A Dissertation

entitled

Advocating for Inclusion of Children with Williams Syndrome

by

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Submitted to the Graduate Faculty as partial fulfillment of the requirements for the
Doctor of Philosophy Degree in Curriculum and Instruction: Special Education

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The purpose of this study was to describe and explore the experience of inclusion of students with Williams syndrome, a rare genetic condition of a microdeletion on chromosome 7 which has medical, behavior, and cognitive issues. The study was conducted by gaining an understanding from the parents’ point of view. The study was twofold. First, the study investigated how the parents advocated for inclusion and then the study investigated accommodations and modifications that have helped their students with Williams syndrome to be included in regular education classrooms in early elementary school.

A qualitative study was conducted by interviewing 10 mothers of children with Williams syndrome who were included for 75% of the day in a regular classroom for two years in kindergarten through third grade. The participants’ interviews on advocating for inclusion for their child and their viewpoint on successful accommodations and modifications were recorded. Findings were reported through 12 major themes which emerged from the data.
None of the mothers described advocating as easy and many discussed the years of work involved to get the supports and services necessary for inclusion and the time involved in attending school meetings and training. Unfortunately, six of the parents described advocating as a “fight.” This still did not stop the parents from continuing to advocate. The three most important things the parents had done to advocate were to network with other parents with and without Williams syndrome, attend a Williams Syndrome Association National Conference, and have their child evaluated at a Williams Syndrome Clinic. These three items provided the mothers with the support information needed to request their child be in the regular classroom and the supports necessary for effective inclusion. Parents often advocated for specific services and accommodations and modifications. All of the children of the parents who participated in the research had a paraprofessional in the classroom. Computers were frequently advocated for by the parents along with specific educational programs. All of the parents had positive stories about how inclusion was working for their children. None of the participants regretted advocating for inclusion and saw many benefits for their children.
This document is dedicated to my family. To my husband, Bill, for helping and supporting me during this journey and for his extreme patience. To my two sons, Bill and Alex, who have taught me so much over the years while advocating for their educations. To my dad, Joe, who took numerous phone calls and knew I could do it.
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This dissertation would not have been possible without the support of the many families of children with Williams syndrome who have advocated for inclusion for their children and continue to advocate. These families know how important their stories are to the families beginning this journey. I owe you my deepest gratitude.

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Chapter One

Introduction

Alexis is a beautiful, petite six year old with long curly brown hair and a big smile. She is very charming and outgoing and will talk to strangers in an instant. Alexis has Williams syndrome—a microdeletion on chromosome 7 occurring 1 in 7,500 people. She was enrolled in a self-contained classroom for her second year of kindergarten. In her first year, the classroom went bowling and learned how to make peanut butter and jelly sandwiches but Alexis did not learn her letters and numbers. Her mother then learned about the educational laws and met students with Williams syndrome who are being educated in the regular classroom. She wanted Alexis to have the same educational rights and attend classes to learn the general curriculum. Alexis is now in first grade learning the general educational curriculum with her peers in her home school with the correct supports and services. Alexis is learning to read!

Background

Special education has existed in some form since the 1800s. Most of the education was private or held in homes and was for children who were deaf, blind, or had cognitive disabilities. The quality of the programs varied and was not available to most children. In the 1950s and 1960s, parents and advocacy groups worked to get some type of education for their children with disabilities. During this time, the Federal government started providing limited programs and services. The Training of Professional Personnel
Act of 1959 (PL 86-158) was enacted to provide training to teachers to educate children with cognitive disabilities. In 1965, the Elementary and Secondary Schools Act (PL 89-10) included Title 1 funding for poor urban and rural areas. Later in 1965, the act was amended (89-313) to include funding for grants to help educate children with disabilities (US Office of Special Education Programs, 2005; Wright & Wright, 2007).

Even after the federal government started to fund special education programs, schools could still not legally provide children with disabilities an education. Students with disabilities were denied access to schools due to their disability and the belief segregation was appropriate (Itkonen, 2007). Children with disabilities were usually kept at home or in an institution. In the early 1970s, two court decisions recognized that children with disabilities were guaranteed an education under the Fourteenth Amendment of the United States Constitution. Pennsylvania Association for Retarded Children v. Pennsylvania (PARC) (334 F. Supp. 1247 (E.D. Pa. 1971)) and Mills v Board of Education of the District of Columbia (Mills) (348 F. Supp. 866 (D. D.C. 1972)) were filed as a result of parents who advocated for their children and decisions in the cases were based on the equal protection arguments used in the case of Brown v. Board of Education (347 U.S. 483 (1954)) (Rangel-Diaz, 2000).

Congress investigated whether children with disabilities were receiving an appropriate education after PARC and Mills and determined millions of children were not receiving an appropriate education. On November 19, 1975, Congress enacted The Education for All Handicapped Children Act (EHA) of 1975 (PL 94-142). Congress wanted all children with disabilities to have access to an appropriate education and for the states and school systems to be held accountable for providing the students with the
education (Wright & Wright, 2007). PL 94-142 guaranteed due process, a free appropriate public education (FAPE) and an Individual Educational Plan (IEP) for children with disabilities, between the ages of 6-21. The law was clear that every child was to receive an education. This has become known as the zero reject principle. School systems are not allowed to exclude any students age 3 to 21 with a disability from receiving an education (Turnbull, Turnbull, Erwin, & Soodak, 2006). The law also stated services should be provided as much as possible in the least restrictive environment (LRE). Colleges and universities began providing training to teachers and specialists who could work with children with disabilities (Keogh, 2007; Wright & Wright, 2007).

EHA was amended in 1986 (PL 99-457) to require states to provide services for preschool-aged children with disabilities and sustained the LRE provision (Grisham-Brown, Hemmeter, & Pretti-Frontczak, 2005).

The Education for All Handicapped Children Act was amended in 1990 and the name changed to the Individuals with Disabilities Education Act (IDEA; Rangel-Diaz, 2000). In the 1990s, the focus in special education slowly shifted from access to outcomes. People began questioning the high cost of educating students with disabilities without seeing any results (Egnor, 2003; Itkonen, 2007; McDonnell & McLaughlin, 1997). IDEA was amended and reauthorized by Congress in 1997 (20 U.S.C. 1400 et seq.). Major changes were made to IDEA for the first time in the history of the law. Students with disabilities are now required to participate in statewide exams and general education teachers are required to attend IEP meetings to help shift the focus from access to outcomes (Itkonen, 2007).
On December 3, 2004, IDEA was amended again. The amendment was named the Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004). One of the purposes of the amendment was to align IDEA with No Child Left Behind (NCLB) and PL 89-313. Now, Congress wanted accountability and improved outcomes and this was stated by emphasizing reading, early intervention, and research-based instruction. Special education teachers who teach core academic subjects must demonstrate competence in the subjects they teach such as the highly qualified teacher requirements of NCLB. IDEA 2004 requires states to establish goals for children with disabilities consistent with the goals and standards for all other students. As part of the emphasis on accountability, schools are required to improve graduation and dropout rates, and to report the progress of children with disabilities on assessments (Wright & Wright, 2007).

Part A of IDEA affirms the importance of parent involvement and the placement of students with disabilities in the regular classroom learning the general education curriculum. Section 20 U. S. C. § 1400 (c) (5) states, “Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by (a) having high expectations for such children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible, in order to— (i) meet developmental goals, and, to the maximum extent possible, the challenging expectations that have been established for all children; and… (b) strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home.” Part B of IDEA again affirms the location of the student’s placement in the regular classroom with the definition of least restrictive environment.
Section 20 U. S. C. § 1412 (5) (A) states, “In General, to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.” Children with disabilities should be educated with children without disabilities whenever and wherever possible (Wright & Wright, 2007).

Even though the law states children should be educated to the maximum extent possible in the regular classroom, this is not necessarily happening. Parents have had to advocate for their child’s educational rights. Parent advocacy has enabled students with disabilities to now receive a free and appropriate education in the least restrictive environment (Wright & Wright, 2006). Parents know their children better than the educators and should have a strong voice in the educational decision-making. If parents had not been determined to educate their children in the 1950s and 1960s, children with disabilities might not be in the classrooms today.

**Statement of Problem**

Public Agenda (2002) conducted a survey of 510 parents of children with special education and found 70% of the parents thought too many children do not receive the correct services or supports if the parents do not know what is available. The survey also found 43% of the parents believed they had to advocate for the services for their child.
Based on conversations with parents of children with Williams syndrome and information which appears regularly on the Williams syndrome list serve, parents of students with Williams syndrome have the same concerns as those interviewed during the Public Agenda survey. Parents of children with Williams syndrome have advocated to ensure the necessary classroom supports for their children. Many schools do not have the services, resources, and attitudes to provide the necessary modifications and accommodations necessary for a child with Williams syndrome to succeed in the classroom (Scheiber, 2002). Williams syndrome (WS, also Williams-Beuren syndrome) is a rare genetic disorder characterized by physical, mental and behavioral characteristics (Bellugi, Lichtenberger, Jones, Lai, & St. George, 2001) occurring approximately 1 in every 7,500 births (Morris, 2004).

Part A of the Individuals with Disabilities Education Act (IDEA) of 1997 points to over 20 years of research and experience demonstrating that educating children with disabilities can be more effective by having high expectations for all students and ensuring access in the general curriculum to the maximum extent possible. In April 2009, the Division of Early Childhood of the Council for Exceptional Children (DEC) and the National Association for the Education of Young Children (NAEYC) issued a joint position statement on early childhood inclusion and the importance of helping all children reach their potential. DEC and NAEYC define inclusion as “…access, participation, and supports” in early childhood programs. A philosophy of inclusion needs to be accepted and from this philosophy will come the access to community and educational programs. Children with disabilities will be able to participate by determining what is needed such as accommodations to the curriculum or different
teaching methods. Then, additional supports can be utilized such as therapies and collaboration with all of the resources involved with the child.

Family involvement and parent teacher collaboration are important for all students. School, family, and community partnerships enhance the learning process by promoting better student attendance, increased graduation rates, less grade retention, high parent and student satisfaction with school, fewer discipline reports, and high achievement scores in math and reading (Epstein, 2001; Ferrara & Ferrara, 2005). The benefits of parent involvement are seen regardless of family background or income (Minke & Anderson, 2005).

Parents of children with disabilities are expected to be even more involved in the educational plan for their children. IDEA includes policies to increase involvement by explicitly stating how parents are to participate in the development of the IEP, give consent, receive notice and participate in hearings, and have access to their child’s records. Parents serve as accountability means to monitor the educational system in implementing IDEA’s requirements (Turnbull & Turnbull, 2000; Turnbull, Turnbull, & Wheat, 1982; Wang, Mannan, Poston, Turnbull & Summers, 2004).

Parents not only need to understand the educational system to provide accountability in implementing IDEA but also understand the basic educational profile for Williams syndrome. Understanding a child’s profile of cognitive and linguistic strengths and weaknesses offers helpful information to educators for program planning. Awareness of a child’s personality traits allows insight into assigning children’s roles within the classroom and providing them with success. Awareness of the potential of certain types of maladaptive behaviors, such as attention difficulties, allows educators to
proactively implement strategies to reduce difficulties within the classroom (Hodapp & Fidler, 1999). Many times the etiology-related characteristics of Williams syndrome, such as learning through music and rhythm, are not considered by special educators, unless parents bring information to an individual education plan (IEP) meeting and advocate for specialized services (Fidler, Hodapp, & Dykens, 2002). Hence, parents have to advocate for the least restrictive environment and also the supports and services necessary based on the characteristics of Williams syndrome.

**Purpose Statement**

Marshall and Rossman (2006) state, “…qualitative methodologists have described three major purposes for research: to explore, explain, or describe a phenomenon” (p. 33). The purpose of this study is to describe and explore inclusion of students with Williams syndrome by gaining an understanding from the parents’ point of view of accommodations and modifications that have helped their students with Williams syndrome to be included in regular education classrooms and describe the resources parents have needed to advocate for effective inclusion. This information will potentially enable more students with Williams syndrome to effectively be included in the future. When parents become aware of typical accommodations and modifications necessary for a student with Williams syndrome to be included in general education and learn how to advocate, they can request that supports and services be available and used in the regular classroom.
Importance of Study

A majority of parents of students receiving services on an IEP have found that school systems do not volunteer information. Parents have to determine what services are available for their child from resources other than the school district (Johnson & Duffett, 2002). The results of this study will provide parents of a child with Williams syndrome with helpful information to understand how other parents of children with Williams syndrome have navigated the educational system and on issues surrounding advocating for inclusion for their child. Parents will then be better prepared with knowledge from parent advocates on the best types of training and what these parents have learned over the years of advocating for the rights of their children. Parents will also be able to use the experience from these parents to know what modifications and accommodations have helped their children in the regular classroom. Since WS is rare, little research and support is available for parents to understand what supports and services might help their child in the regular classroom. The information from this study can also be used by educators to better partner with parents in developing an effective individual education program.

Research Questions

This research study addressed the lack of information on advocating for inclusion from the parents points of view and what parents believe to be the modifications and accommodations necessary to have effective inclusion. The following two questions guided this study.
1. How have parents of students with Williams syndrome in the United States who have been included in early elementary school advocated for their children?

2. In the parent’s opinion what have been the most effective accommodations and modifications in the general education classroom for their child with Williams syndrome?

**Framework - Qualitative Methodology**

A qualitative study was the basis for this research. The study will provide a description of how different families have advocated for their children. Qualitative data provide the missing information related to what parents have done to have their children included in a regular classroom. Understanding the trials and triumphs parents have faced helps other parents to understand the process and be prepared when attending IEP meetings to advocate for their children. Educators can also learn how families are impacted as they advocate for their children. Very little research has been conducted on the dynamics between parents of children with Williams syndrome and the teachers and administration when discussing accommodations and modifications for their child with special needs from the parents’ perspective.

**Overview of the Research Design**

This research is important for families, educators, and service providers to understand the issues facing parents who advocate for their child to receive their education in the regular classroom. This information can best be collected qualitatively while focusing on the individual lived experience. Marshall and Rossman (2006) discuss
the importance of qualitative research for a deeper understanding of the participants’ lived experiences under study.

**Assumptions**

Parents of children with Williams syndrome were interviewed for this research. The researcher wanted information on inclusion in the early grades since parents often start advocating when their child enters elementary school. This is the reasoning for the requirement that interviewees for this study were parents who have children with Williams syndrome who spent 75% of their education in the regular classroom during a minimum of two years in kindergarten through third grade. The underlying assumptions regarding this study are (a) parents have a basic understanding of the United States educational system, and (b) parents fully disclose the effective strategies and information when advocating for their children.

**Limitations of Study**

This study did not include parents who wanted their children with Williams syndrome included but were unsuccessful. Also, the request for participation was only sent in English. Therefore, non-English speaking families did not receive the request to participate. The researcher acknowledges geographical location could be a factor in whether a parent has to advocate more for inclusion or only for specific educational supports and services in the United States. This study did not explore the differences due to geographical location.
Several limitations emerged during the research. Since the parents were all members of the Williams Syndrome Association, the socio-economic status of all of the participants appears to be middle class and eight of the ten participants had an associate’s or bachelor’s degree with two having master’s degrees. Income and education level could help determine the level of involvement of a parent in the advocacy process. The level of involvement based on income and education are not part of this research. Therefore, the parents interviewed are not considered a complete representation of all parents of children with Williams syndrome.

**Researcher’s Perspective**

Although the research was not a complete cross section of parents with Williams syndrome, the researcher tried to provide a cross section which indicates parents do not have to be in the education field to advocate for their child. The researcher is a peer to the parents being interviewed and joined the Williams Syndrome Association in October 1999 when her son was diagnosed with Williams syndrome at less than two months of age. The researcher was an engineer until her son was going into kindergarten and the researcher started her degree in education. The researcher was concerned parents would believe they also had to go back to school and get education degrees to effectively advocate. She has been a guest speaker at national and regional conferences by the WSA on the topics of transitioning into kindergarten, partnering with your school, and education advocacy. The researcher’s son is now in the fifth grade and has been included in the regular classroom since kindergarten.
The researcher was aware of the parental role. She understood the parent and school dynamics and the frustration parents have when schools are not following IDEA. This awareness assisted her in interviewing parents and knowing the different types of training available to parents. The researcher has also socialized and attended music therapy camps with several of the parents who participated in the interviews. In essence, the participants in the study were peers to the researcher.

The researcher was very interested to determine whether her experiences paralleled others. To try and minimize the bias, the investigator followed the interview protocol closely, transcribed verbatim the recorded interviews, and reported the parents’ actual words. The transcriptions and the interpretation of the themes were also reviewed by a master’s candidate with qualitative research experience not affiliated with the investigator’s research. The reviewer believed theme 9 should be revised to reflect parents reported advocating for schools to know how Williams syndrome affects their child but also know their child as an individual. Theme 9 was revised based on the outside review.

Definition of Terms

There are a number of terms specific to the field of special education. The following is a list of terms defined for the purpose of this study to avoid confusion.

**Accommodation**: the topic, product, activities or feedback are changed without lowering or changing the academic standard (Hammeken, 2000). Changes can include presentation format, response format, testing location, and the amount of time taken during testing (Wright & Wright, 2007).
Advocate: a person who argues for a cause; a supporter or a defender (Wright & Wright, 2006, p.4). In educational advocacy, people are taking action by empowering themselves with knowledge and skills and identifying barriers and challenges to ensure quality educational programs for children (Mitchell & Philibert, 2002).

Inclusion: principle of a student’s first choice of placement being in the regular education classroom with supplementary aids and services necessary brought into the classroom (Villa & Thousand, 2003). Access, participation, and supports in all areas of life are the key factors to inclusion as defined by the Division of Early Childhood of the Council of Exceptional Children (DEC) and National Association for the Education of Young Children (NAEYC) (2009).

Individual Education Plan (IEP): a written document developed, reviewed, and revised in accordance with section 1414 (d) of IDEA (20 U.S.C. § 1401).

Least Restrictive Environment: legal requirement to educate children with disabilities in general education classrooms with children who are not disabled to the maximum extent possible (Wright & Wright, 2007, p.427).

Modification: lower or change the academic standard to better meet the instructional needs of a student (Hammeken, 2000). Substantial changes are made in what the student demonstrates including changes to the instructional level, content, and performance criteria. Changes may also include test format and form (Wright & Wright, 2007).
Summary

Chapter One has provided an overview of this research study. A literature review on Williams syndrome, inclusion, and advocacy are included in Chapter Two. The literature review supports the purpose of this study regarding the need to understand parents’ methods of advocating for their children with Williams syndrome.

Two main questions guide this study. First, how have parents of students with Williams syndrome in the United States who have been educated in the regular education classroom in early elementary school for more than 75% of the school day advocated for their children? Second, what do parents believe are the accommodations and modifications that have been most effective for their child in the general education classroom?

Chapter Three describes the research methodology on how these questions will be answered by interviews of the participating parents. The information collected from the interviews was analyzed to find commonalities in advocating for their children and the modifications and accommodations the parents found to be effective.

Chapter Four provides a brief description of the participants and their child with WS. This chapter also includes information on how the participant was chosen to be a part of the study and where the interview was conducted. Chapter Five includes the findings of the research. The individual stories and analyses are included and Chapter Six summarizes the research providing recommendations and conclusions.
Chapter Two

Literature Overview

Introduction

Chapter Two reviews the current literature on the three areas involved in this research: parent involvement in the educational process, inclusion, and Williams syndrome. Parent involvement for a child with disabilities goes beyond attending class parties and helping the child with homework. The parent becomes a member of the IEP team and must be aware of the supports and services and the different learning environments available for their child. One of the environments is the regular education classroom. IDEA states children should be educated with their peers in the regular education classroom as much as possible. Finally, the last section of the literature overview is focused on Williams syndrome and how missing approximately 20 genes can manifest to cause differences in the learning process. The literature discusses the various issues related to educating individuals with Williams syndrome from a strengths-based approach. The first area to review is the literature on parent involvement in the education system and especially parents with children with special needs.

Parents of Children with Special Needs

Parent Involvement

Once a parent understands their child’s strengths and weaknesses then the parent can begin to advocate for their child with special needs. Parents need to be involved in the education of their children whether the children have special needs or not. Joyce
Epstein’s parent involvement theory (2004) discusses the message parents give their children about the importance of attending school and working hard as a student when the parents are involved in their child’s education. Epstein described six types of involvement to help strengthen a comprehensive program of school, family, and community partnerships. The six methods include parenting, communicating, volunteering, learning at home, decision making, and collaborating with the community. School programs may need to help families by providing information related to parenting skills, family support, child development, and creating optimal learning conditions at home for students at all ages. Schools must provide a varied, clear, and productive communication program in order to promote two-way communication between school and home. Families need to be more involved with the schools as volunteers and audiences.

Epstein and Jansorn (2004) also argue that a key component of parent involvement is the ability of the parent to support their children’s learning at home. Parents need to be part of the school decision making process through school councils, improvement teams, committees, and other parent organizations. Finally, Epstein and Jansorn believe that communities must also be involved in supporting families and that means that schools should help community businesses and agencies provide resources for families.

While Epstein’s work (2004) is targeted to parents of typically-developing children, the research is also highly relevant to the ways in which schools must support families of children with disabilities. Parent involvement needs to begin as soon as the child enters school. Children with special needs often enter kindergarten after receiving
both early intervention (Part C services for infants, toddlers, and their families) and preschool special education services. In 1997, Congress reauthorized IDEA that reflected a strong philosophy of family-guided services, particularly in early intervention (Shannon, 2004; Atkins-Burnett & Allen-Meares, 2000). However, barriers exist to Epstein’s family involvement model and IDEA’s family guided model being fully utilized. Many believe that schools fail to produce environments that welcome and support parents and their participation. In addition, teachers themselves might not welcome parent involvement in the classroom or believe that parents can provide meaningful support (Ferrara & Ferrara, 2005). In turn, parents worry about school personnel retaliating against their children if parents advocate for their children’s needs. Parents report frustration from requesting special accommodations such as a one-on-one aide and being told an aide is not necessary. Parents often feel school personnel do not listen when they describe issues which may occur with their children and the best way to manage those concerns. Parents’ perceptions are that teachers do not respond to their concerns and requests whether dealing with behavior or academic concerns (Ferrara & Ferrara, 2005; Mitchell & Philibert, 2002; Trainor, 2008).

