the individual (AAPediatrics, 1999). Proper training in care can lead to quality in health care delivery by educators under the supervision of nurses (Rehm, 2002). Lastly, problems may occur, and it is important that appropriate problem-solving strategies in place in order to deal with them (Hobbs & Westling, 1998).

Conclusions

The following conclusions were drawn from this study:

1. Children who are medically fragile are very unique.

2. Professionals should provide support and information to the parents.
3. Parents need to make informed educational decisions.
4. Educational decisions should be made carefully.
5. Educational transitions should support the family.
6. Benefits and concerns must be prioritized when sending a child who is medically fragile to school.
7. The success of school-based programming depends on the communication between parents, medical professionals and educational professionals.

Recommendations

Based on the review of the literature and the case study, the following recommendations are suggested:

1. Supports need to be developed to assist parents in decision-making.
2. Adequate training of school personnel should be required and provided.
3. Education professionals and medical professionals need to work collaboratively with parents.
4. Educational options should be more clearly regulated at both state and federal levels and information should be provided to parents.
5. Further research is needed to understand the complex issues with sending children who are medically fragile to school.

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APPENDIX A
PARENT INTERVIEW QUESTIONS

Parent Interview Questions

1. Describe your child. Age.
2. Describe health concerns that apply to your child.
 - a. Suctioning b. reflux c. Trachea
 - e. Motor (tone) f. vision g. hearing
 - h. Seizures types: frequency:
 - i. Scoliosis Orthotics: body jacket, Afo's
 - j. Breathing concerns
 - k. Uses vest percussion treatments Other treatments
 - l. Primary nutrition
 - Foods; Oral regular, blended, fork mashed, formula
 - Drinks; regular, thickened liquids
 - Tube Feeding G-tube: J-Tube: How often:
 - n. Pneumonia/illness Rate
 - Rarely Occasionally Frequently
 - o. Primary Mobility
 - independently walks walker wheelchair
 - p. Primary communication
 - Verbal words, sign, behavior, affect (smile, cry)
3. How would you rate your willingness to send your child to school setting.
 - 1-totally against school
 - 2-on the fence regarding school
 - 3-advocate for school
4. Did someone talk to you about educational options for your child? How old was your child? If so, who and what did they say?
5. Did or does your child receive early intervention (birth-3 years) services through Keystone AEA? How often did/does your child receive services? Explain how you began receiving these services.
6. Were you happy with the Early intervention services? What were the strengths and areas of concern about the service? Explain.
7. Did or does your child attend Preschool or Early childhood (3-5 years) programming through Dubuque Community Schools or another district? How often did/does your child attend? Explain how you began receiving this programming.
8. Were you happy with the Preschool or Early childhood program? What were the strengths and areas of concern about the service? Explain.

9. Does your child attend School (5-21 years) programming through Dubuque Community Schools or another district? How often does your child attend? Explain how you began receiving this programming.
10. Were you happy with School program? What were the strengths and areas of concern about the service? Explain.
11. If you chose **not** to enroll your child in any of these services will you please explain why you made your decisions? Who and what influenced your decision?
12. If you chose to keep your child at home past the age of 3 years old, did/do you allow homebound instruction? If no, why? If yes, explain the amount of instruction.
13. What do you feel are benefits for a child who is medically fragile to receive an education? Explain.
14. What do you feel are benefits for a child who is medically fragile to receive an education in the school setting in preschool(3-5) and school aged(5-up)? Explain.
15. What are the problems or concerns of sending a student who is medically fragile to school based instruction (out of the home)?
16. If you chose to keep your child at home, how will his/her growth and development be facilitated?
17. If you chose to keep your child at home, what could be done to help you send your child to school? Explain.
18. If you send your child to school, what helped you with the decision to send him/her to school? Explain.

APPENDIX B
PARENT INTERVIEW TRANSCRIPTS

Transcribed Parent Interviews

The following are transcripts of audiotaped interviews with parents of children who are medically fragile. The statements are taken verbatim as they shared information on the following questions. To protect the identity of each parent and child, each parent will be labeled as Parent 1, 2, 3, etc. with the abbreviation of P1, P2, P3 and each of their children will be labeled, child 1a, 2b, 3c. As the interviewer, I will be abbreviated as I for interviewer.

Interview #1 (5-31-06)

I: Your name is Parent 1. We will be discussing your daughter, child 1a. Overall, please describe your child and how old she is.

P1: She is 8 years old. She is unable to sit, walk, or crawl yet. She is very alert most all most, all of the time. Um.

I: Ok, number three is talking about health concerns. If you could just tell me which health concerns apply to Child 1a.

P1: Child 1a has reflux. She has tone issues. Is visually impaired, hearing impaired. She has multiple types of seizures. She has a seizure or multiple seizures several times a day. Some in length of seconds some in length of several minutes. She on occasion needs to be suctioned; it's been a very long time. She has severe scoliosis. She wears a body jacket several hours throughout the day, mostly when she is at school or traveling. She has what the doctors call chronic lung disease that she uses vest percussion. She uses that twice a day for 30 minutes at 3 different settings. She has tracheal malacia, which you may not know. Tracheal malacia is when the trachea isn't developed at birth and the top of it was collapsed, but obviously she has grown out of it, they said it is a matter of growth of her brain to tell her body to swallow and breath.

I: So that is why she didn't end up with a trachea?

P1: Right. Her nutrition is strictly g-tube, she uses 6 ounces of formula throughout the day. We give her small tastes on her lips on occasion depending on what it may be. Um. She started her g-tube when she was three. She also has a nissan fundoplication done at the same time I should say, which helps with reflux and vomiting. It helps tremendously because she hardly vomits now. If she vomits then we use the decompression tube and release her stomach. We've only had to do that, you know, minimal times. She is able to burp but doesn't burp because of the nissan. She is able to vomit but doesn't only on rare occasions. Which is wonderful because she used to puke her breakfast at suppertime and she did it all of the time. She has a soft pallet which means she pukes and it comes out her nose. It is not pleasant for her.

I: Right.

P1: Her pneumonia rate has gotten tremendously better. It used to be that we were in the hospital frequently for very long lengths of time because of it. The doctors thought that she would aspirate and that would cause her pneumonia, but she has been you know considerably healthy.

I: When was the last time would you say that she has been in the hospital?

P1: Two years ago, two years ago in April. Her primary mobility is by wheelchair or by carrying. Her communication is by smiling, crying, her affect, her verbalizations. She has specific verbalizations for what she wants. It's just a matter of getting to know what they are.

I: Ok, we're gonna to go to 3b. And how would you rate your willingness to send your child to school? 1-being totally against school, 2-being on the fence, and 3-completely for school.

P1: We were totally against sending her to school for health issues.

I: For how long?

P1: We looking into the preschool program when she was 3 and it was shortly there after that she became ill and was in the hospital. You know. So we totally through out the idea of sending her to school.

I: With that being said, we will just move on because that is all I needed from you for that one. Number 4, is did someone talk to you about educational options for your child? How old was your child? If so, who and what did they say? And I am going to go specifically into early intervention, preschool where you can be more specific with the questions but just general statement, did someone talk to you about educational options and who were those people.

P1: No, nobody did. We pressed the issue ourselves eventually when she was 6 months old.

I: Number 5, did your child receive early intervention services through Keystone? How often if she did receive services?

P1: She received services from the time she was 6 months old until the time she was actually 5.

I: How often did she?

P1: She received services from her early educational teacher once a week and she received her hearing services twice a month, and then she would receive her vision services periodically once every 3 months.

I: And did this schedule kinda stay the same from 6 months to 5 years?

P1: Yes.

I: Number 6 is were you happy with the early intervention services? What were the strengths and areas of concern about the services?

