

Phenomenological Study of the Experience  
of Parent Advocates of Students Diagnosed with ADHD

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now behaves maturely, is taller than me and through his intellectual intensity motivates me to learn about the experience of other parent advocates.

## Reflections on Experience

“What matters in life is not what happens to you but what you remember and how you remember it.” -*Gabriel Garcia Marquez, Nobel Prize winning author*

“I never painted dreams, I painted my own reality.” -*Frida Kahlo, Mexican Painter & Activist*

## **Abstract**

Advocates of students with ADHD in the school system are usually parents who must become advocates in response to the child's need for support and a call for parental involvement from the school. Parent advocates are confronted with many challenges, the primary being the daunting, often solitary task of advocating for a child who is often viewed by teachers and peers as unruly, disrespectful and underachieving. Resources available to parent advocates include legal and medical resources regarding ADHD which are regularly resourced to advocates by advocacy organizations and clinicians. Topics include medical diagnosis, treatment and educational rights and planning for ADHD students. In addition, a set of more diverse ADHD resources exists in the literature that discusses various influences on student behavior and achievement that parent advocates can consider in combination or in place of medical and educational ADHD resources. Diverse ADHD resources present a breadth of information ranging from misdiagnosis of ADHD to conditions that contribute to inattentive student behavior such as giftedness, physiology (including the impact of brain maturation, dietary omega-3, ferritin levels, pediatric sensory issues, and eye conditions), environment and exercise. This study uses a phenomenological research method to further understand the experience of parent advocates, specifically by interviewing parent advocates of students with ADHD in school. Findings include several themes organized in the following four categories: 1) Identifying and Treating ADHD in the School Context, 2) ADHD Advocates Need more Support from Schools, 3) Advocate Experience with the School is a Swinging Pendulum and 4) Advocates Struggle to Pave a Path for Success. Recommendations for further research include qualitative research to further understand parent advocate experience in identifying and treating ADHD in the school context,

specifically to understand the impact on advocate interpretation of ADHD-type behaviors after being presented with a list of non-ADHD conditions that precipitate ADHD-type behaviors. In addition, quantitative research is recommended to gather data regarding what advocates need in support from schools as they work to pave a path for success for their children.

The work presented in this thesis explores the experience of parent advocates of students with ADHD in school in an effort to understand and improve parent advocate experience.

*Keywords:* ADD ADHD & advocate, ADD ADHD & parent, ADD ADHD & parent & stress, ADD ADHD & misdiagnosis, ADD ADHD & Gifted, ADD ADHD & brain, ADD ADD ADHD & late brain maturation, ADD ADHD & physiology, ADD ADHD & physiology, ADD ADHD and iron, ADD ADHD & omega 3, and ADD ADHD & green space, ADD ADHD & exercise.

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# CHAPTER 1

## Introduction

### Study Focus

Advocacy, the act of pleading or arguing in favor of something such as a cause or a policy, occurs today in the school system for a wide range of students with disabilities. Advocates spring forth from a variety of relationships to students and can be parents, teachers, counselors, social workers, physicians, psychologists, administrators, policy makers and more. Advocates broadly impact student lives by calling on resources that describe student rights to education. This study focuses on federal education legislation that guarantees student rights to identification, qualified special education services, and public education and as a result improve student opportunities for education and student achievement.

Advocacy for students with disabilities in the school system is driven by the following Federal education laws:

- 1) Individuals with Disabilities Education Improvement Act (IDEA) of 2004
  - a) Designed to protect the rights of students with disabilities by ensuring that all students, regardless of ability, receive a free appropriate public education (FAPE).
- 2) Section 504 of the Rehabilitation Act of 1973
  - a) A civil rights law, Section 504's definition of disability is broader than the definition provided in IDEA 2004 and is used to garner accommodations for students that do not meet the criteria for special education services but are diagnosed with other conditions that impede learning, such as ADHD.
- 3) Americans with Disabilities Act (ADA) of 1990

- a) In addition to student rights to public education and special education provided in IDEA 2004, the ADA law prohibits discrimination of students with disabilities in educational as well as other settings.
- 4) Assistive Technology Act of 2004
    - a) The purpose of the Assistive Technology Act is to support state efforts to provide persons with disabilities access to technology that can assist them in education and work.
- 5) No Child Left Behind Act (NCLB) of 2002
    - a) This law was enacted as one of the most comprehensive federal education reforms in more than three decades , and its mission was to close the achievement gap with accountability, flexibility, and choice, so that no child is left behind.

Many organizations provide advocates with training opportunities, individual assistance and resources that promote advocate learning about the provisions of these laws to include information about student rights, educational policies and procedures regarding student qualification for special education services, educational planning and monitoring of student progress. Key organizations that support advocates for persons with disabilities are:

      - 1) PACER Center (Parent Advocacy Coalition for Educational Rights)
        - a) PACER began in Minnesota in 1977 with the project “Parents Helping Parents” which has become a national model of advocacy for parents of children with disabilities.
      - 2) ICI (Institute on Community Integration)

- a) ICI does not provides services but focuses on developing collaborative research, training, information and best practices to support services providers and advocates of persons with disabilities.
- 3) FAPE (Families and Advocates Partnership for Education)
- a) An extension of the PACER Center, FAPE focuses on improving educational outcomes for children with disabilities by connecting advocates to information and intervention support about IDEA 2004.
- 4) NICHCY (National Dissemination Center for Children with Disabilities)
- a) NICHCY 's purpose is to provide advocates across the nation with an abundance of information focusing on youth with disabilities from birth to age 22.

Advocacy organizations explicitly identify education laws, explain student rights to special and general education and provide a plethora of resources to that explain a range of disabilities identified in IDEA 2004.

A main goal of advocacy organizations is to provide education for advocates who are searching for information related to their particular student. The adult education approach that many organizations use is to offer trainings and workshops that explain laws, student rights and special education processes. Some adult education offerings are based in social constructivist philosophy (Dewey, 1916) where participants identify their own challenges and goals in learning to be an advocate and either in a workshop or with a mentor work toward those goals. They learn about advocacy as they are experiencing their learning about advocacy. For example, learning with a mentor who is also advocate by problem solving for his or her own student can result in experience-based learning that transforms the advocate's approach and effect on advocating for the student.

There are several reasons for looking at the parent advocate's experience in supporting students with ADHD in the school system. Primarily, it has been difficult for parent advocates of students with ADHD to obtain special education services for students because ADHD has only recently been included in Section 504 of the Rehabilitation Act of 1973 and IDEA 2004 in the "Other Health Impairment" (OHI) category thereby establishing that ADHD students are entitled to educational rights under those laws. According to the Federal Register (1999), the following comments were made in support of amending Section 504 to include ADHD:

Commenters suggested that ADHD be listed as examples of conditions that could make a child eligible under the "other health impairment" category at § 300.7(c)(9). A few commenters requested that ADHD be specified as a separate disability category under these regulations. Many of these commenters, parents of children with ADHD, described the tremendous problems they have had, and are having, in obtaining appropriate services for their children. Of particular concern to these commenters was that ADHD is not expressly listed in the regulations (Federal Register, 1999, p. 12542).

In addition to including ADHD in the OHI category of Section 504 in 1999, the 2004 reauthorization of the IDEA law also included ADHD as a disability in the OHI category.

Although these recent legal changes entitle ADHD students to special education rights for assessment and qualified services, the evaluation process to qualify students for special education and the planning process still presents murky waters for advocates to navigate as they work toward obtaining appropriate services for students. A knowledge gap exists in the resources readily available to advocates of ADHD students. Advocates

for students with ADHD can readily find resources regarding student rights and ADHD assessment practice and medical treatment to control inattentive behavior. However, many diverse resources exist in the literature about ADHD that include information about misdiagnosis of ADHD and conditions that give rise to inattentive behavior such as giftedness, physiological issues, environment and exercise. (Baum & Olenchak, 2002; Bental & Tirosh, 2007; Chang, et al, 2012; Faber & Kuo, 2011; Johnson-Gros, 2007; Konofal, 2004; Mota-Castillo, 2007; National Institute of Mental Health, 2008; Piechowski, 1991; Renzulli, Smith, Callahan, White, & Hartman, 1976; Riccio & Jemison, 1998; & Richardson, 2006). In addition, limited information exists in the literature that describes the advocate's experience of being an advocate for students with ADHD in the school system. Research is needed to provide in-depth understanding of advocate experience so that advocates can be connected to a comprehensive set of resources about ADHD, thus benefitting students by using broader resources to address student needs and to recommend interventions.

### **Special Education Laws and Services.**

Background information about how special education and general education laws are implemented and how students qualify for special education services provides a meaningful context that illuminates advocacy issues pertinent to ADHD students. The main federal legislation regarding persons with disabilities and education is reviewed below.

#### ***IDEA 2004 (Individuals with Disabilities Education Improvement Act).***

The federal special education law, IDEA 2004 (Individuals with Disabilities Education Improvement Act), (IDEA, 2004) is designed to protect the rights of students

with disabilities by ensuring that all students, regardless of ability, receive a free appropriate public education (FAPE). Furthermore, the concept of FAPE deems that all students have access to publicly financed education that is appropriate for their age and ability. IDEA 2004 also provides procedural safeguards to ensure consistent national compliance. IDEA 2004 outlines eligibility for special educational services, parental rights, individualized education programs (IEPs), the requirement that children be served in the least restrictive environment (LRE), and the need to provide related (non-educational) services. Decisions on instructional matters such as curriculum and services included in the IEP remain under the discretion of the states and districts (Martin, Martin, & Terman, 1996).

People with disabilities have only recently achieved rights to fair and equitable treatment and to education and work. The original special education law, Education for All Handicapped Children Act of 1975, (Education for All Handicapped Children, 1975) was enacted to stop the exclusion of students with disabilities from enrolling in and attending school. Prior to passage of this law most children with disabilities were denied public education. “In 1970 U.S. schools educated only one in five children with disabilities, and many states had laws excluding certain students, including children who were deaf, blind, emotionally disturbed, or mentally retarded.” (United States Department of Education, 2007). Historically, students with significant disabilities were commonly housed in state institutions where they did not have rights to education and were generally given minimal resources such as food, clothing and shelter in a highly restrictive environment. In the years leading up to 1975 it had been determined that many students with disabilities were not receiving services in education because they had



not been identified as having special needs. As a result, the 1975 special education law and subsequent amendments place an emphasis on identifying students with disabilities the concept and definition of “child find”. According to IDEA 2004, all students have the right to disability assessment and schools are required to provide services to qualified students rather than exclude them.

The Education for All Handicapped Children Act of 1975 was reauthorized under a new name, the Individuals with Disabilities Education Act (IDEA), in 1990 and 1997, and amended in 2004 and titled the Individuals with Disabilities Education Improvement Act. After a law is passed, regulations that guide implementation of the law are passed and recorded in the Federal Register. For example, IDEA 2004 regulations require states that receive federal funding for education to provide free appropriate public education (FAPE) in the least restrictive environment (LRE) (Federal Register, 2006). The goal for all students, especially students with disabilities, is to allow students to be educated with their peers in regular classrooms while maximizing the student’s benefit from special education and other services.

IDEA 2004 is separated into 4 parts:

- Part A- General Provisions including the purpose of the Act and definitions
- Part B- Assistance for Education of All Children with Disabilities includes provisions for children preschool-12<sup>th</sup> grade and outlines eligibility, evaluation for special education services, Individualized Education Programs (IEPs), educational placements and funding formulas, and requirements for procedural safeguards.

- Part C - Infants and Toddlers with Disabilities provides early intervention and other services for infants and toddlers with disabilities and their families.
- Part D - National Activities to Improve Education of Children with Disabilities provides support for activities such as training, technical assistance and research (IDEA Act, 2004).

IDEA 2004 Part B is the foundation upon which special education and related services are built. Part B is organized into 8 subparts: 1) General provisions, 2) State eligibility for funding, 3) Local educational area (LEA) eligibility for funding, 4) Evaluations, eligibility, IEPs and placement, 5) Procedural safeguards, 6) Monitoring and enforcement, 7) Use of funds and 8) Preschool grants.

Of particular interest to parent advocates of students with ADHD is the subpart that discusses IDEA 2004 requirements for evaluation, eligibility, IEPs and placement. The law requires parental consent, determination of eligibility for services, delivery of services, and parental involvement. Students are eligible for special education services if a learning disability is identified and the student is not achieving adequately for his/her age and/or does not to meet state-approved grade-level standards. Eligibility is not determined solely by the existence of a learning disability.

IDEA 2004 identifies the following categories of disabilities in Subpart A (IDEA Act, 2004). Main qualifiers in the definition of each disability are that they exist based on criteria specifically outlined for each disability and that they that adversely affect student's educational performance: 1) Autism, 2) Deaf-blindness, 3) Deafness, 4) Emotional disturbance, 5) Hearing impairment, 6) Mental retardation, 7) Multiple disabilities, 8) Orthopedic, 9) Other health impairment (including ADHD), 10) Specific

learning disabilities, 11) Speech or language, 12) Traumatic brain , and 13) Visual impairment.

Qualified students are entitled to an Individualized Education Plan (IEP) which is a written document that is developed, reviewed and revised according to procedures outlined in IDEA 2004. A specified team of teachers and professionals meet with parent advocates to identify annual student educational goals including progress measures and accommodations such as supplementary aids or services support students as they work toward making the highest achievement possible. Transition service planning is also included.

Parent advocates for students with ADHD often experience frustration during the evaluation and qualification for special education services because it is difficult to demonstrate the required discrepancy between student achievement and grade level achievement standards. Additionally, ADHD has only been identified as a disability in IDEA law since 2004 and ADHD is still not readily viewed by many education professionals as a disability that qualifies for special education services. In fact, students that have ADHD combined with another disability obtain special education services more easily because the second disability more clearly affects the student's performance and is used to meet the special education qualification criteria.

***Section 504 of the Rehabilitation Act of 1973.***

The Rehabilitation Act of 1973 “prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors.” (United States Department of Justice, 2005). A civil rights law, Section

504's definition of disability is broader than the definition provided in IDEA 2004 (United States Department of Health and Human Services, 2006, p.1):

An individual with a disability that has a physical or mental impairment that substantially limits major life activities, either currently or in the past. Major life activities may refer to self-care, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working .

Students that don't qualify for special education services under IDEA generally seek to qualify for services using Section 504. Depending on student needs, Section 504 may offer a quicker more flexible opportunity for obtaining services. This law is often used to qualify students with ADHD for services such as accommodations that allow the student extra time to complete tests, a reduction in homework, a reduction in penalties for lost work, and accommodations that support student need to move around the classroom.

***Americans with Disabilities Act of 1990.***

The passage of the ADA law finally gave persons with disabilities explicit rights that "prohibit discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities. The ADA also established requirements for telecommunications relay services." (United States Department of Labor, 2010; ADA, 1990). In addition to student rights to public education and special education provided in IDEA 2004, the ADA law prohibits discrimination of students with disabilities.

***Assistive Technology Act of 2004.***

Initially enacted as the Technology-Related Assistance Act of 1988, it has been reauthorized in 1994, 1998 and 2004. Technology has emerged as a key innovation

underlying national successes in business, commerce, government and education. The following rationale is outlined in the Assistive Technology Act (2004) regarding the benefit that assistive technology has for persons with disabilities:

Substantial progress has been made in the development of assistive technology devices, including devices that facilitate activities of daily living that significantly benefit individuals with disabilities of all ages. Such devices and adaptations increase the involvement of such individuals in, and reduce expenditures associated with, programs and activities such as early intervention, education, rehabilitation and training, employment, residential living, independent living, and recreation programs and activities, and other aspects of daily living. (Assistive Technology Act, 2004, section 2.a.4)

The purpose of the Assistive Technology Act is to support state efforts to provide persons with disabilities access to technology that can assist them in education and work. A broad range of technological innovations and devices can be used to assist students with disabilities including students with ADHD.

### *No Child Left Behind Act of 2002.*

Research had indicated for years that the success of American education was increasingly falling behind the performance of other nations (Darling-Hammond, 1996 & 1997; Educational Resources Information Center, 2001; Robitaille & Donn, 1992, & United States National Commission on Excellence in Education, 1983). As a result, The No Child Left Behind Act of 2002 was enacted as one of the most comprehensive federal education reforms in more than three decades and revised the Elementary and Secondary Education Act of 1965. According to NCLB (2002) its mission is:

To close the achievement gap with accountability, flexibility, and choice, so that no child is left behind.

NCLB contains provisions to ensure that all children, regardless of race, ethnicity, sex, disability or socio-economic status have equal access to quality education. NCLB identifies four areas that establish the framework from which educational reform is built: 1) Greater accountability for student achievement results, 2) Increased flexibility for states, districts and schools that receive federal funds, 3) Increased parent involvement and educational choices, and 4) Emphasis on developing high quality teachers (NCLB, 2002).