In 1992, the National Parent Teacher Association (PTA) conducted a survey of more than 27,000 local PTA presidents in order to identify barriers to parent involvement as perceived by parents. Parents responded that the biggest issue was not having enough time (89%). The next issues were parents did not believe they had anything to contribute (32%) and parents did not understand the educational system (32%). These issues were followed by lack of child care (28%) and parents feeling intimidated by principals and teachers (25%). School functions were also scheduled at inconvenient times for the
parents (18%), parents encountered language and cultural differences (15%), parents did not have access to transportation (11%), and parents felt unwelcome at school (9%). Once again, this study indicated many parents are apprehensive of the educational system and what teachers and administrators may do to their children if they complain (Edge & Davis, 1993).

**Parent Advocacy**

Parent advocacy is more than being involved with the school system and helping the child with homework. Parents of children with disabilities are expected to serve as an accountability measure for the IDEA educational system (Leiter & Krauss, 2004). During the initial passage of IDEA, Congress determined that school systems could not be trusted to fully implement IDEA; congressional testimony indicated parents could be the checks and balances to the system, advocating to ensure that schools provided the appropriate supports and services necessary to improve the educational outcome for students with disabilities (Wang, Mannan, Poston, Turnbull, & Summers; 2004).

The role of parent as advocate is reflected in the results of a 2002 national phone survey conducted by Public Agenda of 510 parents of children with special needs. In this study over half the parents stated that parents have to find out on their own what is available for their children. Schools do not provide information on the options available. A large majority of the parents surveyed (70%) say parents have to determine services and supports on their own and believed the children with parents who did not learn about services lost out. Forty-three percent of the parents said they had to stay on top of the school and fight for services for their children.
Wang et al. (2004) researched parents’ perceptions of advocacy and the impact the advocacy had on the quality of the family’s life. Parents view advocacy as an obligation to ensure someone is speaking for their child. Parents often advocated by making phone calls, writing letters, contacting administration, and educating professionals about their child’s strengths and weaknesses. Parents believed doing these activities helped their child to receive better services. The parent advocates indicated that to be good advocates they had to develop many skills. Parents believed important and necessary skills were to understand the specifics of their child’s disability, know the educational laws, know where and how to get additional resources, and know how to ask for help. Parents also discussed advocacy as a lifelong endeavor that could negatively affect the physical and emotional well-being of the family. The study found two factors which helped to eliminate the negative impact on advocacy. If the family felt the child was receiving an appropriate education, then the parents did not believe they needed to fight for their child. Also, family and professional partnerships were helpful in developing open communication, trust, and respect.

Many organizations exist to help families to advocate for their children. Wrightslaw and Partners in Policymaking are two national organizations educating parents on how to advocate for their children. Peter Wright and Pamela Darr Wright founded Wrightslaw in order to provide training and information on special education law and advocacy for children with disabilities. The Wrightslaw website (http://www.wrightslaw.com) offers parents and educators information related to special education such as response to intervention, free appropriate public education, and legal
requirements of an individual education plan (IEP). Wrightslaw has also written several books and provides training nationwide on special education law and parent advocacy.

Another organization developed to assist parents in better advocating for their children is Partners in Policymaking. Partners in Policymaking was created over twenty years ago by the Minnesota Governor’s Council on Developmental Disabilities and has become a national training program “to change the way people with disabilities are supported, viewed, taught, live and work.” More than 15,000 parents and self-advocates have graduated from the Partners in Policymaking training programs which are offered as online courses and also in cities across the country (http://www.Partnersinpolicymaking.com, 2009).

Advocating does not have to become adversarial. In his advocacy training, Pete Wright, one of the founders of Wrightslaw, discusses working with the school district. The family and the school district must work like a marriage with no chance of divorce. Schools and families have to learn to work together. Teachers voluntarily admit having minimal training in working with parents. Limited professional development exists at the school or district levels that address the importance of the role of parents and how classroom professionals can benefit from parental influence in order to improve and sustain student learning (Ferrara & Ferrara, 2005). With parents becoming increasingly educated on special education laws and services, educators and school administrators need to understand IDEA, especially in relation to supports and services guaranteed to students under this legislation. Often parents know more about IDEA than the professionals and as a result, professionals often give parents inaccurate information.
More training needs to be provided for the training of the professionals (Leiter & Krauss, 2004).

As stated earlier, family and professional partnerships are important in order to support a free appropriate public education to students with disabilities. Turnbull, Turnbull, Erwin, and Soodak (2006) define partnership between parents and educators as a group of people cooperatively working together with shared rights and responsibilities. Willingly, agreeably, and courteously are all synonyms to cooperatively. Turnbull et al. identified seven principles of partnership: trust, communication, professional competence, respect, commitment, equality, and advocacy. Trust is the principle holding all of the other pieces together. If the educators or the parents do not trust one another, then the partnership will be fragile or will not exist. People naturally want to trust other people but if parents have trusted a school professional only to find later that this trust was abused, the next teachers and educational professionals will not be trusted.

Educators should understand the history between the parents and school system to assist in rebuilding trust. Parents also hear stories from other parents about how school districts or specific teachers have treated children with disabilities. The school may have done nothing to cause distrust with a particular family but the shared history of children with disabilities has already caused parents to be on guard. Parents and teachers need to work together to partner and have trust in one another by being reliable, using sound judgment, maintaining confidentiality and trusting yourself. The other six principles can be developed simultaneously while building trust but all of the people involved need to understand a good partnership will not exist without trust.
Inclusive Education

Definition

The number of students receiving services under IDEA has steadily increased (The Condition of Education 2009). In 1976-1977, the number of students with disabilities under IDEA was 8% of the total public school enrollment of students between the ages three to twenty-one. By 2003-2004, approximately 14% of the total student population was receiving services under IDEA. In the 2006-2007 school year, four disabling conditions account for 79% of all of the disabling conditions that effect students with disabilities: specific learning disabilities (40%), communication disorders (22%), other health impairments (9%), and cognitive (8%).

Inclusive education (inclusion) is defined in different ways by different people. Bauer and Shea (1999, p. 273) define inclusion as “the philosophy that all students, regardless of disability, are a vital and integral part of the general education system; IEP goals and objectives of students with disabilities are rendered in the general education classroom.” General education teachers and special education teachers work together as a team in inclusive classrooms. Adaptations and modifications are incorporated into the general education as part of the curriculum (Bauer & Shea, 1999).

Others define inclusion slightly different. Inclusion is educational services to students with disabilities in the general education classroom with the correct support in the regular classroom. The term “inclusion” means all students in a school are taught together no matter the strengths or weaknesses. All students are part of the school community (Burke & Sutherland, 2005). IDEA does not use the word inclusion. However, IDEA states in section 20 U. S. C. § 1412:
to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Hence, IDEA considers the regular classroom to be the least restrictive environment. When defining inclusion, the Council for Exceptional Children (CEC; 2009) discusses how the students do not have to be doing necessarily the same work as their peers but gaining some benefit from being in the regular classroom. The point is that schools should make every effort to bring supports and services into the classroom instead of the student going to the supports and services.

General educators identify budgetary factors, accountability, access to equipment and materials, and the physical environment of the classroom and the school as barriers to preventing inclusion of students with disabilities. General education teachers cite class size, lack of professional preparation in special education and disabilities, problems with students with behavior and emotional problems, and limited instruction time as factors inhibiting planning for students with disabilities. Teachers mention inclusion is easier if a common goal exists for how the students will be included, an additional person is in the classroom to assist with issues and support personnel are available to assist with technical issues, assessment, and general supports (Bauer & Shea, 1999).
Based on a review of the research on inclusive educational outcomes, Hunt and Goetz (1997) developed the following six guidelines surrounding inclusive education:

1. Parental involvement is required.
2. Students can make positive academic and learning growth in inclusive environments.
3. All students with disabilities need to experience acceptance and friendships.
4. Students without disabilities benefit.
5. School personnel must collaborate.
6. Modifications to the curriculum are necessary.

Several methods and initiatives have been developed to assist teachers in providing a classroom community where all students are learning the general education curriculum and benefitting from being in the regular education classroom. Some of these methods include response to intervention (RTI), differentiated instruction, universal design, co-teaching, and multiple intelligence theory. These methods can be used separately and collectively in the general education classroom in order to support inclusive education.

**Response to Intervention (RTI)**

The response to intervention model was developed as a framework for identifying students with a learning disability and determining if interventions within the classroom could help the student (Fuchs & Fuchs, 2007). The model offers high-quality instruction and intervention matched to a student’s individual needs in two to four tiers of interventions that increase in intensity. Within this tiered model of interventions, a
student who is having academic or behavioral difficulties receives a scientifically based intervention. The teacher or other specialist monitors the student’s progress to determine whether the intervention has worked or if other interventions are necessary. Additional interventions of increasing intensity are tried and monitored if the original intervention did not work. It is important to note that not only is the student’s progress monitored, but educators monitor the implementation to ensure that teachers are delivering it appropriately or as intended. Teachers monitor the progress of all students in a classroom, however the frequency and intensity at which teachers monitor progress depends on the student’s needs and the intervention tier (Berkeley, Bender, Peaster & Saunders, 2009; Reutebuch, 2008).

An example of an RTI process is the three-tier approach. The first tier is the general education curriculum without any additional interventions. Short term monitoring of students at risk occurs. The second tier includes small group tutoring in reading and math. The small groups should receive instruction three to four times per week from 10 to 20 weeks to help guarantee mastery for a majority of the students. The students who master the information require no additional intervention. The students who did not master the curriculum receive additional interventions in tier 3. During the third tier an individualized program is developed and a multidisciplinary evaluation occurs to identify specific disabilities (Fuchs & Fuchs, 2007).

Originally, RTI was adopted to determine a child’s eligibility for special education but the principles work for all students, including those who are not on IEPs, but who are struggling academically (Berkeley, Bender, Peaster & Saunders, 2009; Reutebuch, 2008). Since the least restrictive environment is the regular education
classroom, whether a student has already been identified for special education should not matter. The goal is to provide all students the interventions needed to be successful while learning the curriculum. As stated by Cummings, Atkins, Allison and Cole (2008), “The RTI process is about more than special education eligibility; it is ultimately a focus on school improvement to build effective systems of service delivery” (p. 30).

**Differentiated Instruction**

Differentiated instruction is one useful approach to building an inclusive educational environment. Differentiated instruction is a process where teachers vary approaches to content, process, and product in anticipation of learners’ varying degrees of readiness and different interests and learning needs. Curriculum is not differentiated when the assignments are the same for all students (Bauer & Shea, 1999; Thousand, Villa, & Nevin, 2007). Teachers using differentiated instruction expect students to bring a diversity of experiences, abilities, interests, and styles to learning. Teachers acknowledge this diversity purposefully and address the variations when planning and delivering rigorous and appropriate, yet flexible and responsive, curriculum and instruction (Broderick, Mehta-Parekh, & Reid, 2005).

Tomlinson (1995) offered a description of how instruction could occur in classrooms with differentiated instruction: a cycle of instruction, review, and sharing with the entire class and then individual or small-group investigation for a continuous pattern of teaching and then learning. The teacher and the entire class start work on a topic or concept and then the students use different materials to continue to explore the topic. The entire class then shares what has been learned and determines additional
questions. The students then work on tasks the teacher suggests to further understand key ideas at different levels of difficulty. The entire class meets again to share the findings. Students then choose groups to work together to solve problems related to the subject provided by the teacher. Students choose the areas of interest to apply and continue the learning process. The entire class meets again to share individual projects and determine ways to evaluate the projects.

Teachers can effectively differentiate instruction by: “constantly assessing students’ understandings, teaching responsively, and enabling students to demonstrate competence in varied, meaningful ways” (Broderick, Mehta-Parekh & Reid, 2005, p.200). Then, all students can fully participate successfully as members of a regular education classroom. Effectively differentiating instruction in classrooms is a great tool to assist teachers in creating inclusion (Broderick et al., 2005; Thomas & Loxley, 2001).

**Universal Design for Learning**

When using differentiated curriculum educators are often retrofitting the curriculum or modifying it to meet students’ needs, interests, learning styles, and abilities. The ideal is to use the methods of differentiated curriculum during the planning phase taking into consideration different types of learning styles and facts about the learners. Universal design for learning (UDL) applies the universal design principles architects and product designers use to make buildings and products usable by as many people as possible. A curriculum that is initially designed to meet the needs of all students does not require subsequent modifications or accommodations. Principles of UDL are reflective of an understanding of the importance of flexibility in how students
will use materials to learn and how they will demonstrate their learning. Educators design curriculum to provide all students access to the content, product, or process with minimal retrofitting. *Access to the content* refers to the presentation of the general education content standards. For example, teachers review the curriculum standards to create lessons from the guidelines based on information about the students such as learning styles, past experiences, and prior knowledge. *Product access* is concerned with how the students will demonstrate what they have learned. Students can and should be able to demonstrate what they have learned in many different ways. For example, some may be able to produce written answers on an exam while others may need to verbally provide their answers to the teacher. Teachers should provide for multilevel and authentic assessments. Finally, *process access* refers to how teachers structure the learning activities to match how the students apply the knowledge and have an understanding of the curriculum. *Process access* includes instructional formats, arrangements, strategies, classroom environment, and co-teaching approaches. This may include students working with peers, listening to tape recorded information, or having students draw or compose a song (McGuire, Scott, & Shaw, 2006; Spooner, Baker, Harris, Ahlgrim-Delzell, & Browder; 2007; Thousand et al., 2007).

**Multiple Intelligence Theory**

Thousand et al. (2007) describe the multiple intelligence theory as one supportive framework for differentiating curriculum. Howard Gardner viewed intelligence as multifaceted, not simply the type of intelligence routinely evaluated using a traditional intelligence quotient (IQ) tests (Moran, Kornhaber, & Gardner, 2006). Gardner believes
that intelligence exists in many different dimensions and identified eight distinct categories: linguistic, logical-mathematical, spatial, bodily-kinesthetic, musical, interpersonal, intrapersonal, and naturalist. Gardner believes that people have intelligence in all of the categories but in different proportions. When educators realize that their classrooms are comprised of students who have different types of intelligence, then they can and should implement a wide variety of teaching strategies. For example, teachers can incorporate rhythms, songs, and chants for students who are more musically inclined while not forgetting to use other methods for students who are not musically inclined. No single technique will work best for all students all of the time, therefore teachers constantly change their manner of presentation and assessment. The flexibility in lessons and assessments mentioned in universal design becomes essential when educating students based on the theory of multiple intelligences (Armstrong, 2000; Stanford, 2003; Thousand et al., 2007).

**Co-teaching**

Universal design and differentiated curriculum require collaboration among educators. The special education teacher or intervention specialist and the regular education teacher must work together. IDEA requires collaboration among teachers. Regular education teachers and special education teachers are both part of the IEP team. Co-teaching is a method for collaboration where all educators on a team are responsible for differentiating instruction or developing universal designed curriculum (Hang & Rabren, 2009; Thousand et al., 2007). Thousand et al. (2007) believe that “anyone who has an instructional role in a school can co-teach: classroom teachers, paraprofessionals,
special and bilingual educators, content specialists such as reading teachers, support personnel such as speech and language therapists and school psychologists, volunteers, and students themselves” (p. 121-122).

Thousand et al. (2007) describe four basic approaches to co-teaching as: supportive, parallel, complementary, and team teaching. No one approach is better than another. Co-teachers should not use only one method but a combination of the methods over the school year. In supportive co-teaching, one teacher is the lead teacher while the other co-teacher walks around the room and assists students who need additional help or clarification. During parallel co-teaching, the co-teachers break the class into groups and each co-teacher works with a group of students. All students with disabilities do not need to be placed with the special education teacher. The groups should be based on learning styles and strengths, and group dynamics. One co-teacher improves on the lessons of the other co-teacher during complementary co-teaching. A co-teacher may paraphrase the lesson or provide diagrams to assist in the learning process. Team teaching occurs when the lesson is divided to capitalize on each of the co-teacher’s strengths. Successful co-teaching occurs when students view both teachers equally in the classroom.

**Summary**

This review has demonstrated the importance of parent involvement as discussed by Joyce Epstein (2002), the need for parents to advocate for their children per IDEA as the checks and balances and methods for enabling a child to be taught in the regular education classroom. The last part of the literature review is specific to a rare syndrome. This next section discusses attributes of Williams syndrome, the strengths and
weaknesses and how to make certain the students with Williams syndrome are taught in
the least restrictive environment with parent involvement and advocacy using inclusive
teaching methods.

**Williams Syndrome**

**Introduction**

Williams syndrome (WS, also known as Williams-Beuren syndrome) is a rare
genetic disorder characterized by physical, cognitive, and behavioral characteristics.
Williams syndrome was discovered independently by Fanconi in 1952 and Williams, a
British cardiologist, in 1961 (Bellugi, Lichtenberger, Jones, Lai, & St. George, 2001).
Williams syndrome is characterized by dysmorphic facies (100%), characteristic
cognitive profile (90%), cardiovascular disease (80%), and cognitive delays (75%)
(American Academy of Pediatrics, 2001). Until the mid-1990s, diagnosis was made
principally by clinical geneticists on the basis of characteristics including: distinctive
facial features, cardiac issues, failure to thrive in infancy, and delayed development
(Bellugi, Lai, & Wang, 1997).

People with Williams syndrome have a microdeletion on chromosome 7q11.23 of
approximately 17 genes (Francke, 1999; Korenberg et al., 2000, American Academy of
Pediatrics, 2001). The missing region typically includes the elastin (ELN) gene. The
elastin gene deletion was discovered in 1993. The ELN gene codes for the structural
protein elastin, an important component of the elastic fibers found in the connective
tissue of many organs. The elastin deletion explains some of the characteristics of WS,
such as some of the facial features, hoarse voice, bladder and bowel verticula,
cardiovascular disease, and orthopedic problems. Research has not explained the cause
of other characteristics, such as hypercalcemia, delayed cognitive development, and unique personality traits (American Academy of Pediatrics, 2001).

A reliable test was developed to detect the deletion using fluorescent in situ hybridization (FISH). The FISH test is performed using a DNA probe on a person’s chromosomes through a blood test. The reliability of the FISH test is greater than 99% (Morris, 2001). Williams syndrome occurs approximately 1 in every 7,500 births. Before the availability of a diagnostic laboratory test, previous studies estimated that WS occurred in 1 in every 20,000 births. The parent of origin can be either the mother or father (Morris, 2004).

Men and women are equally affected by Williams syndrome. The syndrome has been identified in all populations and social classes. Neuropsychologists are interested in the genetic etiology of the syndrome to try and explain the link of unusual patterns of cognitive abilities to the deletion of specific genes and understand how specific genes contribute to cognitive ability (Monnery, Seigneuric, Zagar, & Robichon, 2002).

IQ scores of individuals with Williams syndrome typically range between 40 and 90 on the Wechsler Full Scale IQ with a mean of approximately 55 (Bellugi, Lichtenberger, Jones, Lai, & St. George, 2001). Individuals with Williams syndrome typically have a verbal mental age higher than their general IQ (Levy, Smith, & Tager-Flusberg, 2003). Most individuals with Williams syndrome rank in the mild to moderate cognitively delayed range although variability of intellectual function within the population with Williams syndrome exists (Bellugi, Lai, & Wang, 1997; Morris, 2001). The IQ scores of people with Williams syndrome may not accurately reflect true intellectual potential. IQ tests comprise a number of subtests measuring different types of
abilities. People with Williams syndrome typically exhibit large differences across the various subtests of most IQ tests, with peaks and valleys of abilities across cognitive domains (Morris, 2001; Semel & Rosner, 2003).

**Neurobiological Profile**

A series of studies completed by Neville, Mills and Bellugi (as cited in Bellugi et al., 1997) “using event-related potential (ERP) techniques to assess the timing and organization of neural systems active during sensory, cognitive, and language processing in Williams syndrome subjects” (p.339). Responses from the people with Williams syndrome did not show the results received from a person with a normal brain which suggests a different brain organization is responsible for the language capacities. Results of the neuromorphological characterization of the cerebral volume are less than age-matched normal controls. The thalamus and lenticular nuclei are also less preserved in people with Williams syndrome while the neocerebellar vermis and the neocerebellar tonsils are both the same or larger than a normal brain. The specific regions of the neocerebellum sometimes enlarged in people with Williams syndrome are often smaller in people with autism (Bellugi et al., 1997).

“The finding that anterior, temporal limbic, and neocerebellar regions are selectively preserved in Williams syndrome subjects suggests that they all may come under the influence of a single, genetic, developmental factor (Bellugi et al., 1997, p. 340).” Williams syndrome involves specific rather than general cognitive issues and offers an important opportunity for linking specific sections of the brain to specific cognitive profiles (Bellugi et al., 1997).
Behavioral Issues

Advances in human genetic research and identification of over 1000 genetic intellectual disability syndromes have caused researchers to become interested in understanding how the addition or deletion of specific genes affect aspects of cognition, language, and different behaviors. Recently, researchers have been interested in understanding the link between genetics and behaviors (Dykens, Hodapp, & Finucane, 2000; Ly & Hodapp, 2005).