P1: They did stay the same. We were happy with them yes, but I also thought that they could've pushed her a little bit more. She likes to con people. So when she wanted to take a break they automatically gave her a break which she figured that our and took advantage of it. So she would take a break and sleep quite a bit of the time. She also got physically therapy.

I: Number 7 did your child receive preschool services? This would be outside of the home programming through Dubuque Community Schools or another district and how often did she attend?

P1: She did not receive the preschool through Dubuque Community Schools. We stayed with early intervention services and Keystone due to her health. She remained on the once a week for educational teacher, twice a month for hearing, once every 3 months for vision until she was 8.

I: Ok, did someone talk to you about preschool?

P1: Yes. The consultant at Keystone gave us a tour at Eisenhower and then she became ill shortly there after we went through the program to see what it was like and we chose to keep her at home due to her health issues. She had pneumonia two times and was in the hospital for long periods of time.

I: And did the teacher or anyone change when you switched to preschool services.

P1: No, we stayed with the same teacher from 6 months to 5 years. Then at 5 years when she started kindergarten age based program then she was switched teachers.

I: So that goes to number 9, so when she was 5 did she attend school based programming which would have been kindergarten?

P1: The teacher changed but she did not attend school.

I: Did someone talk to you about coming to school-based programming at the age of five?

P1: We did discuss coming to the school based programming but again with her health issues we felt that it was best to keep her home, to keep her more secluded from children that were not necessarily germ carriers but that she could possibly become infected from. We had a meeting with the director of special education from the schools to get this okayed, and we had a teacher from the district come to the house twice a week to do services for her.

I: So at the age of 5 it changed to two times a week from one time a week.

P1: Yes.

I: Did anything else with services change?

P1: No, everything else remained the same. Hearing was twice a month and vision once every 3 months.

I: And continued with private physical therapy?

P1: Yes.

I: We are going to continue to number 11 but I want to ask one question. How often do you think between the ages of 5 and 8 did anyone bring up coming to school?

P1: Child 1a's teacher would say when we're ready she would help us get things going for us but she left it up to us. She didn't push the issue just because she knew how we felt. You know not wanting to send her until the time was right. It was just really important for us to know that you know her health was most important. When her health was where we thought she was safe then we could send her to school.

I: Ok, so she may have mentioned that at IEP meetings every year.

P1: Yeah, right.

I: But no one else other than the teacher ever mentioned anything to you?

P1: No.

I: All right, we are going to go to number 11. If you did not choose to enroll your child in any of these services and you already have but I am going to ask you to repeat yourself and what or who influenced your decision to keep her at home?

P1: We chose to keep Child 1a at home until age 8. Actually we were still keeping her at home until we came to school to see check into the MOVE

program and to see what more available for her to be more functional and be more upright more often. Once we were there and we had a pleasant visit and we saw the MOVE program and discussed it. She was 8 and she was very healthy and we thought we would try it out.

I: Ok, prior to that, um, your primary reason you said to keep her was her health. Did anyone else influence your decision, pediatrician, or was it primarily your decision?

P1: It was our decision. We just needed the backing of the pediatrician. He didn't feel at the time with germs and everything that she was appropriate for her to be in school. But if we wanted to send her he would go along with it as long as it was only the non-flu season. You know, I had a feeling about the age of 7 to send her, no 6, and he wrote an order for her to come to school but only non-flu season and then she got pneumonia.

I: Did you talk to anyone else at age 6 about her coming to school?

P1: It was mostly with the doctor. We were just feeling him out to see what he thought about sending her. We were there just about every week for one reason or another. And he said if we felt comfortable sending her he would. And at that point I probably mentioned it to her teacher but she never once pushed us to send her. It was our decision.

I: Ok. Number 12 you've already explained. You did allow home bound instruction and that was twice a week. And number 13, what do you feel are the benefits for her to receive education? This can be for both settings too. Number 13 is for and education and 14 is for the school setting.

P1: Tough one. I think it is important that Child 1a that she is medically fragile that she receive an education so that she can be upright more often then when she is at home. At home the doctors wanted her to be mobile because of her poor lung function. So for her to be mobile at home was on the floor. She was active on the floor where as when she was sitting up she would be sleeping. So at school, she is upright. She is having stimulation, constant stimulation. Total difference in the activities.

I: Ok, do you see a difference in the education she received at homebound when the teacher would come in for 2 days a week?

P1: Tremendous difference, child 1a would just receive it twice a week for only an hour session each and again she knows how to con people so if she needed a nap she would take a nap, and when she wanted to take a break she took a break. Where as with school, she has so much more constant stimulation and work not necessarily therapy but hands on with her and I see a tremendous difference in her. I think that she has just benefited so much more from being her at school.

I: Ok, we will go on to number 15, what do you see are the problems or concerns of sending a student who is medically fragile to school meaning out of the home?

P1: I would have to say my constant worry and you know I worry about her bringing something home and getting something from school. I worry that things are not going to be just for her. You know, when she first started we knew that if she didn't have someone right there with her, she wasn't going to benefit from it. Her health, of course, is still number one. We worry that if she is sick if it is going to escalate and get that much worse. It may be just a sniffle but lead to pneumonia. But it is just the constant worry and not knowing if she is going to take a dive down.

I: You are kind of at an advantage because you see both but with number 16, when you choose to keep your child at home who will facilitate her growth and development?

P1: I do, her dad does. We are very careful with what we do with her and what she gets to do. We try to do the best for her and I know that here at school that is what they have done for her. It is very important for us that she gets what is right for her. She is getting way more services and stimulation here at school that she has in her whole entire life. And she loves it.

I: Ok 17 and 18 kind of go together, and you will be a go one because you've had to go through this whole transition. If you chose to keep your child at home, what could have been done to help you send your child to school and now that she is at school what things helped you to send her to school? Any thing that could have helped you with this decision?

P1: I think we would have thought about school earlier if her health would have been better. As far as school, I couldn't have asked for a better transition to school. You know we went from a day to just checking out the new program to, my gosh, we are sending her to school. It was a rapid change. I think if she had, you know, had a cold in there we may have second guessed it but it was important to us that when we sent her to school that we had the option of if she got sick that we could home school her again. Her health plan was all in place and that was very important to us for when she started. It was important that she was looked at and treated and cared for the same way we treated her at home.

I: And what was that?

P1: Um, I would have to say that her seizures where being watched and her health, you know, if she were to get a cough that we were alerted to it or if anyone else were to get sick in the classroom we were alerted to it. And that was very important to us and still is important to us. Any kind of recognition to us about what was going on in the classroom, to know that when her friends came into the

classroom that they were washing their hands and they were careful around her. But not to be treated or any of the kids to be treated differently. We insisted when she started school that she didn't participate in all school assemblies and was limited to just a few times to go into class to see how she tolerated it. She was only allowed in her gen. ed. class for approximately half hour forty-five minutes a day just for health issue because we wanted to see that she was being cared for in a way for her health. Everything with child 1a goes back to her health.

I: Number 10, again could you go back to concerns or strengths for school programming.

P1: We couldn't ask for anything better. She goes from constant stimulation with participation with the gen. ed. class to activities in just about anything. And she gets to take a break, if she feels tired, she can. To know that she is able to do that it is reassuring. It is just wonderful. Her participation in any of the programs is just great, art, music, everything is just great, wonderful.

I: And to go back to the transition to school. She started out with 2 hours a day to 5 hours per day until she started full day programming after 6 weeks.