Alignment exists between the NCLB 2002 and IDEA 2004 Acts in that both identify high expectations for all students and include accountability for all students. Both impact students with disabilities in the area of assessment and accountability for student achievement. Regulations for NCLB allow states to develop modified achievement standards for a group of students with disabilities who can make significant

progress but may not reach grade-level achievement standards within the same time frame as other students. As a result, states are better equipped to measure the achievement of students with disabilities, students can demonstrate what they know and what they can do, and information is provided to teachers and parents about the student's progress. NCLB requires that all students have access to a high quality teacher. Much research exists to support the concept that high quality teachers have a positive impact on student achievement (Cohen-Vogel, 2005; Darling-Hammond, 1996; Guskey, 1998; Guskey & Sparks, 1996; Guyton & Dangel, 2004; Hirsch, 2005; & National Commission on Teaching & America's Future, 1997 & 1998). Advocates of students with ADHD have a role in improving the quality of the student's teacher by making teachers more broadly aware of behavioral and instructional interventions for ADHD students.

***2010 Reauthorization of the Elementary and Secondary Education Act.***

The NCLB Act of 2002, a reauthorization of the Elementary and Secondary Education Act of 1965, is currently in the process of being reauthorized. Key changes identified in the United States Department of Education's *A Blueprint for Reform: The Reauthorization of the Elementary and Secondary Education Act*, released on March 17, 2010, include: 1) Raising standards, 2) Rewarding excellence and growth and 3) Increasing local control and flexibility while maintaining the focus on equity and closing achievement gaps. The following with regard to the education of students with disabilities is included:

While the primary funding for programs specifically focused on supporting students with disabilities is through the Individuals with Disabilities Education

Act, our ESEA reauthorization proposal will increase support for the inclusion and improved outcomes of students with disabilities (United States Department of Education, 2010).

Advocates of students with disabilities, including ADHD, would be able to use the revisions suggested to continue to ask for accommodations that will contribute to improving student achievement outcomes.

Since the passage of these acts, millions of students previously denied access to public education now receive special education services in the public school system.

***Advocacy.***

The general education (NCLB, 2002) and special education laws (IDEA, 2004) identify many regulations for schools that receive federal funds to include the involvement of parents and student access to a high quality teacher. Research shows that parental involvement positively impacts student achievement for all students and especially for students with disabilities (Epstein, Simon, & Salinas, 1997; & United States Department of Education, 2004). Research also shows that student achievement increases when students have high quality teachers and that student achievement is a main indicator of school effectiveness, teacher effectiveness, and the impact of teacher professional development (Darling-Hammond, 1996; Guskey, 2003; Haycock, 1998; Lowden, 2006; Marzano, 2003; & Sparks, 2000). The value of teaching and, ultimately, the value of each teacher is measured by the impact the teacher has on student achievement (Guskey, 1996; Loucks-Horsley, 1995; & Stiles, 1999).



Parent advocates of students with disabilities lean heavily on federal legislation (IDEA, 2004) and regulations to ensure students have access to FAPE, high quality teachers and parental involvement in student educational planning and progress. In addition to information about student progress, parents are entitled to know the qualifications of teachers and the performance of schools. Legislation ensures that parent advocates receive the information necessary to make appropriate choices for their children, share responsibility for student success with schools, and help schools develop effective academic programs (IDEA, 2004).

Although education laws have established student rights and guide educational policies, there are a few key organizations that provide resources, training and individual support for advocates of students with disabilities, as well as the students themselves. The organizations are: PACER (Parent Advocacy Coalition for Educational Rights), ICI (Institute on Community Integration), FAPE (Families and Advocates Partnership for Education), and NICHCY (National Dissemination Center for Children with Disabilities).

***PACER Center (Parent Advocacy Coalition for Educational Rights).***

According to PACER Center (2010), PACER serves children with all disabilities and their families and offers more than 39 programs for parents, students, professionals, other parent organizations and works in coalition with 18 disability organizations.

PACER began in Minnesota in 1977 with the project “Parents Helping Parents” which has become a national model of advocacy for parents of children with disabilities. In the PACER model parent advocates who have a child with a disability support other parents that have a child with a disability by sharing their experiences and knowledge gained as a result of advocating for a child with a disability. The PACER model facilitates adult

education by having adults share their lived experience of being an advocate with adults that are learning to become advocates. However, research that gives these advocates a voice and documents their narratives is not easy to locate, if it even exists (PACER Center, 2010).

The main PACER program that advocates engage with to learn about advocacy for students with disabilities in school is the Minnesota Parent Center (PACER, 2010). This program connects advocates to information about NCLB 2002 and IDEA 2004 through workshops, publications, research, an e-newsletter and online links. With an emphasis on parental involvement, the program also offers a parental involvement planning packet and a parental involvement model based on Epstein's model of parent and community involvement (Epstein, 2002). PACER programs are generally organized to provide information about student rights in education, coaching on how advocates can access services, and training to develop advocacy skills that advocates use to negotiate services for their students. Additional PACER programs pertinent to students with disabilities in the school system have developed using IDEA 2004, NCLB 2002, and the Assistive Technology Act of 2004 as guideposts and are listed below:

- American Indian Parent Network.
- Bullying Prevention.
- Count Me In Puppet Show: A puppet show that teaches inclusion of students with disabilities. There are many characters including, Ben, a child with ADHD.
- Dispute Resolution: Information, resources and training to help advocates resolve disputes related to special education services.

- Dropout Prevention: Supports national implementation of IDEA 2004 and focuses on partnerships with state and national organizations to encourage parent involvement to reduce drop outs and increase completion rates. Conducts research on this topic.
- Early Childhood Intervention.
- Emotional or Behavior Disorders (EBD) Program: Includes legal information, advocacy skills, mental health advocacy skill development for many issues including ADHD.
- Leadership Academy: Training on use of assistive technology and career transitions.
- Parent Leadership in Special Education: Participates in education advisory committees.
- Minnesota School-wide Positive Behavior Interventions and Supports.
- Simon Technology Center: Training to support students in using assistive technology.
- Surrogate Parent Program: Advocacy for students in foster care or state guardianship.
- Technical Assistance ALLIANCE for Parent Centers: Provides technical assistance to more than 100 Parent Centers funded under the IDEA.

Although PACER offers an incredibly broad range of resources, training and assistance for students with disabilities, comprehensive information needed by advocates of students with ADHD in the school system is not readily accessible from PACER (PACER, 2010). Upon searching “ADHD” on the PACER website, the following types

of information are found: 1) A clinician's guide to ADHD and treatment, 2) Overview of symptoms of ADHD, 3) Class curriculum that includes behavior management and instructional strategies, and 4) Information about student rights identified in IDEA 2004 and NCLB 2002. These are necessary resources, however, ADHD advocates need to be connected to more diverse information available in the literature (Baum & Olenchak, 2002; Bental & Tirosh, 2007; Chang, et al, 2012; Faber & Kuo, 2011; Johnson-Gros, 2007; Konofal, 2004; Mota-Castillo, 2007; National Institute of Mental Health, 2008; Piechowski, 1991; Renzulli, Smith, Callahan, White, & Hartman, 1976; Riccio & Jemison, 1998; & Richardson, 2006). Although PACER advocates generally have a child with a disability and speak about students with disabilities from their own experience, qualitative research that describes advocate experiences are not available from PACER.

***ICI (Institute on Community Integration).***

According to the Institute on Community Integration (2010), ICI is located at the University of Minnesota and is designated as a federal University Center for Excellence in Developmental Disabilities. ICI does not provides services but focuses on developing collaborative research, training, information and best practices to support services providers and advocates of persons with disabilities. Much of the work that ICI conducts relates to education, work and community integration. ICI has 73 projects that address disability issues across a person's lifespan. ICI partners with six affiliated centers and two other University of Minnesota groups that focus on the following topics (Institute on Community Integration, 2010):

- Center for Early Education and Development (CEED): Improves developmental outcomes for young children through applied research and training.
- Minnesota Leadership Education in Neurodevelopmental and Other Related Disabilities (MN LEND): Prepares future leaders who serve children with Autism Spectrum Disorders (ASDs) and other neurodevelopmental and related disabilities (NDDs) and their families.
- National Center on Educational Outcomes (NCEO): Develops assessment and accountability systems measuring outcomes for all students.
- National Center on Secondary Education and Transition (NCSET): Fosters access and success for students with disabilities in from high school to employment, independent living, and community participation.
- North Central Regional Resource Center (NCRRC): Provides technical assistance to eight states as they implement IDEA 2004 regulations.
- Partnership for Accessible Reading Assessment (PARA): Researches and develops reading assessments, especially for students with disabilities affecting reading.
- Research Institute on Progress Monitoring (RIPM): Develops a progress monitoring system that reports on the effects of individualized instruction for student with disabilities in general education.
- Research and Training Center on Community Living (RTC): Provides research, training and assistance regarding community support for persons with disabilities.

ICI participates in many national and local projects that support the goal of improving education, work and community integration for persons with disabilities. Advocates for students with ADHD in the school system can find many resources by searching the ICI website where it is possible to locate 78 articles that include references to students with ADHD. (Institute on Community Integration, 2010). Most of the content in these references discusses broad disability topics that also include students with ADHD in discussions about special education services, technological innovations, behavioral and instructional management, and career readiness. Two main resources retrieved from the ICI website relevant to ADHD students are the *ADHD Parents Medication Guide* (AACAP, 2007) and the United States Department of Education (2003) publication, *Identifying and Treating Attention Deficit Hyperactivity Disorder: A Resource for School and Home*. Although these resources are very helpful to advocates of ADHD students, there is an emphasis on assessment, diagnosis, and treatment that does not include comprehensive information about ADHD, especially with regard to misdiagnosis and diverse resources about behavioral and instructional interventions that relate specifically to students with ADHD.

***FAPE (Families and Advocates Partnership for Education).***

An extension of the PACER Center, FAPE focuses on improving educational outcomes for children with disabilities by connecting advocates to information and intervention support about IDEA 2004. FAPE also connects advocates to other PACER partner sites such as the Technical Assistance ALLIANCE for Parent Centers.

***NICHCY (National Dissemination Center for Children with Disabilities).***

According to NICHCY (2010), the organization's purpose is to provide advocates across the nation with an abundance of information focusing on youth with disabilities from birth to age 22. Topics covered are parent advocacy, IDEA 2004, NCLB 2002, specific disabilities, research on effective educational practices, special education and related services for children in school, information about IEPs, and connections to resources in every state in Spanish and English.

Advocates of students with ADHD can search the NICHCY site and locate more than a thousand articles that include a reference to ADHD. More specifically, articles that focus on ADHD issues in education cover topics such as student rights under IDEA 2004, discussion regarding what ADHD is and what occurs in schools related to ADHD, cognitive-behavioral behavior management approaches, and instructional strategies. Although links to these resources provide important information about ADHD students in the school system, NICHCY does not offer a comprehensive set of resources that includes diverse research about ADHD (NICHCY, 2010).

### **Purpose of the Study**

The most common referral for mental health evaluation of American children is for Attention Deficit/Hyperactivity Disorder (ADHD). ADHD is a condition that affects approximately 3-7% of school-aged children (FDA, 2007). The National Center for Health Statistics in 2008 that there were 4.5 million children 3-17 years of age (7%) diagnosed with ADHD and that boys were twice as likely as girls to have ADHD (11% and 4%) (Bloom & Cohen, 2007. P.5). ADHD is characterized by the demonstration of the majority of symptoms in either category of inattention, hyperactivity, and impulsivity that are present in at least two situations such as home and school, impair social and

school functioning and persist past six months. Behavioral descriptions in more detail are:

- Inattentive ADHD behaviors such as failure to pay close attention to details, doesn't appear to be listening, trouble organizing tasks, easily distracted, or forgetful.
- Hyperactive ADHD behaviors such as squirms in seat, inappropriately leaves seat, inappropriately runs or climbs, appears driven or "on the go".
- Impulsive ADHD behaviors such as answers questions before they have been completely asked, interrupts, or has trouble waiting turn (American Psychiatric Association, 2000).

The route to student ADHD diagnosis usually begins with teachers identifying ADHD behaviors in a student and in turn making a referral to a school psychologist or via parents to a physician or mental health practitioner for ADHD evaluation. At that point a most practitioners ask parents and teacher to complete a CCPT (Conners' Continuous Performance Test) questionnaire which gathers information about the student's behavior. Diagnosis of ADHD is based on the demonstration of a high level of symptoms that are associated with significant impairments in social or educational areas. After an interview and review of the student file and CCPT, students can be diagnosed with ADHD and treated with stimulant medication to reduce inattentive behaviors.

Although a simple medical diagnostic test is not available to diagnose ADHD, identification of ADHD behaviors does not provide enough information to generate an automatic referral for ADHD diagnosis. In fact, according to Johnson-Gros



(2007), "misconstruing behaviors as causative explanations [does not warrant] a reflexive diagnosis of ADHD." Due to the subjective nature of the CCPT, ADHD diagnosis is vulnerable to clinician and parent/teacher bias which leaves many parent advocates of students with ADHD questioning whether the child truly has ADHD, whether or not to medicate the child and what course to take to support the child in school (National Institute for Clinical Excellence, 2008, p.106). Misdiagnosis of ADHD has serious ramifications for students because of health risks posed by the most common treatment, stimulant medication such as Ritalin or Straterra. In fact, the concern has prompted the FDA to issue a warning that cardiovascular adverse events and drug-related psychiatric events may occur as side-effects of taking the medication (FDA, 2007). Preventing misdiagnosis of ADHD is a topic weighed heavily by parent advocates of students diagnosed with ADHD (Baum & Olenchak, 2002; Brinkman, et al, 2009; Hartnett, Nelson, & Rinn, 2004; & Mota-Castillo, 2007).

Low student achievement is a common trigger for parents to seek ADHD diagnosis and often medication. Many parents agonize over whether or not to medicate students for ADHD. They are often concerned about the negative effects that daily use of stimulant medication may have on their child and are at a loss for readily available resources that offer information about alternative treatments or alternative causes of ADHD behaviors. (Brinkman, et al, 2009) As parents observe the student falling behind peers in achievement, they become increasingly motivated to accept the ADHD diagnosis and medication in order to improve the student's achievement.

Regardless of whether the student actually qualifies for special education services in the school system, advocates need a comprehensive set of resources about ADHD, and

advocates of students with ADHD need to have their voices heard regarding the nature of their experience as advocates for ADHD students.

### **Problem Statement**

Parent advocates for students diagnosed with ADHD may not have appropriate access to a comprehensive set of resources, therefore advocates are inhibited from being effective because they do not understand the range of information that can be considered when advocating for students diagnosed with ADHD.

### **Significance of the Problem**

This research seeks to understand the experience of parent advocates of students with ADHD in the school system. PACER Center, a nationally recognized parent advocacy organization that supports advocates of students with disabilities, offers advocates resources that mainly focus on student rights, special education processes, and interventions as well as information about ADHD assessment, diagnosis and treatment. However, an abundance of literature exists that has not made its way from theory to practice that could support advocates in designing interventions targeted to improve student behavior and educational planning. (Baum & Olenchak, 2002; Bental & Tirosh, 2007; Chang, et al, 2012; Faber & Kuo, 2011; Johnson-Gros, 2007; Konofal, 2004; Mota-Castillo, 2007; National Institute of Mental Health, 2008; Piechowski, 1991; Renzulli, Smith, Callahan, White, & Hartman, 1976; Riccio & Jemison, 1998; & Richardson, 2006). These diverse resources sparsely dot the landscape of literature on ADHD students and are not easily located.

A comprehensive set of resources relevant to ADHD students in the school system would also include information about the following issues that should be

considered when advocating for ADHD students because referral for assessment and educational planning happen in the school and involve parent advocates:

- Understanding a variety of factors based in learning, environment and physiology that are characterized by behavior that mimics ADHD behavior.
- Information about misdiagnosis and over-diagnosis of ADHD.
- Information about the side effects of medical treatment of ADHD.
- Information about a variety of non-medical treatments including behavioral and instructional interventions.

### **Statement of the Research Questions**

The research questions for this phenomenological study are:

*Textural question:* “What is the experience advocating for your child who is diagnosed with ADHD?”

*Structural question:* “What contexts or situations have affected your experiences of advocating for your child who is diagnosed with ADHD?”

### **Qualifications of the Researcher**

I am a doctoral student at the University of Minnesota in Education in the Department of Organizational Leadership, Policy and Development. In addition, I have a master’s degree in Counseling Psychology from the University of St. Thomas and a bachelor’s degree in Psychology from Illinois Wesleyan University. Professionally, I have worked as a human resources manager and consultant on projects that required behavioral interviewing, analysis and feedback. I have also worked as a counselor both

in a federal job training program and as a student advisor in higher education where both positions involved interviewing participants in educational programs. As a doctoral student, I have taken a doctoral level qualitative research methods course which included practicing phenomenological interviewing. I also have taken a doctoral level advanced qualitative research course, Narrative Research. On a personal level, I am the parent advocate of a high-energy child who had been referred by teachers for ADHD assessment. I have been advocating for him in educational settings since he started preschool ten years ago and still fill this role now that he is in seventh grade and it is one of the most frustrating yet rewarding jobs I have ever had.