Klein-Tasman and Mervis (2003) conducted a study comparing 8 to 10 year olds with Williams syndrome and 8 to 10 year olds with developmental disabilities of other origins. The children with Williams syndrome “were shown to be more anxious, more fearful, more curious, and less reserved toward strangers” (p.272). In another comparison with children with developmental disabilities of other syndromes, the children with Williams syndrome were “rated higher on the items ‘often initiates interactions with others,’ ‘never goes unnoticed when in a group,’ and ‘has many fears’” (p. 273). The children were also observed as having attention problems compared with typical children. However, the attention problems were similar to children with other developmental disabilities.

Tomc, Williamson and Pauli’s study (as cited in Klein-Tasman & Mervis, 2003) examined the disposition of 204 children diagnosed with Williams syndrome from 1 to 12 years old by comparing parents’ ratings to norms for children with typical development. “Relative to chronological age (CA) norms, the children with Williams syndrome were rated as significantly more approaching, significantly higher in intensity,
distractibility, negative mood, and significantly lower in persistence and threshold of excitability” (p.272).

In Dykens’ study (as cited in Fidler, Hodapp, & Dykens, 2002) of fears and anxieties, a majority of children with cognitive delays reported only two fears - parents getting sick and getting a shot or injection.

In contrast, more than half of the group with Williams syndrome endorsed 41 different fears. Some involved interpersonal issues like being teased (92%), getting punished (85%), and getting into arguments with others (85%). Others involved physical issues, such as getting shots or injections (90%), being in a fire or getting burned (82%), and getting stung by a bee (79%). Other fears related to hyperacusis or clumsiness (loud noises or sirens 87%; falling from high places 79%; and thunderstorms 78%). Though not every child with Williams syndrome shows any or all of these fears, the vast majority do appear to be overly fearful compared to most children with mental retardation (p.81).
Children with Williams syndrome display high levels of attention-seeking behavior, social disinhibition, and overly friendly behavior (Davies, Udwin, & Howlin, 1998). Endearing early on, overly friendly behaviors put children with Williams syndrome at risk for abuse at older ages (Dyckens & Hodapp, 1997). In addition, although the behavior may be superficially friendly, children with Williams syndrome often lack the skills necessary to maintain appropriate friendships. Many children with Williams syndrome are described as being socially isolated (Einfeld et al. 1997; Udwin, 1990).
Auditory Perception

Levitin, Cole, Lincoln, and Bellugi, (2005) studied whether children with Williams syndrome had a lowered hearing threshold, true hyperacusis, or auditory allodynia which is an aversion or fear of certain sounds. Parents of 118 children with Williams syndrome participated in the study. The results indicated children with Williams syndrome have four unusual auditory perceptions: hyperacusis, odynacusis, auditory aversions, and auditory fascinations. The hyperacusis might be described as an attentiveness to sounds either too soft or insignificant to others. Both odynacusis, a lowered pain threshold for loud sounds, and auditory allodynia create pain in people with Williams syndrome and together cause dislikes to certain sounds. The study also indicated an extreme fascination to certain types of sounds which were often the same sounds the child was frightened by when younger. Sounds causing an aversion were water running, babies crying, toilets flushing, vacuum cleaners, and fire alarms. Parent report 95% of their children had a decrease in hearing issues with age.

Physical Issues

Williams syndrome affects a person physically in many ways. People with Williams syndrome are often small in stature and have small, widely-spaced teeth (Scheiber, 2002). Individuals with Williams syndrome can have many health issues. The health problems can be severe and some life threatening such as the cardiac issues. Most individuals with Williams syndrome require recurrent medical and dental checkups, tests, and procedures. The physical issues are often treated before the child with Williams
syndrome reaches school age. Low muscle tone, however, continues to be an on-going problem. Individuals with Williams syndrome often have poor or low muscle tone, or hypotonia. Hypotonia does not allow controlled motion of the joints and is often accompanied by poor posture. Other individuals with Williams syndrome have the opposite muscle problem of excessive muscle tone or hypertonia. Hypertonia is manifest by resistance to movement, tight joints permitting a limited range of motion, and awkward or stiff posture. Physical therapy and occupational therapy are usually a part of the treatment plan. Therapists generally focus on improving body trunk stability, and assisting the individual with improving their ability at fine and gross motor activities (Semel & Rosner, 2003).

**Educational and Cognitive Characteristics**

Students with Williams syndrome do not all learn in the same manner or have the same abilities. However, most of the students have similar characteristics when observing their language development, spatial relationship skills, implicit learning, and reading approach. An educational profile has not been developed of the best accommodations for inclusion in the regular education system due to the range of IQ scores, physical and behavioral characteristics.

**Language Development**

Research indicates individuals with Williams syndrome have vocabulary skills at or above expected levels given the person’s cognitive deficits based on IQ scores (Mervis, 1999). Researchers found 48% of a sample of 85 children and adolescents with
Williams syndrome scored in the normal range (≥70) on the Peabody Picture Vocabulary Test-Revised (PPVT-R), a test of receptive vocabulary (Mervis, Morris, Bertrand, & Robinson, 1999). Individuals with Williams syndrome are capable of working with grammatical structures, and are also able to examine and correct ungrammatical sentences (Bellugi et al., 1997).

A study comparing children with specific language impairment, children with Williams syndrome, and typically-developing children indicated the children with Williams syndrome performed almost as well as their typically-developing peers even though their average IQ score was 36 points lower. Another example of the peaks and valleys in the skill levels of children with Williams syndrome is how they function near adult level on tense markings even though their general language development is comparable to children with specific language impairment (Rice, 1997).

Robinson, Mervis, and Robinson (2003) study indicates “children with Williams syndrome share a stronger relation between working memory and grammatical ability than typically developing children” (p. 28). The children were able to maneuver items in memory rather than simply memorize and store in short-term memory verbal items. This operation is believed to be a crucial factor in the acquisition of grammar. The importance of working memory to the grammatical development of children with Williams syndrome indicates a critical difference in how children with Williams syndrome acquire language.

Another study which provides evidence to the difference in language development of children with Williams syndrome was completed on 10 French native-speaking individuals with Williams syndrome. The people with Williams syndrome performed tasks similar to the control group on the categorization task. The individuals with
Williams syndrome had no issues with gender agreement. The data demonstrated people with Williams syndrome are able to take word endings into account and made use of the ending clues more efficiently than the control group. The results indicate people with Williams syndrome build language-specific phonological representations (Monnery, Seigneuric, Zagar, & Robichon, 2002).

Results from a study completed in Britain are consistent with the results of the French study. Seventeen individuals with Williams syndrome, ranging in age from 8 years to 35 years were recruited via the British Williams Syndrome Foundation. The researchers found phonology to be relatively unimpaired in individuals with Williams syndrome. However, at age 5 years, when children start to use other methods for word association, individuals with Williams syndrome continued to rely a great deal on the ability to retain phonological material in short-term memory. All the results indicate people with Williams syndrome only demonstrate a relative advantage of language over other cognitive areas. Strengths and weaknesses still occur within the language domain (Grant et al. 1997).

Ypsilanti, Grouios, Alevriadou and Tsapki’i’s (2005) study of six children with Williams syndrome with a chronological age from 10.2 to 17.8 years documents that receptive language is not always a relative advantage in children with William syndrome. The variability suggests individuals with Williams syndrome may not exhibit a single cognitive profile. The projection of linguistic abilities in children with Williams syndrome may be unpredictable.

The research on vocabulary and word acquisition of infants with Williams syndrome supports the infants also follow an unusual developmental pattern. Word
production is more advanced than word comprehension (Singer, Bellugi, Bates, Jones, & Rossen, 1997). The delayed vocabulary acquisition often precedes by up to 12 months the emergence of extensive categorization and the ability to link sound patterns to unnamed objects (Mervis & Bertrand, 1997). The research of infants with Williams syndrome suggests alternative ways to acquire vocabulary not seen in characteristic development may exist (Nazzi & Bertoncini, 2003).

**Spatial Relationships**

A majority of the people with Williams syndrome have severely impaired spatial cognition together with relatively spared language (Frangiskakis et al., 1996; Mervis et al., 1999; Morris, 2001). The issue of spatial location is an important function of cognitive development. Spatial location is crucial to perception, action, and language. The ability to focus and track objects over time, complete actions on stable and moving objects, and discuss the identities and locations of objects relative to each other such as above, below, first or second is important for individuals (Landau & Hoffman, 2005).

The nature of the spatial issues in people with Williams syndrome is not well understood. Variability exists even within the broad domain of special cognition. The results of the study completed by Landau and Hoffman (2005) show preservation and breakdown in the use of spatial reference systems among children and adults with Williams syndrome. Despite the classic profile of severe deficits in some aspects of spatial cognition, people with Williams syndrome often develop reference systems to represent an object’s location, as well as to talk about the locations.
Implicit Learning

Don, Schellenberg, Reber, DiGirolamo and Wang (2003) studied implicit learning in 27 children and adults with Williams syndrome ranging in age from 9 to 49 years of age. Implicit learning occurs without conscious awareness and believed to be a more basic form of learning.

The results indicate that individuals with WS are capable of implicit learning in at least two contexts: (a) a categorization task in which stimulus grammatically depends on a complex, probabilistic, and unstated set of rules (artificial grammar learning, AGL), and (b) a simple, repetitive motor-learning task (RP) (p. 218). However, on both the categorization and repetitive motor-learning task the participants with Williams syndrome were below the levels of a chronologically age matched control group. Don et al. found the same issues as Landau and Hoffman (2005) indicating people with Williams syndrome have definite strengths and weaknesses. When researching the cognitive strengths, the people with Williams syndrome appear to accomplish the tasks “by nonstandard processing mechanisms” (Don, et al., 2003, p. 222).

Reading

Laing, Hulme, Grant, and Karmiloff-Smith (2001) studied 15 individuals with Williams syndrome ranging in age from 9 to 27 years. The researchers recruited participants through the Williams Syndrome Foundation, the United Kingdom support group for parents, and were from middle- to lower-middle-class socioeconomic backgrounds. The results indicate some individuals with Williams syndrome can learn to read; however the level of reading ability obtained is low. On average, individuals with
Williams syndrome are better at decoding skills than reading comprehension skills. The researchers determined the critical need to examine the exact process students with Williams syndrome use in learning to read rather than merely the final product of learning indicated by performance on standardized reading tests. Reading may not just be delayed in the student with Williams syndrome but the reading process may not follow the same developmental structure as typical students (Laing, 2002).

Levy et al. (2003) also completed a study on reading where 20 individuals with Williams syndrome were tested during the United States National Williams Syndrome Association Family Conference in July of 2000. The ages of the individuals ranged from 12 to 20 years. The results indicated a wide range of reading levels. Three individuals were not able to name some letters of the alphabet or read familiar or non-words while three participants achieved the age-appropriate level of performance on the non-word reading test. The important implications for educational programming for teaching reading skills to children with Williams syndrome are to emphasize the phonics approach. Morris (2001) has also studied reading levels of individuals with Williams syndrome and has found higher achievement in reading than other academic areas with the mean reading level at fifth grade. Reading levels ranging from first grade to college were observed.
Educational Placement

Classroom Placement

Most children with Williams syndrome are being educated in the regular education classroom for at least part of the day. However, approximately 40% of the students are in a special education class placement (Fidler et al., 2002). Students with Williams syndrome seldom can be educated in a standard classroom without supports and services mainly due to their unusual ability profile. The regular classroom is important for the modeling and contact with normally developing peers and should be considered for at least part of the day. However, the curriculum and learning programs need to be considered in accordance with the student’s strengths and weaknesses no matter where the academic placement is made. Program flexibility, concrete instruction, active learning, built-in success and realistic program goals are important for positive academic outcomes (Semel & Rosner, 2003).

Many times the etiology-related characteristics of Williams syndrome are not considered during the IEP meeting unless parents bring information to an IEP meetings and advocate for services. Services depend on how much the IEP team knows about the syndrome and the behaviors associated with the syndrome. Due to the low incidence of Williams syndrome, it is reasonable to assume that special educators, administrators, and related service providers may not be aware of how Williams syndrome impacts learning and academic success. For education professionals, parents who have raised children with Williams syndrome for a number of years can be a good source of information. Unfortunately, parents are primarily informed about the behaviors associated with
Williams syndrome but are less attuned to the cognitive-linguistic profile (Fidler et al., 2002).

Fidler et al. (2002) completed a study about the educationally related behaviors of children with Williams syndrome as compared to two other genetic syndromes. Twenty-one participants with Williams syndrome with an average age of 12.76 years and a range of cognitive impairment levels (as reported by parents) participated in the study. Most of the students who participated in the study had mild (66.7%) or moderate (28.6%) delays. In this study, only 19% of the students with Williams syndrome received their education in the general education classroom. The majority of students (42.9%) received services in self-contained special education classrooms, while 38.1% received services in “mainstreamed” settings. An aide was in the regular education classroom for 71.4% of the students and a one-on-one aide was provided to 38.1% of the students.

![Classroom Placement of Students with WS (2002 study)](image)

Figure 2: Classroom placement of students with Williams syndrome from the 2002 study.
Fidler et al. (2003) report that, “in general, most parents probably do not hold strong opinions on the larger issue of etiology-related versus non-categorical programming” (p.197). However, parents do scrutinize their child’s school progress and may attempt to align the child’s particular strengths and weaknesses to the educational programs the child receives. For example, parents of a child with Williams syndrome might pursue programs related to music- or language-oriented instruction, as well as increased numbers of classroom aides to help with anxieties, fears, and socialization (Fidler et al., 2003).

In an open-ended education questionnaire, parents were asked the question: “If you could tailor your child’s current educational program to „fit‟ your child more adequately, what changes would you make?” (p. 199) Half the parents with children with Williams syndrome believed their children needed more services from a classroom aide. Many different reasons were cited for wanting an aide. Some parents thought an aide would make it feasible for the child to be in the regular education classroom with typical children. Parents believed the aide was needed to help the child stay with the class academically. The parents of children with Williams syndrome also more frequently expressed a desire for increased musical instruction whether private lessons or more use of music during instruction in the classroom (Fidler et al., 2003).

Parents seemed concerned about musicality and social issues of the syndrome issue but not the visual spatial processing problems. Findings from Fidler et al.’s (2003) study “suggest that parents may support the tailoring of educational programming to meet the syndrome-specific needs of their child in terms of classroom instruction and services received” (p.203). Although Fidler and colleagues did not directly ask whether parents
supported a syndrome-specific approach to special education, the answers suggest parents are aware of the strengths and weaknesses of their children and do want these taken into account when determining the educational approach.

Weiner (1985) as cited in Ly and Hodapp (2005) also researched parents’ perceptions regarding their children’s abilities. Weiner found parents had different views on failure depending on the abilities of their children. If the child was considered to have lower abilities, then the parents expected the child not to succeed. In the study by Ly and Hodapp (2005), parents of children with Williams syndrome were engaged in more directive interactions with their children and provided greater amounts of help and reinforcing behaviors than did parents of normally-developing children. Parents reacted to the children with Williams syndrome based on the accepted behaviors of the syndrome. Because children with developmental delays learn at a slower rate, parents may adapt reactions and behaviors to the child’s functioning. As a result, parents may have lower expectations and standards for success; such expectations may sometimes be incorrectly low given the child’s capability at a specific task.

Parents should be educated about the specific strengths and weaknesses generally found in Williams syndrome. Knowing the strength and weaknesses provides the parents more accurate expectations of the child’s performance. Parents must also realize every child with Williams syndrome will not have all of the behaviors associated with Williams syndrome. Instead of focusing on the child’s weaknesses, parents can encourage their child’s efforts (Ly & Hodapp, 2005).
Educational Strengths

Expressive Vocabulary

Many students with Williams syndrome have excellent vocabularies as reflected in test scores higher than other academic or developmental domains. High scores on vocabulary tests may inaccurately reflect their overall ability levels (Levine, 1993). Unusual words and phrases are common for children with Williams syndrome. The unusual vocabulary can be advantageous for telling stories and for participating in social situations (Hepburn, Philofsky, John, & Fidler, 2005).

Long-term Memory

Once students with Williams syndrome have learned information, they tend to be relatively good at retention. As a result, teachers can capitalize on short and long-term auditory memory when teaching reading. Preschool age children with Williams syndrome are able to memorize songs and storybooks and begin to follow along with the text long before the children are able to read (Levine, 1993). Semel and Rosner (2003) found individuals with Williams syndrome had relatively good phonological rote memory and verbal long term memory skills. This information is useful in understanding how to best help students learn and retain information. For example, asking students with Williams syndrome to verbalize the facts such as names and events in the areas of social studies, science, and language arts helps them retain this information. While initially new material is hard for the child with Williams syndrome to learn, taking the time to teach the information is worth the effort since the information will be retained (Levine, 1993).
**Hyperacusis/Sensitive Hearing**

Teachers can take advantage of the sensitive hearing found in students with Williams syndrome to assist in developing reading skills. Phonetic approaches to reading are often successful since the student is able to easily hear letter sounds and use the sounds to develop word-finding skills (Levine, 1993). However, educators also need to be aware of the child’s hypersensitive hearing and the sounds in a school building such as fire alarms and school bells (Scheiber, 2002). Teaching self regulation strategies such as self-talk can help the students deal with the noise. Alternatively, teachers can give the child some control over the sounds such as allowing the child to push the button for the school bells (Semel & Rosner, 2003).

**Musicality**

Some people with Williams syndrome seem to possess astonishing musical talent or at a minimum a great passion for music. Even though attention span for most tasks is short, many will listen to music, and sing and play instruments with amazing diligence. Most people with Williams syndrome cannot read notes but some of the people with Williams syndrome have perfect or nearly perfect pitch and a sense of rhythm. A number of individuals remember melodies and verses of complex music for years. One person with Williams syndrome sings songs in 25 languages. Youngsters with Williams syndrome discriminate melodies well and show significantly more interest and emotional response to music than people from the general population. One child with Williams syndrome said, “Music is my favorite way of thinking.” Experienced musicians with
Williams syndrome also eagerly sing harmonies, improvise and compose lyrics (Lenhoff & Wang, 1997).

Several strategies and techniques, combined with a great deal of patience, are necessary when teaching a musical instrument to individuals with Williams syndrome. Individuals with Williams syndrome often have physical limitations such as very full lips. The flute and French horn are difficult to play with larger lips. In addition, a limitation in the rotation of wrists and forearms (radio-ulnar synostosis) may require a deviation from standard hand positions (Stambaugh, 1996).

Teachers can capitalize on the musicality of students with Williams syndrome in order to promote learning. For example, students with Williams syndrome are more likely to attend to, learn from, and retain information from lessons or activities that incorporate with music. “Music, songs, and rhyme seem to „speed up the learning process”” (Udwin & Yule, 1998 as cited in Semel & Rosner, 2003, p. 245). Students with Williams syndrome seem to be helped by setting rules of reading to music or rhyme such as “hooked on phonics.” Counting songs, rhymes, and rhythm help students with Williams syndrome establish mathematical relationships (Semel & Rosner, 2003).

**Educational Accommodations and Modifications**

**Receptive Language**

Accommodations should be made in the educational environment to address difficulties in receptive language. Accommodations which can help with a deficit in receptive language include: (1) presenting information verbally and visually by using gestures, facial expressions and pictures; (2) guaranteeing the child is paying attention to
directions by calling the child’s name and touching the child; (3) breaking directions into smaller sections; (4) grouping together similar pieces of information; (5) using applied learning and modeling to teach new skills; and (6) choosing classroom seating minimizing sound distractions (Hepburn, Philofsky, John, & Fidler, 2005).

**Attention Skills and Persistence**

Attention skills and persistence are critical for succeeding in a classroom environment. Structured teaching strategies developed by the TEACCH program (Schopler, Mesibov, & Hersey, 1995 as cited in Hepburn et al. 2005) may be helpful in encouraging persistence.

Ideas include the following: (1) using a visual and verbal schedule to outline the order of activities and expectations; (2) using visual and verbal reminders of how much work is expected (e.g., saying ‘one more minute’ … (3) using a finished box and visually structured tasks such that when all the task pieces are gone, the task is over; (4) starting with brief work periods, followed by rewarding social interactions and gradually increasing the duration of work; and (5) employing errorless learning strategies in difficult activities… (p. 241).

Levine (1993) also suggests allowing some degree of choice for the child in terms of activity, having the child work in small groups and consulting with a behavior support interventionist familiar with positive behavior management approaches.
**Handwriting and Other Fine Motor Tasks**

Students with Williams syndrome generally have illegible writing. Handwriting remains difficult at all ages (Morris, 2001). Students struggle to produce neat, expressive written work. The student may learn much less from the assignment due to focusing on writing mechanics instead of content. After spending more time on an assignment than peers, the students understand the material less. Accommodations need to occur to reduce the impact writing has on learning or expressing knowledge without substantially changing the process of the product. If necessary, modify the curriculum by changing the assignment or expectations to meet the student’s individual needs for learning (Jones, 2005).

The use of computers should be included in the Individual Education Plan (IEP). The student should be taught basic computer skills and also the computer should be used as a tool for other subjects such as math and reading. If name writing is difficult, accommodations could be to use either a name stamp or write just the first letter of the student’s name (Levine, 1993).

**Mathematics**

Mathematics is more challenging than reading for most students with Williams syndrome. Most students can master simple addition and some can learn to use a calculator (Morris, 2001). Teachers should plan instruction to provide concrete examples then move to symbols before progressing to abstract problem solving. Strategies helpful for teaching students with Williams syndrome math include: using
number lines, limiting the number of problems on a page, using real-life examples for measurement, time, and money concepts, and using music to teach math with the principle of multiple intelligence (Scheiber, 2002).

Conclusions

Students with Williams syndrome, teachers, administrators and parents need to understand the necessary accommodations for successful inclusion in the regular educational system. As behavioral and educational information becomes better known to all of the people working with a student with Williams syndrome then more targeted, successful etiology-based instructional accommodations can be developed (Fidler et al. 2002). More research needs to be completed on the best methods to develop the etiology-based instruction which can still be applied in the general education classroom for all students with disabilities. None of the teaching methods such as response to intervention, differentiated instruction or universal design are specific to students with Williams syndrome.