P1: It is wonderful. She just loves it. You can actually tell in her disposition that she misses it one her days off. She wakes up with just a lot of energy but when she doesn't go to school she changes her whole routine for the day. She doesn't get the same stimulation than she does at school. At home it is more loving and cuddling but I think she gets plenty of that here too but its just that its different routine for the day. It helps her I think with her health and the constant stimulation to being upright more she is getting that much more developed. I'm becoming a little bit more reserved with pulling her out of school knowing that she is doing that much better.

Interview #2 (6-9-06)

I: If you'd just tell us your name.

P2: Parent 2

I: Could you describe your daughter for us?

P2: My daughter Child 2b is 12 years old. She just finished 6th grade at the middle school. She is a very delightful loving child. She is expressive with her eyes. She is non-verbal. She is very much a gift.

I: Ok and she is how old?

P2: 12.

I: Ok, we are going to go to number 3 and I know that Child 2b had some things when she was younger that she doesn't have now if you could just describe those things.

P2: Some of the things on this paper. She still has a lot of tone, muscle spasticity and tone. Um, does have periodic seizures. They are generally mild involving her arm extending out and her mouth quivers and she does have some color changes as well, but she generally comes out of them well and smiling usually. No real breathing concerns. When she was younger and just starting school she had more difficulty swallowing and eating as well as after her strokes when she was two she had difficulty emotionally adjusting to new things and people. She doesn't have that so much now.

I: She did have a feeding tube at home point in time?

P2: Yes, she did. She had a peg tube in her stomach that she received for about 1 ½ to 2 years because after her strokes she had to relearn the whole process of swallowing again. Her primary mobility is her wheelchair and she does require a blended and soft diet with regular liquids but requires total assist to eat. And all of her care. She is non-verbal and uses her behavior to communication. She also has a device with picture cards that we use. And we use high 5 for choices and she is very alert. But does a nice job of indicating what she likes and doesn't like.

I: If you would rate yourself on your willingness to send your child to school.

P2: Definitely a 3. I'm 100% advocate for the school system.

I: Ok, did someone talk to you about your education options for your child? If so, who and how old was she?

P2: Good question. Yes, Child 2b was about preschool age when she first started school and it was the social worker involved in her care and it might have been Iowa City Hospitals. Anyway, we did get her into preschool at Eisenhower not quite a full year of preschool. And she was there on up.

I: Did she receive home intervention, which would have been birth to 3 someone coming into your home to provide services before preschool?

P2: Most of the people at that time were private therapists and stuff. Physical therapists. Keystone did come in and evaluate her I believe, but she received all of her services like speech from outside agencies.

I: Ok, and how often did she receive these services?

P2: Back when she was diagnosed they came on a regular basis. Probably 2-3 times per week and gradually decreased over time.

I: Were her happy with those types of services?

P2: Yes. I would say the strengths well, speech did not help her with her ability to speak but it helped her relearn the ability to swallow and eat. Physically therapy was very helpful initially until she had another massive stroke and I think she would have probably been walking today if it hadn't been for that last stroke. But really, both services allowed us to care for her more easily.

I: Ok, she did attend preschool. It was a 4-day a week program?

P2: Yes it was and half day.

I: Were you happy with that program? Do you see any strengths or weaknesses?

P2: I was very happy with the program. It was a difficult time for child 2b, she had difficulty adapting to the new environment after surgery and stuff. So I was glad to get her into that environment but it was probably her hardest year of school. Preschool and kindergarten were for her adjustments.

I: Do you have any concerns or suggestions for preschool?

P2: I was very satisfied with it given the situations.

I: Ok, number 9 refers to her school years and she has always attended these?

P2: Correct. 5 days a week full day school.

I: Number 10, are there any strengths or concerns that you'd like to explain?

P2: I have all positive thoughts for the school program. They have helped to accomplish so many things with child 2b. Maintained her mobility, allowed her to be more social and adjust to more environments, you know, made things fun for her and involved her in the community. Um, really I credit the school system a lot for her being as social and well functioning as she is now.

I: When I look at number 11 and 12, it is talking about someone who has kept their child at home and that hasn't been the case here so we will just to number 13.

P2: Ok.

I: What do you feel has been a benefit of someone who has medical concerns to receive an education? If you could explain a little about that.

P2: Um, I think it is very beneficial for a child with special needs to be involved in a classroom setting with other kids with similar disabilities and with kids who do not have disabilities. Um, even if they are medically fragile and have needs that way, it does so much for their self-esteem and for child 2b it has just been an absolute blessing.

I: Number 14 is more specific on the schooling. Are there benefits you'd like to add?

P2: Preschool is a little harder to evaluate just because she wasn't there very long and some of the time she was even down at the hospital. But as far as kindergarten on up, that has all been beneficial for Child 2b as far as her eating, her social skills, computer skills, communication purposes, you know, emotionally it has given her confidence and courage, so she feels part of a group and it has allowed her to go out into the community as well, which are things that she wouldn't otherwise have been apart of.

I: Ok, number 15 addresses keeping your child at home. But just your perspective, do you feel there are some concerns with sending some children who are medically fragile to school?

P2: Um, I think that has to be kind of an individual decision. I think in the program that we have been in it is always hard when you have a child who is medically fragile to trust that their needs are going to be met in that environment but from what I have seen, um the staff that I've been involved with and the nurses in the schools I have always felt very comfortable with them handling Child 2b specifically. So I feel confident in those people. But for someone who has a child with other specific illnesses than Child 2b I was concerned after surgeries but at Eisenhower the staff did a marvelous job.

I: Number 16 and 17 address keeping someone at home so I think we can go to number 18.

I: Thinking back to all of those transitions in sending Child 2b to school are there things, people who talked to you who helped with the decision to send her to school?

P2: Yeah, myself, and husband, Child 2b's grandparents and the physician as well. I think everyone involved in her care at the time felt like it was important for her once we had her medical conditions under as much control as we could that it was an important thing for her to be apart of. To make friends to feel apart of a group and for her education as well.

I: Just trying to better understand what parents are going through to send their child to school are there things that would be helpful to a new parent?

P2: I think a parent contact and visiting school help your piece of mind. Seeing what the environment and talking to another parent would have helped me feel better too. Needing to know you can trust the people. Any communication would be helpful.

Interview #3 (6-14-06)

I: Parent 3

I: If you would describe your child.

P3: She is 7 years old. Smiles a lot and doesn't cry a lot. She likes to bite and hit. All around a pretty good girl.

I: If you can point out which medical issues apply to her

P3: Suctioning, tone is up and down, she can definitely see and hear very well, She got a small trachea, seizures which she hasn't had for 3 years.

I: But when she does have a seizure what does it look like?

P3: She has all kinds, from just her mouth twitching to grand mal, body shaking, Once she has one seizure she's not going to stop. They have to put her to sleep to stop. Scoliosis of the lower back but she seems to be doing ok, eventually she will have to have it treated and fixed but for now they are going to let it go and in August recheck her and see if she has gotten worse and they will fix it. Breathing at times she doesn't breath. She uses her vest, at nighttime is her worst time when she is sleeping she doesn't breath as well. She gets her vest 2 to 4 times per day and she loves the vest. She laughs and makes all sorts of funny noises with it. She gets pediasure now but she was on the ketogenic diet for seizures. She is tube fed up to 20 hours a day, she generally gets a 4 hour break but with food she can go longer. She can eat orally, she eats baby food. She doesn't get blended foods yet. She eats her stage 3 baby food twice a day. She has a j-tube and a g-tube and I give her 8 oz of water a day through her g-tube to see if it will help, she is constipated now. She isn't going to the bathroom enough so they want the water to go into her belly. So we are going to try that. They don't want to take it out so we will be stuck with two tubes. Her pneumonia occasionally, it is pretty much worse in the wintertime than in the summer time. She gets it about once or twice in a winter and maybe once in the summer but her vest takes care of that.