### **Definition of Terms**

Achievement Gap refers to the disparity in education in the achievement between culturally and socio-economically diverse groups of students.

Americans with Disabilities Act of 1990 (ADA) is a law that prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications and governmental activities.

Attention Deficit Disorder (ADD) is a mental health disorder characterized by inattentiveness.

Attention Deficit with Hyperactivity Disorder (ADHD) is a mental health disorder characterized by inattentiveness, impulsivity, and hyperactivity.

Advocate is a person who pleads or argues in favor of something such as a cause or policy.

Assistive Technology Act of 2004 is a reauthorization of the Technology-Related Assistance Act of 1988 and has the purpose of supporting state efforts to provide persons with disabilities access to technology that assists them in education and work.

Child Find refers to the concept in the Education for All Handicapped Children Act of 1975 that students with disabilities need to be identified in school so services can be delivered.

Diagnostic and Statistical Manual IV (DSM IV) is the Psychiatric Association's guide to diagnosis for mental health disorders.

Disability refers to a disability that can be considered in the qualification of disabilities for special education outlined in IDEA 2004 including autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic, other health impairment, specific learning disabilities, speech or language, traumatic brain, and visual impairment.

Education for All Handicapped Children Act of 1975 is the original special education law enacted to stop exclusion of students with disabilities from public school.

Free Appropriate Public Education (FAPE) is what the IDEA law is designed to offer all students, regardless of the student's ability.

Families and Advocates Partnership for Education (FAPE) is a partnership that aims to improve the educational outcomes for children with disabilities by linking advocates to information about IDEA 2004.

Federal Register is a federal government document that includes new laws, regulations for implementing those laws, and current changes to existing laws and can have more than 80,000 pages in an annual volume.

Individual Education Plan (IEP) is required by IDEA 2004 and involves parents and education professionals in educational planning and monitoring of services for a student with a disability who is qualified for special education services.

Individuals with Disabilities Education Improvement Act of 2004 (IDEA) is the reauthorization of IDEA 1990 and 1997, guarantees all students to FAPE and categorizes ADHD as a disability.

Individuals with Disabilities Education Act 2004, Part B refers to the section of IDEA 2004 that outlines provisions for special education assessment, qualification, services, monitoring and funding.

Institute on Community Integration (ICI) is an organization that provides research and resources to improve the education, employment and community integration for persons with disabilities.

Least Restrictive Environment (LRE) is a concept in IDEA 2004 that places emphasis on inclusion of students with disabilities in general education classes to the extent possible.

National Dissemination Center for Children with Disabilities (NICHD) is an organization that provides support and resources for advocates of students with disabilities.

National Resource Center on ADHD is an organization that provides advocates resources about ADHD.

No Child Left Behind Act of 2002 (NCLB) is a comprehensive educational reform law that reauthorized the Elementary and Secondary Education Act of 1965 with an emphasis on closing the achievement gap.

Other Health Impairment (OHI) is a disability category in IDEA 2004, and ADHD is identified in this category.

PACER Center (Parent Advocacy Coalition for Educational Rights) is a nationally recognized organization that supports advocates of persons with disabilities.

Parents Helping Parents is the PACER Center's model of educating and supporting adult advocates for students with disabilities.

Section 504 of the Rehabilitation Act of 1973 is a law that prohibits discrimination on the basis of disability in federal agencies, employment and programs that receive federal funds.

## **Summary**

While useful resources exist for parent advocates of students with ADHD in school, additional and improved resources are still needed. A qualitative research method that gives a voice to parent advocates would allow advocates to reflect on and describe their experience of being an advocate for students with ADHD. The parent advocate voice would give insights to advocate needs relative to their experience as an advocate. In the following chapter the literature relating to the major ADHD resources that are

easily resourced by advocates and the more diverse resources found mostly in academic literature will be discussed.



## CHAPTER 2

### Review of the Literature

#### Introduction

Advocates are often considered to be politicians, attorneys and activists who represent government, business or global entities such as the environment, endangered species, human rights, or literacy. Passion for a cause or group drives advocates to follow their convictions and use provisions of the law to stand up for groups or individuals that are not receiving the full benefit of their legal rights. In contrast, advocates of students with ADHD in the school system are usually parents who become advocates in response to the child's need for support and a call for parental involvement from the school. ADHD advocates are confronted with many challenges, the foremost is to advocate for a child who is all too often viewed by teachers and peers as unruly, disrespectful and underachieving. In addition to being challenged in this role, parent advocates also experience personal stressors when advocating for an ADHD student because emotions such as anger and embarrassment are evoked when the student misbehaves, frustration occurs when the school places external pressure on parent advocates to take action to improve student behavior, and feelings of helplessness arise as the advocate searches for a solution (Brinkman, et al., 2009). Research shows that parental involvement positively impacts student achievement for all students, and especially for students with disabilities (Epstein, Simon, & Salinas, 1997; & United States Department of Education, 2004). As a result, schools and teachers expect parent advocates to be involved in identifying the cause of the student's behavioral challenges and to partner in finding solutions to improve student behavior and achievement.

Advocates for students with ADHD in school also face the challenge of not being formally trained in education and child development, yet needing to find resources which is complicated because each student has unique educational and behavioral development needs and requires a multifaceted education plan. An initial step advocates take following a school referral is to have the student assessed for ADHD by a psychologist or physician. Once the advocate becomes involved in the ADHD assessment and educational planning process, frustration can build as the advocate debates issues such as the subjectivity of the ADHD assessment process (National Institute of Health, 2008), the possibility of misdiagnosis of ADHD (Hartnett, Nelson, & Rinn, 2004; Haber, 2003; Baum & Olenchak, 2002; & Mota-Castillo, 2007) and concerns about whether or not to use stimulant medication to treat the child (Food and Drug Administration, 2007; & Brinkman et al, 2009). Advocates might attempt to search for comprehensive resources that cover ADHD assessment, diagnosis, medical treatment and behavioral treatment. The preferred treatment for ADHD students is medication, and it is more difficult for parent advocates to find resources that offer information about approaches such as behavioral treatment and parent education. In addition, financial burden can prohibit parent advocates from engaging a psychologist for support in developing behavioral treatment plans instead of or in combination with the medication as treatment approach.

Beyond challenges parent advocates experience during ADHD assessment and treatment, they also experience difficulty obtaining special education services for ADHD students. A problem that parent advocates face is that ADHD students often don't meet the IDEA 2004 (IDEA, 2004) criteria that qualifies students for special education services and requires that students demonstrate achievement that is two grade levels

behind their current age and grade level. A diagnosis of ADHD is not enough to qualify students for special education services. In fact, only recently has ADHD been included in Section 504 of the Rehabilitation Act of 1973 and IDEA 2004 thereby establishing that ADHD students are entitled to educational rights under those laws (Federal Register, 1999, p. 12542; Rehabilitation Act, 1973; & IDEA, 2004). Regardless of the recent addition of ADHD in the special education law, ADHD is still not readily viewed by many education professionals as a disability that qualifies for special education services. In fact, students who have ADHD combined with another disability obtain special education services more easily because the second disability more clearly affects the student's performance and is used to meet the special education qualification criteria.

Parent advocates, frustrated in this new role and seeking support and education, often connect with two main organizations that offer education and support for advocates of students with disabilities in education. These organizations are PACER Center and the Institute on Community Integration. PACER Center is a nationally recognized parent advocacy organization that supports adults as they learn to advocate for students with disabilities. PACER refers advocates of ADHD students in school to many major resources that mainly focus on student rights, special education processes, and school-based interventions, as well as information about ADHD assessment, diagnosis and treatment. PACER Center also connects advocates with mentor advocates that educate and support advocates by sharing their own experiences of advocating for a student with a disability in school. The PACER model facilitates adult education by connecting advocates to other advocates that share their lived experience (van Manen, 2007) of being an advocate with parents who are learning to become advocates. However, qualitative

research that gives parent advocates a voice and describes their storied narratives is not easy to locate, if it even exists (PACER Center, 2010). The lack of research documenting advocate experience leaves a significant gap in the literature which can be filled with qualitative research that gives a voice to the experience of parent advocates.

The Institute on Community Integration (ICI) is the second nationally known organization that advocates of ADHD students in school go to for resources. Although ICI does not provide services, it focuses on developing collaborative research, training, information and best practices to support service providers and advocates of persons with disabilities. Advocates for students with ADHD in the school system can find many resources that discuss broad disability topics relevant to students with ADHD such as special education services, technological innovations, behavioral and instructional management, and career readiness.

Although legal and medical resources regarding ADHD are very useful to advocates of ADHD students in school, a set of diverse resources exists in the literature that can be applied to practice and contribute to the improvement of ADHD student behavior and achievement in school. Diverse resources present information about ADHD on topics such as misdiagnosis of ADHD and conditions that contribute to inattentive student behavior such as giftedness, learning disabilities, physiology, and environment (Baum & Olenchak, 2002; Chang, et al, 2012; Faber & Kuo, 2011; Haber, 2003; Konofal et al., 2008; Mota-Castillo, 2007; National Institute of Mental Health, 2008; Piechowski, 1991; Renzulli, Smith, Callahan, White, & Hartman, 1976; & Richardson, 2006). However, parent advocates do not regularly locate this information, thus much meaningful research does not make its way from research to practice and

advocates miss opportunities to utilize meaningful research outcomes in education planning and practice.

### **The Available Literature and Research**

The purpose of this literature review is to establish the context of the research problem and provide evidence from the literature to support the assertion that research about parent advocate experience is needed. This section looks at literature from the perspective of a parent who is an advocate for a student with ADHD in school . Major research projects were located that are frequently located by advocates and research advocates find useful but do not readily accessible was identified. Ultimately, the composite of literature developed in this section presents a comprehensive perspective on ADHD research that is useful to advocates of ADHD students as they negotiate for students in the school setting. Furthermore, the significance of the research problem is clarified in this section by identifying the more diverse literature that advocates do not commonly locate, thus laying a foundation for a need to more deeply understand parent advocate experience. (Hart, 1998; Randolph, 2009).

Parent advocates need information that is useful in educational planning meetings where action plans are developed to target improving student learning opportunities, designing approaches to reduce the frequency of ADHD behaviors in the classroom, and facilitating the improvement of student behavior and achievement. The nature of experience that parent advocates have is sought in order to more deeply understand what it is like to be a parent advocate of a student with ADHD in school.

I will analyze the research outcomes to more fully understand parent advocate experience, and I will develop a discussion that relates to more deeply identifying parent advocate needs (Cooper, 1988). Additionally, this literature review does not take a systematic approach to critically reviewing research methodologies or theories. Literature beyond major resources centered on psychological and legal aspects of ADHD will be not be selected for this review because the depth of research about ADHD in those fields is not relevant to the education setting.

### **Major Resources on ADHD Students and School Resourced by PACER Center and ICI**

An abundance of literature on ADHD exists, most of which looks at diagnosis, drug treatment, behavioral treatment and the impact of such treatments. Most of the ADHD literature has been conducted in and is discussed from a clinical psychological or medical perspective. Following are results of a literature search for major resources on ADHD that are readily accessible and frequently resourced to advocates of ADHD students in school. The literature is organized from two perspectives that represent the typical search process that advocates use as they search for information about ADHD and school. The first is a search for ADHD information, relevant to advocate learning, on the websites of the two main organizations that provide services and resources regarding students with disabilities: PACER Center and the Institute on Community Integration. The second is a search for ADHD in education and advocate literature using internet search engines that search refereed journals, books, theses, and government documents. Resources published between 2005 and 2012 have been included in the search parameter and resources published before 2005 are justified.

### **PACER Center resources.**

Searching “ADHD” on the PACER website yields many resources that include a bibliography of publications, a list of curriculum taught by PACER to advocates, descriptions of several workshops and various articles and books. Most of the resources listed on the PACER website do not meet the search criteria because they are older than 2005, or they have not been published in a refereed journal.

A main author widely published in ADHD literature and referenced on the PACER website is Dr. Russell Barkley, a clinical professor of psychiatry and pediatrics at the Medical University of South Carolina in Charleston. In fact, Dr. Barkley has developed a widely referenced model of executive functioning, which refers to a set of organizational and decision-making skills that ADHD students are challenged with and includes executive skills defined as planning, organization, time management, working memory and metacognition (Barkely, R. A., 1997). Barkley’s 2005 book, *Attention Deficit Hyperactivity Disorder: A Handbook for Diagnosis and Treatment, 3rd Edition*, is referenced by PACER to advocates. This 757 page guide covers mainly clinical psychological issues to include: Nature of ADHD, history, symptoms, theory, assessment, and treatment. There is a short chapter on the treatment of ADHD in school settings, however much of what is covered relates to assessment and treatment of ADHD. Some information about parent training is also included which indicates that Behavioral Parent Training (BPT) impacts ADHD students positively by reducing ADHD behaviors. A criticism of this resource is that it is heavily weighted with ADHD assessment and treatment information. If more explicit information was offered regarding BPT and the successful impacts it can have on students, such as how to obtain training, the resource

would be more broadly meaningful to ADHD advocates. Although some information is meaningful to advocates, the bulk is not very useful to advocates of ADHD students in schools.

In addition, workshops are listed on the PACER website that focus mainly on issues of ADHD and special education rights and processes and on the topic of using assistive technology to support learners. There is also a workshop on skills for effective parent advocacy which includes “understanding your child's disability, knowing your school district, knowing your rights and responsibilities, using clear and effective communication, understanding the special education process, and knowing the dispute resolution option”. Much of the literature in workshops focuses on how to navigate the special education process but does not include information about ADHD misdiagnosis or conditions that mimic ADHD behaviors such as giftedness. Topics such as ADHD and physiology, ADHD and exercise and ADHD and green space are not included.

Reviewing the PACER Center website to understand resources that advocates of ADHD students are guided toward confirms that most resources are focused on ADHD assessment, diagnosis and treatment with medication and the navigation of assessment for special education services for ADHD students in school. Many resources do not meet the search parameters for this literature search because they are either older than 2005, are not primary resources, or are articles that have not been published in a peer refereed journals. Although the literature and approach to advocate learning through mentoring and transformative learning (Mezirow, 2000, p.4) that occurs by working with experienced advocates from PACER is meaningful to advocates, a knowledge gap does exist in the resources offered advocates by PACER Center.



### **Institute on Community Integration resources.**

The Institute on Community Integration (ICI) differs from PACER Center in a way that is significant to the purpose of this literature review. While PACER offers services such as education and mentoring to advocates, PACER does not conduct much original research and is not particularly attuned to the requirements of scholarly publication. In contrast, ICI does not provide services, yet does focus on developing collaborative research, training, information and best practices to support service providers and advocates of persons with disabilities. In fact, ICI is located in the University of Minnesota's University Center for Excellence in Developmental Disabilities. Two major resources retrieved from the ICI website as a result of searching "ADHD" are: 1) *ADHD Parents Medication Guide* (American Academy of Child and Adolescent Psychiatry, 2007) and 2) *Identifying and Treating Attention Deficit Hyperactivity Disorder: A Resource for School and Home* (United States Department of Education, 2003).

The *ADHD Parents Medication Guide* (AACAP, 2007) primarily discusses ADHD diagnosis, treatment, and medication including side effects, risks, and disorders that can coexist with ADHD, psychosocial treatments, and unproven treatments. Although the content is mostly focused on diagnosis and medication-based treatment of ADHD, a discussion on psychosocial treatment is meaningful to advocates of ADHD students:

Whether or not your child is on medication, behavioral treatment can help manage ADHD symptoms and lessen their impact on your child.

One study showed that you may be able to lower your child's medication

dosage if behavioral therapy is working well (AACAP, 2007, p. 17).

This is promising information, especially for advocates that are concerned about medicating their children. The criticism I have of this publication is that this section does not include examples of tested and effective behavioral treatments. The advocate is introduced to this idea but left with no example or link to find more quality resources about behavioral treatments. Similarly, this section suggests that teachers benefit from using behavioral training techniques but does not offer any further resources that advocates can use to develop these skills. Closing the ADHD knowledge gap requires effective, practice-oriented behavioral training resources.

A section on school and the ADHD child is also included in this publication that encourages advocates to communicate frequently with teachers who observe ADHD behaviors and make the initial referral for ADHD assessment and diagnosis. Special education law and student rights to special education assessment and qualified services are covered, however, the following resources listed in this publication meet the criteria for this literature review.

*The Identifying and Treating Attention Deficit Hyperactivity Disorder: A Resource for School and Home* (United States Department of Education, 2003) resource offered by ICI mainly connects families with typical information regarding ADHD assessment, diagnosis and treatment and information about special education services. Limited references to recent, if any, research are included especially regarding more diverse resources about ADHD and school.