Once parents understand Williams syndrome and the effects of the microdeletion, they then need to begin to advocate for their child. IDEA was written with parent advocacy providing the checks and balances for the education of children with special needs. Parents need to know the laws and understand the need for this accountability system. Parents, teachers and administrators also need to understand different methods for inclusion and the philosophy behind inclusion. Collaboration, modifications,
accommodations and differentiated instruction are all methods to assist in the successful inclusion of students with Williams syndrome and also other students with disabilities.
Chapter Three
Research Methodology

Introduction

This chapter provides a description of the qualitative design of the research study. The study was designed to gain an understanding of how parents have advocated for their children with Williams syndrome to receive an education in the general education classroom. IDEA states this is where children should be educated whenever possible with the right supports and services. A qualitative design was necessary to analyze what the parents have done to have their child in the regular education classroom in early elementary school. The researcher explored how the parents had to advocate for the rights of their children and whether the parents believed they were successful. The parents’ views of what they consider to be the right supports and services were also researched.

Research Questions

Two basic questions guided this study. First, how have parents of children with Williams syndrome in the United States who have been educated in the regular education classroom in early elementary school for more than 75% of the school day advocated for their children? Second, in the parent’s opinion what have been the most effective accommodations and modifications in the general education classroom for their child with Williams syndrome?
Overview

A qualitative research approach was chosen for this study, as it was the most appropriate way to answer the research questions. “Quantitative research is a type of educational research in which the researcher decides what to study; asks specific, narrow questions; collects quantifiable data from participants; analyzes these numbers using statistics; and conducts the inquiry in an unbiased objective manner” (Creswell, 2008, p. 46). The researcher was interested in how parents have advocated, a question that does not easily lead to quantifiable data since the researcher wanted to capture the experience of advocating. Another limit to quantitative research is the number of people needed for the statistical analysis. Because Williams syndrome is relatively rare (1 in 7,500), difficulty exists in finding enough families who have children who have been taught in the regular classroom for a majority of the school day in the early elementary grades. However, parents and educators of children with Williams syndrome want to know how parents have advocated for inclusion and what supports and services were useful to effective learning experiences.

“Qualitative research is a type of educational research in which the researcher relies on the views of the participants; asks broad, general questions; collects data consisting largely of words (or text) from participants; describes and analyzes these words for themes; and conducts the inquiry in a subjective, biased manner” (Creswell, 2008, p. 46). The researcher wanted to know the parents’ views on how they have advocated and the parents’ opinions on the best accommodations and modifications for their children. This research was best accomplished through qualitative research by looking for similarities and differences among the parents’ views. Therefore, the
researcher used a qualitative approach based on the research questions driving the methodology. This study explored and explained advocacy by researching how parents of children with Williams syndrome advocated for their child’s educational rights from the parent’s point of view.

**Research Design**

**Setting and Population**

A sample of parents of students with WS who have received over 75% of their education in a regular classroom for two years from kindergarten through third grade were interviewed. The researcher recruited participants through the Williams Syndrome Association (WSA) in their quarterly newsletters, computer list serve, conference information, and parents the researcher had previously met through the WSA.

The WSA was formed in 1982 by families with children with WS. The WSA is the only association in the United States committed to improving the lives of people with Williams syndrome. The association provides information and emotional support, develops programs and services, increases public awareness, and encourages and supports research related to Williams syndrome (http://www.williams-syndrome.org). There are presently 3,220 families which are members of the WSA. The WSA is divided into 16 regions in the United States. The Great Lakes Region (Michigan, Indiana, Ohio, and Kentucky) with 451 families and the Tri-State Region (New York, New Jersey, Delaware, and Pennsylvania) with 448 families are the two largest regions representing 28% of the membership (A. Tipton, personal communication, October 30, 2009).
The researcher interviewed parents at a WSA event, the interviewee’s home or an agreed upon location once it has been confirmed by the parent that their child with WS was included a minimum of two years in kindergarten through third grade. The interview site was chosen based on the convenience for the parents and researcher to meet. The students with WS ranged in age from 8 to 18 years and from beginning second grade to beginning eleventh grade.

**Participants**

The number of individuals interviewed for a qualitative study depends on the type of study being conducted. The researcher interviewed 10 parents to develop a cross section of data to show differences and similarities in the approaches to advocacy. The researcher used purposive sampling to recruit the participants. For this study, all the parents had successfully advocated for their children with Williams syndrome to be taught in the regular education classroom. The parents met all three requirements of having successfully advocated for their child’s education, have a child with Williams syndrome, and have the child taught in the regular education classroom. Marshall and Rossman (2006) cite Miles and Huberman’s (1994) 16 sampling strategies in qualitative research. The researcher reviewed the 16 sampling strategies and chose to use a combination of maximum variation, random purposeful, and opportunistic.

The researcher maximized the variation of the sample by interviewing parents with children of various ages and from various geographic locations. The school districts also ranged from rural to the outskirts of a large city. Because the researcher is a part of the community, she personally knew two families who have advocated for inclusion for
their children and knew interviews with these families would gain valuable insight into the advocacy. The researcher was opportunistic in following new leads through Williams syndrome association (WSA) camps, gatherings, conferences, and the WSA computer list serve. Four participants were recruited during the pilot study at the WSA music camp. Two participants were recruited through the WSA computer list serve and two from the Ohio State University email lists from gatherings.

**Limitations of the Study**

As stated previously, all 10 of the participants were members of the Williams Syndrome Association (WSA) and had participated in music camps, national conventions, and WS clinics. All of the participants were mothers of children with Williams syndrome. No fathers responded to the request to participate in the study. The participants were not culturally diverse. All of the mothers appeared to be Caucasian and middle class. The interviewer was not aware of the lack of cultural diversity until the interviews occurred since four of the interviews were scheduled through emails and phone calls. The results may have been different if the participants had been more culturally diverse or if they had not been as active in the WSA. However, finding families not active in the WSA would be difficult since the syndrome only occurs in 1 in 7,500 people.

Trainor (2008) first researched the diversity issue and the different approaches to advocacy. Trainor found four variations in approaches to advocacy: intuitive advocate, disability expert, strategist, and change agent. The intuitive advocate used the knowledge about their child to advocate. The disability expert had the advantage of understanding
more about the specifics of the particular disability of their child. Parents who were strategists were knowledgeable about the educational laws and procedures to advocate for their child while the change agent also used the knowledge of the laws and procedures to advocate for other children with disabilities (Trainor, 2008). The researcher analyzed the data to determine the type of advocate of each of the participants and presents this information in Chapter Four and Chapter Five.

Another limitation to the study was the amount of time the child had to be in the regular classroom to meet the researcher’s definition of inclusion. Several parents contacted the researcher who had children which did not meet the requirement that the child be in the regular classroom 75% of the day in kindergarten through third grade for a minimum of two years. All of the participants in this study met this requirement. When the mother’s were asked to define inclusion, 8 of the 10 participants wanted inclusion to be defined as having their child in the regular classroom all of the time. However, only one child had been in the regular classroom all of the time in early elementary school.

**Soundness of Design**

**Researcher’s Role, Subjectivity, and Ethics**

Since the researcher has a son with Williams syndrome who has received his education in the regular education classroom, she was part of the community interviewed for this research. The research was considered “backyard research” (Glesne, 2006, p. 31). The interviewees did not appear to have any trouble separating the researcher’s role from that of a mother of a child with WS since the researcher spent time talking to the participants before beginning the interview and explained the importance of answering
each question completely. “Backyard research can be extremely valuable but needs to be entered with heightened awareness of potential difficulties” (Glesne, 2006, p.33).

The participants were given full and complete disclosure of their participation in the research project. The researcher has protected the anonymity of the participants by changing the names of all the participants and their children. No information gathered during the interviews will be used to exploit the participants and all of the participants quotes are from the interviews and not other contact with the individuals.

The researcher met with each parent one time during the data collection. The researcher will share the research results with parents, will make the results available for publication in the WSA newsletter and will offer to share the results at WSA conferences. The parents are aware of how little information is available right now and are willing to assist in research projects to help families of younger children with WS.

**Data Collection Method - Interview**

The interview responses were the source of research data. The researcher conducted interviews with the parent who had the most direct experience advocating for their child who had been included in the general education classroom. One parent was interviewed and the researcher requested this to be the parent who had spent the most time advocating for the child. This approach was necessary to ensure the researcher was able to determine all of the advocacy techniques the parents had employed while their child was included in kindergarten through third grade, especially since the researcher had a limited amount of time with the parents.
The researcher met with each participant and had a short conversation to make the participant comfortable with the interview process. During this time, the participant completed the consent forms. The informal conversation lasted anywhere from 10 minutes to 30 minutes. The researcher used a voice recorder to record the interviews once the consent forms were completed so it was not necessary to take notes during the interview. Then, the researcher started the voice recorder and began asking the protocol questions. The researcher used a structured individual interview approach with many open-ended questions. The first 4 interviews had 27 protocol questions and then the final six interviews had 24 questions. The researcher wanted to build rapport by having more of a guided talk with the parents and not stopping to take notes. The total interview lasted anywhere from one hour with the parents of two of the younger children who did not believe they had to advocate to over two hours with three of the parents who had more experience with advocating.

**Data Management**

Hard copy and electronic data binders were kept with a section for field notes, interviews, documents, the proposal, and University of Toledo internal review board (IRB) approval information. Within the sections, each family had a designated name placed on all field notes, interview transcriptions, and documentation. The researcher coded transcriptions based on divisions such as demographics, education training received by the parent, school reaction to inclusion, accommodations, and modifications utilized by the student. As suggested by Marshall and Rossman (2006), the researcher’s
transcription coding was completed with the literature review and previous data in mind for the transcription to become a useful part of data analysis.

**Data Analysis**

The researcher used immersion in the data to assist in the analysis. Reading and rereading the data three or four times facilitated the researcher to become intimately familiar with the data. The information was constantly going through the researcher’s mind (Marshall & Rossman, 2006). The 10 cases were reviewed individually and then similarity between the cases was analyzed. The proper balance suggested by Merriam (1988) is 60%/40% or 70%/30% in favor of description. The researcher strived to use the participants’ words and describe the advocacy using the 70% description and 30% analysis. The researcher looked for commonalities and patterns between the participants in the ways the parents have advocated and the types of accommodations and modifications which they believe have been effective for their children.

**Validity**

Creswell (2007) recommends two forms of validation for a qualitative study. The researcher used triangulation, a detailed description of the participants’ answers and an external audit for three forms of validation. Triangulation is using multiple sources for information to get different perspectives (Cresswell, 2007). Since the researcher interviewed 10 parents from different school districts, this provided for different ideas and methods for advocacy and the accommodations and modifications for students with WS in early elementary school. The researcher audio recorded all interviews and
transcribed all recordings soon after each interview and listened to each interview a minimum of two times. Chapters Four and Five use the participants’ own words, wherever possible, when describing the participants’ experiences.

The third method of validity was a review conducted by a master’s degree candidate with qualitative research experience and no connection to the study. The person reviewed all of the transcriptions and compared the interviews to the interpretations or the themes developed from the study. The reviewer found theme 8 needed to be revised to address how the parents wanted the schools to understand the basics of Williams syndrome but also to see their child as an individual. The researcher concurred and this revision was completed.

**Qualitative Study**

The researcher completed a qualitative study using thematic analysis. The researcher in Chapter Four introduces and describes the background and personal experiences of the 10 participants in advocating. Chapter Four provides the mother’s education level, how old the child was at diagnosis of Williams syndrome, how Williams syndrome affects the child at school, the mother’s definition of inclusion, information on how they have advocated and their greatest triumph with inclusion.

After the researcher described the participants, the researcher went back to the transcripts and developed a list of significant statements. The researcher analyzed for any particular training, any specific activities for advocating, and modifications and accommodations which were stated. The researcher then went back and analyzed for significant statements dealing more with the actual feelings of advocating.
The next step was to take the significant statements and develop themes. Twelve themes were developed explaining the advocacy experience. Chapter Five provides a description and a summary of the twelve themes.

The final step in the analysis was the narrative composite description of the experience of advocating for a child with Williams syndrome in the early elementary grades and the accommodations and modifications to make inclusion effective. The final analysis is presented in the summary in Chapter 6.

Glesne (2006) recognizes how qualitative researchers use subjectivity:
“…subjectivity is always a part of research from deciding on the research topic to selecting frames of interpretation…Subjectivity, once recognized, can be monitored for more trustworthy research and subjectivity, in itself, can contribute to research” (p. 119). Creswell (2007) also discusses the importance of a written description of the researcher’s experiences available prior to the interviews. This experience helped the researcher set aside the experiences from the interviewees and is included as Appendix E: Subjectivity Reflection. This is one of Husserl’s concepts and is called *epoche* or *bracketing* (Moustakas, 1994, as cited in Creswell, 2007). The researcher did not complete a written description before the pilot study, but answered all of the questions in the interview protocol and wrote a narrative about why the research questions were important to her based on the researcher’s experience with her son before completing the remaining interviews. Glesne (2006) discusses the importance of monitoring subjectivity and being aware of the researcher’s emotions. The researcher was aware of the subjectivity of the material through the entire interview and research process.


Pilot Study

The researcher chose to begin the research with a pilot study. Pilot studies are helpful in testing the proposed research. The pilot study helps the researcher to better define the questions and demonstrate capability in conducting the research. Researchers can use pilot studies to revise interview questions or review the techniques with the researcher and prepare the researcher to begin gathering data (Glesne, 2006; Marshall & Rossman, 2006). The researcher conducted a pilot study to determine if the interview protocol included questions focused on the research questions and to determine the appropriate order of the questions. The participants in the pilot study were not requested to provide feedback on the interviewing process. The researcher reviewed the interviews during transcription to determine if the questions and the order of the questions were satisfactory.

The pilot study was completed at the Williams Syndrome Association Whispering Trails Music Therapy Camp for children with Williams syndrome from ages 6 to 12 from June 13, 2009 to June 17, 2009. The children attended the camp for four days with either a parent, grandparent, or teacher. The researcher attended the camp with her nine-year-old-son who has Williams syndrome. The director of the Williams syndrome camp approved the researcher interviewing parents at the camp and the University of Toledo IRB approved the pilot study. The researcher immersed herself in the camp with her son and during the first day talked to parents about their children’s education. She then found parents who had children who had been included in the general education classroom for at least two years who were interested in being interviewed on how they had advocated for their child. Four mothers were interviewed during the camp while their children were
participating in other camp activities. The interviews were approximately 30 minutes to an hour in duration.

Based on the four interviews, the researcher removed several of the questions. The researcher found parents did not know about the teaching techniques used in including such as co-teaching and differentiated curriculum unless the parent happened to be a teacher. As a result, she removed Question 11, a question that required the researcher to become a teacher in explaining these techniques versus gaining information on parent advocacy. The researcher also removed Questions 18 and 19 on hiring a lawyer and going to due process because all four interviewees shared earlier in the interview process that they had not hired a lawyer. Based on these interviews, the researcher believes a parent who has hired a lawyer would share this information without being asked a direct question.

The researcher changed the order of the questions to improve the flow of the interview. The researcher preferred to ask some questions on inclusion before the specifics about the person. The questions seemed to be very direct to the interviewee at the beginning. Since the interview protocol was not changed significantly, the researcher included interviews conducted with the participants in the pilot study as part of the ten participants in the final data representation.

The interviews indicated some important issues with advocacy. Parents need a peer or advocate to help them with the process. The role of that individual was different for all of the parents. For example, one parent knew a parent with an older child who she would ask questions while another had become friends with her daughter’s preschool teacher and still contacted the preschool teacher before IEP meetings each year. The
parents felt this relationship with another parent or mentor was most important for getting the necessary supports and services for their child. The parents talked about the “gut feeling” of knowing when a goal or service felt right or not. Often, they would run this by the other person to get that encouragement.

All of the students had aides and the parents had all advocated for the aides or having the right aide or set of aides. One parent had said her school district wanted to give her son a different aide every hour of the day and the parent had explained how disruptive this would be for the teacher and her child. All of the parents had some basic training in the Individuals with Disabilities Education Act (IDEA). The parents felt having a basic understanding of the law had helped them to know when to advocate for services for their child. One mother had spent several years working to get her child moved from a self contained classroom to the general education classroom.

Summary

This methodology enabled the researcher to collect the data necessary to analyze the experience of parent advocacy for inclusion of elementary age children with WS as shown in Chapters Five and Six. The intent of the research was to provide parents of elementary age children who wish to have their children educated in the regular classroom information on the experiences of how other parents have advocated for inclusion. The second part of the research concentrated on the type of accommodations and modifications from the parents’ perspectives that have helped their students to be successful in the regular classroom. The researcher did not expect this to be a complete list of successful accommodations and modifications but only a possible starting place
when parents are working with their IEP team members. It was not the intent of the researcher to determine whether inclusion was the best placement for every student with WS or to conclude that if a parent follows what the 10 participants in this research have done that there will not be other issues that occur with advocating for inclusion. The research from this study should also be helpful for parents of children with other types of disabilities to better advocate for their children. Chapter Four describes the participants so families and educators can understand the educational background which might be necessary for advocating. The chapter also describes the ages and background of the children with Williams syndrome. Chapter Five then describes the findings from the analysis of the data. Chapter Six provides the summary, recommendations and conclusions.
Chapter Four

The Participants

Chapter Four introduces and describes the 10 participants in the study and their experiences with advocacy. The participants in this study were 10 parents of children with Williams syndrome who were included for 75% of the day in the regular classroom for a minimum of two years in kindergarten through third grade. All 10 participants were the mothers of children with Williams syndrome. The interviewer did not ask to interview mothers but the person who had advocated the most for their child. All of the participants were interviewed in person and the interviews were held in a location chosen by the participant. The locations included people’s homes, a library and a community center along with the pilot study group at Indian Trails Campground. Observation field notes and transcriptions of the 10 interviews provide the data for the descriptions of the participants. The participants described in rich detail their roles as advocates for their children with Williams syndrome.

A summary of the education background of the participants and their child’s age and grade at the time of the interview is provided in Table 1. All of the children attended public schools during early elementary school. Julia’s son now attends a charter school. The names of the participants have been changed.
Table 1

Participant Information

<table>
<thead>
<tr>
<th>Name</th>
<th>State</th>
<th>Mother’s Education</th>
<th>Child’s Age</th>
<th>Child’s Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrea</td>
<td>Wyoming</td>
<td>Bachelor’s Education</td>
<td>8 years</td>
<td>2\textsuperscript{nd} grade</td>
</tr>
<tr>
<td>Ilene</td>
<td>Pennsylvania</td>
<td>High School</td>
<td>8 years</td>
<td>2\textsuperscript{nd} grade</td>
</tr>
<tr>
<td>Georgette</td>
<td>Ohio</td>
<td>Associate’s Early Childhood</td>
<td>8 years</td>
<td>2\textsuperscript{nd} grade</td>
</tr>
<tr>
<td>Donna</td>
<td>California</td>
<td>Bachelor’s Preteaching</td>
<td>10 years</td>
<td>5\textsuperscript{th} grade</td>
</tr>
<tr>
<td>Cathy</td>
<td>Ohio</td>
<td>BS Computer &amp; Information Science</td>
<td>11 years</td>
<td>5\textsuperscript{th} grade</td>
</tr>
<tr>
<td>Evelyn</td>
<td>Michigan</td>
<td>Bachelor’s Political Science</td>
<td>11 years</td>
<td>5\textsuperscript{th} grade</td>
</tr>
<tr>
<td>Faith</td>
<td>Ohio</td>
<td>BA &amp; Master’s Social Work</td>
<td>11 years</td>
<td>5\textsuperscript{th} grade</td>
</tr>
<tr>
<td>Barbara</td>
<td>Ohio</td>
<td>Bachelor’s Business</td>
<td>12 years</td>
<td>6\textsuperscript{th} grade</td>
</tr>
<tr>
<td>Helen</td>
<td>Pennsylvania</td>
<td>Bachelor’s Anthropology</td>
<td>17 years</td>
<td>10\textsuperscript{th} grade</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Master’s Environmental Sociology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Julia</td>
<td>Michigan</td>
<td>High School</td>
<td>18 years</td>
<td>10\textsuperscript{th} grade</td>
</tr>
</tbody>
</table>

A description of each of the participants is included to help provide a familiarity and understanding of the parents’ background for advocating. The descriptions are provided starting with the mothers of the youngest children with Williams syndrome and include the mother’s education background including any advocacy training attended and the mother’s description of how Williams syndrome has affected her child in the education setting. All of the mothers were also requested to define inclusion and these definitions are also provided.
Andrea

Andrea lives with her family in Wyoming. She is the mother of an eight-year-old with Williams syndrome who has just completed the first grade in his neighborhood public school. The school district is a rural district with 2500 students covering 2800 square miles. Her son was diagnosed with Williams syndrome when he was six months old.

Andrea has a bachelor’s degree in education. She taught third and fourth grade and then took several years off to be with her children. She started teaching kindergarten when her son with Williams syndrome was in kindergarten in a school district which believes in inclusion. Her experience was different from the other participants since she was actually her son’s kindergarten teacher. Andrea said, “It wasn’t the best idea to be the teacher. Because when I was the teacher and the parent, I didn’t get a lot of respect.” She felt her teaching helped her to know and understand IDEA and the standards. She has participated in the national advocacy program, Partners in Policymaking, and attended Wrightslaw training.

Andrea believes Williams syndrome has a major effect on her son in the school setting. He receives occupation therapy (OT), physical therapy (PT) and speech therapy (SLP) and has an aide with him during the school day. One of the reasons for the aide is for assistance in the bathroom because he has severe scoliosis and wears a full body brace. The only service he was pulled from the regular classroom for was the physical therapy. All other services were provided during recess or natural parts of the day.