I: Has she been hospitalized for that?

P3: Not since '03. So, she has been doing very well with that and like I said it is the vest that has kept her out of the hospital. So she has been out of the hospital

for a little bit only to put her tube back in that she pulled out. She's in a wheelchair. That is her source of transportation cus' she can't walk. Her eyes and her smile and she sometimes cries for her communication but that isn't much only when she bites herself or she is really sick. I think her vision and her hearing are her main source of communication and her eyes. She watches everything you do.

I: The next is how you would rate your overall willingness to send her to school. 1 being totally against school, 2 on the fence and 3 advocate for school.

P3: Now, I guess a 3. I don't mind her going to school. In the beginning, I didn't. They had taken care of her for so long that I didn't have a chance to be her mom. I wouldn't have her home long and she would be back in the hospital. So, I had her home for about a month and they wanted her to go to school and that was hard. I wanted to be her mom and if she was in school I wasn't with her. But now it's not so bad. It gives me a little bit of a break and she enjoys school a lot. If it wasn't for all you guys she'd be home with me.

I: Number 4, did someone talk to you about the educational options for her to go to school and who was that?

P3: I think, Keystone AEA, teacher talked to me about school and she set it all up with school when she was 3. She went to preschool for half a day.

I: Did she receive early intervention birth to 3.

P3: Yes, she came twice a week for 1-2 hours. She would stay longer and play with child 3c she really enjoyed her and child 3c enjoyed seeing her. But at that time she was pretty sick and spent more time in the hospital than she did at home.

I: Did she receive any other services?

P3: PT and OT, PT first they came to the house because I didn't want to take her out. If she caught a cold she was back in the hospital. Even in the hospital they came to the hospital. She had music therapy in the hospital. That is why she likes music so much cus they would come play the guitar for her.

I: With the early intervention services, were you happy with them? Do you have strengths or concerns?

P3: No actually, they were very interesting. They taught me a little bit more about what to do and how to position her. She rolled everywhere! It helped me with her. She did sit in her bouncy seat and they brought in stuff for her. They did good with her.

I: She did attend preschool with the district, which was ½ day?

P3: Yes, she did.

I: With those services, how did you transition to those services? What was it like?

P3: Um, it was the teachers that helped a lot. But I did go to school with her for 3 weeks and stayed with her. Then one day my mom said she had a dentist appointment and that we would only be gone an hour but she lied to me. I was gone for like two. But you know child 3c was ok without me. I was a little nervous. I watched through the window and it took me 3 weeks to go home and leave her there. She was the only one in a wheelchair and the only one that wasn't mobile and she was a lot of care. She was one on one and there were so many kids that I was afraid. They all loved to play with her and entertain her and be right in her face, but she didn't complain.

I: Were you happy with preschool? Do you have any strengths or concerns?

P3: No, preschool actually did a lot for Child 3c. As far as focusing on what she needs to do like coloring. They did everything with her, so she got to experience cutting, and making pictures. She got really excited with finger-painting. Finger-painting was one of her biggest things there. So, she and I liked it.

I: Do you have any concerns?

P3: No, she had a great time in preschool. But she had a great teacher too so that helped.

I: She does attend school now from the time she was 5.

P3: Yes, kindergarten she was ½ days. This was the first year that she grew up and stayed all day. But that was hard since I was used to having her home, that was really hard.

I: And how did you work through that transition in Kindergarten?

P3: I came with her a couple of days and she was only ½ days. She did stay until 1 twice a week for music and PE but that took me a little while. I am so used to having her and having to give her to others to care for her. She was in a regular classroom too. I was used to her being with all of her special needs friends with one teacher. But I got over it.

I: With that are you happy with her schooling so far? Are there strengths or concerns that you've had?

P3: Um, I don't know. No, she has done really well. She enjoys going so it's not really hard for her to get up in the morning when it is time. I don't have to fight

with her to go so I am ok with that. And she is learning how to do her switch and play on the computer. You know she has just gotten...she has grown up.

I: I know that you have chosen to send her to school but I know that you had some reservations. So what were your decisions and reservations in sending her only ½ days to school?

P3: I just wanted her home. I've only been her mom, well, I've been her mom for 7 years but she hasn't been home that long. For the first 14 ½ months she was in the hospital. I'd bring her home for a day or two and I'd have to bring her back to Iowa City again. So she didn't come home very often and one time she stayed another 7 months but then I got to keep her home for about a year and she was back in the hospital. She had hip surgery and I was afraid to send her to school until she was herself again.

I: When she was hospitalized, what was the illness?

P3: Her epilepsy, her seizures were the basic reasons, well and feeding issues. She kept pulling her tube out.

I: Ok, we are going to go to number 13. What do you feel are the benefits of sending a child who is medically fragile to school?

P3: They learn a lot. Like I said, she has learned to operate things that I probably wouldn't have made her do anything. She is spoiled rotten. I don't make her do anything and at school she does work on the computer and draw pictures, play with her switches and music. However, music is a big thing here but I wouldn't have made her do any of it. I'm the mama, she doesn't have to do it.

I: Specifically, do you feel there are benefits between the schooling?

P3: They are similar, but like at preschool it was more like playtime and at school she has to work a little bit harder in kindergarten and first grade now. She has to work a little bit harder. It is a little tougher on them to do more.

I: And then 15, do you see there are some concerns with sending a child who is medically fragile to school?

P3: No, I don't think so. I think, they should go, at least try it and if for some reason it doesn't work. I tried it with Child 3c and it worked. I think, it would work for most kids.

I: Now, number 18, if you send your child to school what helped you with the decision to send her to school?

P3: I don't think I made the decision to send her to school. I think it was more or less Keystone that said try it. But I didn't have to send her. But as I got used to it along with Child 3c I got used to her going to school.

I: Do you have any advice or things that you think might help a parent who is worried or leery to send their child to school?

P3: I would say just try it. If you have to go to school with them the first 3 weeks then that is ok. They don't force you to send them. You can come and go. I think just trying it is beneficial. If you can observe and stay it gets better. I think it would have made it easier to talk to another parent for me.

I: To talk to someone with has a child with similar needs?

P3: Right. To know that child isn't the only one out there. It really does work. Child 3c has come along way. Had she not gone, I don't think she would be like she is. I think she would be bored with life or at least bored with me. Although, she loves her mama.

Interview #4 (6-22-06)

I: Ok, Parent 4, could you just describe your Child 4e?

P4: Well, she is 4 years old. She is incredibly happy. The only time she is upset is when something is wrong with her, if she is not feeling well or wants to be held. Other than that she is happy. She can laugh. She can play. She is the center point of our family.

I: Ok, good. Could you share the medical needs for Child 4e?

P4: She is a big ball of medical problems. I can give you the technical terms. She's got an unbalanced translocation of her fourth and fifth chromosome, there is technically no term for it. Her condition mirrors chr du chat. She is trachea dependent. She is g-tube dependent. She is missing the corpus callosum of her brain which is the center piece that connects two halves. She has a trachea cus she was born with breathing problems and was intubated right after birth. She's got a subglottic and paralyzed vocal cords and her little voice box is too small. Reason she has a g-tube is when she was first born she was aspirating everything she ate. She also has a seizure disorder that she developed recently in her brain. Within the last year and a half. She also has bilateral hip displacia and her hip popped out. Her feeding routine is a little different. She gets a pump feeding at night which is 750 of fiber which is one step above pediasure with water and we mix in baby food in there. But she gets bolus fed during the day. We give her 2 jars of stage 2 baby food and 120 cc of water at breakfast, at lunch she gets yogurt a jar of baby food and 120cc of water, and the same for supper. She gets this pushed through her stomach

like a normal baby would be eating it. At about the same rate. It makes her feel full during the hours she is away cus if she doesn't have that instant gratification she gets really upset. But that isn't real common.