## **Standard Resources on ADHD Students & School, Resourced in Published Literature**

Internet search engines such as EBSCOhost ([www.ebscohost.com](http://www.ebscohost.com)) and Wilson Web ([www.hwwilsonweb.com](http://www.hwwilsonweb.com)) accessed through the University of Minnesota libraries were selected that search more than 5,000 scholarly publications dating back to 1975 in education, psychology, and social sciences. Search parameters include primary resources, articles published in a peer refereed journals, dissertation theses or government publications, and resources published between 2005-2012, discussed herein that is published prior to 2005 will be justified. The following section of the literature review was conducted by searching the following keywords:

ADHD & advocate, ADHD & parent, ADHD & parent & stress, ADHD & misdiagnosis, ADHD & over-diagnosis, ADHD & referral, ADHD & gifted, ADHD & giftedness, ADHD & brain, ADHD & physiology, ADHD & brain maturation, ADHD & iron, ADHD & omega-3, ADHD & sensory issues, ADHD & sensory, ADHD & green space, ADHD & exercise.

Due to the limits of the length of this review article a broad number of topics were identified. However, the review is not exhaustive within each topic. The criteria for selecting literature was:

1. Research about advocate experience, learning needs regarding ADHD students in school, and information that contributes to closing the advocate's ADHD knowledge gap.
2. Research that illuminates factors that may influence the expression of inattention, hyperactivity, and/or impulsiveness which are typical ADHD behaviors.

3. Research that can be used to meet Martin's Principles of Advocacy (2010, p. 52):
  - 1) Take Responsibility: Be a Leader, 2) Learn: Be an Expert, 3) Think Critically: Be Discerning, 4) Speak with Authority: Be Proactive, 5) Document: Be Prepared, 6) Collaborate: Be a Team Builder, and 7) Educate: Be a Voice for Your Child.

Articles are categorized by topic areas as follows: ADHD and misdiagnosis, ADHD and giftedness, ADHD and physiology, ADHD and environment and ADHD and exercise.

### **Advocating for ADHD students.**

A meaningful book recently published that contributes to closing the ADHD knowledge gap is: *The Everyday Advocate: Standing Up for Your Child with Autism* (Martin, 2010). Although this book focuses on advocacy for youth with autism, a great deal of information provided can be used by advocates of ADHD students. The book integrates many case studies of advocacy for autistic youth revealing advocate frustrations, emotions, and ways of learning to advocate for the youth in a variety of settings.

Martin (2010, p. 52) identifies the following seven principles of advocacy which she has uniquely identified in her book which is a primary resource that can be reviewed and modified to support advocates of ADHD students in school:

1. Take responsibility: Be a leader,
2. Learn: Be an expert,
3. Think critically: Be discerning,
4. Speak with authority: Be proactive,

5. Document: Be prepared,
6. Collaborate: Be a team builder, and
7. Educate: Be a voice for your child.

These principles certainly apply to advocates of ADHD students in school and are guideposts that can be supported with ADHD relevant information rather than information relevant to autism. For example, principles such as being an expert, thinking critically and educating can be achieved if ADHD advocates are able to locate a broad range of literature and resources that can support advocates in leading others by offering explicit examples of behavioral, physiological, and environmental accommodations that are effective in supporting ADHD students in school. Furthermore, an aspect of this book that is helpful to advocates is the listing of specific skills that advocates can develop to achieve each principle and models of what advocates can say in response to family members, teachers and peers. In fact, the end of each chapter includes a section called “Putting it into Action” where bullets are listed that identify steps that advocates can take to put ideas into practice.

Another helpful inclusion in Martin’s (2010) book are models and examples that ADHD advocates can use apply directly to their own learning about advocacy. Sections that are not as relevant to ADHD advocates because ADHD students do not have a severely limiting disability are topics such as: 1) Balancing a Career and Autism, 2) Legal Consultation: Our Family’s Choice for Inclusion and 3) In the Community: Integrating Your Child (Martin, 2010, p. 52).

Although Martin (2010) lists references organized by chapter in the endnote section at the end of the book, a criticism is that she does not reference guiding theories or authors that contribute to the development of the Seven Principles of Advocacy. These principles would carry much more authority and gain broader buy-in from readers if the development of them did not rely so heavily on Martin's (2010) opinion but instead on a combination of her opinion supported by scholarly influence relative to theory, philosophy and published research on advocacy for students with disabilities in school.

Jensen's book, *Making the System Work for Your Child with ADHD*, is readily accessible to advocates and offers a place to begin learning to advocate for ADHD students in school (Jensen, 2004). This resource, published prior to 2005, is included in this literature review because some of the content speaks uniquely to advocacy for students with ADHD. Topics pertinent to ADHD advocates include: 1) Issues that contribute to advocate frustration in learning about ADHD advocacy, 2) Developing plans for your child, and 3) Getting the best from your child's education.

Dendy's book, *Teenagers with ADD and ADHD: A guide for parents and professionals*, is also readily accessible to advocates and offers frequently covered information about the description, diagnosis of ADHD, treatment, medication dilemma, and the parent's role in advocating for the ADHD teen in school. Following the constructivist and experience-based model of advocate learning established by PACER Center, Dendy is a mental health professional and mother of 3 children that have ADHD. She speaks from her experience and draws on literature to create a resource for advocates support their learning about ADHD students in school. She includes a separate chapter on medications and provides details on specific drugs, and what research shows about

their effectiveness in improving attention, impulse control, and distractibility. Dendy discusses recent research about the role of executive function problems and how advocates can work with schools to identify success strategies for students. In addition, the book covers some information about coexisting disorders such as learning disabilities, depression, anxiety, Tourette syndrome, and Asperger syndrome. However, Dendy does not present information in a way that addresses possibilities of misdiagnosis with of ADHD instead of the second disorder, and she does not fully address the issue of giftedness and related misdiagnosis issues.

### **Behavioral training advocacy for ADHD students.**

A search conducted using “ADHD & behavioral training” produced less than 30 qualified resources. Interestingly, a resource with great relevance to advocate learning and ADHD students was found that intersects with other literature discussed in this review. Dawson and Guare’s 2010 book, *Executive Skills in Children and Adolescents: A Practical Guide to Assessment and Intervention*, offers in-depth discussion of ADHD and executive function, behavioral skills training and case study research that captures qualitative information from the ADHD student, classroom and parent perspectives. In addition, one of the guiding models the authors use to frame discussion and interventions to improve executive function is Dr. Russell Barkley’s Hybrid Model of Executive Function which is described in a resource referred to advocates by both PACER Center and the Institute on Community Integration.

Dawson and Guare’s (2010) book offers a unique perspective on ADHD students which is a focus on executive function skills and school-based interventions that can be used to train ADHD students to improve these skills and thereby reduce ADHD

behaviors and increase achievement. Dawson and Guare (2010) take Barkley's psychiatric model of ADHD and executive function skills and apply it to classroom-based interventions while also conducting qualitative research that generates meaningful information for advocates of ADHD students. Explicit steps and tools are identified that can be used to train ADHD students to improve executive skills such as organization, self control, and memory. Case studies of students in school and the advocate's perspective are included as well as descriptions of classroom interventions and steps to connect suggested interventions to a widely practiced behavior management system used in schools called Response to Intervention (RTI). The book also includes 50 pages of reproducible forms that can be used in a school setting as part of an intervention to improve ADHD student executive functions and ADHD behaviors. This resource connects advocates to explicit steps to interventions that can be implemented in school settings.

Although this book focused on application of behavioral training for executive skills in the classroom, a criticism of Dawson and Guare's (2010) book is that diverse ADHD topics such as misdiagnosis, giftedness, physiology, environment and exercise are not included. In fact, none of the diverse ADHD literature reviewed in this paper is included in the content or references. Although the executive function interventions are solidly supported by a range of psychological and medical resources, there isn't a balance of literature that includes resources that discuss influences on ADHD behavior that are not based in cognitive behavioral deficits. A more comprehensive contribution to ADHD student interventions applicable in the classroom would exist if this resource also included information about diverse ADHD behavioral influences.



These resources are very helpful to advocates of ADHD students. However, an emphasis on assessment, diagnosis, and treatment exists and does not include comprehensive information, especially regarding misdiagnosis and diverse resources related specifically to ADHD students.

### **More Diverse Resources on ADHD Students & School, Resourced in Published Literature**

Much ADHD literature discusses ADHD assessment, diagnosis and treatment. However, diverse and less frequently resourced literature exists that can be very meaningful to advocates of students with ADHD in school. Martin's Principles of Advocacy (Martin, 2010), learning to be an expert and thinking critically, require that advocates have access to a range of information including controversial information. Diverse ADHD literature includes a variety of learning and physiological factors that influence student demonstration of inattentive, hyperactive and/or impulsive behaviors. Following is a critical discussion of literature that is outside the standard body of resources frequently resourced to advocates of ADHD students. The literature is organized by topics that are categorized according to the type of diverse ADHD issue and the influence that the topic has on student expression of ADHD behaviors in school.

#### **ADHD and misdiagnosis.**

Preventing misdiagnosis of ADHD is a topic weighed heavily by parent advocates of students diagnosed with ADHD (Baum & Olenchak, 2002; Connor, 2011; Chermak & Musiek, 2007, Haber, 2003; Hartnett, Nelson, & Rinn, 2004; & Mota-Castillo, 2007, Mental health weekly, (1995) because of concerns related to medicating students,

especially if students may not have ADHD. Connecting ADHD advocates to the possibility of misdiagnosis and to less frequently resourced literature that discusses factors that contribute to misdiagnosis impacts decisions made regarding treatment and educational planning for ADHD students.

The route to student ADHD diagnosis usually begins with teachers identifying ADHD behaviors in a student and in turn making a referral to a school psychologist or via parents to a physician or mental health practitioner for ADHD evaluation. At that point a practitioner asks parents and teacher to complete a CCPT (Conners' Continuous Performance Test) (Conners, 2000) questionnaire which gathers information about the student's behavior. In most cases, after an interview and look at the student file, students that demonstrate inattention, hyperactivity and/or impulsivity at home and school are diagnosed with ADHD and treated with stimulant medication. However, the literature indicates many diverse factors can influence the expression of ADHD behaviors. For example, ADHD behaviors such as inattentiveness, hyperactivity, and impulsiveness are also typical of gifted students who demonstrate over-excitabilities as well as students that may have physiological issues.(Chermak, 1997; Hartnett, et al, 2004; Konofal, et al, 2008; NIMH, 2008; Oner, et al, 2010; PT in Motion, 2011; Richardson, 2006; and Sinn, 2008) Advocates need diverse information about influences on the demonstration of ADHD behavior in order to become experts, critical thinkers, leaders, and educators (Martin, 2010) who can make informed decisions as they advocate for ADHD students.

Johson-Gros (2007) wrote *ADHD: The great misdiagnosis* which is a review of a book by Haber (2003) called *ADHD: The Great Misdiagnosis*. Johnson-Gros makes the following comments about Haber's (2003) book which largely support a need for ADHD

resources to include more diverse ADHD resources. However Johnson-Gros has a perspective that expects more information on behavioral training for ADHD students, yet does not seem to focus on the significance of the cases and discussion Haber provides regarding misdiagnosis:

1. Haber summarizes several aspects about ADHD, including issues surrounding diagnosis, coexisting disorders, educational services, and medications. I agree with this comment, however, the point Haber was making in discussion “coexisting” disorders was to draw advocate attention to the idea that ADHD may be misdiagnosed, not that they coexist.
2. The book gives a good but brief review of the “imitators” that need to be considered when a comprehensive assessment is conducted. I agree and feel that Haber should revise the book again and include many diverse ADHD resources that have been published since 2003.
3. Haber devotes an entire chapter (chapter 8) to alternative therapies, which include nontraditional medication therapies. Although this topic is pertinent to the readers, it is disappointing nonetheless that other psychological and behavioral interventions were not given more attention. A criticism of Johnson-Gros’s comment is that Haber’s purpose in this book was to provide alternative ideas and treatments to what typically occurs. The executive function behavioral training information discussed in this paper would be an appropriate addition in a revised edition.

Mota-Castillo (2007), *The crisis of over-diagnosed ADHD in children*, is a commentary written by Dr. Mota-Castillo, a psychiatrist. Dr. Mota-Castillo offers his

strong opinion that over-diagnosis of ADHD occurs because of “superficiality that characterizes the process of diagnosing attention-deficit/hyperactivity disorder (ADHD) in children—usually followed by the prescription of one of the most powerful drugs on earth, methylphenidate”. A criticism of the article is that it does not report on a quantitative or qualitative research study but rather case stories of Dr. Mota-Castillo’s clients that have been misdiagnosed with ADHD. Although the article is flawed from a methodological perspective, he identifies the following useful factors that contribute to misdiagnosis: (a) failure to obtain a complete family history, (2) cultural and linguistic barriers, (3) failure to communicate with clinicians who know the client well, & (4) misconstruing behaviors as causative explanations. Further studies whether quantitative, qualitative or mixed-method, could be conducted to investigate the role these factors play in misdiagnosis of ADHD.

The Baum and Olenchak (2002) article, *The Alphabet Children: GT, ADHD and More*, present a literature review and case study to explore the phenomenon of students that receive multiple diagnoses after initially receiving an ADHD diagnosis. The student profiled in the case study is gifted and diagnosed with ADHD and subsequently was diagnosed with oppositional defiant disorder (ODD), generalized anxiety disorder (GAD), and learning disabled (LD). This student’s case is told in order to exemplify the problem and raise reader awareness to the problem of misdiagnosis which is valuable. However, from a methodological perspective, the authors do not clearly define whether the purpose in the article is a literature review, a qualitative case study or a mixed methods approach. They provide an excellent overview of literature that demonstrates an overlap in reasons for ADHD behaviors but a standard case study methodology in

collecting or analyzing data is not followed. They emphasize seeking causal relationships (a quantitative, not qualitative and case study approach) between the literature and the narrative which they weakly refer to as a case study. Although the literature review and student narrative are valuable sources of information, the design and interpretation of the study is weak.

Additional articles located in the literature about ADHD and misdiagnosis identify conditions that can be misdiagnosed as ADHD. One is a recent article in *PT in Motion* (2011), *Pediatric sensory issues commonly mistaken for ADHD*, which reports the results of “a survey of more than 500 pediatric physical therapists, occupational therapists, and speech-language pathologists where 68% of respondents evaluated or treated children between 3 and 8 years old that had previously been misidentified with learning disabilities or behavioral issues. The respondents said that 90% of those children who-were misidentified had been initially diagnosed with attention-deficit/hyperactivity disorder (ADHD).” Traumatic experience is another issue that may result in a student demonstrating behaviors that can be used misdiagnose ADHD. In the article, *Trauma Often Misdiagnosed as ADHD*, Seith (2009) states that “children traumatised by abuse and neglect often receive inappropriate treatment because they are misdiagnosed as suffering from attention deficit hyperactivity or bipolar disorders.” This article does not present any research, however it offers expert clinician opinions and a brief discussion about how behaviors that look like ADHD symptoms may actually be the result of different underlying causes such as trauma or speech and language problems. Improved teacher training on ADHD and misdiagnosis is also identified as a need in this article.

Another article that identifies disorders that are misdiagnosed for ADHD was published by Foli & Elsisy in 2010, *Influence, Education, and Advocacy: The Pediatric Nurse's Role in the Evaluation and Management of Children with Central Auditory Processing Disorders*, and discusses the occurrence of misdiagnosis of ADHD when the student may actually have a central auditory processing disorder (CAPD). This article presents a very comprehensive review of CAPD including an overview and definition of CAPD, description of behavioral symptoms that indicate the presentation of CAPD, a discussion regarding distinguishing CAPD from other disorders such as ADHD and information on screening, evaluation and diagnosis. A main practice implication identified in the article is that “the common indicators of central auditory processing disorders often mimic other childhood disorders such as attention deficit hyperactivity disorder. Testing for central auditory processing disorders is optimized when children are on the appropriate medication at the time of testing.” In addition, discussion regarding nurse advocacy for CAPD patients is very well developed and advocate behaviors are presented in a table in the areas of influencing, education and advocating. Parent advocates of students with ADHD would find this article meaningful because of the clearly described misdiagnosis issues that exist between ADHD and CAPD as well as the discussion about advocacy.

These articles offer parent advocates of students with ADHD important data and support for advocates to question the ADHD diagnosis as a possible misdiagnosis for a different learning disability or behavioral issue that may stem from a variety of issues.

### **ADHD and giftedness.**

Several researchers have recently published articles regarding the notion that giftedness can be misdiagnosed as attention deficit hyperactivity disorder (ADHD) (Goerss, Amend, J. T. Webb, N. Webb, & Beljan, 2006; Haber, 2000; Nelson, Rinn, & Hartnett, 2006; & Webb et al, 2005). The issue of misdiagnosis of ADHD for gifted and talented (GT) has been increasingly discussed because GT students demonstrate typical ADHD behaviors such as inattentiveness, inconsistent completion of tasks, disorganization, high activity levels, and impulsiveness. (Piechowski, 1991; Renzulli, et al., 1976; Silverman, 1998). Giftedness is not a medical condition, therefore the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR, APA, 2000) does not discuss the possibility of confusion of GT for ADHD and does not discuss the impact of giftedness on the diagnosis of ADHD. However, the DSM-IV-TR does state that "inattention in the classroom may also occur when children with high intelligence are placed in academically understimulating environments"(APA, 2000, p. 91). The following ADHD and GT literature is useful to advocates in learning that behaviors of inattention, hyperactivity and impulsivity are demonstrated by GT and ADHD students.