Andrea defined inclusion as:
My definition of inclusion is to have the child in the classroom with regular students during probably 90% of the day. There are a couple of times that they might need to be pulled out but inclusion is adapting the curriculum to meet their needs so that they can complete their day with the rest of the kids.

Andrea believed inclusion could be effective and described advocating as a fight:

In the beginning, I fought pretty darn hard for some things…I fought to have one aide and not multiple aides during the day. I had to fight for the specific aid that I wanted that had the right personality for him. I had to initially fight pretty hard for the assistive technology— for them to do the screening for that and then for them to implement it and get the equipment that I needed. That took me awhile.

Andrea spent a year trying to get the school system to complete the evaluation for assistive technology and put the technology into place. The school eventually provided the items. Andrea’s son now uses a slant board for writing, stamps some times for his numerals, pencil grips and a chair to sit on when the other children are sitting on the rug. He uses the computer when he has extensive writing. Based on Trainor’s (2008) approaches to advocacy, Andrea would be considered a change agent. She knows the laws and she is working to not only improve inclusion for her son but for the other students.

Andrea’s greatest triumph in advocating was “to get the professionals to come into the classroom because it is not just working for him but for all the kids now.” When Andrea was asked what else she would want parents to know, she responded:

Children with Williams syndrome sit on the line. They [school districts] try to push them to the high needs room. To me, they [students with Williams
syndrome] are more like the regular classroom children. They are imitators. They will imitate whatever behavior they are around the most and so as parents we need to push them into inclusion and get them the supports they need. They will grow a whole bunch more in that environment than they will in with the high needs kids. The modeling is huge and their growth potential is so much better in that environment than the other environment and for parents that is a hard push because it is kind of easier to put them into a high needs classroom that is already set up. This takes more work but the benefits are way huger. They [students with Williams syndrome] have good potential. They can live on their own and do their own things. Anyway, as a parent that is where they have got to be.

She believes her son is accomplishing all four of the frequently identified goals of public education: mastery of the curriculum, community as in belonging, independence and generosity in being able to give back by offering empathy and being a responsible citizen (Villa & Thousand, 2005). She is very happy with his progress in the curriculum. He has completed first grade and is reading on a middle upper kindergartener level.

Ilene

Ilene lives with her family in Pennsylvania near Pittsburgh. She has an eight-year-old daughter with Williams syndrome who is in the second grade in the neighborhood public elementary school in a district with 4,500 students. Ilene’s daughter was diagnosed with Williams syndrome when she was two years old.

Unlike Andrea, Ilene does not have a teaching degree or work in the education field. Ilene graduated from high school and attended business school for one and a half
years. She has attended a class on ideas for learning to read and two of the National WSA conferences.

The major effects of Williams syndrome on Ilene’s daughter in the classroom is trouble with fine motor, trouble with math and reading comprehension and the fire alarms. Writing is very difficult. She is removed from the regular classroom for math and has been going to a reading specialist for some extra help with reading. She receives OT and Speech therapy. She was in the regular class for both math and reading until the second grade. She is informed ahead of time of the fire drills. She is told about an hour before the alarm is going to happen so she can be prepared to put her hands over her ears.

Ilene’s definition of inclusion is more personal. She only referred to her own child. Ilene said, “Just including my child in every day school activities whether it be art, gym, science, reading, whatever.” Ilene is not convinced all children should be included in the classroom and said, “I think it is my personal opinion is that it [inclusion] should be on a case to case basis…it is a personal decision that everybody needs to make on their own.”

Ilene believed that she really had not done anything to advocate. Her daughter’s school wanted her included. However, Ilene had talked to other families about supports and services and had also contacted Dr. Mervis, director of the Williams syndrome clinic at the University of Louisville, about how to teach reading comprehension. Ilene had then shared any information received with her daughter’s school. Ilene is a disability expert based on the different types of advocates (Trainor, 2008). Ilene has attended two National Williams Syndrome Association (WSA) conferences and understands not only her daughter but has information about Williams syndrome.
“I just never thought she would really come as far as she has. She didn’t speak a word until she was two. Now, she gets 100% on her spelling tests. She’s really smart. I am just so proud,” responded Ilene when asked about her greatest triumph with inclusion. Her daughter is also invited to birthday parties and does things with her classmates.

Georgette

Georgette and her family live near Columbus, Ohio, in the urban fringe. Downtown Columbus can be seen in this community. Georgette has an eight-year-old daughter with Williams syndrome who is in the second grade in the public school in her neighborhood. Georgette described the school district as very small with approximately 1,200 students and only one elementary, one junior high and one high school. Her daughter was diagnosed with Williams syndrome at 14 months of age.

Georgette has an associate’s degree in early childhood. She also has a father who was a former school superintendent. Her daughter’s preschool provided training to the parents on IEPs. She has not attended any National WSA conferences but has attended a couple of regional conferences. Georgette said:

I found the best place for parents to learn the most was sitting in therapy waiting rooms. You have nothing else to do but you know you have that connection and that’s what you talk about. You find out about programs. You find out about classes. You find out this worked for me and that didn’t. You find out about other school districts.
Georgette’s daughter has some issues with fine motor and gross motor. She has more issues academically with math and has used TouchMath as an accommodation. TouchMath is a program using dots on the numbers to engage students of different learning styles. She is reading on grade level. Second grade is the first year that she has been on medication for ADD to help focus. As soon as she was put on the medication, her handwriting improved drastically.

When Georgette was asked to define inclusion she stated, “I define inclusion by anyone, everyone, being included no matter your disabilities or any abilities I guess.” Georgette did not have to advocate for her daughter to be in the regular class but she has provided suggestions for supports and services. Georgette is similar to Ilene in that they both have young daughters and both would be described as disability experts by Trainor (2008). Georgette has attended a couple of local WSA conferences and has taken her daughter to Williams syndrome clinics.

“We just try to stay involved with what is going on in our own district and keeping our ears open and seeing what we can do. I check things on line from time to time… “(Georgette). Math was an area where Georgette suggested using TouchMath. The teachers knew about TouchMath but had not thought to use the approach with Georgette’s daughter.

Georgette described her daughter as “pretty independent.” Georgette’s daughter is reading on a lower second grade level about two months from the end of second grade. She told the story of her daughter being a second grade buddy to a kindergartener. The students are paired and get to know an older student by playing on the playground and doing activities together. Her daughter has loved being the big buddy.
Georgette believed the integrated preschool program was so good that her younger daughter presently attends as a child not on an IEP. When Georgette was asked about inclusion and what other parents should know, she responded,

I kind of go back to the preschool level. Again, it [inclusion] does nothing but help everybody. It just gives you the understanding. We are all people. We are all just a little different….You are doing nothing but help each other grow in a good way.

**Donna**

Donna lives in California with her family. She has a 10.5 year old daughter with Williams syndrome who has just completed the fourth grade in the public school. Donna’s daughter is in a very large school district with 22 elementary schools and 20,000 students 35 miles from Los Angeles. Her daughter was diagnosed with Williams syndrome at nine months of age.

Donna has a four year degree in pre-teaching social studies, history and geography. She is very familiar with the state guidelines but admits that she does not concentrate on IDEA and No Child Left Behind. She has attended a couple of WSA National Conferences and reads information on the Internet. Donna is also friends with her daughter’s preschool teacher who is very familiar with inclusion and the teacher has shared information over the years. The teacher has provided support after the preschool years in answering questions and reviewing her daughter’s IEPs.

Donna’s daughter had some issues with behavior due to changes in the classroom schedule. Her daughter has learned to work through the transition issues over the years.
Attention has not been a major problem. “It doesn’t look like she is paying attention but they are amazed when they ask her a question and she can answer it” (Donna). Her daughter does have major fine motor issues and is barely writing at age 10.5. She did not start using a pencil until she was eight. She had severe strabismus and had eye surgeries on both eyes twice.

Donna defined inclusion as, “To be in the classroom doing basically everything the other kids are doing in the classroom and having it so she can understand it to” (Donna). Donna’s daughter started her education in a special day class not in her daughter’s home school.

Our first three years of school were not good. In kindergarten, we [her daughter] were put in an SDC — special day class and it was like babysitting. They watched videos. They just took walks around campus and that was just the extent of their day and she had an hour three times a week in the regular kindergarten classroom and they never told the regular kindergarten teacher why she was there until I got a hold of the teacher and told her she is supposed to be here to participate and not observe and that is when she started including her. She [the teacher] had been told she [Debbie] was just there to see what other kids do. (Donna)

Donna’s daughter was starting second grade when she was finally included. Donna described the experience: “We finally got out. It took three years to get out of the SDC school.” Two situations occurred which helped Donna to change her daughter’s educational placement. Donna’s son was getting ready to start school at the neighborhood school and the principal was willing to try inclusion. Inclusion was not
occurring at any of the schools in Donna’s district. When Donna was asked whether inclusion is worthwhile, she responded, “When we started, we were told this is her best placement in the special ed class and it wasn’t and we knew it wasn’t and we moved her. It took three years to fight to move her but once we moved her she just opened up and learned.”

Donna would probably be described as a disability expert or a strategist by Trainor (2008). Donna is not fully educated on IDEA but she is aware of the local standards and knew her daughter had a legal right to be educated in the regular classroom with the correct supports and services. She kept pushing the school until she found an administrator willing to try inclusion.

When Donna was asked about her greatest triumph with inclusion, Donna responded, “She has found friends.” When asked for more information, she said that her daughter had attended sleepovers. She is also at reading level but the comprehension is a little low and math is a couple of grades behind but is improving. Her daughter is learning to do more on her own.

**Cathy**

Cathy lives in Ohio with her family about 20 miles from Columbus. She has an 11 year old with Williams syndrome who has just completed the fourth grade in the neighborhood public school in a suburban school district with 3800 students in a 26 square mile area. Her daughter was diagnosed with Williams syndrome at 10 months of age.
Cathy has a Bachelor of Science degree in computer and information science. She has attended lots of training on IDEA, No Child Left Behind, and the state standards. She has attended Wrightslaw training and also several WSA National conferences and regional events.

Cathy’s daughter has had some issues with Williams syndrome which effect her in the school setting. Cathy said her daughter definitely had attention deficit disorder (ADD) and is presently on medication which has been successful. She is not at grade level for math, reading, or writing and that undeniably affects how she can interact with the other children in the school setting. Cathy’s daughter started keyboarding using an AlphaSmart provided by the school district in fourth grade so she could not keep up with note taking. An AlphaSmart is a durable, lightweight word processor with a four line screen.

When Cathy was asked to define inclusion she stated, “I define inclusion actually a little bit differently than how it is implemented for my daughter. Inclusion to me would be that everything is in the classroom and her aides are there to help her in the classroom.” “We are very fortunate that our school district is very special education minded and I have never had to fight for anything,” said Cathy. Cathy has requested changes to the goals and objectives during her daughter’s IEP meetings. One example was her daughter’s teacher wanted her daughter to start using a calculator before she understood multiplication. Cathy did not want her daughter to become calculator dependent. Cathy said, “I kind of picked this up from Dr. Mervis was if it doesn’t make sense to you —you have got to bring it up.”
Cathy would be described as an advocate who is a strategist by Trainor (2008). Cathy has attended several conferences and training on IDEA. She knows the laws and how to use them when necessary. When Cathy was asked what parents should know about advocating she responded:

I would have to say just follow your gut because you are the one who knows. You might not know every single law and every single little detail about everything but if something isn’t working out for your child, you just have to go with your gut and say this is how I see it…The other thing is that if there is questions pick up the phone and call somebody or send an email or something like that. I think a lot of parents kind of shy away from that. They tend to not bring it up. They don’t want to rock the boat. They don’t want to make waves but sometimes you just have to ask the question…I had gotten a draft IEP from her classroom teacher and it didn’t have any speech therapy or any APE or any OT goals on it. I sort of freaked out for a minute and then thought oh my God are they going to try to take this away. Then, I shot a short email—okay, I am seeing her academic goals what else is going on here and at least the classroom teacher said, „Oh no. This is just mine. You will get everything else.’ You can’t get yourself all worked up. You have to ask questions.

Her daughter’s biggest triumph is the belonging or being a member of the class. Cathy told the following story about how the students help celebrate her daughter’s accomplishments:

My daughter, in second grade, at the beginning of the year could not put her chair on top of her desk by herself and that was the end of day routine
that everybody puts their chair up on top of their desk. The first day that my daughter did it the entire class clapped for her and her teacher was actually out in the hallway trying to coordinate with another teacher and came in and asked why are you guys clapping…

**Evelyn**

Evelyn lives in Michigan with her family. She has an 11-year-old son with Williams syndrome who is in the fifth grade and attended elementary school in his neighborhood school down the street from his home. The school district has 6,300 students in an 85 square mile region. He was diagnosed with Williams syndrome when he was 22 months of age.

Evelyn has a bachelor’s degree in political science. She started investigating IDEA and No Child Left Behind when her son was in early intervention. Evelyn said:

The early childhood room was right across the hall from the severely mentally impaired students’ room and the kids in that room literally sat in their wheelchairs or in beds and watched Barney. That is what they did. It didn’t matter what age they were so we [the other parents] all started kind of investigating what were the different ways to get our kids out of that situation because it seemed like that was what all of the professionals in the school district were telling us that was our kids’ future.

Evelyn is a Partners in Policymaking graduate, attended Wrightslaw training, and has attended numerous workshops and conferences. She found conferences for educators and would attend these without telling them she was a parent because she wanted to hear
the conversation between the educators. She has also attended WSA National conferences. She believes Partners in Policymaking was the most helpful.

Evelyn also worked with a group of parents in her area and applied for a grant for nationally known speakers on inclusion to speak locally to parents and school district personnel while their children were in the play structure at McDonald’s. The parents received approximately $20,000 over a four year period. The school districts did not want to participate and very few parents attended. Evelyn said one reason for the low attendance by parents was access to tell the parents about the program due to privacy issues.

Williams syndrome does effect Evelyn’s son in the classroom. Evelyn’s son has very prominent attention deficit hyperactivity disorder (ADHD). He is very active. He has a one on one aide and has been fully included since kindergarten and is now in the fifth grade. Evelyn stated, “He has difficulty writing—significant difficulties writing. He loathes math. He has a real difficult time in math with the exception of geometry. He does really well in geometry. He loves science.” Evelyn also said her son had trouble with anxieties over people and also subjects. An aide caused her son anxieties and was reassigned. He also had girls on the bus calling him names and he has had trouble resolving the issue. He still occasionally talks about the event as if the name calling just occurred and gets anxious about having to take the school bus.

Evelyn told the following story:

Fire alarms were a really big deal for us. So what did we learn about– It was important to us that he know what to do if there was a fire. We thought he had to participate in the drill and it was devastating to him to
have to participate in those drills. It was frightening. He wouldn’t go back to school again. It took a long time to get over those but we couldn’t just pull him out of school. We couldn’t figure out what to do. We got him headphones to wear that would silence out the noise. Unless— if they didn’t put them on him beforehand, he would still hear the noise. The principal one year, she was an amazing woman, decided to have him be in charge of the fire drill. That is something I’ve learned now. If he is making the noise, it doesn’t bother him. He did this one year and now he has become conditioned to the fire alarms.

When Evelyn was asked to define inclusion she quickly said, “I would define that as him being in the same classroom that he would be in without a disability.” Evelyn has been very involved with advocating for inclusion throughout the years. Evelyn is an advocate who is a change agent (Trainor, 2008). Evelyn not only wants her son included but wants other parents and administration to understand inclusion. As mentioned earlier, Evelyn along with a group of other moms received a grant to bring national speakers on inclusion to her region.

“I purchased books for so many teachers out of my own pocket because they were just stymied by a problem that they couldn’t figure out,” said Evelyn. When asked what families should know about advocating for inclusion Evelyn responded:

The big philosophical question. I think first you need to believe that what you are doing is the right thing for your child. Then, you need to go a step further and believe that it is the right thing that you are doing for your community and society. Inclusion is a very selfish, selfless thing…The kids in [Edward’s] class
are learning so much. The teachers in [Edward’s class] are learning so much….The next time….they’re going to be better equipped. These kids aren’t going to grow up some day and have a child with a disability and sob hysterically because what they remembered as being this segregated exclusive hushed thing that nobody talked about.

Evelyn quickly answered when asked about greatest triumph with inclusion, “Community, independence and generosity. Mastery we are still working on.” She does believe he is mastering the curriculum better than he would in a different type of classroom. She believes the exposure is very important. Evelyn’s son participated in a Christmas pageant for the first time in fifth grade. Previously, his anxieties had held him back from participating. After the pageant, the fifth graders and their parents were coming up to congratulate him and the music teacher was in tears at how well he had performed.

Faith

Faith lives with her family in a suburb of Cincinnati, Ohio. She has an 11-year-old daughter with Williams syndrome who is in the fifth grade in her neighborhood school. The district is 15 square miles and has 4800 students. Her daughter was diagnosed at 22 months of age.

Faith has a bachelor of arts and then a master’s in social work. She has attended Wrightslaw training and has completed her own research. She has also attended training provided by the Special Education Regional Resource Center (SERRC) and has read all of the laws pertaining to special education.
Faith’s daughter is affected by Williams syndrome in the classroom. Her daughter has anxiety over fire drills so she is notified before the bell rings for fire drills. She has ADHD and is on medication but this is still one of the main reasons for the one on one aide. Her IEP outlines goals in math, speech, behavior, and reading. She has a modified curriculum which started in the third grade. She has fine motor issues and the aide takes dictation. She has had a one on one aide since first grade. She is pulled out for OT, PT, Speech, and reading.

Faith defined inclusion: “Inclusion is learning in the classroom, period, with the other students.” Faith believes in inclusion so much that even though she does not have an education background, she is helping to modify the curriculum. Faith said, “I have spent a lot of time this year reviewing what they are doing currently and what they have done and modifying the homework at home and saying this is what you should be doing in the classroom.” Just as Donna used the word “fight” to describe getting her daughter into the regular classroom, Faith used the words “battle” and “fight.” Faith stated, “We had to choose, in third grade, what battle we were going to fight whether it was reading or math and we chose reading. We will be taking on the math battle this year.”

Faith does admit that her background as a social worker made her a natural advocate for her daughter. …” but there are so many parents with the school knows best attitude. You are allowed to question it. You are allowed to question the school” (Faith).

Faith is an advocate who is a strategist (Trainor, 2008). With her social work background and having attended conferences on the education laws, she is able to “fight” to get the supports and services her daughter needs. Faith could probably make a good change agent to help other children with disabilities and may have advocated for others
but she did not mention this during the interviews. When Faith was asked about what has been her daughter’s success with inclusion she stated, “I may say this wrong but it is a life experience of being treated as an equal by those around her.” Faith said her daughter is more independent and more aware of the behaviors of the other girls. She has speech delays and being in the regular classroom enables her to get speech all day long.

**Barbara**

Barbara lives in a mid-size metropolitan city in Ohio with her family. She is the mother of a 12-year-old with Williams syndrome who has just completed the fifth grade and attends the neighborhood schools in a district of 3800 students. Her daughter was diagnosed at the age of 18 months.

Barbara has a bachelor’s degree in business. She has attended local training through the Special Education Regional Resource Center (SERRC). Barbara believes she learns a lot from just talking to other parents in the school district. Barbara talks to a mother in her school district because the mother knows how to work within the district.

Williams syndrome has affected her daughter in school in several ways. Barbara’s daughter had some anxiety issues at a younger age but has pretty much worked through the anxieties. Fire drills used to be an issue until the school personnel decided to give her advance notice. Paying attention was an issue but she is doing much better now that they give her breaks when she needs them. She received OT, PT, and speech services. She writes pretty well but is learning keyboarding through OT. She has had an aide full time since kindergarten and she is going into sixth grade.
When Barbara was asked to define inclusion she said, “[Inclusion is] being in the regular classroom setting and being included.” Barbara also used the word “fight” when discussing advocating. She said, “You don’t have to fight for a whole lot except for in the beginning. Once you get it, you don’t have to fight as long…” “In the beginning, I had to really fight. I had talked to a parent who had a boy with Down’s syndrome and she had an aide and he is older. She told me exactly what to do and that is how I got the original aide” (Barbara). Then, Barbara said two years ago the school had reorganized and had tried to take her daughter’s aide away. “…that is when I had to go talk to an advocate and threaten to bring her to a meeting and that is when we got to keep her aide” (Barbara).

Barbara is probably considered an advocate who would be a disability expert (Trainor, 2008). Barbara mainly talks to other people in her district to learn how to advocate and is aware of how Williams syndrome specifically affects her daughter. Barbara’s greatest triumph with inclusion is how her daughter has modeled correct behaviors. She is able to master the curriculum with some accommodations and modifications such as a calculator for math. The kids are very accepting of Barbara’s daughter.

Helen

Helen lives with her family in a suburb of Pittsburgh, Pennsylvania. She has a 17-year-old daughter with Williams syndrome in the 10th grade. Her daughter attended a public elementary school but not the neighborhood school in a district with 7300
students. Her daughter’s neighborhood school was not ready for inclusion. Her daughter was diagnosed at 17 months of age.

Helen has a bachelor’s degree in anthropology and archeology and a master’s degree in environmental sociology. She has attended Wrightslaw training and local training and seminars on IDEA, IEPs, and rights and responsibilities. She has attended National and regional WSA conferences. Helen said,

[I]…did a lot of reading but generally a lot of my information came from talking to other people. When [Hailey] was diagnosed, I joined a support group of other parents of kids with disabilities, not just Williams syndrome, so we talked a lot about what level of inclusion we wanted, etc.

Williams syndrome did affect Helen’s daughter in the classroom. Helen’s daughter had some issues with focus. Helen said, “She always had an aide in the classroom and we always worked with her on how to redirect, how to make sure she was paying attention.” In the younger grades, she did have troubles with fire drills and loud assemblies. Ear plugs or not participating during assemblies were options which were used. She is able to deal with the noises now.