I: You said that she has a trachea. Do you suction her too?

P4: Yes.

I: Does she have reflux?

P4: Yes. We have her on a medication to prevent it.

I: You had indicated that she had some hip concerns. Does she have tone concerns?

P4: No not really. She has had hip surgery and do to that fact it is harder for her to sit up. She is really tight in the hips. She is ok if she is standing or sitting but she needs to be supported for sitting.

I: How is her vision and hearing?

P4: In her right eye it is not so good but her left eye is perfect and her hearing is perfect as well. She has absolutely no problem with her hearing.

I: You had mentioned her seizures. What do they look like and how often does she have them?

P4: Actually, they are not common. Her arms go out straight and her legs go out straight and she stops breathing for 15 seconds and then she laughs afterwards. We were not even sure that's what they were. She doesn't have them anymore. They are controlled with medication.

I: Breathing. Does she have some concerns with her breathing.

P4: She doesn't retract. She is on oxygen at night and a ventilator cus she has sleep apnea as well. She uses a vest treatment once per day.

I: How is her back? Does she have scoliosis?

P4: Yes, she does. She does not tolerate the body jacket. Since it hasn't gotten any worse we just put it on her when she is sleeping. It is the only time she can tolerate it. She doesn't know it is on then.

I: For mobility. She is not able to walk right now?

P4: She can not walk but she rolls around and she plays on the floor and does all of that stuff.

I: How often would you say that she has been sick? Does she get sick often?

P4: She just had pneumonia in January and was hospitalized for a week. That is pretty common for her.

I: Would you say she gets pneumonia frequently or occasionally?

P4: At least twice a year. And that's, we don't take her out. We don't do anything with her. That just from it happening and that is exactly why she doesn't go to school. She gets it and she is still house bound.

I: Did they call it aspiration pneumonia or...

P4: It is both.

I: Her primary communication you indicated that she laughs ..

P4: When we have family come into town that we haven't seen for awhile she get really strange. She gets over stimulated, and we have to take her out of the room to calm down. New faces and new routines really throw her off.

I: Overall, how would you rate your willingness to send her to school? 1-totally against, 2 being on the fence and 3 being an advocate for school.

P4: I am totally against it for her.

I: Ok we will go into why later. But did someone talk to you about educational options for your child? How old was she and who did that?

P4: We've had people, we were involved with birth to 3 and went over all of the options. Between her doctor and myself and the fact that she would only be able to attend a short period of time, we just don't feel the benefits outweigh the risks. And we have been informed. We have the right to have a tutor and that's fine just not during cold and flu season. We were told the whole thing from the beginning on.

I: Did you receive early intervention services? Any how often was that?

P4: Yeah, they were coming in about once per week when she was first born and trying to evaluate her. Then it was twice a month and once a month and now during cold and flu season they don't come at all. We don't have birth to 3 anymore cus she is four.

I: Were you happy with the services you got?

P4: For the most part yeah.

I: Do you have any strengths or concerns you'd like to share?

P4: Well, I just think that um there were a couple of people that came into our house and I don't want to say names but they say they have allergies and stuff and it wasn't to me, if you are sneezing, you don't need to be in my house. That was my only concerns was their decisions as to what they thought was illness and what they thought was allergies.

I: As far as the delivery of instruction, for programming were you...

P4: No, I didn't have a problem. They just basically talked to me and I was the one who did everything with her so. That's not an issue.

I: When she turned 3, did they talk to you about preschool?

P4: Yeah, and we decided not too.

I: Who talked to you about preschool?

P4: It was the birth to 3 people here in Dubuque and we went through the whole list of things and like I said it was not worth it to us.

I: Could you have retained the early intervention services?

P4: We did, we had the school system come to us. It's not, I have no problem with her learning. I just have a problem with her being sick.

I: Sure, I understand. I am able to skip some of the questions about sending her to school since you didn't. So we will get to your reason which you were explaining. The next question, if you did not choose to send your child to school-based programming, can you explain your decision and what influenced your decision.

P4: We decided not to send her to school is the fact that we have her basically isolated here in the house through cold and flu season and she still gets sick. And school is a major germ pit. We have 3 older daughters that go to school and when they come home sniffing we have to keep them completely away from her 100% of the time when they are sick. So, there's not really an option for me to tell the whole school to stay away from her, don't touch her, cough on her or sneeze on her cus they are kids. It's not going to happen. So, between myself, my husband and her doctors we weighed the risks and the benefits and there just are not enough benefits to sending her to school. Plus, she does get over stimulated with too much noise too many people and too much anything. So, we decided that it's just not an option for her and she is doing just fine here at home. We value her being healthy more that her education. We live with the fact that one pneumonia could be..that's it. She does

have chronic lung disease. So, every pneumonia she gets causes ulcers on her lungs and it just is not worth it to us.

I: Ok, um, the next question refers to the benefits you see for a child who is medically fragile to receive education whether it be in the home or not.

P4: Well, I think that if they can make it accessible in the home, I do believe that some children can benefit from it. She is at a 4 month level with her development so it is basically what they can tell me that I need to do for her cus there really is nothing else that they show her that she catches on to. So I mean for other children it would probably work better. You know then it does for her. I can see that it would be important for a child that is medically fragile but does have more of a normal learning ability to have those services.

I: Ok, then do you feel that there are benefits for someone who is medically fragile to attend school?

P4: In the case of my daughter. No, I don't believe she is going to benefit at all from it. I think that it is just such a danger for her that there is nothing they could offer her that would be worth it.

I: What are some of the concerns and problems with sending someone to school who is medically fragile?

P4: The cleanliness, the amount of germs, the amount of coughing and sneezing with the kids not covering their mouth. The lack of attention that my daughter would receive. Like I said, I know that the amount of associates that they have to the number of kids doesn't add up for me either. So that's not an option. My daughter is used to one on one time with everybody so that's not an option either.

I: Ok, have you visited school?

P4: Yes, I have.

I: Ok, the next one, if you chose to keep her at home which you have what are some of the things that you do to help her growth?

P4: We work with her everyday. Like I said, we have the teachers come in and drop off materials. We work with her. I mean, we do about an hour of physical therapy with her a day and we are constantly playing with her and do things with her to help her develop more independence with sitting and stuff like that. We're not really working on her ever talking because she is trachea dependent so that's not an issue. Um, it's more repetitiveness with her, trying to keep the skills that she does have and you know, is there anything new to slowly add them in so it doesn't throw her for a loop.

I: Ok, the last question is since you have chosen to keep her at home and I understand your position there, is there anything that the district could do to make you feel more comfortable about sending her to school?

P4: Just basically respect my decisions. Don't think that I'm going to change my mind. That is another thing that they keep...have you thought about it?, is she better this year than last year?, and we're not changing our minds. You know, unless she suddenly woke up and didn't need her trachea anymore, then you know it would be a totally different subject. That would be the only thing. To just, you know, respect what I am saying instead of thinking they know better for my daughter than I do. Sometimes we do get asked that way too many times.

I: Ok, so you feel that you will probably keep her home for a long period of time?

P4: Yes, she is not going to school. She's not. It doesn't, the benefits do not outweigh the risks. And the risks are just way too high.

Interview #5 (6-23-06)

I: If you could tell me about Child 5e.

P5: Ok, well let's see. He is eleven years old and he will be going into the sixth grade. Um, he had a bilateral lung transplant and is currently in chronic lung rejection.

I: How old was he when he had the transplant?

P5: He was 3 years 10 months. He is enrolled in school in order to attend but misses quite a bit of school because of his immune suppression. He gets sick very easily.