The Hartnett, Nelson, and Rinn (2004) article, *Gifted or ADHD? The Possibilities of Misdiagnosis*, is a primary research article that was methodologically well-designed and executed, investigated the possibility of misdiagnosis of ADHD for GT in students. Graduate school counseling students participated in a quantitative study and were asked complete form A or form B to diagnose a young boy described in a vignette who had demonstrated inattentive, impulsive and hyperactive behaviors.

Both forms asked the participants to read the passage and answer the questions following the passage. Form A asked, "If this child were referred to you by his teacher for evaluation, what do you think the underlying explanation for his behavior would be?" Form B asked, "If this child were referred to you by his teacher for evaluation, do you think the cause of his behavior could be attributed to Attention Deficit Hyperactivity Disorder (ADHD) or due to his being gifted and talented (G/T)?" (Harnett, et al., 2004).

The form was the independent variable and the diagnosis was the dependent variable. The chi-square analysis demonstrated a significant main effect between the form and the diagnosis made. The mere suggestion to consider giftedness as a reason for the demonstration of ADHD behaviors "swayed nearly half the subjects" to consider giftedness. The results of the study demonstrate that counselor training programs may not adequately clarify the differences between ADHD and giftedness for students which impacts whether or not a student is referred for ADHD assessment and ultimately diagnosed. Future studies could replicate this study with parents and teachers who both participate in ADHD assessment. Understanding advocate knowledge of the overlap of ADHD and GT behaviors would inform educators of advocate training needs.

The Mika (2006) article, *Research Commentary Point-Counterpoint: Diagnosis of Giftedness and ADHD*, is a primary resource and commentary in response to the previous article by Hartnett, et al. (2004). The article is criticized for offering mostly strong opinions supported by few pieces of literature. Furthermore, it's disappointing that Mika disputes the idea that GT students are misdiagnosed with ADHD by discrediting the



notion that misdiagnosis of ADHD for GT exists. Mika claims there is no evidence to support this trend, and that there is no evidence to support the definition that GT includes ADHD behaviors. However, Mika uses Dabrowski's theory of disintegration to support evidence in the literature for over-excitabilities in gifted youth to suggest that undiagnosed ADHD rather than misdiagnosed ADHD exists. However, this seems to be simply her opinion and her bias is toward ADHD diagnosis. She takes the position that ADHD behaviors should not be dismissed as "signs of undefined giftedness." One criticism of Mika's position is the actual status of ADHD misdiagnosis for GT is not documented well in the literature which cannot be construed as non-existent. Instead of refusing to consider this trend, more research should be conducted that can reproduce the Hartnett et al. (2004) research or offer a unique contribution to this literature. The second concern is that Mika relies on her bias to drive her argument in that she views misdiagnosis from a clinical psychology perspective, and is presenting her argument to professionals in her field.

The Goerss, et al. (2006) article, *Comments on Mika's Critique of Hartnett, Nelson and Rinn's Article, Gifted or ADHD? The Possibilities of Misdiagnosis*, is a primary resource and commentary that analyzes the previously discussed Hartnett, et al. (2004) and the Mika (2006) response to Hartnett, et al. Goerss, et al. disagree with Mika's logic which underlies her position that there is no empirical evidence of misdiagnosis of gifted children as having ADHD. Goerss et al. claim that such misdiagnosis does occur. Goerss, et al. present the opinion that the Hartnett, et al. study was well planned and provided a valid case for factoring giftedness into the differential ADHD diagnosis. Goerss, et al. identify many pieces of evidence that misdiagnosis of

ADHD for gifted occurs and also point out that many cases of misdiagnosis are not brought to light. Regardless of the perspective advocates accept, this literature gives advocates diverse ADHD information that facilitates advocate development of Martin's Principles of Advocacy: becoming an expert and thinking critically.

Rinn and Nelson (2009) replicated the Harnett, et al. (2004) study using a sample of preservice teachers rather than preservice school counselors for the purpose of "adding to the empirical literature concerning the potential for the misdiagnosis of ADHD and giftedness, as very little empirical research has been conducted in this area and more is needed (Goerss, et al., 2006) and to extend what is known about the diagnostic decision-making processes of preservice teachers." The results of this study were similar to those of the Hartnett, et al. (2004) study, where results demonstrated that preservice school counselors were not likely to consider giftedness to explain student behaviors typically associated with ADHD.

In summary, behaviors that characterize ADHD are viewed by parents and teachers as negative. When developing behavioral and achievement improvement plans for students, Webb, et al. (2005), suggest that professionals working with students seek the least negative and pathological explanation for student behavior. Advocates of ADHD students in school can use information from these studies as they apply Martin's Principles of Advocacy to lead and educate others regarding the overlap of GT and ADHD.

### **ADHD and physiology.**

### ***Brain maturation and influence on ADHD behaviors.***

Physiology and ADHD is a topic of many research studies due to the interest in finding a biological cause of ADHD. Many studies exist in the area of psychopharmacology that investigate the effects of stimulant medication such as Ritalin and non-stimulant medication such as Strattera on ADHD behaviors. The literature reviewed in this section regarding physiology was selected by virtue of offering evidence of a confounding factor that influences ADHD behaviors, and the results can be used by advocates for ADHD students in school.

In a search using “ADHD and Brain”, a National Institute of Health article was located that involved a brain imaging study, *ADHD—Late Brain Maturation*, (NIMH, 2008). This quantitative study and primary resource was well-designed and executed and utilized a new image analysis technique that allowed researchers to analyze 40,000 points of measurement that evaluated the thickening and thinning of thousands of cortex sites in students from both ADHD and non-ADHD groups. The results demonstrate a significant number of ADHD participant brains reach peak thickness at an average age 10.5 compared to the non-ADHD group that reached the same brain maturation at average age 7.5. The greatest maturation delay in ADHD participants occurred in the frontal and temporal areas that integrate sensory information with executive functions such as self-control, attention, working memory and movement inhibition.

One conclusion drawn from this study is that, due to a 3 year delay in brain maturation when compared to peers, ADHD students may outgrow their symptoms as the brain continues to thicken but that maturation will occur closer to age 10.5 rather

than gradually between ages 7.5-10.5. “The findings support the theory that ADHD results from delay in cortex maturation“ (NIMH, 2007). The quantitative approach and solidly designed study also includes validity measures that indicate the results are generalizable, and the results of this study should be used when advocates consider ADHD diagnosis, treatment and educational planning. Additional implications for ADHD advocates are that executive function training should be adapted for the ADHD student. The student should be given time to outgrow the ADHD-like behaviors, especially if the student does not have a confounding educational challenge that would qualify the student for special education or other mental health services. This suggestion is meant for advocates that are concerned about the possibility of misdiagnosis of ADHD and is in contrast to broadly held psychiatric opinions that ADHD, once diagnosed will not go away and in fact will persist into adulthood. In order to be experts and critical thinkers (Martin, 2010), advocates need to be aware of this information when making treatment and educational plans.

***Brain maturation and executive function skill development.***

Another article meaningful to advocates of ADHD students located during the “ADHD & brain” search is, *ADHD and Executive Functions: Lessons Learned from Research*, a publication by Mahone and Silverman (2008). This is a secondary resource that reviews literature from 20 years of research conducted on child brain development and behavior at the Kennedy Krieger Institute. Research-based “lessons learned through research on brain development and behavior in children with ADHD” are outlined and implications for advocates are discussed. Authors discuss the ADHD student’s challenge developing executive function skills which results in ADHD student difficulty in making

self-regulatory decisions required to execute organizational and planning tasks. The authors have the perspective that although ADHD behaviors may become infrequent as the student matures, a student with an accurate diagnosis of ADHD will continue to demonstrate executive functioning difficulties in middle school and high school. The authors also report that other conditions often exist with ADHD such as motor control issues, other psychological disorders and learning disorders. A message important to advocates of ADHD students is that “executive functions, like most other skills, can be explicitly taught, and with the right training and support, the severity of ADHD symptoms can be reduced substantially.” Furthermore, the authors recommend the following resource that advocates can use to meet student behavior: 1) *Executive Skills in Children and Adolescents: A Practical Guide to Assessment and Intervention*, by Peg Dawson & Richard Guare. This information contributes greatly to the ADHD knowledge gap by affirming that behavioral training can improve ADHD student executive functioning and by referring advocates to a training resource.

***Dietary influence of omega-3 on ADHD behaviors.***

Another physiological issue that ADHD advocates can consider is student diet. Omega-3 fatty acids are dietary essentials that are critical to brain development and function, and a lack of omega-3 may contribute to many psychiatric and neurodevelopmental disorders. The Richardson (2006) article, *Omega-3 fatty acids in ADHD and related neurodevelopmental disorders*, is a review of scientific literature that includes various quantitative research studies that evaluate the effect of omega-3 fatty acids on various disorders. This article is detailed, thorough, consistently grounded in established methods for conducting literature reviews and includes results compared in

table form that compare randomized treatments with omega-3 and the results.

Richardson reports, “with respect to treatment, there is preliminary evidence from three randomized controlled trials that supplementing the diet with omega-3 HUFA can alleviate ADHD-related symptoms in children with a primary diagnosis of either dyslexia, ADHD, or dyspraxia/DCD,”. Although omega-3 is not supported by current evidence as a primary treatment for ADHD, the author recommends further research on omega-3 as a potential ADHD treatment. The impact of this article for advocates is that diet can be considered as part of a multifaceted plan to mitigate student ADHD behaviors.

The Sinn (2008) article, *Nutritional and dietary influences on Attention Deficit Hyperactivity Disorder*, is a literature review that generated “an up-to-date account of clinical trials that have been conducted with zinc, iron, magnesium, Pycnogenol, omega-3 fatty acids, and food sensitivities” and the impact of diet on ADHD behaviors. The review is well-conceptualized and executed within guidelines and standards of literature reviews. A refreshing aspect that Sinn offers regarding the conceptualization of ADHD is an emphasis on “ADHD: Contributing Influences”. Although Sinn is focused on physiology and dietary impacts on behavior, her unique perspective not wholly focused on standard approaches to ADHD assessment and treatment contributes meaningful literature to the more diverse set of ADHD resources that advocates can use to influence ADHD treatment and educational plans. Specifically, advocates can consider the diet to determine if the child may be lacking omega-3, and advocates can consult a pediatrician to request omega-3 therapy in combination with or instead of medical treatment for ADHD. Further research is needed to investigate a combination of dietary treatment and

executive function skill training to determine if a combined non-medical, yet physiological, and behavioral training treatment would improve ADHD behavior.

***Ferritin levels and influence on the ADHD behavior hyperactivity.***

Another physiological aspect to consider for ADHD students is stored iron or ferritin levels. The Konofal, et al. (2008) article, *Effects of iron supplementation on attention-deficit hyperactivity disorder in children*, is a primary resource and quantitative study that investigates the effect of iron therapy on ADHD students. The study is incredibly well-designed from a methodological perspective in that participants were qualified for the study by meeting ADHD and stored iron level deficiencies. They were randomly selected into treatment and placebo groups and the results analyzed according to quantitative research standards. More importantly, the effect of iron therapy was measured using 2 common forms of measurement that are used to assess students for ADHD: (a) Conners' Parent and Teacher Rating Scales and (b) ADHD Rating Scale. Significant decreases in ADHD behavior occurred with iron treatment as measured by the ADHD Rating Scale but decreases in behavior did not reach significance on the Conners' Scales. Two implications of this study for further research are: (1) iron treatment does decrease ADHD behavior and should be investigated on a larger scale, and (2) consideration about the subjectivity of the Conners' Scales and parent/teacher bias should be investigated as that may contribute to inability to identify ADHD behavioral improvement.

Another recent article that investigated the role that ferritin levels play in the expression of ADHD behaviors is the Oner, et al. (2010) article, *Effects of zinc and*

*ferritin levels on parent and teacher reported symptom Scores in Attention Deficit Hyperactivity Disorder.* In this primary resource a quantitative methodology, linear regression analysis, was used to compare independent and predictor variables to understand the relationship between age, gender, ferritin, zinc, hemoglobin, mean corpuscular volume and reticulocyte distribution width and behavioral symptoms of children and adolescents with ADHD. “Results indicated that both low zinc and ferritin levels were associated with higher hyperactivity symptoms. Zinc level was also associated with anxiety and conduct problems. Since both zinc and iron are associated with dopamine metabolism, it can be speculated that low zinc and iron levels might be associated with more significant impairment in dopaminergic transmission in subjects with ADHD” (Oner, et al., 2010, p. 447). This study builds on the Konofal, et al. (2008) study and adds to literature that indicates that low ferritin levels influence the demonstration of hyperactive behaviors. Advocates of ADHD students in school would benefit from having this information and using it to consult with the student’s physician to determine if low ferritin levels are contributing to the student’s demonstration of ADHD behaviors.

### **ADHD and green space.**

A search conducted using “ADHD & environment” produced several articles from different disciplines. Pertinent to advocates of students with ADHD is Harder’s (2004) article, *Nature reduces kids' signs of attention disorder.* This article was included although it was published before 2005 because it provides unique information about student playgrounds and examines the impact of playing in green space on ADHD student behavior. Researchers developed a questionnaire that gathered information from



parents about how children with ADHD respond to dozens of extracurricular activities in settings including leafy backyards, indoor playrooms, and artificial outdoor environments such as urban playgrounds. The results indicate that when ADHD students play in green environments, attention and focus improves. In a separate study, students were evaluated on a test of attention after either walking a nature trail or walking in an urban setting. In addition, the setting, not just the activity had the effect of improving attention. Although this study offers important results that advocates can use, further research should be conducted that replicates this study but uses standard assessment tools such as the Connors' Parent and Teacher scales or the ADHD Rating Scale. Results using these scales would be more credible and broadly understood by readers, advocates and clinicians.

Faber and Kuo published in 2011 the article, *Could Exposure to Everyday Green Spaces Help Treat ADHD? Evidence from Children's Play Settings*. They report that “findings suggest that everyday play settings make a difference in overall symptom severity in children with ADHD. Specifically, children with ADHD who play regularly in green play settings have milder symptoms than children who play in built outdoor and indoor settings. Interestingly, for hyperactive children, the apparent advantage of green spaces is true only for relatively open green settings.”

Advocates of ADHD students can consider the amount of green playtime students receive when participating in education planning meetings and advocates can use this research to ask for more frequent opportunities for green outside time as an intervention that is effective in reducing ADHD behaviors. Advocates may also select a school for ADHD students that offers more green outside experiences, such as an environmental

magnet school. Adding this factor to advocate learning would contribute to closing the ADHD knowledge gap.

### **ADHD and exercise.**

Recent approaches to treating ADHD in children look at the effects of exercise on behaviors that are symptomatic of ADHD such as attention, impulsivity, distractibility and especially on the demonstration of executive function skills in ADHD students. Chang, et al (2012) published the article, *Effects of acute exercise on executive function in children with attention deficit hyperactivity disorder*. The article reports on simple yet a well-designed study where ADHD students were given pre and post-tests to assess executive function. After the pre-test, some ADHD students participated in 30 minutes of acute exercise while some ADHD students watched a running/exercise related video. The results demonstrate that the exercise group increased executive function performance whereas the non-exercise group did not. Gapin and Etnier published their study in 2010, *The Relationship Between Physical Activity and Executive Function Performance in Children With Attention-Deficit Hyperactivity Disorder*. Similarly, this study was designed well and measured student executive function performance before and after exercise with the results being that exercise improves executive function in ADHD students.

In addition to studies that evaluated the effect of exercise on ADHD student executive function performance, research exists that demonstrates that exercise can have a positive effect on reducing ADHD behaviors, specifically on hyperactivity. Azrin, et al (2006) conducted a study of an ADHD student where scheduled vigorous exercise was

implemented as a reinforce for increased calm behavior. The results demonstrate that exercise does have the positive effect of increasing calm behaviors in ADHD students.

### **Summary**

While useful resources exist for advocates, a knowledge gap exists between the standard set of resources that guide advocates of ADHD students in school and a more comprehensive set of diverse resources. Establishing the scope and significance of resources for advocates of students with ADHD is difficult because there is limited research that qualitatively describes the advocate's need for information about ADHD students and school. Surveying the literature from an academic perspective and generating set of ADHD resources relevant to ADHD students and school, can add to the main body of research offered to advocates, however the voice of the advocate is still missing.

The subject of the proposed dissertation research is the parent advocate who is experiencing advocating for an ADHD student in school. An approach that can be taken to add qualitative data to the literature regarding the parent advocate's experience is a phenomenological study in order to understand the parent advocate's experience in greater depth and detail. It is the voice of the parent advocate speaking about his/her experience of advocating for the ADHD student that is sought in this research.