She also had difficulty with handwriting and math. Third grade was the first year she was pulled to a learning support math class to learn the same curriculum but at a slower pace and taught different ways. The two most helpful programs in the early grades were TouchMath and Handwriting without Tears. She used the wooden pieces from Handwriting without Tears to learn to identify the capital letters. She received OT, Speech and PT during the early years.
Her daughter is presently in the 10th grade and is still included in the regular classroom or an inclusion classroom where there is an extra person in the room and the class might be more hands on. The only special education class she attends is a support math class.

Helen said, “I would define inclusion as having our kids in the classroom and activities in school with the supports that they need in the regular classroom and extracurricular activities etc.” Helen does not have a degree in education but she was the person putting together the list of accommodations for her daughter in early elementary school.

…it was like working upstream in those early years because they weren’t used to including kids…it was a struggle in those younger years…It was definitely hard. I was more afraid of the later years but it seems like it was a lot harder in the younger years (Helen).

Helen also talks about the “fight” and “battles.” Helen stated, “…the biggest issue was keeping her in the classroom for language arts and math until I really didn’t want to fight anymore for the math because I felt it wasn’t as beneficial...” “…you have to pick and choose your battles” (Helen).

Helen is an advocate who is a strategist based on Trainor’s research (2008). Helen’s daughter is 17 years old and inclusion was discussed even less than now. Helen had to be aware of the laws and the rights of her daughter.

“What I think has been the best thing from it [inclusion] — just her feeling like she is a regular person, fitting into the community and also her independence. That is huge and that has really taken off in the last—in high school” (Helen).
Julia

Julia lives with her family in a more rural area of western Michigan. She has an 18-year-old son with Williams syndrome in the tenth grade. In elementary school, her son attended the neighborhood public elementary school in a consolidated school district with 2900 students. He was diagnosed with Williams syndrome when he was five months old.

Julia is a high school graduate who has taken a few college courses. She has prepared herself for advocating by reading much information, attending seminars, several National WSA conferences, TASH, and participating in a regional leadership colloquium. “I was on the hunt for information. I was the best darn internet searcher, book reader, library person there was…” (Julia).

Williams syndrome effects Julia’s son in the regular classroom. Julia’s son has never had any attention issues, which is usually an issue as described by some of the other participants. However, his problems with fine motor and gross motor skills are more significant than many children with Williams syndrome. He has major visual spatial issues which make handwriting difficult. Julia describes her son as, “Completely willing to bend over backwards to make you happy and try his ever hardest at everything he did.” He started being pulled out of the regular classroom for math in the second grade but Julia felt this was ineffective. She found the same worksheets came home year after year.

Julia’s son is in the 10th grade and is in the regular classroom for all of his classes and presently does not take a math course. Julia decided the school had spent enough
time trying to teach something for which he had no aptitude. He takes courses at a private college near his high school part of the school day.

Julia was quick to respond to the request for a definition of inclusion:

For me, it is a civil right to be a fully participating member of society. It is not about education… It is about life. It is about every part of being a human being and doing what people do at that age group and having the belief that not only are you entitled to do those things but that despite your disability there should be people and things in your life to help you so that you can fully participate and be a member of society and educational environments are just one of those locations. Church communities, recreational activities—you name it—through adulthood. And the fact that having community members who have the expectation that you are going to have a typical life and not even to the degree that you can achieve—not to maximize potential but to the life that person is choosing so it is about building a life of people’s choosing and not having choices limited by people’s stereotypes or misconceptions about what someone can or cannot do but assuming the least dangerous assumption that people are going to live a typical life in all domains, in all environments and then having people who believe in finding access and opening doors, windows and blowing off roofs if necessary for that to happen.

Julia’s son did not start his education in a regular classroom. The school originally had her son in a “segregated pre-primary in a TMI classroom originally” (Julia). When asked to explain TMI, Julia said the acronym stood for trainable mentally impaired and her son’s IQ was 78. “…they had him in a TMI room because that teacher
was the only one who had that endorsement. It was ridiculous” (Julia). Once she heard about inclusion by the time her son was going into kindergarten and realized her son could live a typical life, Julia and her husband knew that was what they wanted.

Julia became an advocate who has been a change agent per Trainor’s definition (2008). Julia not only has advocated for her son but gives presentations on assistive technology and inclusion at conferences. She spoke at the National Williams Syndrome Association Conference in St. Louis in 2010.

Julia was a young mother who had just graduated from high school when she had her son with Williams syndrome. Julia felt part of her issue with advocating was being young but she added, “I think it’s hard no matter who you are or what age you are—you come into the situation ignorant. You also have been taught and trained that you are supposed to respect your elders or that you are supposed to respect authority…” Julia continued:

It’s just really, really a difficult thing to not just conform but to stick to what your gut is telling you your child needs and that effectively getting people to not fight with you but to believe in what you believe in and when that happens, you can live. When that’s not happening, your family doesn’t live. You struggle and you make it through and you—it’s just not living. It’s abusive. It’s just abusive. And it doesn’t have to be that way.

Julia said the following when asked about the greatest triumph with inclusion:

…our biggest achievement is that he is empowered. He is empowered to find the people he needs, the tools he needs to get the things he wants out of life and the community of people who have the same presumption. They have taken the least
dangerous assumption that he wants to be an announcer, well he is going to be one. Darn if he isn’t on the radio. We have built a life with him that has allowed him to have a life… and nobody is thinking it is so extraordinary or unordinary….Like any other kid—that’s success!

Summary

All 10 mothers were passionate about ensuring their children with Williams syndrome received the best education possible. The parents were willing to share their experiences in the hopes other parents might learn from them and have higher expectations for their children with Williams syndrome. To the greatest extent possible, the parents’ words are shared to help empower the next generation of parent advocates. The interviews conducted for this study resulted in close to 200 pages of transcriptions from the 10 interviews.

The backgrounds and locations of the parents are diverse along with the ages of their children with Williams syndrome at the time of the study. Three of the parents have degrees in the education field. None of the parents had been special education teachers or worked in the special education field. Two of the parents did not have college degrees. The parents discussed having learned either through a conference or another parent about inclusion and knowing this is what they wanted for their children.

All of the children had been diagnosed with Williams syndrome by the age of two. Because their children were diagnosed before elementary school age, the parents had time to research or hear about inclusion before their child was kindergarten age. Four of the participants described advocacy as a “fight” or a “battle.” Other parents
alluded to the idea of a battle but did not use the words “fight” or “battle.” All of the parents were constantly listening to other parents about services and supports or types of modifications and accommodations and providing ideas back to the teachers or administrators.

The 10 mothers who participated in the study were either disability experts, strategists, or change agents based on Trainor’s study (2008). Three of the mothers were disability experts. The mothers understood Williams syndrome and what supports their child might need in the classroom but were not knowledgeable on educational laws such as IDEA. Four of the parents were strategists since they knew the laws and could use them when necessary to advocate for their child. The other three mothers were change agents. These mothers not only wanted to help their own child but help other children with disabilities. Trainor’s research (2008) found most parents who were the strategist advocate or change agent were European American parents not in the lower economic levels, a conclusion echoed by this research. The words of the mothers are presented in Chapter Five according to the themes which emerged from the data.
This study was designed to gain an understanding of how parents have advocated for their children with Williams syndrome to receive an education in the general education classroom. IDEA states this is where children should be educated whenever possible with the right supports and services. The interviewer also researched the parents’ views of the accommodations and modifications used by their children in the regular classroom. This chapter will review the two research questions and the themes which emerged from each of these questions.

**Research Questions**

First, how have parents of students with Williams syndrome in the United States who have been included in early elementary school advocated for their children? Second, in the parent’s opinion, what have been the most effective accommodations and modifications in the general education classroom for their child with Williams syndrome? The following provides a discussion of the data.

**Overview of the Study**

Glesne (2006) states, “Data analysis involves organizing what you have seen, heard, and read so that you can make sense of what you have learned” (p. 147). The researcher listened to each interview three times during the transcription process. The data from the transcribed interviews with the parents were analyzed by reviewing each
individual interview and then also by each of the interview questions. Two binders were assembled. One binder had each of the complete transcribed interviews and the other binder was by each of the protocol questions. The author reviewed the two binders a minimum of five times analyzing the interviews for significant statements. The statements were then grouped into themes. Twelve themes emerged during this analysis. The results of the data analysis are provided using the mothers’ actual words whenever possible so their words can tell their stories. Evelyn summed up the feelings of most of the participants:

Do I wish I could be an obtuse parent who just put their kid on the bus in the morning and got their kid off the bus at night and hoped everything went well? There are days when I long to be that person but I simply am not that person.

**Themes**

1. Parents spend more time advocating for inclusion than just attending an IEP meeting.

2. Parents believe networking with other parents assists parents when advocating.

3. Parents really want to partner with their school districts and worked to find a person in the school district who would partner or listen to their ideas.

4. Parents often were the advocates for how much time their child spent in the regular classroom.

5. Parents reported information obtained at the Williams Syndrome Clinic and the Williams Syndrome Association National Conferences had helped them to be better advocates.
6. Parents reported IDEA and the special education state standards were important to know.

7. Parents reported advocating for inclusion because being in the regular classroom is important for their child in being a part of the classroom and learning from peers.

8. Parents reported advocating for inclusion to ensure the children learned the curriculum considered important for every other child.

9. Parents reported advocating for schools to know how Williams syndrome affects their child and for schools to know their child as an individual.

10. Parents reported feeling that they were going to have to fight or did have to fight for the rights for their children.

11. Parents reported they were the people to suggest the accommodations and modifications for their child in the IEP meetings.

12. Parents reported the important accommodations and modifications were for handwriting and attention issues.

**Research Question One**

How have parents of students with Williams syndrome in the United States who have been included in early elementary school advocated for their children?

Ten themes were identified which answered research question one. Table 2 summarizes the information provided by the parents on how to advocate for inclusion of children with Williams syndrome in the early elementary grades.
Theme One

Advocating for inclusion requires additional time than just attending an IEP meeting.

Advocating for inclusion is a time consuming process where one phone call or email usually does not resolve the issue and attending training and learning about modifications and accommodations is not a one hour training session. When Andrea discussed getting the correct assistive technology for her son she said, “That took me a while…took me a whole year…” Cathy had “reconvened her IEP.”

Donna had advocated the longest for getting her child included in the classroom. Donna said, “We finally got out. It took three years…” Evelyn had “spent the better part of April” learning content standards to help determine how to modify her son’s curriculum. She also talked about “things take forever to happen” when she and her husband wanted to purchase items for her son to use in the classroom but were told no.

Where often IEP meetings last an hour, Faith’s meetings had often lasted much longer. The team met “an average of three hours per meeting” and four meetings might occur for an IEP. Georgette said, “…have to go in and talk to somebody” and not just send emails or letters. IEP meetings are often held during the school day when most people are working. Four meetings could mean four days or half-days off of work.

Nine of the ten mothers had taken their children to a Williams syndrome clinic. The clinic conducted by Dr. Mervis is usually two days when the children are younger plus the travel time to get to and from the clinic. Helen had taken her daughter for testing with Dr. Mervis, “Two until 17—we have gone every year for her.” Helen also “put together a list for the teacher in those early years.” Ilene did not believe she had to
advocate but she said, “…real concerned about the comprehension. I did talk to Dr. Mervis last month and I relayed it to the school…” and Ilene had made an appointment to take her daughter to the clinic.

Three of the participants discussed how they had to keep current with information. Cathy mentioned “keeping up” by attending regional events and conferences. Barbara said, “Staying on top of it…” and Donna also said, “Keeping up on the state standards.” Other parents such as Evelyn and Julia implied the importance of keeping current by the amount of training they still attended as their children got older.

Theme Two
Parents believe networking with other parents assists parents when advocating.

The participants throughout the interviews discussed the importance of networking with other parents. Seven of the ten parents mentioned networking with parents in some capacity during the interviews whether the information from parents came from: a support group, therapy waiting room or the WSA list serve. The parents with whom they networked did not need to have children with Williams syndrome but the information the parents of children with Williams syndrome could share was helpful. Parents also needed to network with other parents from the school district or school districts nearby to understand the way to advocate for specific supports or services in their community. Helen said, “When [Hailey] was diagnosed, I joined a support group of other parents of kids with disabilities, not just Williams syndrome, so we talked a lot
about what level of inclusion we wanted, etc.” Helen also stated the WSA National conventions were a great place for networking with families.

When Barbara was asked what training was the most helpful for her, she replied, “Just talking to other parents - talking to a mother in my school district because she knew.” Georgette reiterated this idea:

I think the best thing that sticks with you most is listening to other parents talk…I found the best place for parents to learn the most was sitting in therapy waiting rooms. You have nothing to do but you know you have that connection and that’s what you talk about. You find out about programs. You find out about classes. You find out this worked for me and that didn’t. You find out about other school districts.

Evelyn also networked with other parents. When her son was 18 months old, he participated in a class once a week with children with different disabilities. Evelyn said, “…there was a bunch of parents I bonded with there.” This is the group of parents who later formed a group to bring advocacy training to the area. Faith has formed a network of five parents. She described the parents as “becoming known as a force” in her school district. Networking provides the parents the knowledge that they are not alone in working with their schools and the parents shared information helpful when working with their districts.

**Theme Three**

Parents really wanted to partner with their school districts and worked to find a person in the school district who would partner or listen to their ideas.
Parents often worked to find the person in the school district who understood inclusion and was willing to work with the families. Nine of the ten participants had found a partner in someone in the school district. This partner was usually a principal or special education director.

Four of the mothers reported the school districts understood inclusion and the entire team partnered together. Julia’s family had moved when her son was in junior high to have him educated in a district which believed in inclusion. Cathy said, “We are very fortunate that our school district is very special education minded and I have never had to fight for anything.” Georgette had the same experience, “I think we are really lucky here having talked to so many other people. I just think that we really have a relationship – everybody – the school secretary. We know everybody – open communication. We can just email each other.”

Three of the parents partner with the special education director or the assistant special education director. One family knew the school district superintendent and will go to the superintendent if the principal is not willing to listen. Then, the mother will continue through the chain of command. Evelyn explained the special education director attends all of her son’s IEP meetings. She believes the teacher makes all the difference. Evelyn said:

We have a really great relationship. His teacher sends me the new units and the things he is going to be responsible for knowing before the unit happens. That was something we pulled off this year. It did not happen earlier. We have been asking and asking and asking.
Helen had her child attend a different elementary school because she knew the principal would be a better partner. Helen recounted:

The principal in the elementary, until the middle of third grade, was my partner. We didn’t always see eye to eye but he was great because I could go in and we could hash things out and I knew where he stood. He could say, „No, we can’t do that.” and we could compromise or whatever. He just knew how to talk to his staff and support his staff. He was well liked by everybody. He was huge in those early years.

After the principal changed, Helen started going to the special education director. Helen explained, “I would just call the special ed director and would say these are the issues and then you know – it would get done.” Later in the interview she also added, “The most important thing is to build a good relationship…if you show that if you are willing to compromise and not go after everything under the sun then they are more willing to work with you.”

One of the ten participants did not have a partnership with her school. This is the parent who had attorneys attend meetings for three issues by third grade to have her child receive the supports and services needed. All three times the child eventually received the supports and services. Faith’s comment on partnering was, “I would like to partner with the school but the relationship is not there to do so.”

**Theme Four**

Parents often were the advocates for how much time their child spent in the regular classroom.
The parents truly had to believe in inclusion to advocate for the regular classroom. The school districts did not make the process easy. Parents had to stand up to the school district which would not be easy when the smallest IEP team would include an administrator, regular education teacher, special education teacher and possibly a school psychologist and therapists. Barbara said she had to advocate for inclusion. She did not consider agreeing with the educational placement of her daughter a choice. “They wanted to put her in a separate building. They wanted to bus her across town and put her in a separate building and I said, „No. I want her in the neighborhood school.”” Evelyn had the same experience, “Preschool teacher wanted/suggested we go and visit the self contained [room] …she really wanted us to visit the self contained cross categorical classroom and I flat out refused.” The school continued to suggest the self contained classroom until Evelyn made it very clear. “I actually screamed, „I don’t want to hear it again. It is not an option. We are not going to look at it. Quit bringing it up.’” And nobody has ever said anything …” As Evelyn has indicated, once parents state they want their child included, the school district does not always agree with the placement. Donna spent three years advocating for her daughter to receive her education in the regular classroom. Helen had to advocate for inclusion since the school had a resource room program for reading and math. She had to convince the school the resource room program was not going to work for her daughter. Julia also was told the special education room was where her son belonged. Julia said, “We were told that if he was in the regular ed room that he could not have academic goals. That they were only allowed to be social goals… it took a lot, a lot, a lot of persistence on our part…” As Julia stated,
“persistence” is part of advocacy and Donna showed this persistence with her three years of advocating before her daughter was included. If these parents had not advocated for inclusion, their children would not be in regular classrooms today.

**Theme Five**

Parents reported information obtained at the Williams Syndrome Clinic and the Williams Syndrome Association National Conferences had helped them to be better advocates.

Nine of the ten parents interviewed had taken their children with Williams syndrome to a Williams syndrome clinic and nine of the parents had also attended at least one Williams Syndrome Association National Conference. Eight participants had attended two or more of the conferences. Parents reported the Williams syndrome clinics to be instrumental in helping to advocate for their children. One parent took their child to the Salk Institute and the other eight parents had taken their children for testing with Dr. Carolyn Mervis at the University of Louisville. Reported from the WSA website (August 8, 2010):

Dr. Carolyn Mervis conducts clinical research studies primarily devoted to the cognitive processes in WS. Her team is conducting longitudinal studies of Language and Cognition in WS, as well as studies of language in very young children and the relationships between language, cognition and adaptive behavior in Williams syndrome.
None of the families lived within an hour of the University of Louisville. Most families were traveling five or more hours by car to have their child spend a day or more being tested using several different types of achievement and IQ testing.

Andrea had taken her son to the Salk Institute and said, “She gave a lot of recommendations for him educationally.” The parents who had taken their child for testing at University of Louisville reported using the information for their child’s IEP and sometimes the MFE. “They actually used it for her MFE” (Barbara). “We never got a written report from them but we did take basically anecdotal information back with us…I actually reconvened her IEP and pointed out the things that were wrong and actually had the parts of her IEP rewritten” (Cathy).

Faith has been taking her daughter every year to be tested by Dr. Mervis since she was four years old. Faith explained:

She tells you what you are doing right and what you are doing wrong and whether your expectations are too high or too low and that tells me once a year that what I am doing is okay. So I need that parent feedback.

Helen has been taking her 17-year-old daughter every year to be tested by Dr. Mervis since she was two years old and Dr. Mervis was located at Emory University. She believes the testing at the Williams Syndrome Clinic has been the biggest help to her in advocating for her daughter. Helen said, “That [Williams syndrome clinic testing] has really helped our educational advocacy especially in those young years because we always came with that report stating what she needed every year.” Julia, who also has a 17-year-old, had taken her son to be tested by Dr. Mervis repeatedly. The tests she had
seen Dr. Mervis use had helped her to realize another reason for inclusion. Julia recounted:

…when she does her testing she will show them four pictures and say show me a picture of disastrous. And if you aren’t getting instruction in reading books that have words like disastrous in it then they don’t know what that means and every time they go and have a vocabulary kind of test with her that is correlated to an IQ score…and inherently are going to have an IQ equivalency or grade level equivalency lower…

Ilene has not had to advocate for inclusion for her daughter but still wanted her daughter assessed by Dr. Mervis. She had scheduled an appointment with Dr. Mervis but had not been to see her before the interview. Ilene’s reason for wanting to visit was, “I just want to see where she is at – or whether we are doing enough. I want to see if we need to do more.”

The WSA National Conferences were also important for advocating. When Cathy was asked what is the first thing you would tell a parent just starting to advocate for their child she said, “I would say it would be one of the national conventions just because it is a great conglomeration of all the different levels and you start off trying to get them ready for preschool and then there is the transition to kindergarten and then all of the transitions.” Faith also stated, “They are helpful at certain points in life…It’s the transition points.” As stated earlier, Helen believed the conferences were helpful for the networking. Julia also said, “I think the National Williams syndrome convention is very, very useful. I think it is useful for everyone but I think early on it is very useful.”
Theme Six

Parents reported IDEA and the special education state standards were important to know.

Five of the mothers had attended the national training, Wrightslaw, on IDEA. None of the parents wanted to have to use the laws but most felt it was important to be aware of their rights. All of the participants appeared to be aware of IDEA and the least restrictive environment. Julia commented:

I think that knowledge is power…Those [the laws] are your last resort. You need to know what they are so you are not being fooled but it doesn’t help you to be wielding the law around constantly making enemies. You have to find a way to work together.

As stated earlier, Faith was the only parent who had used an attorney to advocate for supports and services. In all three instances, the school district has agreed to provide the supports or services before the mediation meeting. Faith said, “In preschool, it was over music therapy. In kindergarten to first it was over the aide and in third it was over reading.”

Theme Seven

Parents reported advocating for inclusion because being in the regular classroom is important for their child in being a part of the community and learning from their peers.

Two of the parents used the word “phenomenal” to describe the interaction between the peers and the children with disabilities. Cathy described how the children
interact with another child, Lydia, with more severe disabilities, “She has had Lydia in her inclusion classroom for the past two years and the way the kids interact with Lydia is just phenomenal.” Cathy explained that Lydia communicates through a communication device with programmed responses. Evelyn said:

What was really nice about that [going to his neighborhood school] was that the kids that we lived with also went to school with him and they really got to know him and the peer supports they provide are phenomenal…I really appreciate their willingness to help him out and it is a beautiful thing to behold and it is really helpful to [son’s name] and it is teaching them how to help people who need help in the proper way. Letting them do what they are capable of, asking if they need help, when they need help.