I: Just go through some of his health issues that he has to deal with. Any special treatments?

P5: He sleeps with a bi-pap machine on.

I: What is that?

P5: I don't know if you've heard of people who use a c-pap? C-pap is for people who have sleep apnea. Bi-pap, gives you the inhaled and the exhaled. It gives you both settings so it's a little more severe. He has what they call lower lobe emphysema which means that his lower lobes have become sponges so they aren't expanding anymore. So the bi-pap makes sure that the air goes in and comes out and if he does not wear that he has CO2 retention which gives him headaches. And it's not safe for him. He wears that at night. At naptime, he wears the oxygen. And he does. One of the really tough things with school is that he receives nebulizers. He receives an hour and a half of nebulizers every morning and 20 minutes of chest therapy. We

have what is called the Vest. And he has another hour and a half of nebulizer before bed and 20 minutes of chest therapy. And that is when he is healthy and when he has something going on everything increases to like four times a day. So, it is basically meds, meds, meds and treatments.

I: I know that sometimes he wears a mask. Is that just when he is lower on his immune?

P5: No, it is more to protect him. Like whenever we go in to a setting where there is a large group of people he is suppose to wear a mask. We kinda do it based on the time of year when viruses are out there and such. So with summer time out there right now I wouldn't have him wear it because there is not a viral load in our community but in the winter months he wears a mask. We don't send him to school with a mask. The institution that we go to is one of the few that don't require them to because it is important for these kids to um, they want to be normal. They don't want people to know that they are sick. They don't want people feeling sorry for them. They just want to be another one of the kids. So, for the psyche part of it they don't require that they wear it to school.

I: Does he have any other medical issues like nutrition?

P5: He has a problem with gaining weight however, he has been maintaining lately. Um, we have since before transplant to everything we can so he doesn't have to have a G-Tube. So, um his body was not designed to be the size that it is. He should've been a much bigger kid than he is but because of everything that he has gone through his body has to work harder than most peoples. His lung function is now down to 22%. So it has to work a lot harder just to move and it burns more calories. He had a metabolic study done. He looses weight even when he eats. He had the metabolic study and found out that his metabolism is so high that he looses weight when he sleeps. So, high calorie foods that's why when he is in school you'll see him with drinks and snacks. He needs to eat and eat and eat to keep the weight on. Yeah.

I: For his rate of illness or hospitalization, do you want to give an overview of what that has been like since his transplant.

P5: Ya know, they kind of look at it by years. They will say this year was a really good year or this year wasn't a good year. Generally, he gets sick at the turn of the seasons. Like he will get sick in spring, he'll get sick in the fall. Um, and there is not reason for that for him. So he is usually in the hospital every October. It seems likes once he, we are kind of figuring out now that once he is in school for a month it kind of drains him and we've found out that this was causing him to go into the hospital. He was trying to do too much. So, he goes into the hospital a lot of times in October. This past year was October/November. Um, the year before he made it through that span but was in January/February then. And then in the spring.

I: How long is he usually in the hospital when he is there?

P5: Usually about 4 weeks.

I: What kind of treatment do they do for him when he is there?

P5: Oh, gosh. They, all kinds of things, they do all of the same treatments that we do. We also have a pulmonary function machine at home so that we can monitor his pulmonary function which is his lung function, to Milwaukee. They do a lot of them there. It depends on what he has got going on. He has a lot of IV's. That is why we had the pic line put in. they usually do the IV therapy but this time it effected his kidneys. So now we don't know what we will do the next time he gets sick. We have to keep his kidneys healthy so that he is eligible for another transplant. But he's been in the hospital after transplant he had a hard time coming out of intubation. He failed intubation, exhibiting where they take you off the ventilator. Um, 2 or 3 times. So he was on the ventilator for a good 2-3 months and he was in active ICU for 79 days. At that time he was able to write or spell yet cuz' he was only four so what we had was picture boards. Creative picture boards. I am sure you probably would use them. So he pointed to what he needs. Now that he is older and needed to be intubated, he knows how to write.

I: How often does that happen?

P5: Not often at all. Basically, he is only intubated you know to do biopsies and stuff. He's been very successful coming off of that since the transplant.

I: Did they talk about tracheas? Does that go along with that? I'm just asking, I don't know.

P5: Everyone else would have been trached. There was lots of controversy up in the ICU because all of the other doctors, except for his doctor wanted him trached. His doctor knew that it was something else going on that he could survive. Um, they just didn't know what was going on. Well, his diaphragm was paralyzed and actually came home on an iron lung. That they use for polio. He slept in an iron lung for 6 months until he got strong enough. It was just that the muscles were too weak because of the mal nourishment. Until he got stronger, he could not sleep lying down. Because gravity opens up the diaphragm, when your standing up, but when you are laying down the muscle takes over and the muscle was too weak. He would basically suffocate to death.

I: Is positioning still used now with him.

P5: Yeah, just with pillows though. Yeah.

I: I know that he needs to rest. What is that like for him with his activity level?

P5: Right now, his activity level is poor. Um, he is, for him there is no rhyme or reason, he defies all of the numbers. Anybody else that has his numbers can not get out of bed and they don't know why that is but he was like that before transplant too. Um, the numbers that he had one was a pulsox and one of the numbers means your organs start shutting down. Once your pulsox hits 60. And child 5e is 38 and he was out riding a bike. They can't explain why he is able to do it. Um, he is in case studies up there now. But um, so now his lung functions are really down. So just walking from the kitchen to living room wears him out.

I: Is he wearing oxygen at home?

P5: Only when he needs it and only when he wants it. He 100% decides it. He can't be pushed, cus he can't do it. It is hard to watch him sit on the step watching his brother play baseball. And it is hard on the other kids cus they don't understand it. You know, we have talked to them about it but you know, like they'll let Child 5e, bat first if he does play he gets a base hit and he is done. If its somebody else's turn to bat and child 5e is not playing defense. So, every year the beginning of summer that is the fight and then they understand eventually. They can see it. They notice the deterioration.

I: Does Child 5e handle this ok, or ..?

P5: Yeah, he does. He gets frustrated. Um, he thinks there is an easy cure. And that would be another transplant. And he has made a comment that um, why aren't we getting it for him. But he doesn't understand the whole seriousness of it.

I: Is he on the list? How does that work?

P5: Well, we are waiting for the final opinion. He has been cleared through Milwaukee docs up there but they wanted to send it away for an unbiased opinion. Cus everybody up there knows Child 5e, he has been up there his whole life. And they all want him to have it but they need an unbiased opinion. Once that comes through then he will be listed. He has done all of the testing and everything like that.

I: I appreciate you explaining all of this to me. Now, if you would just rate your overall willingness to send him to school. 1-being totally against school, 2-being on the fence and 3 being an advocate for school.

P5: Ok, in Child 5e case definitely school. Not only the, there is always a chance. He is a very intelligent child and he deserves the right to have dreams to grow up to be what he wants to be. And I am not ever going to take that right from him. So, he has dreams and if I pull him out of school and don't give him the education that he deserves, then he won't be able to fulfill his dreams. And what if that miracle does happen? So, I want him to have his education. Secondly, there is such a social aspect of school for him is one of the things that keeps him going. You know, when he is in

the hospital, he is calling his friends at home and they are calling him in the hospital. No matter how sick he is he wants to talk with his friends. So, you know, family is one thing but to have that social interaction is really important for his health. It gives him goals. So, definitely I want him to have his education.

I: Ok, then going back to when he first had his transplant, and when he was starting all of his medical needs. Um, did someone talk to you about any special education or anything like that?

P5: No.

I: When did he start going to school.