## CHAPTER 3

### Research Design and Methodology

#### Overview of Resources Available for Advocates of Students Diagnosed with ADHD

Advocates of students diagnosed with ADHD are usually parents who become advocates in response to the child's need for support and a call for parental involvement from the school. ADHD parent advocates are confronted with many challenges, the foremost is to learn to advocate for a child who is often viewed by teachers and peers as unruly, disrespectful and underachieving. Major resources regarding ADHD generally offer information that parent advocates can use to navigate special education services and educational planning, as well as ADHD assessment and diagnosis. Major resources are referred to parent advocates by advocacy organizations such as PACER Center and the Institute on Community Integration. However, a more diverse set of ADHD resources exists in the literature that would support parent advocates in developing a comprehensive understanding of ADHD students but parent advocates do not readily access these diverse resources. Parent advocates do not have appropriate access to information about ADHD on topics such as misdiagnosis of ADHD and conditions that influence inattentive student behavior such as giftedness, learning disabilities, physiology, and environment (Baum & Olenchak, 2002; Bental & Tirosh, 2007; Chang, et al, 2012; Haber 2003, Faber & Kuo, 2012, Johnson-Gros, 2007; Konofal et al., 2008; Mota-Castillo, 2007; National Institute of Mental Health, 2008; Piechowski, 1991; Renzulli, Smith, Callahan, White, & Hartman, 1976; & Richardson, 2006).

#### *Problem Statement.*

Parent advocates for students diagnosed with ADHD may not have appropriate access to a comprehensive set of resources, therefore advocates are inhibited from being

effective because they do not understand the range of information that can be considered when advocating for students diagnosed with ADHD.

### ***Research Questions.***

The research questions for this transcendental phenomenological study are:

*Textural question:* “What is it like experience advocating for your child who is diagnosed with ADHD?”

*Structural question:* “What contexts or situations have affected your experiences of advocating for your child who is diagnosed with ADHD?”

### **Research Methodology**

The problem statement suggests that parent advocates of students diagnosed with ADHD do not have appropriate access to ADHD resources which limits their understanding of ADHD students. The research in this proposal takes a naturalistic approach to understanding the lived experience of parent advocates. Researching the phenomenological, or lived experience (van Manen, 2007) that parent advocates of ADHD students have will add rich contextual information about the advocate’s experience to the literature. Instead of investigating tangible events such as quantifying the frequency in which advocates locate major ADHD resources, diverse ADHD resources or a comprehensive set of resources, a qualitative research approach will be used to study the phenomenon of how parent advocates experience advocating for students diagnosed with ADHD.

“Qualitative research stresses the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry” (Denzin & Lincoln, 2005, p. 10). The problem that shapes

this research is unique to each advocate because it is situational, contextual and evolves from the perspective of an individual's experience which in this case is the experience that advocates have when they advocate for students diagnosed with ADHD. Creswell describes qualitative research as a fabric that is woven with many worldviews and perspectives to include the researcher's educational philosophies such as constructivism and interpretivism (2007, p. 35). The approaches to qualitative inquiry that are rooted in these philosophies include narrative research, phenomenology, grounded theory, ethnography, and case study.

In this dissertation phenomenological research will be used to conduct an investigation of the lived experience of parent advocates for students diagnosed with ADHD in school. Strengths of qualitative research pertinent to this research study include (Creswell, 2007; Denzin & Lincoln, 2004):

- Provides interpretive information gathered from advocate interviews.
- Describes complex phenomenon, such as advocate learning.
- Describes complex phenomenon situated in a specific environment and within specific relationships.

Disadvantages of qualitative research include (van Manen, 2007):

- Qualitative research is subjective and can lead to procedural problems.
- Qualitative studies can be difficult to replicate.
- Researcher bias is unavoidable due to the subjective nature of data collection.
- Qualitative research is labor intensive and can be expensive.

After reviewing the theoretical foundations of qualitative research, this research paradigm is most appropriate for studying the phenomenon of parent advocate experience because it has the potential to generate new understandings of complex human phenomenon. Practical knowledge about parent advocate experience is sought and that knowledge is embedded in the world of meanings and of human interactions. More specifically, the use of phenomenological research methodology will allow me, as the researcher, to gather information about the lived experience of parent advocates which will render possible an interpretive understanding of advocate lived experience that includes multi-dimensional meaning.

### **Phenomenology**

Phenomenology is considered a human science due to the focus of the research being on the structures of meaning of the lived human world (van Manen, 2007). Phenomenology is the study of lived experience which is collected from research participants prior to reflection, classification or conceptualization (Husserl, 1970; Schutz and Luckmann, 1973; van Manen, 2007). As such, phenomenology can bring us in very direct contact with the human world and the lived experience of the advocate as he/she has lived it. A leading phenomenological theorist, Heidegger, says phenomenology is “to let that which shows itself be seen from itself in the very way in which it shows itself from itself” (Heidegger, 1962, p. 58).

Phenomenology is not positivistic and does not seek to offer theories that can be used to explain, control, or predict the world but instead is the study of the essence of something, or more specifically, the study of internal meaning structures of lived experience (Husserl, 1982; van Manen, 2007). When considering the results or end-

products of phenomenological research, Merleau-Ponty (1973) says, “phenomenology, not unlike poetry, is a poetizing project. It is an incantive, evocative speaking, a primal telling”; there is no results-oriented summary or conclusion, but “the words speak the human worldview rather than speaking of it” (Merleau-Ponty, 1973).

### **Phenomenological Method**

A transcendental or psychological phenomenological study describes the meaning of the same experience of a phenomenon for several individuals.

Phenomenologists describe what all participant experiences have in common. “To do phenomenological research is to question something phenomenologically, and, also to be addressed by the question of what something is “really” like” (van Manen, 2007, p.42).

The approach of using transcendental phenomenology to look at the structure and interpretation of individual experience, rather than written text, is considered transcendental phenomenology. Transcendental means the moment when “everything is perceived freshly, as if for the first time” (Moustakas, 1994, p. 34). It is a “research methodology aimed at producing rich textual descriptions of the experience of selected phenomena in the lifeworld of individuals that are able to connect with the experience of all of us collectively” (Smith, 1997, p. 80).

Several key concepts are involved in the transcendental phenomenological research method. The main concepts are: *phenomenological reduction or bracketing and search for essences* (Husserl, 1970; Moustakas, 1994; Giorgi, 1997). Husserl, the father of phenomenology and also a mathematician, borrowed the mathematical term bracketing to use in phenomenological analysis to refer to the researcher’s role in “suspending one’s beliefs in the natural world in order to study the essential structures of



the world” (van Manen, 1997, p. 175). Creswell (1998) presents phenomenological data analysis as a series of reductions (bracketing), analysis of participant interview into themes, and search for meaning. The researcher brackets, or sets aside prejudgements, conducts an in-depth interview with 5-8 participants, records and then transcribes the interview into a text document. The text is analyzed by using layers of reduction to arrive at themes that describe a universal essence or “that which makes a thing what it is (and without which it would not be what it is),” (van Manen, 1990, p. 177). A textural description of interviewee experiences and a structural description of situation and context of how they experienced the phenomena will be combined to convey the essence of the experience. The essences sought in this study will be the common themes of experience that parent advocates have.

## **Analysis**

### ***Overview.***

Psychologist Moustakas (1994) offers a systematic analysis procedure that can be used to analyze interviews for a transcendental phenomenological method. Moustakas also provides guidance for writing textural and structural descriptions. The analysis steps are taken from Creswell (2007):

- In-depth interviews are conducted with a variety of people who have experienced the phenomenon. Polkinghorne (1989) recommends that researchers interview from 5 to 25 individuals who have all experienced the phenomenon.
- “The participants are asked two broad, general questions (Moustakas, 1994): What have you experienced in terms of the phenomenon? What

contexts or situations have typically influenced or affected your experiences of the phenomenon? Other open-ended questions may also be asked, but these two, especially, focus attention on gathering data that will lead to a *textural* description and a *structural* description of the experiences, and ultimately provide an understanding of the common experiences of the participants” (Creswell, 2007, p. 61).

- Interviews are recorded and transcribed. Significant statements and themes that provide an understanding of how participants experienced the phenomena are highlighted and noted as “*meaning units*”.
- Themes are used to write a description of what participants experienced and the context that influenced their experience.
- The researcher writes about their own experiences and the context.
- The structural and textural descriptions are used to write a combined description that presents the “*essence*” of the phenomenon.

### ***Strategies for Interpreting Data.***

An initial step in data analysis is to consider researcher bias that exists due to the researcher’s preconceptions of the phenomenon. A standard phenomenological strategy that is employed to make research findings more accurate is *bracketing*. Chapter 4 in this study focuses on researcher bias and discusses Husserl’s approach to bracketing which refers to the researcher’s role in “suspending one’s beliefs in the natural world in order to study the essential structures of the world” (van Manen, 1997, p. 175). The researcher “brackets”, or sets aside preconceptions in order to allow the phenomenon itself to be expressed in an authentic manner.

Theme analysis is another primary strategy for analyzing interviews. Interviews are transcribed and reviewed many times, initially for bracketing and then to isolate essential themes. Van Manen (2007, p. 78) explains that theme analysis' refers to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work." He also describes phenomenological themes as structures of experience. According to Dahlberg et al. (2001), the approach of "whole-parts-whole" can be used for analysis. The text is read for an overall impression to render a sense of whole, then it is read to isolate themes for a sense of the parts of the whole, and again it is read as a whole to obtain overall meaning. A product of theme analysis is a series of *meaning units*. According to Giorgi (1997, p. 246) the meaning units "are constituted by the attitude and activity of the researcher." Once the meaning units are described, clusters of meaning for each interview can be developed and then a return to whole text analysis in an effort to isolate and reject non-essential themes and to retain invariant themes. This process of whole-part-whole analysis is termed *horizontalization* because the possibility for discovery is unlimited.

A next step in analysis is to use the strategy of imaginative variation where the researcher varies the frames of reference and the perspectives while considering the polarities and reversals. Imaginative variation results in the development of structural themes. A final strategy in phenomenological analysis is to synthesize of meanings and essences.

## **Selection of Participants**

### ***Researcher Involvement.***

A consideration regarding phenomenological data collection and analysis is the researcher bias. In order to understand my bias, as the researcher, I was interviewed by a colleague who was familiar with qualitative research methods. I used the bracketing and horizontalization techniques to analyze my interview so that a description and deeper understanding of my bias regarding this topic could be developed. I referred to this analysis before conducting interviews and when analyzing the participant interviews in order to keep my influence separate from data collection and data analysis and interpretation. I am the parent of a child who had been referred for ADHD assessment, yet was not diagnosed with ADHD. I have advocated for my child who is gifted and who has had a history of demonstrating behaviors that can appear to be ADHD in school. I have some experiences in common with ADHD advocates, specifically interacting with the school and teachers as an advocate for my child. However, I do not have experience obtaining an ADHD diagnosis or advocating within the school in the area of special education or 504 planning. It was important for me to have a reference that describes my bias to consider when collecting data and analyzing data.

***Population, Sample Size and Selection Process.***

Participants were invited to participate in this study by an invitation letter (See Appendix A) that was sent to several schools. Participants who were interested contacted me and if the person was a parent of a student diagnosed with ADHD, the person was invited to participate in an interview. Data was collected through in-depth interviews from 5 individuals who share experience of the same phenomena which is advocating for students diagnosed with ADHD. Participants were invited from a variety of schools including public and non-public schools.

Because participants have been invited to volunteer for the study, consideration is given to research effects that may occur when participants self-select. For example, the “halo effect” which is a social psychology concept where the overall judgments that, in this case the researcher, has about the participant may bleed into evaluative judgments and interpretations of phenomenological study data. Gall, et al., (2007), also identify indicators that can be used to determine when to end data collection: (a) Exhaustion of sources, (b) Saturation of categories, (c) Emergence of regularities, and (d) Overextension.

### ***Interviews.***

Interviews can be described as (a) informal conversational, (b) guided, (c) or open-ended. (Patton, 2002). This study used an open-ended interview so that similar questions were asked of each participant. Initial questions included in the interview:

1. “What is it like to experience advocating for a student who is diagnosed with ADHD?”
2. “What contexts or situations have affected your experiences?”

The interviews were audio-recorded and transcribed by me.

### **Treatment of Data**

#### ***Ethical Considerations.***

A variety of ethical problems can occur during interpretive research such as the participant experiencing emotional difficulty and difficulty in protecting the privacy of participants. Denzin & Lincoln (2005, p. 144-148) outline a code of ethics for social science research:

1. Informed consent: Participants have opportunity to give informed consent and establish an agreement of confidentiality for personally identifying information is necessary. In addition, participants are entitled to change their mind and leave the study at any time.
2. Deception: The code of ethics opposes deception in any form and fosters explicit communication with participants.
3. Privacy and Confidentiality: Participants have the right to personal privacy related to their personal data and information.
4. Accuracy: Ensure data is accurate.

In addition, any time human subjects are involved in a setting such as the University of Minnesota, the IRB (Institutional Review Board) policies and guidelines are followed to ensure research ethics are known and followed.

### **Data Analysis Process**

The interview of me was recorded and transcribed and analyzed in order for bracketing to suspend my experience and reduce the influence of my experience on the analysis of the participant interviews. Results and of the analysis of potential bias are discussed in Chapter 4. The analysis process included using the technique of horizontalization or a whole-part-whole review of each interview text. (Giorgi 1997, p. 246) In this process, all of the interview texts were read and re-read. The texts were also compared to each other to further develop common themes. Participants were asked to review the themes and reflect on the themes for accuracy relative to their experience. Themes were generated and honed with the goal of crystallizing a description of the true nature of the participant experiences.

Following analysis of the interview data using previously described phenomenological analysis methods a chapter of discussion and recommendations follows which connects participant experiences with the literature review and develops potential ADHD policy model that could be adapted by schools which would lay a foundation for how schools and parent advocates can develop a collaborative approach to supporting students that have ADHD.

### **Summary**

This research seeks to use phenomenology to discover the meaning of what it is like to advocate for students diagnosed with ADHD in school. Investigating the meaning of experience for parent ADHD advocates contributes experiential data to the literature that is contextual and structural. This unique perspective on advocacy contributes meaningful data that can be used as a reference when developing further research and ADHD advocate educational and support programs.

## CHAPTER 4

### Analysis

#### Analysis of Researcher Bias

“I never painted dreams, I painted my own reality.”

*-Frida Kahlo, Mexican Painter & Activist*

The phenomenological researcher has an obligation to separate any past knowledge or experience from the analysis of the study participant’s expression of his/her experience, thus allowing for greater authenticity. The relationship between the researcher and participant in a phenomenological interview study is less likely to influence the participant’s response if the researcher has been interviewed and then has analyzed her experience for bias on the topic. A technique called bracketing (Van Manen 1997. P, 175) is used to identify and separate researcher experience from the experience that participants describe. Following are the identification, description, and illustration of themes of experience that I have bracketed prior to conducting participant interviews and text analysis.

#### **Theme One: I Had No Idea...**

This theme describes my evolution of realizing that my son demonstrated behaviors that were not typical of most children. Following are my quotes that illustrate this theme.

I truly had no idea what I was in for as a parent:

“First child I had, I had no idea that he was a little bit out of range of what is typical for kids as far as behavior.”



It slowly dawned on me that I was spending a unique amount of time managing my son:

“Realizing that I had spent a lot of time sort of monitoring his behavior in play groups and knowing what he was doing and always kind of aware of how energetic he was being, whether he was offending other kids or not. That was kind of something I was always thinking about.”

The following narrative tells about my experience with my son when he was in a preschool class, and I just started to realize that he might have a future loaded with disruptive behavior in school.

“So then the class is over and all the parents line up and start collecting their kids. I kind of look in the door, and they are sitting on their carpet pieces looking real cute. Except for my son. He is sitting on the lap of the teacher, pulling the arm of the teacher like she can hardly hold him because he’s this big kid who started walking when he was 8.5 months old, and just had a lot of energy. So she sees me and started pointing to me to come over and pick the kid up. Yeah, this is what I’m used.”

I also realized that he could be counted on to be disruptive and run away in most situations:

“You know, I couldn’t take him to lunch, I couldn’t take him anywhere. He was very difficult to work with.”

**Theme Two: I Just Want to Grab Him and Run Out of There!**

Not having much control over a very energetic, often out of control child, left me with few choices and often feelings of panic:

“I was thinking, “ok, ok,” just wanting to grab him and run out of there which was a very common experience.”

Those feelings gave way to worry that he would not be able to survive in school:

“Shock and not knowing, ‘What did you end up with in this child?’ and what do you now have to do to make sure that this child can actually be in school.”

Typical parenting situations that, through the momentum of my son’s behavior, often resulted in me being embarrassed of my parenting skills:

“I could hear him outside of the parent meeting room. ‘Yah! Yah!’ I could hear the teacher yelling my son’s name. I just stayed in the class. I thought, ‘Ok, I’m not going to get up. It will be really embarrassing if I go out there. I will just see what happens.’”

Another situation where I felt like running was when confronted by the preschool teacher about his behavior:

“Anyway the teacher started talking to me in front of the class and other parents. “Oh, your child has a problem, something is wrong with him, you need to take him for an assessment!” It was very up-setting. And this is in front of other

parents. I was kind of agreeing with her in my head, and I was really embarrassed and trying not to cry.