Faith discussed the peer interaction, “allowing my daughter to be around typical peers that will push her and have expectations for her. I think it is good for the typical peers to be around my daughter to understand that kids are different and some kids need more help than others. And hopefully that attitude will continue though life for them.” Faith also stated when discussing the benefits of inclusion, “it is a life experience of being treated as an equal by those around her.”

Georgette has sent her typical daughter to the special needs preschool. Georgette explained:

She is friends with people that she probably wouldn’t know under different circumstances. One of her best friends can’t speak to her, she is in a wheelchair. She takes care of her all day. It [inclusion] does nothing but help everybody.
Theme Eight

Parents reported advocating for inclusion to ensure the children learned the curriculum considered important for every other child.

Donna’s daughter started her education in a special education classroom. One of the benefits she sees to inclusion is the friendships. Donna said, “She has gone on sleepovers and the slumber party with the kids from class. I felt more like she has friends now that she didn’t have at the other school.” Evelyn commented:

He is getting exposure to – He has a laptop, for God’s sake, that he takes back and forth to school and I would wager to guess that there aren’t very many people in the ed center or self contained classroom that have those experiences.

Faith said, “She is more independent. She’s more aware of what she should be doing…” Georgette discussed the community aspect of how her daughter participated in the second grade buddies program.

One thing she really loved this year is that second graders are buddies with kindergarteners. It is not like she has to have assistance being that buddy. She is just Grace’s buddy and they play on the playground and they go down and do their activity…She is pretty independent (Georgette).

Helen stated, “just her feeling like she is a regular person, fitting into the community and also her independence.” Julia responded with the following:

When we started out, we said we wanted [James] to live a life of his choosing and not limited by people who couldn’t see him but embraced and assisted by people who could see him. Not see his disability but see him….And the fact that we
have achieved that and there are teachers and that he himself sees himself as a whole person with talents and struggles...And expects the same things out of life and is going about getting those things...So our biggest achievement is that he is empowered.

Julia’s son informed his parents and school that he wanted to be an announcer. The school has helped him to participate weekly on a Christian radio station and volunteer as a bingo caller at a senior citizen center.

**Theme Nine**

Parents reported advocating for schools to know how Williams syndrome affects their child and for schools to know their child as an individual.

The parents did not believe school personnel needed to understand everything about Williams syndrome but did need to know how Williams syndrome had affected their child. Some of the parents felt that the school personnel became overwhelmed when given all the ways that Williams syndrome could affect a child. None of the parents had seen a child who was affected with every issue associated with Williams syndrome. Parents also wanted the school personnel to view their child as an individual. Evelyn explained:

I think not focusing so much on Williams syndrome...We have some videos and tv shows that we have shown them [the school personnel] before and talked to them about the website and stuff but it is more important for them to know [my son] as an individual...They are all individual people just like we are...So a dear
friend of mine once told me to stop introducing my son as [my son] he has Williams syndrome and just introduce him as [Edward]. They will figure the rest out on their own.

Georgette wished she had talked to the school before her daughter started kindergarten, “I kind of wish I would have put a face to [Ginger] with the new principal and maybe kind of talked to them about who [Ginger] was before school started.” Julia, who has been advocating the longest, said:

You know when [James] was little we thought …people don’t understand his disability…as time has gone on we realize it is less about the disability and informing people about the disability and having people understand who [James] is as a person for people valuing the effort he puts forth and the kind of person he is and the kind of decisions he makes and the way he treats people.

**Theme Ten**

Parents reported feeling that they were going to have to fight or did have to fight for the rights for their children.

The researcher never referred to advocating as a fight or battle when asking the participants to describe their advocacy. However, an underlying theme throughout the interviews was recounting advocacy as a fight or battle. Eight of the ten parents used the word “fight” to describe advocacy during their interviews.

Georgette and Ilene, who have two of the younger children, were the only participants not to use the word “fight” during their interviews. Cathy and Evelyn commented how they had not had to “fight” while advocating. Cathy said when
asked about advocacy, “…I have never had to fight for anything…we are so very fortunate that we are not fighting tooth and nail for everything that we get for her.” Evelyn commented, “We are lucky. We have music therapy. We don’t fight for it.” Evelyn implies she believes other parents do have to “fight” for music therapy.

Unfortunately, the other six mothers were not quite so lucky. Andrea said, “I fought pretty darn hard…I fought to have one aide…I had to fight for the specific aide…” “I had to initially fight pretty hard for the assistive technology…” Barbara stated, “You don’t have to fight for a whole lot except for in the beginning. Once you get it, you don’t have to fight…”

Donna’s advocacy for her daughter to be in the regular classroom took the longest of any of the participants. Donna described her three years of advocating for her daughter a change of placement from a special education classroom to a regular classroom as a fight. Donna said, “It took three years to fight to move her…”

For Faith, fighting was a given. She was choosing which fight to have first. Faith said, “…what battle we were going to fight, whether it was reading or math…” Helen also stated, “…I really didn’t want to fight anymore…” and later in the interview she said, “…you have to pick and choose your battles…so I’m not going to fight for that.” Julia summarized what the researcher believes all the parents really wanted when she said, “…getting people to not fight with you but to believe in what you believe…” The parents wanted their children included and even though IDEA says the parents are part of the IEP team, the fact eight of the ten parents described advocating as a “fight” does not give credence the parents believe they are part of the team.
Research Question Two

In the parent’s opinion, what have been the most effective accommodations and modifications in the general education classroom for their child with Williams syndrome?

Theme Eleven

Parents reported they were the people to suggest the accommodations and modifications for their child in the IEP meetings.

The one support all 10 of the children had was an aide or paraprofessional to assist them in the classroom. The aide’s purpose may have changed over the years but even the two high school students still had an aide. For two of the parents, this was one of the biggest advocacy issues. Andrea’s school wanted to give her son a different aide for each hour of the day. Andrea explained to the school how one aide would be better for the teachers and for the students and the policy was changed for all of the students with aides in the school. Georgette’s daughter also was given more than one aide initially. Georgette recounted the following:

I was surprised when it wasn’t the same person going to be there from the start of school to the end of school…We tried to give them a heads up…I guess they took that information and did whatever they wanted with it. But then they realized, we kind of knew our daughter and they saw that it wasn’t working and kind of made the changes.

Faith had to get an attorney involved to get an aide for her daughter. Faith said:
Our reasoning was because of the attention that we didn’t want her attention to hold her back and you weren’t going to teach attention deficit out of her. That is like asking a Parkinson’s person to stop shaking. But that the aide, while the aide didn’t need to hover, the aide needed to be there to say, „Get back to work. That’s not your conversation. Stay on task.’ And to help her comprehend or reword things that were above her comprehension level. And that is how we have used the aide. And as handwriting has become an issue and not being able to stay up with the class speed wise, we use the aide as someone she can dictate to.

Cathy did not have to advocate for an aide but she did have to request the use of an AlphaSmart. Cathy said, “I asked for the AlphaSmart in the beginning of April and she had it in two weeks…” Fortunately, Cathy had learned about the tool from the WSA list serve and Dr. Mervis at the University of Louisville.

Evelyn commented about her school system providing information on accommodations:

They [the school personnel] have never given me an ala carte menu of things to choose from. It was always something that we had to suggest. I have gotten better over time with how I suggest…I have gotten better at maybe saying well why don’t we – there has to be a better solution – is there something that maybe we can come up with together with me making a few suggestions.

Faith was asked who had decided the accommodations for her daughter:

We have advocated for most of them. The way in which we approach the school is whenever we ask for anything whether a service of anything we have the
research to back it up….We have had our IEP meetings usually last 12 hours on average.

Helen had a list of accommodations which she would have the school personnel review at the end of the year to determine the accommodations for the next year. Helen said, “I think initially in those first years it was probably you know 50 to 70% me. But since then, it has been a real partnership.”

**Theme Twelve**

Parents reported the important accommodations and modifications were for handwriting and attention issues.

The parents of the children in later elementary through high school indicated more modifications were necessary to the curriculum as their child progressed in school. However, in kindergarten through third grade the main accommodations and modifications were for handwriting and attention. As mentioned previously, attention issues were usually helped with the assistance of the aide.

Seven of the ten participants mentioned the AlphaSmart or computer as an important accommodation for their child. Helen said, “We started with the AlphaSmart when she was in the k-3…maybe second grade. She went to a laptop in fifth or sixth – a regular laptop.” The interviewer asked why her daughter used the AlphaSmart and she responded:

Because the handwriting was really difficult a lot of times, when she would write, even if it was one sentence, the actual writing was taking so much effort that she
would forget what she was going to say and it was miserable. It was work...Overall, if I had to say what was most helpful besides programs on learning has been her laptop because that has made her more able to be more independent and focus on the topic instead of the process. Even today, I can’t imagine life without.

Cathy had learned about AlphaSmarts from the WSA list serve. She said:

So the AlphaSmart is something that I wanted to start in the fourth/fifth grade so that by the time she gets to middle school she is used to it and the other kids in the class are used to it. That is another thing I read on the list serve is that it is a distraction at first…

Donna found the visual spatial issues her daughter had caused the multiple choice tests to be difficult. Her eyes did not track to a second column. All of the choices needed to be in one column and not two. Her daughter was failing all of the multiple choice tests. Donna explained this several times to the teacher and aide until her daughter’s tests were designed correctly.

TouchMath was mentioned specifically by three of the mothers. Georgette asked her school to start using the program and found her daughter had success. Evelyn described deciding the time was right to allow her son to use a calculator:

[Edward] has just not shown any aptitude for rote math at all and so we finally just decided. I don’t know. We had an aha moment one day. I work in a job where I don’t do a lot of accounting or bookkeeping or anything like that. If I had to do any kind of math, I pull my calculator off my shelf.
Summary

Two basic questions guided this qualitative study. First, how have parents of students with Williams syndrome in the United States who have been included in early elementary school advocated for their children? Second, in the parent’s opinion, what have been the most effective accommodations and modifications in the general education classroom for their child with Williams syndrome? These two questions were answered by interviewing ten mothers of children with Williams syndrome using the guidelines of 24 interview questions. The responses to the questions were analyzed and 12 themes emerged. Ten of the themes assisted in answering question one and two of the themes assisted in answering question two.

How have parents of students with Williams syndrome in the United States who have been included in early elementary school advocated for their children? The parents have developed a network of parents who have children with Williams syndrome and also a network of parents who have children with other disabilities. The parent to parent network provides someone to ask questions and understand the services and supports available to their children. Training is nice but not as important as networking with other parents.

Most parents have to advocate for inclusion. Three parents discussed how their school districts wanted their children to go to a segregated classroom starting in kindergarten. Other parents had to advocate for their child to remain in the classroom instead of being sent to a resource room for a portion of the school day. Unfortunately, only three participants believed their schools were really following the least restrictive environment per IDEA when their child was in kindergarten through third grade.
The Williams Syndrome Clinic at the University of Louisville was instrumental in providing parents the background testing to help advocate for their children. Eight of the ten parents had taken their children for testing at the University of Louisville and used the information provided when attending IEP meetings. The testing also helped the parents know their children were making adequate progress.

Partnering between the school districts and parents is important. Parents often compromised on some of the issues to help the relationship. One parent had moved to a different school district because there was no relationship and another parent had brought an attorney to IEP meetings on three different issues. This parent did not have anyone she could partner with in her school district.

All of the parents enthusiastically agreed that even with all of the work in advocating for their children, they would do it again. The parents believe there is no other choice. None of the parents reported inclusion as being the wrong choice or any major problems with inclusion. All of the parents believed their children were treated better by peers and had mastered more of the curriculum by being in the regular classroom.

However, even though all of the parents enthusiastically agreed with inclusion 8 of the 10 parents described advocating as a “fight.” Two of the parents who used the word “fight” did so describing how fortunate they were to not have to “fight.” Both parents implied they knew other parents who had to “fight” for inclusion or the supports and services necessary. The other six mothers used the word “fight” when describing how they had advocated. The parents had to continue to push the school with research or information from experts on education services for children with Williams syndrome.
from people such as Dr. Mervis from the University of Louisville. One parent did use an attorney to “fight” for appropriate services.

Parents did not believe the school districts needed to become experts on Williams syndrome. Children with Williams syndrome are still individuals and the parents felt the schools should treat their children as individuals who have Williams syndrome and not as the Williams syndrome child. The effects of Williams syndrome which would manifest in the classroom needed to be discussed, but not every issue associated with Williams syndrome.

Accommodations and modifications were often parent driven. Parents needed to be aware of the types of accommodations and modifications and suggest their use at the appropriate time. The parent network, WSA syndrome conferences, and the WSA list serve were places parents mentioned having heard about specific accommodations and modifications. All 10 of the children had an aide in the regular education classroom. The biggest issues for the children were with handwriting and attention in the early elementary grade years. Computers or AlphaSmarts, calculators, Handwriting without Tears and TouchMath were some of the accommodations and modifications mentioned by the parents.

Chapter Five presented the thematic analysis of the qualitative study accomplished from the data collected from the ten parents who were interviewed for this study. The purpose of the analysis was to gain an understanding of the total experience of how parents of children with Williams syndrome have advocated for their children for inclusion in the regular classroom. The discussion presented in this chapter provided the themes that emerged through the data analysis. The contribution to the literature is how
the analysis is provided in the participants’ voice of how the mothers advocated for inclusion. The participants discussed the struggle and tremendous time involved in advocating for inclusion but still believed in the benefit of inclusion and continued to advocate. The parents talked about the importance of informal networking wherever they happened to be with parents of children with special needs, whether at the therapy waiting room or a conference. In the long run, even with the struggles, the parents wanted to partner with the school. A summary of the results, as well as the limitations, recommendations, and conclusions, are discussed in Chapter Six.
Chapter Six
Summary, Recommendations, and Conclusion

This qualitative study was designed to gain an understanding of parents’ advocacy when their child is included in the regular classroom in early elementary school. This study was completed by analyzing the views and perceptions of parents of children with Williams syndrome who have been included in the regular classroom. Chapter Six provides a discussion of the results of the study in regards to the two basic research questions, summarizes the implications of the results and contribution to the literature. The final part of the chapter proposes recommendations for future research in regards to advocacy and inclusion of children with Williams syndrome.

Research Questions

First, how have parents of students with Williams syndrome in the United States who have been included in early elementary school advocated for their children? Second, in the parent’s opinion, what have been the most effective accommodations and modifications in the general education classroom for their child with Williams syndrome?

Review of Methods

The researcher chose a qualitative approach for this study to understand the experiences of 10 parents as they advocated for inclusion for their child with Williams syndrome. The researcher had experienced advocating for her own child with Williams syndrome for inclusion and believed the experiences of other families to be important for
families of younger children to understand. The research focused on what the families did to prepare to advocate for their child and the parents’ view on the accommodations and modifications necessary for inclusion.

The researcher interviewed 10 mothers of children with Williams syndrome who had been included for a minimum of two years for 75% of the day in kindergarten through third grade. The researcher requested parents who had advocated for inclusion and only mothers replied to the request. First, the researcher conducted a pilot study at the WSA Music Therapy Camp for children 6 to 12 years old at Indian Trails Camp near Grand Rapids, Michigan, in June 2009 with four mothers of children with Williams syndrome who met the inclusion requirements of this research in early elementary school. The four parents were interviewed individually during the camp while their children were busy with other activities. These interviews were included as part of the final research.

Discussion of the Findings

Research Question One

How have parents of students with Williams syndrome in the United States who have been included in early elementary school advocated for their children?

The parents through their words made the researcher aware of the difficulty of advocating for inclusion. Ten themes emerged from the analysis of the 10 interviews pertaining to what parents did to advocate for inclusion for their children with Williams syndrome. The results of this study parallel Hunt’s and Goetz’s (1997) guidelines surrounding inclusive education:

1. Parental involvement is an essential part of effective inclusion.
2. Students can make positive academic and learning growth in inclusive environments.

3. Students with severe disabilities and intense educational needs experience acceptance and friendships in inclusive classrooms.

4. Students without disabilities benefit from functioning in inclusive classrooms.

5. Collaborative efforts among school personnel are essential to achieving successful inclusive schools.

6. Curricular adaptations are a vital component in effective inclusion efforts.

Parental involvement was key with all 10 of the children being included. The participants discussed all six guidelines. However, parental involvement had taken these parents from volunteering occasionally or helping in a classroom at school to researching Williams syndrome and learning about educational technology such as AlphaSmarts and educational programs such as TouchMath. Parental involvement at the level of the mothers in this study takes time. Time is needed to learn about Williams syndrome and how the syndrome might affect their child in the classroom and time for advocacy to work. Time is required to attend the workshops and conferences to be aware of the laws and the effective means of inclusion.

Changes in the school districts do not happen quickly. Parents may have to advocate for years to have their child placed in a regular classroom or receive the supports or services necessary. Parents often did not wait for the supports but provided the supports. Mothers with no background in education before their children were born are reading the content standards and determining modifications to the curriculum.
Seven of the parents were not teachers or involved in the education process before advocating for their children.

Six of the parents in Chapter Four discussed the “fight” or the “battle” for their child to be given their educational rights. The parents who did not fight talked about how lucky they were. Through networking and training, the parents knew advocacy could become a fight to get the educational placement or supports needed. The parents of the two older children did offer hope to the parents of the younger children. Both, Helen and Julia, believed advocating had become easier as their child moved to junior high and high school. Parents talked about the younger years being the hardest, but once supports were in place, school was easier for both the student and parent.

The three most important things the parents had done to better advocate for their child with Williams syndrome was to network with other parents with and without Williams syndrome, attend a Williams Syndrome Association National Conference, and have their child evaluated at the Williams Syndrome Clinic at the University of Louisville with Dr. Mervis. These three items provided the mothers with the support information needed to request their child be in a regular classroom and the supports necessary for effective inclusion. The results of the interviews support the 2002 national phone survey conducted by Public Agenda where 70% of the parents stated they had to determine services and supports (Public Agenda, 2002). The parents interviewed stated networking, WSA conferences, and the WS Clinic were the methods utilized for determining the supports and services.

Parents wanted to partner with their child’s school. Unfortunately, the schools did not always make this easy. Not all teachers wanted a child with Williams syndrome in
the regular classroom. Often, the parents had to find someone else in the school district to partner. Principals and special education directors were frequently found as allies when advocating for inclusion. This supports Ferrara’s and Ferrara’s claims (2005) about the minimal training teachers receive on working with parents. Only one parent found no one in the district to partner and this is the parent who had to involve attorneys for her daughter to receive the supports necessary.

Parents had attended Wrightslaw (http://www.wrightslaw.com) training to learn about IDEA or were aware of the training. Of the parents interviewed, Wrightslaw was the most popular training on educational law. Parents believed being aware of the laws was worthwhile but the consensus was that parents really did not want to have to use the laws to force the school to educate their child in the least restrictive environment or provide the needed supports and services.

Unfortunately, parents often had to advocate for their child to be included in the regular classroom. Four parents described their schools as believing in inclusion and the parents only had to advocate for specific supports or services. One parent felt so strongly about the importance of inclusion that the family found a school which believed in inclusion and sold their house and moved to be in the school district.

Parents continued to advocate for inclusion and believed inclusion was important due to the positive experiences for their children. Parents observed their children mastering curriculum which they never expected. The parents also saw peers treating their child with respect and their children learning positive behaviors and independence. During the research, no parent mentioned a negative experience for their children or expressed a desire to have their child placed in a segregated classroom.
The final theme with research question one was the amount of information parents would provide on Williams syndrome while advocating for their child for inclusion. Parents believe school teachers and administration do not need to know or understand the entire syndrome. However, parents do need to provide information on how Williams syndrome will affect the child in the school setting. Teachers and administrators should be aware of the sounds such as fire alarms which will cause anxiety and attention issues and the best methods for redirecting. Parents believed too much information could overwhelm or scare the school personnel.

Table 2 provides a summary of what the parents did to advocate for their children with Williams syndrome. Not all of the parents had done all of the items in the table. Advocating is an ongoing process. All of the parents discussed the importance of networking and having a parent to call when the parent and school district are not in agreement or to question if what they are asking for is reasonable.

Table 2

*How to Become an Advocate for Inclusion for a Child with Williams Syndrome*

- Network with parents of children with disabilities – with and without WS.
- Partner with your school – find someone who will work with you.
- Determine your vision of inclusion for your child.
- Attend a WSA National Convention.
- Have your child evaluated at a WS Clinic.
- Learn the basics of IDEA.
- Know the positive outcomes of inclusion.
Research Question Two

In the parent’s opinion, what have been the most effective accommodations and modifications in the general education classroom for their child with Williams syndrome?

Parents often advocated for specific services and accommodations and modifications. All of the children of the parents who participated in the research had an aide or paraprofessional for most of the time in the regular classroom. The aides were utilized in the early elementary grades mainly as a scribe to help eliminate handwriting and to help redirect or assist the child on focusing. The high school students still had their aides but the aides were used more as assistants for organizing or scanning assignments or documents into the student’s computers.