P5: He started in Kindergarten but he started a year late. Because he had his transplant basically at the age of 4, 3 years 10 months. Um, once you come out of the transplant you are going to be assigned to your home for an entire year. So he had in home nursing come in everyday while we went to work, (I worked days at the time) that stayed with him. He was not allowed to leave the house because your immune suppression is so low. So, his one-year anniversary was June 26th. So, since the thing is, I was not going to take him from being confined to the home for an entire year to putting him out there with all of those germs. And not having any chance of regaining any immune, to colds and stuff like that.

I: How did you work through the transition from home to school?

P5: He was completely normal. It was just, he didn't know any different. So, it was basically, he went to daycare for a year. To a private person with his brothers and he didn't know any different.

I: When he went to Kindergarten did you have any special circumstances in place for him? Did he have a 504 or anything?

P5: Not at that time. Um, we just started that process this year. Um, Child 5e, has actually done really well in school. Um, when he is in the hospital we do his homework with him. The teachers just fax it back and forth. Um, so there wasn't a need for it. There was medical needs. You know medicines and a special line he had after the transplant. So, it was important that people knew what they could and couldn't do with him, like pull his shirt. They could pull the line out. So, it was really scary on my part to send him to school. But when we were in the kindergarten line, he said to me, "Oh, you don't have to stay." It's like, but I want to. He was ready to go.

I: Who did you communicate with the nurse..?

P5: I do talk to the teacher every year. There are all kinds of things. Like one year there was a teacher who had a bird in the classroom. Ok, these lung transplant kids

can not be around birds, cats, or turtles. They can be in a room with a cat but not a bird. So those are three things that we are restricted from having. So that was one of the problems. Um, things like they need to know that his meds give him chronic diarrhea. So, he can't ask to go to the bathroom a lot of times he just shoots to the bathroom. You know, he has to have access to drink at all times. He has Gerd, severe, so one of the things that does help him restrain from vomiting is drinking. He can actually control it, which is actually weird. But, um if he has a drink with him at all times he can keep from vomiting. So, um, if he got any cuts or anything, they have to be Neosporin and bandaged. One of the biggest things for him was like recess. He can't go out to recess once it is 20 degrees or below. He can't handle the cold. Um, his lungs can't. It hurts him. It physically hurts him when it is that cold. So winter time he stays in. And hand washing with the other students and not sharing desks. So, all throughout school he didn't share a desk with anyone else. In kindergarten and first, he did sit at a table with others. You know, but as he got older, and the transplant started rejecting more, um, he's got to be really careful about germs. They actually told us last June, it was a year ago, that he wasn't going to survive the winter. That the next virus would take him. So, it has been really crucial that school understands. The school nurse calls us, what we do is at the beginning of every year the teachers talk to the parents, they technically don't have to tell them what their child has when they call in that they are sick but because of a certain situation. And you know, by third grade, second grade, everybody knew. But if they wouldn't mind telling what the child had when they call in. And then that is where we start at if Child 5e starts showing any symptoms of any kind. Then we know where to start looking and testing him. The nurse would let us know, you know, we have a case of strep throat in Child 5e's class. You know things like that. This year there was flu and mumps that kept him out a month longer from school.

I: Was he sick from that?

P5: No, we just keep him out cus to keep him from getting sick. Cus he will always be immune suppressed.

I: I know you are in contact with your doctors. How do they help with your decisions?

P5: They support us. What ever our choice is they support us 100%. If they tell us it's not a good idea, we are the first ones to pull him. There is, you know, education is one thing and having your life in another. So, if there is any doubt at all he's not coming.

I: When he is at home does he have homebound services?

P5: A tutor comes in. Yeah, at first when he got home from the hospital. This year she came every day but when she got him caught up she came like every other day or 3 days a week. She would stay anywhere between an hour or an hour and a half.

I: Were you happy with your school services? Are there any concerns?

P5: The only problem that we have had, like I indicated earlier, Child 5e has an hour and a half breathers in the mornings and at night and in the winter we will throw an extra one in the afternoon. And he has all of these meds. I think he takes; he is up to 18 or 19 meds a day throughout the day he has to take them. Our biggest problem is homework. You know, if you send home an hour worth of homework, he has no play time, he's got to eat somewhere in there. And then, if he goes to school and comes home and starts his homework right away, he gets done about 4:30, supper is at 5:00. And if we don't get those breathers started by 6:30, I can't have him in bed by 8:30. If you throw in an hour of homework, he is up until 9:30. It gives him no extracurricular activities, no shower time. It gives him no lets go shopping time. So that was our biggest problem. That is why the 504 came in. Even, you know, one of his teachers would say, "Just do what you can for homework." Ok, that works and it doesn't work. It, because my husband always wants him to get his homework done and to me, its like, forget it, he is a kid. So, let him enjoy what he has left of his life. What surprised me was you have a tutor come in for an hour to an hour and half, 3 days a week and he doesn't do all that extra redo the homework or do this so we know that you got it for sure. They know that Child 5e is one that once he's taught it, he doesn't forget it. So, why send him home with repetitive things. When the tutor was here he didn't have that repetitive stuff. He took the same test as everyone else and he did fine.

I: So they need to get together, don't they?

P5: Yeah, in Milwaukee when they send up the school work he was suppose to do the teacher refused to have him do it all. No kid should have to do this much work in his situation and when you really sit down and think about it, this is what is bringing him down. You know, he is having no time for himself.

I: With the transition to middle school, did you start the 504 or when was that?

P5: The middle of this year probably.

I: Have you had a meeting for the transition to middle school?

P5: We had a meeting. Um. Not with the teachers, just with the vice principal.

I: Were you the one the initiated the meeting or did someone else?

P5: Eisenhower did, someone did. I know the nurse was wonderful with everything, and between her and the principal and counselor. I think the three of them work really well together. Yeah, the vice-principal was wonderful. She actually came up with some really great ideas. I guess, at middle school the nurse's office is way far away from the house that he is in. It is at the other end of the building. So, we are in the process of trying to get him a scooter. You know, like an indoor scooter. So that

he is not going to be able to walk it and if he is sick he is really not going to be able to walk it. So, he can use that to go back and forth every day to the nurse to get his meds. Um, he will be using the elevator. They were really good. We talked about the homework and stuff like that. That is one of the things that we really need to stick to and I think, they have like that last period or something is homework. So they are going to schedule that so Child 5e can get his homework done. Our biggest problem is going to be getting him to school on time. It starts earlier and what is a reasonable time to get a child up in the morning? You know, even though he's got an hour and half breather in the morning, he needs to eat breakfast, do his hair, his teeth, get dressed. You know, so mornings are really hard. So, I am going to try to schedule so that he is not in core classes the first period. So if he misses it will be ok.

I: Will he still have time at school that if he needs to rest?

P5: Yeah, they are trying to schedule that so that it's not when he has a core class. So, yeah they have worked really well with us.

I: This has all been under the 504 and your wishes?

P5: Yeah, but I know like Milwaukee has written scrip's for meds and stuff. And oxygen and they have had a lot of contact with the school nurse. You know any time that she had a question; we signed a release that she could call Milwaukee. So, she has had discussion with Milwaukee on what she should do with him too.

I: What do you think are the benefits for him or other students who are medically fragile to attend school setting?

P5: I think it depends on how medically fragile they are and really it's got to be each individual parent's decision. I really do. There are kids in Child 5e situation that do not go to school and basically, it is the fear of them getting sick. It should be up to the parents.

I: In your case, has it been?