These were difficult situations that drew very emotional and personal reactions from me because I felt like I was not measuring up as a parent.

### **Theme Three: What, Exactly, Am I Supposed to Do to Help This Kid?**

This theme describes the desperate nature of experience that the I had when realizing I needed parenting help, searched for help and ultimately realized that I needed to become a parent advocate for my challenging child. Quotes from me follow as illustrations of this theme.

“So we left, and I went home in tears in the car thinking, “What am I supposed to do with this kid?” You know I have a master’s degree in Counseling. I don’t know what to do with this kid. Who knows what to do with this kid?”

“I want help. I’m a parent and I don’t know what to do with this kid and I should know what to do for him. I need help.”

I started searching for resources by looking for things to read and finding people to talk to. The internet hadn’t developed as a ready resource at that time. I even visited the University of Minnesota searching for help:

“I was so frustrated in not finding resources when I went to the U. I couldn’t find someone to tell me, “These are the things that have worked, “ or “ Yes, I understand what you are going through so why don’t you try this?” or “Have you

thought about these 3 issues that sometimes look like ADHD but there truly are these 3 or 4 influences that increase this type of behavior in a child.”

I did not get many answers delivered to me but I continued to know that I would have to support him in school with regard to managing his behavior.

#### **Theme Four: It Became My Job to Really Work for Him in Advocating for Him in School**

I decided when my son was in Kindergarten and still demonstrating disruptive behavior, that I would do whatever I could to help him be successful in school:

“And it became my job to really work for him in advocating for him with the school. To build relationships with teachers, to figure out what was the best setting. My goal was to make sure that during the ages of 6-9 he didn’t develop a very low self-esteem and develop into a person who feels like he was a bad person. And I saw some of that happening when he was in first grade. And so I have been an advocate for him. Although he was not actually diagnosed with ADHD, he certainly acted like it. (laughing.)”

I was still searching for resources and help that would facilitate me developing into the advocate that I knew I needed to be for him:

“Mainly trying to understand, you know, how do I help my son? How do I make sure he’s achieving and then how do I work with the institution he’s in? “

In addition to determining what my role was, I also struggled with the school and where boundaries should exist between what parents guide, what schools can require and

how mental health services sought outside of the school are or are not shared with the school. As a parent advocate, I struggled with:

“At what point do you really stand up to the school and say, ‘No, I don’t agree with this and I’m going to move on?’ “

I also did not like having a teacher diagnose my child and encourage me to get him

assessed for ADHD:

“Or they assume, and the teacher will come to you and say this kid had ADHD, you really need to have him assessed.”

“So knowing that there is a culture, and in my experience also in the school system, where parents are being told, you know you need to do this. And you’re kind of feeling like, they are telling me to do this, do I have to do this? “

“If I don’t cooperate with them and do these sorts of things, what’s going to happen? If I don’t do this, are they going to treat him unfairly? “

“So, I didn’t really feel very good about the school system quite honestly, the general attitude.”

I had a very personal perspective on the feeling of justice and the rights I had as an advocate, the rights my son had as a student and the responsibilities the school had to both of us.

**Ph.D. in Education is My Self-Help Program**

I was inspired to pursue the Ph.D. in Education by my experience parenting my young son who demonstrated ADHD-type behaviors, which generated a need for me to develop a unique set of parenting skills, specifically parent advocacy skills. I refer to this doctoral program as a self-help program that has supported my journey in becoming a parent advocate for my child who demonstrates ADHD-like behavior in school.

Following is a narrative about how I entered this program:

“So I called the University of Minnesota. They have a Preschool Behavior project and I talked to them. “Who is going to help me figure out what to do with this kid? They sent me to the Family Education program and I talked with a professor, Marty Rossman. I talked with her for a while and she said, “You have great ideas why don’t you apply for the doctoral program?”

“You should follow this idea and this could be your research. So I said, ‘ok, fine.’”

“I applied for the program and was accepted and started taking classes along this theme and along the theme of researching about a person’s experience and did writing for papers about what it was like or what advocates need when working with kids that have ADHD in school. So that’s why. He’s pretty much grown up now, and I’m ready to move on so I think I should finish the program.  
(laughing.)”

“Ok, so the topic of my research is, “What is it like to be an advocate of a student who has ADHD in school?” The experiences with my son pretty much drove my interest because, although my son has not actually been diagnosed with ADHD,

when he was 3 until about 8 years old he demonstrated many behaviors typical of a student with ADHD: high energy level, distractibility, impulsivity, umm sort of erratic, non-typical classroom behavior. ”

I have learned a great deal about ADHD, educational programs for students with disabilities and parent advocacy. I have also met many parents who are still struggling to develop parent advocacy skills. My perspective in reflection is:

“I felt...this has been really hard for me. I want to figure this out and I want to share this information with other people or be a resource for other people.”

I would like to share with other parent advocates this idea:

“So if a student is demonstrating impulsivity, what could be some of the other reasons, either combined with ADHD or different from ADHD. Some of the things that are in the literature review are that the student may be gifted and talented and distractible or might have a sensory integration problem. The student might have a hearing problem. The student might need outside space. All of these things.”

These are the main themes of experience that I bracketed by and considered before interviewing participants and conducting analysis.

## **Analysis of Participant Interviews**

“What matters in life is not what happens to you but  
what you remember and how you remember it.”

–*Gabriel Garcia Marquez*

A phenomenological methodology was used to collect participant interview data that could describe the meaning of the experience for several individuals. Following the guiding principles and analytical methods, this study seeks to describe these participant experiences. “To do phenomenological research is to question something phenomenologically, and, also to be addressed by the question of what something is “really” like” (van Manen, 2007, p.42). Participants were asked:

*“What is it like to experience advocating for your child who is diagnosed with ADHD?”*

Theme analysis was used after interviews were recorded and transcribed. Van Manen (2007, p. 78) explains that “ ‘theme analysis’ refers to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work.” He also describes phenomenological themes as structures of experience. Dahlberg et al. (2001) describes the analysis approach of “whole-parts-whole” or horizontalization which was used as a guide for analysis in this study. The transcribed interviews were read for an overall impression to render a sense of the whole, then each was read to isolate themes for a sense of the parts of the whole, and again it was read as a whole to obtain overall meaning. Meaning units that characterize advocate experience were developed following this step.



A next step was to use the strategy of imaginative variation where the researcher varies the frames of reference and the perspectives while considering the polarities and reversals. Imaginative variation results in the development of structural themes. A final strategy in phenomenological analysis was to synthesize meanings and essences.

Advocates of students with ADHD in the school system are usually parents who must become advocates in response to the child's need for support and a call for parental involvement from the school. Following are three main categories and twenty-one major themes that emerged from this study and describe the experience of parent advocates of ADHD students in the school setting.

### **Category One: Identifying and Treating ADHD in the School Context**

This category includes parent narratives about their experiences in the school setting as they listened to teachers describe their child, as they approached counselors for information and support regarding ADHD, as they sought diagnosis for ADHD and as they considered medicating their child as a treatment for ADHD.

#### **Theme One: That Year Sat Very Heavily on my Heart**

Parent advocate comments below reflect their experience from noticing to accepting that their student was having trouble in school. The time between having an inkling that challenges might exist for the student and acknowledging those challenges is described in their narratives of experience as quoted below.

“And part of the problem was the youngest one graduated with a 3.8, and it wasn't showing up. We knew there was a big deal going on because she would get A's, you know, one hundred percent on all of her assignments, but she would get C's on her

tests so we knew there was a disconnect there. And my youngest one was just kind of a goof-off in school. (laughing) So we knew that she would have trouble living up to her potential in general and it wasn't as much of a flag in high school as it is now in college."

(Interviewee #6)

Another advocate described the experience of noticing her son's academic challenges at a young age but since the student did not qualify for special education services, the advocate thought the child would catch up over time:

"Starting maybe with the academic piece is when we started seeing challenges. Maybe we didn't notice anything in kindergarten as much but started seeing that he just wasn't in the same place as other kids were. When they are at such a young age you think they'll catch up." (Interviewee # 5)

One parent described thinking about the influence of differences between boy and girl behavior when hearing about her son's atypical behavior from the teacher. She also expressed the feelings she had when she began to accept that her son had a leaning challenge.

"My son is 12 years old now and he's in 6<sup>th</sup> grade so we probably started having concerns when he was in 2<sup>nd</sup> grade. And I think the only reason we didn't have concerns in 1<sup>st</sup> grade was because he had a first year teacher. I think that she didn't really catch it. By the time we got to 2<sup>nd</sup> grade, at the parent-teacher conference, the teacher was a seasoned teacher and literally said to us, "I don't know what to do with him." Because my first child was a girl who was very studious and always followed directions, I attributed it to the fact that he was a boy. And the teacher said, "I think it's a little more

than the other boys.” The way she said it to me was really disheartening. I immediately started having that pang in my heart.” (Interviewee # 4)

Parents also described intense emotional reactions of worry for their children when they realized that they truly had a learning challenge:

“But that year sat very heavily on heart that there is something wrong, you know.” (Interviewee # 4)

One parent described acknowledging her child had a learning challenge at the point where his grades dropped and assignments were not being turned in:

“So the 4<sup>th</sup> grade teacher was very kind but every time I would see her, like at pick up, I’d ask, “how’s it going with him? Is it getting better?” And she’d say, “No, he’s the same. You know I’ve tried this and that but he’s the same.” So it was in 4<sup>th</sup> grade that I started getting concerned because he would get C’s, and I think the level of the work jumped up a bit and he was turning in work that was incomplete.” (Interviewee #4)

Some parents in this study felt like they realized over time their child had a challenge with learning whereas some were convinced of this when their child was just entering school.

### **Theme Two: She was Always the Naughty One**

Parent advocate experience described below reflects a more immediate identification and acceptance that their child was challenged in school.

“My daughter is the middle child and she is also a twin. She was diagnosed with ADHD when she was probably about 3 years old. She was always the naughty one.

Have you seen the movie Ramona and Beezus? She was just totally always the one in trouble, you know not meaning to be, but everything was always fun. She had a spray painting phase where she'd see it and she'd have to spray it. Everything was always fun and creative. And she always in trouble. There was a time out chair, and I think she sat in it most of her early childhood." (Interviewee # 3)

Another parent described her struggle with the school to get an assessment for her son which the school was reluctant to do because he was very young:

"You know our situation is a little unique in the sense that this is the first time that I know of, in an educational setting, where a parent is almost begging for an evaluation, and the school is dragging their feet. In my situation, I started asking for information as early as September last year. I was just noticing that his behaviors were causing him to have to leave the room a lot because he's impulsive and he's easily frustrated." (Interviewee #2)

Parent advocates whose children are diagnosed with ADHD are given a choice regarding how to treat the child, and often stimulant medication is offered by a pediatrician or psychiatrist. Parent advocates have a conflict when faced with this decision because the positive effects on student behavior are negatively weighted by side effects such as sleep disturbance, weight loss and additional mood and behavioral changes. Parent advocate comments below relate to their experience in deciding whether or not to medicate their child as well as their experience and reflections on how the medication affected their student.

### **Theme Three: A Good Thing and a Bad Thing**

One participant described her strong emotional feelings, both positive and negative, about her experience having her child diagnosed with ADHD and medicated.

“The diagnosis was a good thing and a bad thing. It’s really hard when you’re a parent thinking, ‘Oh my gosh, I’m going to medicate my child.’ It was hard because a lot of the medications change the child’s personality. So you try different medications. One medication, I gave it to her and a couple hours later she locked herself in the bathroom. She wouldn’t come out. She was crying and my husband of course was out of town. So I’m crying. She’s crying. I can’t get her out. And then another medication made her so sullen that she didn’t have any friends. It took a long time of working with different doctors and different professionals to find the right combination that worked for her. Every year we figure that out because she grows and changes. Now she’s in eighth grade and she studies later at night. The medications wear off over time so getting the right mix is hard.” (Interviewee # 3)

Another participant shared his feelings about choosing to medicate his daughter, and his experience negotiating with the child’s mother regarding this decision.

“I was advocating for a diagnosis long before my wife was. She had a big perception that one, we should be doing significant diet changes and holding them more accountable than we had, or than I had. I was kind of a stay-at-home dad so I was doing most of the work with this. I was always more than willing to let them go and get assessed. She was against taking the prescriptions at first. And with our oldest daughter, once she came through and started taking them, we noticed significant behavioral differences. She started thinking this was a good thing and was much less against our

younger daughter getting the same kind of help. Once we saw the first daughter, it was easier for the second one. These can be helpful. I do believe but I also kind of still wonder if a lot of it is just discipline. You know, we've become a kind of drug-crazed society a little bit too. I'm not necessarily an advocate for them if things can be changed through diet or exercise or just a little bit more discipline, whatever that has to be. And where that line is, who knows." (laughing) (Interviewee # 6)

Another participant described her decision to medicate her son as a last resort because he was having such a negative experience at school:

"Last year our son was not medicated and this year he is. As things escalated throughout the year, our pediatrician felt it was a good plan to do this so he could maybe end the school year more positively. But the damage had already been done. He doesn't like school." (Interviewee # 2)

Parents in this study shared stories of crisis where their child's behavior was out of control as well as situations where they gave in to the option of medicating their child because they wanted to see if what seemed like milder symptoms would improve for their child.

#### **Theme Four: I Think We've Found a Good Fit**

Participants shared their feelings about how the medication used as a treatment for ADHD affected their child. Many felt somewhat ambivalent to give their child medication but overall they expressed relief when a medication was identified that had positive effects on their child. One participant shared:

“And she did get sent to a psychiatrist who did prescribe meds for her which was a godsend. It was an amazing experience once they figured out the right ones to use. She was always a good girl. We didn’t even know some of this stuff was going on until some of the meds kicked in and she was more willing to talk about stuff. In terms of advocacy, seeing the results was huge for me so I am a strong advocate for it. I just don’t know where that gray line is where there’s really something there.” (Interviewee # 6)

Another parent described feeling that she did the right thing in medicating their daughter because her behavior when medicated was more under control which meant she was less likely to hurt herself and more focused on school work:

“That’s a real challenge because her behavior is totally different without the medication. Her behavior is off the wall and her friends just love it you know. She’s the life of the party. She’s like a drunk kind of. She’ll do wild and crazy stuff. Yeah, funny, funny, funny. You know, not good. That’s the risk taking thing. As far as the medication thing, we are doing well with it. I think we’ve found a good fit. As she gets older she is able to say things like, “I am so glad I’m on the medication. I can tell when it runs out. I can tell when I’m not focused. I don’t know how kids without medication, how they even manage.” So it makes me as a parent feel good, like we did the right thing. She hasn’t been getting into so much trouble since the medication which is a good thing. She would do things like she would take a bike and ride it down the side of a cliff because it looked like fun. And she would be all bloody.” (Interviewee # 3)

Parents in this study have shared feelings of ambivalence and relief when reflecting on their experience medicating their child for ADHD treatment.

### **Theme Five: They Wanted Him to be Medicated**

Some parent expressed feeling criticized and blamed by teachers or school staff when talking to them about their child's behavior and some also felt pressure from the school to medicate their child. One participant shared an experience of feeling pressure from the school to medicate her student:

“Or they would work with us a little bit but they wanted him to be medicated so they could do what they do. They wouldn't do what they do with a different child but they do what they do with a child that learns that way.” (laughing) (Interviewee # 5)

Another parent shared her experience of feeling pressured by the teacher have her son diagnosed and medicated for ADHD:

“When I met with that teacher, she just gave me the vibe right away that he had something wrong with him and he should be on medication. She would say, “Have you taken him to the pediatrician? What does the pediatrician have to say?” She would constantly say that to me. And she would say’ “He does things like this but you know it's not his fault.” (Interviewee #4)

Some parents feel blame and pressure from school staff to have their child assessed, diagnosed and medicated for ADHD.

### **Category Two: ADHD Advocates Need more Support from Schools**

A theme that broadly was described by parents in this study was a desire for teachers, counselors and school psychologists to have more education and training on ADHD. Parent comments below describe their experience.



## **Theme Six: The Schools Didn't Do Much of Anything**

Parents described experiences of going to the school counselor to find support and information about ADHD and expressed frustration with the results. One parent talked about a lack of resources:

“Going to the school that they went to, there was not a good knowledge base or resources available to help her with that specific issue in terms of having support people in the school to help. The counselor from the school that we went to told us he had no resources to help nor did he have any referrals to guide us to help find some resolution to some of these issues. We ended up finding psychologists and psychiatrists on our own.”