Computers or AlphaSmarts were another accommodation frequently advocated for by the parents. Levine (1993) stated that computer use should be included in the IEP and involve teaching the use of the computer as well as using the computer for reading and math. AlphaSmarts were used in the second or third grade and most of the students started using a computer by fourth or fifth grade with the parents advocating for the technology. Parents were the person on the IEP team to suggest programs such as Handwriting without Tears for teaching the alphabet and TouchMath for learning math facts. Parents learned about the programs and supports which worked for other children by networking with parents.
### Table 3

**Accommodations and Modifications**

<table>
<thead>
<tr>
<th>Category</th>
<th>Type of Accommodation or Modification</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Handwriting</strong></td>
<td>Slant board</td>
</tr>
<tr>
<td></td>
<td>Stamps</td>
</tr>
<tr>
<td></td>
<td>AlphaSmart</td>
</tr>
<tr>
<td></td>
<td>Computer</td>
</tr>
<tr>
<td></td>
<td>Special paper</td>
</tr>
<tr>
<td></td>
<td>Scribe</td>
</tr>
<tr>
<td></td>
<td>Special writing tools</td>
</tr>
<tr>
<td></td>
<td>Handwriting without Tears</td>
</tr>
<tr>
<td><strong>Math</strong></td>
<td>TouchMath</td>
</tr>
<tr>
<td></td>
<td>Calculator</td>
</tr>
<tr>
<td></td>
<td>Graph paper to keep problems in columns and rows</td>
</tr>
<tr>
<td><strong>General Academics</strong></td>
<td>Computer</td>
</tr>
<tr>
<td></td>
<td>Tests written in single column</td>
</tr>
<tr>
<td></td>
<td>Exams given orally</td>
</tr>
<tr>
<td></td>
<td>Two sets of books – one at home</td>
</tr>
<tr>
<td></td>
<td>Warnings for major sounds – such as fire drills</td>
</tr>
<tr>
<td></td>
<td>Longer time for homework and exams</td>
</tr>
<tr>
<td></td>
<td>Study guides in advance for exams</td>
</tr>
</tbody>
</table>

Table 3 is not the entire list of accommodations and modifications used by the students in kindergarten through third grade. The parents did not have their children’s IEPs with them during the interview. Helen was the only parent who brought her list of accommodations with her to the interview. She felt this was necessary since her daughter was now in 10th grade.
Implications for Practice

Parents need to understand how important they are to their child’s education and the outcomes. The participants in this study talked about parents being scared to speak up or believing the schools are the ultimate authority. Parents need to learn either from other advocates or other service providers that parents have the right and are expected based on IDEA to question the schools and not just accept the services provided for their child.

Advocating is not a simple process. Donna said she advocated for three years before her daughter was transferred back to her home school in a regular classroom. Parents will often have to advocate for placement and also for the supports and services. Parents need to realize their importance on the IEP team and attend the IEP meetings as a full participant coming prepared with ideas and questions. The best way for parents to learn about educational issues is in a less formal, unstructured format such as the waiting room while their child participates in therapy. How can service providers or school districts provide networking opportunities between parents? The typical support groups are not available to parents with children with Williams syndrome since the syndrome occurs in 1 in 7,500.

Given the importance of networking, teachers and school administrators need to have names of families willing to network with families and be willing to provide this information to the parents. School administrators should partner with parent advocacy groups to ensure advocacy groups are in touch with parents. Teachers and educators must also be aware of the other issues surrounding the family of a child with special needs. Support groups may sound effective but when a family is taking their child to
doctor visits and spending hours working on homework with their child, the parents do not have time to attend a support group meeting unless the parent has a specific issue at the time. It is the researcher’s suggestion that support groups take place in the natural settings such as therapy waiting rooms, doctor’s office waiting rooms, or other places where parents of children with disabilities might gather. Parents need to be given names of parents on an ongoing basis and not just when the child has been diagnosed.

Educators and therapists could play a pivotal role in helping families in the network role. The Ohio Department of Education believes strongly in family and civic engagement. As part of House Bill 1, Section 3313.821, every Ohio school district board of education must appoint a family and civic engagement team and develop a written plan on how families will be connected with the schools and community programs (ODE House Bill 1, 2010).

**Recommendations for Further Research**

Speaking with parents and listening to their words about what they have found to assist them in advocating for their children is important. These interviews have provided the researcher with many more questions to answer about inclusion of students and specifically those with Williams syndrome.

One area for further research is the amount of support the student receives from an aide or paraprofessional. All 10 students in this research have a paraprofessional while in the regular classroom. Giangreco and Broer’s (2007) research on paraprofessionals indicates the number of paraprofessionals in the schools continues to increase. In their research they found, often the only way the student was included in the
regular classroom was with the support of a paraprofessional. Suter and Giangreco (2009) stated:

Overreliance on or inappropriate utilization of paraprofessionals has been documented to result in a host of unintended negative consequences. Some of these are (a) physical and programmatic separation from classmates, (b) unnecessary dependence, (c) interference with peer interactions and relationships, (d) interference with teacher engagement, (e) stigmatization, (f) loss of personal control, (g) loss of gender identity, (h) provocation of behavior problems, and (i) increasing likelihood of being a target of bullying (Broer, Doyle & Giangreco, 2005; Downing, Ryndak, & Clark, 2000; Giangreco, Broer, & Edelman, 2001, 2002; Giangreco & Doyle, 2007; Giangreco, Edelman, Luiselli, & MacFarland, 1997; Marks, Shrader, & Levine, 1999)

Another issue to research would be to monitor the paraprofessional support of the eight younger students to determine if any of the detrimental effects occur. The two older students who were in high school still had a paraprofessional but based on the interviews the paraprofessionals were used more as assistants to the teacher and student and not as a primary educator.

The researcher would also like to interview the parents in five years when the two older students will have completed school and the younger students will be in middle school and high school to determine how the advocating and accommodations and modifications changed over the years. Helen and Julia, the parents of the two older students, both stated advocacy for inclusion had gotten easier. Additional research could include a longitudinal study of the students as they progress through the educational
system and transition into adulthood to determine whether the vision the parents had for their children and the benefits the mothers saw in the earlier years continued into early adulthood.

This study was completed on Williams syndrome, a rare syndrome occurring in 1 in 7,500 births, which means often the parents do not have a local support group of families of children with Williams syndrome to network. Not every family with a child with Williams syndrome has the luxury of attending national conferences across the country or taking their child to a clinic for educational testing specific to their child’s disability such as the participants in this study. Further research with families without the ability to attend the national conferences or Williams syndrome clinics and have successfully advocated for inclusion for their children would be helpful for providing a more in depth representation of advocacy.

Additional research on the experience of advocacy should also be conducted on higher incidence disabilities for a comparison. Would the parent advocacy requirements be different if the child had a more common disability such as autism or Down syndrome? Would the parent need to attend national conferences or specialized clinics? Would it be harder or easier for a parent to advocate for inclusion if the school knew more about the disability? Further research should be conducted with parents of children with other disabilities to compare the methods and preparation for advocating. The researcher believes due to the local support the parents would not need to attend the national conferences and specialized clinics. The researcher also believes parents of higher incident disabilities would have additional support from parent advocates when attending IEP meetings.
This study involving 10 mothers who have advocated for their children with Williams syndrome for inclusion in the regular classroom has provided only a starting point for parents who want to understand the educational advocacy process. Associations for specific disabilities and school districts need to be aware of these issues and work with parents to provide children a free appropriate public education in the least restrictive environment.
References


Giangreco, M. F., Broer, S. M., & Edelman, S. W. (2002). “That was then, this is now!” Paraprofessional supports for students with disabilities in general education classrooms. *Exceptionality, 10*, 47-64.


Tipton, A. M. (WSA personal communication, October 30, 2009).


Appendix A

Informed Consent for Research

Pilot Study
ADULT RESEARCH SUBJECT - INFORMED CONSENT FORM
Advocating for Inclusion in Education – Pilot Study

Principal Investigator: Laurie Dinnebel, Ph.D., Associate Dean of Graduate Studies,
419-530-2467
Michelle Self, Doctoral Student, 419-874-0507

Purpose: You are invited to participate in the research project entitled, Advocating for Inclusion in
Education – Pilot Study, which is being conducted at the University of Toledo under the direction of
Dr. Laurie Dinnebel and Michelle Self. The purpose of this study is to research how parents have
advocated for their children with Williams syndrome to have them educated in the regular classroom
and also to investigate the best accommodations and modifications for students with Williams
syndrome to use in the regular classroom. This pilot study will provide guidance for further research
to gain insight on the parental role in having their child included in the regular classroom.

Description of Procedures: This research, “Advocating for Inclusion in Education – Pilot Study,” will
take place in Grand Rapids, Michigan, at the Williams Syndrome Music Therapy Camp from June 13
through June 17, 2009. You will be asked to complete a short interview answering questions
regarding how you have advocated for your child with Williams syndrome to be included in the regular
education environment from kindergarten through third grade. You will also be asked to describe the
types of modifications and accommodations which you believe have been the most helpful for your
child. Your participation will take about one to two hours. The interview will consist of open-ended
questions and will be conversational. You may stop the interview at any time and may choose to not
answer any part of the interview questions. The interviews will be audio recorded to accurately
capture your responses for transcription purposes only.

“Permission to record: Will you permit the researcher to audio record during this research procedure?

YES NO Initial Here

After you have completed your participation, the research team will debrief you about the data, theory
and research area under study and answer any questions you may have about the research.

Potential Risks: There are minimal risks to participation in this study, including loss of confidentiality.
If any of the questions cause you to feel anxious or upset you may choose to not answer a particular
question or to stop the entire interview.

Potential Benefits: The only direct benefit to you if you participate in this research may be that you
will learn about how research projects are run and may learn more about education advocacy. Others
may benefit by learning about the results of this research.

Confidentiality: The researchers will make every effort to prevent anyone who is not on the research
team from knowing that you provided this information, or what that information is. The consent forms

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with signatures will be kept separate from responses, which will not include names and which will be presented to others only when combined with other responses. Although we will make every effort to protect your confidentiality, there is a low risk that this might be breached.

**Voluntary Participation:** Your refusal to participate in this study will involve no penalty or loss of benefits to which you are otherwise entitled and will not affect your relationship with The University of Toledo or the Williams Syndrome music camp. In addition, you may discontinue participation at any time without any penalty or loss of benefits.

**Contact Information:** Before you decide to accept this invitation to take part in this study, you may ask any questions that you might have. If you have any questions at any time before, during or after your participation or experience psychological distress as a result of this research you should contact a member of the research team: Dr. Laurie Dineheal at 419-530-2467 or Michelle Seif at 419-874-0507. If you have questions beyond those answered by the research team or your rights as a research subject or research-related injuries, please feel free to contact the Chairperson of the SBE Institutional Review Board, Dr. Barbara Chesney, in the Office of Research on the main campus at (419) 530-2844.

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

**SIGNATURE SECTION – Please read carefully**

You are making a decision whether or not to participate in this research study. Your signature indicates that you have read the information provided above, you have had all your questions answered, and you have decided to take part in this research.

The date you sign this document to enroll in this study, that is, today's date must fall between the dates indicated at the bottom of the page.

Name of Subject (please print)  
Signature  
Date

Name of Person Obtaining Consent  
Signature  
Date

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**THE UNIVERSITY OF TOLEDO**
**SOCIAL, BEHAVIORAL & EDUCATIONAL INSTITUTIONAL REVIEW BOARD**

The research project described in this consent form and the form itself have been reviewed and approved by the University of Toledo Social, Behavioral & Educational Review Board (SBE IRB) for the period of time specified below.

SBE IRB #: 106524  
Approved Number of Subjects: 5

Project Start Date:  
Project Expiration Date:  

**UNIVERSITY OF TOLEDO IRB 106524**
**APPROVAL DATE: 06/12/09**
**EXPIRATION DATE: 06/11/10**

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Appendix B

Pilot Study Interview Protocol
Pilot Study Interview Protocol

The following questions were used as the basis for the interviews:

Question 1
What is your formal educational background?

Question 2
What was the age of your child’s diagnosis and present age and grade?

Question 3

Question 4
How much do these issues affect their education? How?

Question 5
Have you taken your child to a Williams syndrome clinic for educational testing? If so, why?

Question 6
How do you define inclusion?

Question 7
How much of the day did your child spend in the regular education classroom in kindergarten? 1st grade? 2nd grade? 3rd grade?

Question 8
If the amount of time the regular education classroom changed, why did it change and who initiated the change?

Question 9
What have you done to learn about the IDEA, NCLB, and state standards?

Question 10

What have you done to learn more about inclusion?

Question 11

What have you done to learn about co-teaching and differentiated curriculum?

Question 12

Do you believe inclusion is effective? Why or why not?

Question 13

If your child is no longer included, then why not?

Question 14

What modifications and accommodations did your child receive in kindergarten through 3rd grade? Do you believe they were successful?

Question 15

How did you advocate for the modifications and accommodations or did the school provide them without any advocacy on your part?

Question 16

What advocacy worked and what did not work? If you could do it over again, what would you do differently?

Question 17

Were you able to develop a partnership with your school system? Did you feel like an equal partner in the IEP team meetings? Was there a mutual agreement on the education of your child? Was there a sharing of information on WS? Educational opportunities? Modifications and accommodations?
Question 18
Have you ever taken a lawyer to your educational meetings? Why? Was the outcome successful?

Question 19
Have you taken the school to due process? Why? Was the outcome successful?

Question 20
What is your greatest triumph on how inclusion is working for your child? Mastery? Community? Independence? Generosity?

Question 21
What has been your biggest issue while you have advocated for inclusion for your child?

Question 22
Have you ever switched schools or districts due to inclusion issues?

Question 23
Have you attended any other types of training that you felt were helpful?

Question 24
Do you attend the WSA National Conferences? Why or why not?

Question 25
Are you a graduate of Partners in Policymaking?

Question 26
Are you a member of any parent teacher organizations, special education organizations and/or support groups?

Question 27
Is there anything else you would like other families to know about advocating for inclusion for their children?
Appendix C

Informed Consent Form
ADULT RESEARCH SUBJECT - INFORMED CONSENT FORM
Advocating for Inclusion for Children with Williams Syndrome

Principal Investigator: Laurie Dinnebeil, Ph.D., Professor & Judith Daso Herb Chair
419-530-4118
Michelle Self, Doctoral Student, 419-874-0507

Purpose: You are invited to participate in the research project entitled, “Advocating for Inclusion for Children with Williams Syndrome,” which is being conducted at the University of Toledo under the direction of Dr. Laurie Dinnebeil and Michelle Self. The purpose of this study is to research how parents have advocated for their children with Williams syndrome to have them educated in the regular classroom and also to investigate the best accommodations and modifications for students with Williams syndrome to use in the regular classroom. This study will provide insight on the parental role in having their child included in the regular classroom.

Description of Procedures: This research, “Advocating for Inclusion for Children with Williams Syndrome,” will occur at a mutually agreed upon location with you and the researcher. You will be asked to complete a short interview answering questions regarding how you have advocated for your child with Williams syndrome to be included in the regular education environment from kindergarten through third grade. You will also be asked to describe the types of modifications and accommodations which you believe have been the most helpful for your child. Your participation will take about one to two hours. The interview will consist of open-ended questions and will be conversational. You may stop the interview at any time and may choose to not answer any part of the interview questions. The interviews will be audio recorded to accurately capture your responses for transcription purposes only.

“Permission to record: Will you permit the researcher to audio record during this research procedure?

YES ❌ NO ✔️

Initial Here

After you have completed your participation, the research team will debrief you about the data, theory and research area under study and answer any questions you may have about the research.

Potential Risks: There are minimal risks to participation in this study, including loss of confidentiality. If any of the questions cause you to feel anxious or upset you may choose to not answer a particular question or to stop the entire interview.

Potential Benefits: The only direct benefit to you if you participate in this research may be that you will learn about how research projects are run and may learn more about education advocacy. Others may benefit by learning about the results of this research.

Confidentiality: The researchers will make every effort to prevent anyone who is not on the research team from knowing that you provided this information, or what that information is. The consent forms

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with signatures will be kept separate from responses, which will not include names and which will be presented to others only when combined with other responses. Although we will make every effort to protect your confidentiality, there is a low risk that this might be breached.

**Voluntary Participation:** Your refusal to participate in this study will involve no penalty or loss of benefits to which you are otherwise entitled and will not affect your relationship with The University of Toledo or the Williams Syndrome music camp. In addition, you may discontinue participation at any time without any penalty or loss of benefits.

**Contact Information:** Before you decide to accept this invitation to take part in this study, you may ask any questions that you might have. If you have any questions at any time before, during or after your participation or experience psychological distress as a result of this research you should contact a member of the research team: Dr. Laurie Dinnebier at 419-530-4118 or Michelle Self at 419-874-0507. If you have questions beyond those answered by the research team or your rights as a research subject or research-related injuries, please feel free to contact the Chairperson of the SBE Institutional Review Board, Dr. Barbara Chesney, in the Office of Research on the main campus at (419) 530-2844.

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

**SIGNATURE SECTION – Please read carefully**

You are making a decision whether or not to participate in this research study. Your signature indicates that you have read the information provided above, you have had all your questions answered, and you have decided to take part in this research.

The date you sign this document to enroll in this study, that is, today’s date must fall between the dates indicated at the bottom of the page.

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**THE UNIVERSITY OF TOLEDO**
**SOCIAL, BEHAVIORAL & EDUCATIONAL INSTITUTIONAL REVIEW BOARD**

The research project described in this consent form and the form itself have been reviewed and approved by the University of Toledo Social, Behavioral & Educational Review Board (SBE IRB) for the period of time specified below.

SBE IRB #: 01/07/10  
Approved Number of Subjects: 10  
Project Start Date: 01/07/10  
Project Expiration Date: 06/11/10  
Date: 01/07/10  

Barbara Chesney, Ph.D., Chair  
UT Social Behavioral & Educational IRB
Appendix D

Interview Protocol
Interview Protocol

The questions may include but are not limited to the following:

Question 1

How do you define inclusion?

Question 2

What have you done to learn about the Individuals with Disabilities Act (IDEA), No Child Left Behind (NCLB), and state standards?

Question 3

What have you done to learn more about inclusion?

Question 4

What is your formal educational background?

Question 5

What was the age of your child’s diagnosis and present age and grade?

Question 6


Question 7

How much do these issues affect their education? How?

Question 8

Have you taken your child to a Williams syndrome clinic for educational testing? If so, why?

Question 9
How much of the day did your child spend in the regular education classroom in kindergarten? 1st grade? 2nd grade? 3rd grade?

Question 10

If the amount of time the regular education classroom changed, why did it change and who initiated the change?

Question 11

Do you believe inclusion is effective? Why or why not?

Question 12

If your child is no longer included, then why not?

Question 13

What modifications and accommodations did your child receive in kindergarten through 3rd grade? Do you believe they were successful?

Question 14

How did you advocate for the modifications and accommodations or did the school provide them without any advocacy on your part?

Question 15

What advocacy worked and what did not work? If you could do it over again, what would you do differently?

Question 16

What kind of a partnership do you have with your school system? Did you feel like an equal partner in the IEP team meetings? Who helped decide the educational placement? Was there a mutual agreement on the education of your child? What kind of information did you share about WS? Who determined the modifications and accommodations?
Question 17
What is your greatest triumph on how inclusion is working for your child? Mastery? Community? Independence? Generosity?

Question 18
What has been your biggest issue while you have advocated for inclusion for your child?

Question 19
Have you ever switched schools or districts due to inclusion issues? If so, why?

Question 20
What other types of training have you attended that you felt were helpful?

Question 21
Do you attend the WSA National Conferences? Why or why not?

Question 22
Are you a graduate of the national advocacy training program Partners in Policymaking?

Question 23
Are you a member of any parent teacher organizations, special education organizations and/or support groups?

Question 24
Is there anything else you would like other families to know about advocating for inclusion for their children?
Appendix E

Subjectivity Reflection
Subjectivity Reflection

Researcher’s Story

My interest in the two research questions started in October of 1999 when my son was diagnosed with Williams syndrome at six weeks of age. When he was about two years old, I met a mother of a son with Williams syndrome that was a year older than my son. This mom told me that I needed my son included in school. I asked the mom why and she told me to remember how students with special needs were treated in the school I attended. I could not remember any students with special needs in my school. My brother had a friend who had a sister with special needs but she went to a different school. We only saw her a couple times during the summer at the swimming pool. I thought about whether I wanted my young son to go to a school somewhere else and not really be known by the other kids in the neighborhood.

I decided I needed to understand what inclusion meant. I attended a couple of presentations in Michigan and heard a mother speak who had a son in a wheelchair who could only answer yes or no questions by moving his head to the right or left. He was being taught in a regular classroom. I thought if this young man could be in a regular classroom then it would not be a problem for my son. I attended more presentations and conferences on inclusion. I went through Partners in Policymaking and Wrightslaw training.

I started asking questions of other parents and discovered that inclusion was not usually done in my school district. While my son was still in preschool, I started writing his vision statement that he be included and be prepared for going to college and being
independent but I could tell the IEP team did not really believe it. When my son started kindergarten, my husband and I requested that he be in the regular classroom all day. The principal questioned how much he would really learn in the regular classroom. His comments made us question whether the teacher planned to really teach our son. By the time this meeting took place, I had attended training on inclusion and the law so I asked questions about services and supports and an aide was provided to my son after I made the request. Another child in the class started the school year without an aide, because his parents did not advocate for supports and services.

In first grade, my son had a teacher who questioned why he was not going to the resource room even though she had never seen our son. I also started noticing other children with special needs at my son’s school and how they were not given the supports necessary to succeed in the classroom. Parents started calling me with questions and concerns and I started speaking on advocacy at Williams syndrome conferences. I found that it was common for children with WS to be placed in classrooms for cognitively delayed students even when they were not cognitively delayed. I felt the full potential of the students was being lost and then the parent’s expectations were soon lowered. Often I would have parents email me after I spoke at a conference asking specific questions. I wanted to not only share my experiences but the experiences of other families who have advocated for the inclusion of their child.

I really thought it was all the training that had caused me to be successful in advocating for my son. After the pilot study, I thought about what one mom had said about needing a peer who understands to ask questions and run ideas. I realized she was right. I had forgotten how important that first mom was who helped me learn about
inclusion. When I am having trouble with my son’s school district, she is usually the first person I contact to ask what she would do. I often use her son as an example when talking with my school district.

My son is now going into the fifth grade. He is still included in the classroom. Unfortunately, we still have to advocate for the least restrictive environment and also the supports and services needed. The only partner I have in my son’s school district is the Director of Pupil Services. The Director of Pupil Services contacted the Ohio Department of Education and requested a facilitator attend my son’s IEP meetings. My son is now starting to receive the supports and services he needs. There are days when I am tired of advocating and think about homeschooling or moving to another school district. Right now, I know this is the right place for my son to be included in the regular classroom and I will continue to advocate!