P5: Yes, in our case. You know, I have a friend who has a daughter in this situation who do not send her to school. But I can tell you that in the winter, she never leaves the house and when her siblings have a cold they spend all the time in their bedroom, on their own without being told. Because if she gets sick, any thing at all, she ends up in the hospital for weeks and weeks and weeks. And she doesn't recover well. You know, and that is why. If that was Child 5e's situation, I wouldn't be sending him either. Because it's not fun to be in a hospital for 6 weeks, 9 weeks sick. Because of, you know, education is important but it depends. Are you going to have a chance of getting something from it? You know, where Child 5e has a chance.

I: Are you comfortable with the services he receives when he stays home?

P5: Yeah. Well right now when he stays home, I work nights because of it. So that I am up with him during the day. So he doesn't really get any nursing services like that. Schooling, that is awesome.

I: What are the problems or concerns with sending someone to school that is medically fragile?

P5: The germs!

I: How has the absenteeism been with being out and returning?

P5: Just this last year, he was out all winter. And he doesn't realize that when he goes back to school it doesn't pick up where he left off. Your friends have moved on, things have happened in school that you have no clue about. So probably the first 2 weeks are really hard for him. But then once he got back in with his friends and with the groove with what is going on. Then it became fun again. Even though they talk on the phone and stuff like that, things happen in school that you're not a part of. Just science projects and art projects. So it was hard for him but he bounces back so quickly. Within 2 weeks, he couldn't wait to go to school again.

I: The next, we have already addressed. But when he is not able to go to school, do you initiate the tutor or..?

P5: No, school did. This is the first year he has had the tutor. It was just this winter. Other times he was able to stay out and we did his homework with him. This time, just because he missed so much. I think he missed 120 days or something. So, um, they said when ever he was ready just to call them and she was there.

I: Was he sick during all of the time out of school?

P5: No, he was in the hospital for 2 weeks, home for 1 ½ weeks, and back for 2 weeks, we sent him. It was maybe another week and it was coming upon Christmas and all of a sudden everyone was getting sick. And you know it just wasn't worth it. So we pulled him out through the holidays. We talked about sending him back after the holidays and in talking with the school, and I work at the hospital so I know what is going on. When the hospital is full, there is no way he should be out in the public. We do things like in the wintertime he's got to get out. We might take him on a weekend night to Wal-Mart at 11:00 at night. It will be a family trip. People might think that is really weird but that is one why we can get him out and shop and there isn't a lot of people. If we go to a movie theater, we always go extra early so we can get the back row so nobody is coughing up on him. We do a lot of things like that. We never go to a movie when the movie is first released. It's always when its about to leave cus there's not as many people. We do a lot of things like that. He does fine with that.

I: So, overall how would you say Child 5e deals with everything?

P5: He knows no different. So I would have to say he has done really really good.

I: Any advice you would want to share with parents?

P5: Go with your gut feelings and your child. That is one thing I can honestly say, I have no regrets. I won't allow myself to say I shouldn't have.

You know, if I think he shouldn't go to school, he's not going to school. Because if I send him and something happens and he dies, I will not be able to live with myself for making that decision. So, I think they need to use their gut instincts. They know their child better than any one else.

I: Does Child 5e, ever get mad at the decision not to go to school?

P5: No, he doesn't. We haven't come right out and told him the severity but he knows. He is the one sometimes that says, "Maybe I shouldn't go then." You know, he does not want to be sick. He will say, "I want to live. I want to be here." You know it breaks your heart. He is really an exception. He is really knowledgeable.

APPENDIX C
MEDICAL TERMS

Medical Terms

The following medical terms were used within the body of this paper. The terms were defined using the source www.medicinenet.com.

Bilateral Lung Transplant: the grafting of one tissue or organ to another.

Chest Therapy (Vest): percussion to the chest or to improve bronchial.

Chronic Lung Disease: disorder that persistently obstructs bronchial airflow.

Chronic Lung Rejection: the refusal by the body to accept transplanted lungs.

Corpus Colupsum: a great connection between the two cerebral hemispheres of the brain.

Gastrointestinal (G-I) System: including the stomach and intestine.

G-Tube: tube through skin into the stomach (gastrostomy) for internal nutrition.

Malacia: softening of the tissue and/or cartilage and/or muscle.

Musculoskeletal System: including the muscles and the skeleton.

Neurological System: including the study of the nervous system.

Respiratory System: breathing to respiration.

Spasticity: increased tone or contractions of muscles causing stiff and awkward movements.

Siezure Disorder: a sudden attack of pain of a disease by or of certain symptoms.

Stroke: Sudden loss of consciousness followed by paralysis caused by hemorrhage into the brain.

Scoliosis: unnatural curvature of the spine.

Trachea: a tube like portion of the respiratory tract that connects the voice box with Bronchial parts of the lungs.

Traceal Ketogenic diet: diet for severe seizure disorders that don't respond to Conventional medical treatment. Comprised of almost entirely of fats and proteins.

Unbalanced Tramplocation Chromosome: missing or dislocated chromosome.

APPENDIX D
PEDITRICIAN SURVEY QUESTIONS AND RESPONSES

Pediatrician Survey Questions and Responses

Two of the six surveys were returned by local Pediatricians' offices within the Dubuque Community. To protect the identity of the Pediatricians, Pediatrician 1 and Pediatrician 2 will be used for this information.

Pediatrician Survey

1. Name Pediatrician 1
 Pediatrician 2

2. Do you help with the educational decisions to send children who are medically fragile to school?

Pediatrician 1: On a very limited basis

Pediatrician 2: Occasionally

3. What is your role in the decision to send children to school? Explain.

Pediatrician 1: I try to advise parents of medical concerns of sending child to school. Advise on what special medical needs might have that school needs to be aware of.

Pediatrician 2: As a physician my decision is to make sure the child is free of communicable diseases and that school attendance would not be detrimental to patients health.

4. What is the role of the parent (residential) in the decision to send their child to school? Explain.

Pediatrician 1: Major! There lives at home life and child's ongoing health issues can be majorly impacted by the decision.

Pediatrician 2: On any given day the parent decides if child is "physically" and "mentally" able to attend school. If ill the family may consult me to see if child should attend school.

5. When faced with a difference in opinion, what do you tend to do?

Pediatrician 1: Talk, Talk, Talk about differences, work toward a compromise or try something for a while, modify as needed, be flexible.

Pediatrician 2: I haven't really had this situation (that I can recall).

6. What are the benefits of sending children who are medically fragile to school? Health related and skill related?

Pediatrician 1: Socialization, education, rest for parents

Pediatrician 2: Benefits would be interacting with peers and opportunity to learn. For the severe and profoundly mentally retarded children they may still learn some "life skill," although at a great cost to school to accommodate the child's special needs.

7. What is the role of the school in educating and caring for children who are medically fragile?

Pediatrician 1: Maximize educational experience, help with socialization, and maximize health needs.

Pediatrician 2: To provide (within reasonable cost) a learning environment that does not threaten/worsen the child's medical condition and to appropriately teach/challenge the mentally retarded child.

8. What are the problems/concerns with sending children who are medically fragile to school?

Pediatrician 1: Exposure to sick children, potential that medical needs won't be continued, time consuming for school and expensive.

Pediatrician 2: 1) High cost for accommodations for severe and profound mentally retarded children. 2) Potential for exposure of medically fragile (eg. Bone marrow transplant or other immune compromised child) to infectious diseases. 3) Concern of safety of the fragile child (from teasing, belittling) as well as needing to provide safe access to school facilities for handicapped/disabled child.

9. What supports could be provided to help parents' transition their children to school?

Pediatrician 1: Have parents stay for some length of the day early on., ½ days, other day, etc.

Pediatrician 2: I'm not sure.

10. Are there any concerns or questions you have for educators of students who are medically fragile?

Pediatrician 1: Do they receive adequate training, have adequate back ups.

Pediatrician 2: Not at this time