(Interviewee # 6)

This parent also expressed anger about the lack of counseling support for students with ADHD:

“But I was so pissed off when it came to the counseling services there. Really all the counseling services there were focused on getting kids into college. They really didn't do much of anything else which is what we went there (private school) to find support for.” (Interviewee # 6)

Another parent expressed extreme disappointment about her meeting with the school psychologist:

“We met with the school psychologist but she was not helpful at all. She would do a check list and have us and the teacher fill it out and then she would say that he is at risk for ADHD but she could not tell me that he had ADHD. She couldn't make any

recommendations. I don't understand the purpose of her being there. And she was not supportive to the parents whatsoever." (Interviewee #4)

Parent advocates of students with ADHD in this study turned to school counselors for resources and support but did not receive the support they were looking for. Parents in this study also shared stories of interacting with teachers and they expressed a desire for teachers to have more education about ADHD. One parent share the following:

"I just wish that the teachers would have more education about ADHD because when you have that teacher that makes you feel like you are doing something wrong, or makes you feel like you should put your child on medication. I mean it's really not her place to do that. It makes you feel really bad. And I just think it's wrong. I just wish they had more education about the diagnosis, and you know, about what other things they can do in the classroom." (Interviewee #4)

Another parent shared the following story about talking with a teacher about her son and also about the way that the information about her son was shared for assessment purposes:

"We were just dumb-founded. And at one point, doctor and her colleagues came in and questioned if the teacher had filled out the questionnaire on the wrong student because their testing was showing all of the same things that we had said. Therefore, we would have had the diagnosis of ADHD. I'm not sure if the teacher was experienced. I try not to think it was deliberate. It was interesting to see that verbally she was telling us one thing but when we requested formal documentation, we get something entirely different." (Interviewee # 2)

## **Theme Seven: If I Was the School, I Would Have a List of Resources**

Advocates describe frustration over not receiving broader resources from the school staff other than a typical referral to the pediatrician for ADHD assessment. Some parents in this study expressed frustration that schools don't offer advocates enough support. Advocate comments below describe some of these experiences.

“In a private high school, they should have had more resources available to us considering what we spent to put the kids through there. They should have had much stronger resources and if not resources, they should have had a much stronger referral network that they had cultivated to deal with this. They don't have the resources of a public school at all nor do they have the expectation of a public school to address these issues. If I was the school I would have a list of resources. I would think that they should at least have a list of different options and programs to help to deal with it.”

(Interviewee #6)

Another parent also talked about needing more support from the school:

“And I also wish that they had more resources and support for parents. They had a school psychologist but she just was not helpful at all to me and she never followed up to me about how he was doing.” (Interviewee #4)

One parent shared feelings of frustration over the lack of resources for her child in the classroom as well as her experience volunteering in the classroom in an effort to support her child:

“I think it was very frustrating because I wanted there to be more help for her than there was and then I would offer my help because I was laid off at the time and home. It was frustrating for me to see her come home with everybody else’s papers. She would just go to the mailbox and pull out papers because she didn’t care. And they weren’t hers. Some of the time she couldn’t do the work and she would color pictures all around. So then I felt like I had to go in, which was fine. I didn’t mind donating my time. But it was frustrating because I saw all the wasted time. And I felt bad for the teachers and it wasn’t their fault. They have so many different kinds of kids. They are trying to teach to high learners, they have kids rolling around under the table, they have kids crying. It was just that the poor teachers were trying to handle everything. And that’s where my daughter became frustrated because she would be in line to ask a question and every day that line would get longer and longer. And it’s hard to have people come in and help because we couldn’t answer those questions. That was something the teacher had to answer.” (Interviewee # 3)

Parent advocates in this study express a need for more resources and training for teachers and counselors about ADHD and for more support from the school as they try to advocate for their ADHD child in school.

### **Category Three: Advocate Experience with the School is a Swinging Pendulum**

Parent advocates shared narratives that reflected both negative and positive experiences with school staff. Their stories include very emotional descriptions of interactions with staff, punctuated at times with spontaneous tears or laughter. Following are advocate narratives of experience with school staff.

## **Mom, My Teacher Doesn't Like Me**

Some parent advocates shared narratives that one parent described as “heartbreaking” when reflecting on negative experiences they or their child had with staff. One parent talked about her experience with the Dean of Students:

“‘Your kid’s just naughty’, (the Dean of Students said). Well, I’m not questioning that he is not breaking the rules, I’m questioning why he’s not getting help so he can follow the rules. I questioned him and asked how can you say that he’s just choosing not following the rules when he has a history of these challenges? How can you stand there and say that he’s choosing not to follow the rules versus I’m not sure he can follow the rules.” (Interviewee #2)

Another parent shared her negative experience with a teacher:

“The 3<sup>rd</sup> grade teacher, right away was like he doesn’t want to sit in his seat, he doesn’t want to follow directions. She just really portrayed to me a lot of negativity. And it was really heartbreaking because, oh, I’m going to cry right away. Because he would come home from school and say, “Mom, my teacher doesn’t like me.” And that is really heartbreaking when you consider that he is spending 7 hours a day with a woman that he knows doesn’t like him.” (Interviewee #4)

Another parent shared the experience of her son being humiliated by a teacher:

“I think what would happen was that the teacher would be little our son in the classroom and you know, make him feel like an idiot. She would say he did not know what the answer was to this, even though we just talked about it and would say things out

loud in front of others...sorry (tears). And that's where his self-esteem just plummeted that year, when the teacher said that." (Interviewee # 5)

One parent shared how disappointing it is that her son doesn't want to go to school:

"It's not very common for a 7 year-old to hate school. Little kids like school. They love their teachers. They typically enjoy going to school, and that's been a challenge." (Interviewee #2)

Another parent expressed anger and extreme disappointment that the teacher did not seem interested in her son but only in his lack of performance in class:

"You know I am a therapist myself, a physical therapist, and it really made me angry because I work with kids that have significant needs and here I have kid who is funny, athletic, musical and just a lovely kid. You know, not oppositional or defiant but the teacher was so negative and did not take any time to get to know him personally. It was heartbreaking."(Interviewee # 4)

### **Theme Nine: We are the Only People who Understand this Kid**

Some parents shared feelings of isolation in that they felt school staff did not understand the root challenges that their child was having. One parent said:

"But when you feel like they are not there, and they are not on your side, you feel like we are the only people who understand this kid and are supporting him and helping him get through all this. That's a very isolating, very lonely place to be." (Interviewee #5)

Parent advocates seek support from the school and when they do not receive it, they feel like they are the only ones who can help their child.

### **Theme Ten: We Wanted Him to Succeed There so Badly**

Parent advocates shared narratives characterized by disappointment and hopelessness when their child was not succeeding in a certain school. One parent shared:

“Yeah, extremely disappointing. Devastatingly disappointing. We wanted him to succeed there so badly but then realizing that is totally not where he is going to succeed.” (Interviewee # 5)

Another parent talked about her frustration regarding an experience with a teacher’s daily report:

“But what she agreed to do, and to this day I think back and it makes me really angry, was to every day send me home a report of how he was doing. She literally sent me a card every day with the percent time he was on task. It was like beating me over the head every day because it was often 25% or less time he was on task. But I guess she would look up and if he was on task he would get a check mark. But when you consider that they had 34 kids in the classroom, I would venture to say that it was very hard for her to be 100% on when she was judging whether he was on task. And she was coming at him from a very negative perspective. She just wanted to hit me over the head that he was mostly off task all day long. So that was a very difficult thing.” (Interviewee #4)

The surprise felt by one advocate when she was not supported by the school is described below:

“So that experience there was the first experience that really shaped our views and disillusionment on kind of what the school would do for a child when they don’t necessarily fit the mold. Kind of shocking and surprising that they wouldn’t be more supportive and view it more as a team approach. So I guess it didn’t really feel that way. It didn’t feel like we’re all in this together. It felt like, ‘It’s your problem, you need to have him assessed.’” (Interviewee # 5)

One parent talked about her disappointment regarding her son being pulled from the classroom for long periods:

“So he was out of the classroom for at least half of the day and sometimes he was out of the classroom the entire day. We’ve had very challenging experience in dealing with our son. Because the school has been so challenging we’ve had to seek outside help and services.” (Interviewee # 2)

Advocates also shared narratives of the hopelessness they felt when they realized their child was not achieving they needed to find a way to support him. One parent talked about her feelings below:

“You go through all of this, the challenges, and you feel hopeless. You know, ‘oh, my god, he’s not going to succeed and he might actually fail’ to the financial stressor of it. You pay for all of it. You pay for counselors. You pay for tutors. The time stress, you know, you’re dealing with the emotional well-being of your child, and you’re having to deal with them around the clock to keep them going and happy and going to school. And you have to take him to all these tutors and counselors (laughing). So definitely, it



makes a huge difference if the school is supportive and working with you so you don't have to be the lone advocate. (Interviewee # 5)

A parent also shared feelings of panic and desperation when reflecting on the need for her as an advocate to try to make her son become successful in achieving in school, in spite of his learning challenges:

“I just think you get kind of desperate because you are spending your energy just trying to get your kid to go to school. So it isn't trying to get them to learn their math facts or to learn their geography. It's just trying to get them to go to school. So then there's panic. It sends you all sorts of feelings and you try not to think of the worst. You start to think, 'Oh, my God, are they going to succeed?' And not all parents are on the same page with that. Some will take it to a deeper place, you know. (laughing) Even that it's absolutely the end of the world, and he will never succeed and that feeds negative energy into the whole family. But even for both of us it's just so worrisome. If you have to spend energy trying to get your kid to go to school, which is a whole different place than, 'Oh, what are they learning today?' So you try to get them to go and to feel good about themselves, and not like they are stupid. That whole thing. So not to have the advocacy within the school is really an amazing stressor. (Interviewee # 5)

When advocates do not feel supported by the school, they can find themselves feeling like the lone advocate which can leave them with feelings of hopelessness, disappointment and isolation.

### **Theme Eleven: It's the Parent's Fault**

Some advocates have had the experience of being blamed for their child's behavior by school staff. One parent said:

“And that really rubbed me the wrong way because the implication was if it wasn't his fault whose fault was it? Was it my fault? And that was the implication. She would say things like, “how structured are you at home?” She just really made me feel bad about my child and made him feel bad clearly because he would come home and say that. (Interviewee # 4)

Another parent felt that the teacher was judging her parenting:

“I was just floored. Implying I'm not doing things right with my son who has ADHD. It's like clearly questioning my parenting skills.” (Interviewee #2)

A parent in this study also described the very poor feelings she had about herself when reflecting on negative interactions with her child's teacher during the third grade year:

“With the third grade teacher, it was only negative stuff. She would also give foreshadowing of doom and say, ‘I don't know what he's going to do when he gets to fourth and fifth and sixth grade when the work load gets so higher.’ It's almost like she was threatening me that if I didn't put him on medication that his academic life was doomed. That's how I felt when she talked to me, and I left meetings more than once in tears. I left meetings with the principal more than once in tears because I felt so crappy interacting with that teacher.” (Interviewee # 4)

Parent advocates in this study have shared narratives of their experience where they feel they have been blamed for their child's behavior because they are not doing something right as a parent. Advocates share intense feelings of anger and disappointment about these situations.

### **Theme Twelve: She Gets My Child!**

Advocates also share narratives that swing in the opposite direction from the negative stories described previously. Following are narratives from advocates that are laced with intense emotions of excitement, gratitude and relief that advocates felt when reflecting on positive experiences with school staff. One advocate tells the story of the "glorious year" her son had with one teacher:

"It was always positive. I always left after having an interaction with her feeling like, 'She gets my child!' She understands that he has some challenges, but she sees him as a whole person. And she actually asked me, 'Can I come to one of his hockey games?' I mean, she just went out of her way to see him as a total child. That is such a gift to any parent! And it was a glorious year. He started getting A's and B's. And I just feel like she believed in him from day one." (Interviewee # 4)

The advocate also described her positive experience requesting a certain teacher:

"The teacher is the kind that was born to be a teacher. You walk into her class and it just runs like a well-oiled machine. So I met with her at the end of the year. I told her I requested her. I told her about my son, and then I met with her at the beginning of the year and right after we did the 504 plan." (Interviewee # 4)

One advocate shared feeling “excited” and “overjoyed” when she realized her son was looking forward to going to math class:

“Well probably just yesterday, when on his way to school he mumbled under his breath, ‘I’m kind of excited for math class today.’ (laughing) He looked shocked, ‘What’s going on? What’s wrong with me, I’m excited for math.’ So I thought, ‘How very interesting. He’s feeling supported and successful in this school.’ And you know, it’s new into this school year but already it feels like a completely different experience than probably anywhere. I just wanted to jump up and down but I stayed cool and calm and said, ‘That’s good.’ But it was very exciting and just that tiny little sentence was really enough to hear. I was overjoyed to hear it.” (Interviewee #5)

Another advocate shared feeling relieved when her child was achieving in school:

“She can see her progress. Because of that I can take a step back, and I can breathe a little bit easier. The communication with the teachers is every week so I feel like I know what’s going on with her, and I don’t feel like I have to run in and check or be there or volunteer. I feel like they’ve taken over, and I don’t have to worry so much.” (Interviewee # 3)

Advocates in this study share positive experiences when reflecting on situations where the school is communicating regularly with them, when teachers are interested in their child and when their child is achieving and looking forward to going to school.

### **Theme Thirteen: A Strong Triangle Between Parent, Student and School**

Parents in this study shared narratives about situations where they felt like they were partners on a team with the school, working together to advocate for and support their child toward achieving in school. One parent talked about feeling supported by the school:

“The amount of information they are willing to share to the support that they give and the classes for parents. We get emails all the time for ways that we can feel supported both for our own education and counseling sessions to support groups, great speakers, all sorts of things. So this is quite exciting to feel this way. You finally feel like you can take a breath and think, ‘Okay, I think they are going to be able to educate him here, and we are not going to have to kill ourselves anymore.’ It feels like a really strong triangle between parent, student and school. So it is exciting, very exciting.”

(Interviewee # 5)

Another parent described the experience of a teacher who was very positive, approached the advocate as a team member and wanted to work together to support her son in the classroom:

“And the thing that was so different about the fifth grade teacher that just warmed my heart so much was that she instantly liked him. He’s a funny kid with a great personality and a great sense of humor. She loved that he played hockey, and she literally, see that’s the difference, every time I interacted with her she came at me with something positive about him first. And then she talked about where he may be having some challenges, and then she talked about what we could do together to help him. And there was just no comparison to interacting with her.” (Interviewee # 4)

One advocate described the experience of working with the school to develop an educational plan that was meaningful to the student and resulted in decreasing stress for the advocate, the student and the family:

“So having this road map is just so helpful. You feel like the stress is just absolutely diminished down to a manageable level. I feel like we are more at a level of stress management that people with typical kids have. It’s more like regular stress in life instead of that off the chart stress. Like what it’s going to be like from week to week, let alone year to year. So I think it’s really liberating. It frees you up to have space for other worries and hopefully some joy and to enjoy your child.” (Interviewee # 5)

An advocate also described a situation where she worked with the teacher to set up an effective behavior management program for her son:

“So with that teacher we set up a behavior modification program in the classroom. He had a paper about directions on his desk, and if he got a certain number of stickers then he could go to the treasure box. That seemed to help a little bit.” (Interviewee # 4)

Previously, advocate narratives have described both positive and negative experiences with school staff. More specifically, some themes that evolved from in this study relate to advocates engaging school staff, and the results swing from limited cooperation to high levels of cooperation. Advocate reactions to these experiences of different levels of cooperation range from daunting and frustrated when cooperation is limited to relieved and grateful when cooperation exists. Advocate narratives of experience follow below.

## **Theme Fourteen: I Wish There was More Consistency Across the Board**

Advocates shared stories of both positive and negative interactions with the school. The narratives below describe situations where advocates experienced limited cooperation with teachers or the school and the feelings they had as a result. One parent talked about the effect that limited cooperation had on their experience supporting their son outside of the classroom:

“One particular year he had some challenges. The teacher was really not very understanding, and it made him feel bad. You can really see the difference when you don’t have the support and that kind of teamwork approach. Also, that your child isn’t effective somehow. You know, there’s something wrong with him, and he’s choosing to be this way. So we had to advocate by seeking outside counseling for him that year. We had to take a lot more of our home, personal and family energy and family time to support him that year when the school wasn’t supportive or the teacher wasn’t very supportive. That’s probably the big difference when the school isn’t advocating as a team. It puts immense strain on the family.” (Interviewee # 5)

Another parent talked about asking for cooperation regarding implementing a point sheet:

“We have not had too good of experiences in working in the school setting with our son. It’s been a struggle to get the school to work with us and to acknowledge the ADHD and to work with us. They didn’t follow thru on anything that we asked. I asked for a daily point system because our son has lower self-esteem. He’s always in trouble and has very negative feelings toward school. He cries all the time when he has to go to

school. Sometimes even when he had a positive day, he dislikes school so much he would come home and tell us it was horrible. So I had requested a point sheet and nothing happened.” (Interviewee # 2)

An advocate described the experience of not getting cooperation from all school staff:

“We did talk to the school principal. We talked to the school counselor. We talked to the teachers. Some of the teachers were aware of it and helped accommodate things, or gave her a break here and there because they knew there were some issues they had to deal with. The administration-wise, didn’t really do much about it.” (Interviewee # 6)

One parent described how a teacher one year cooperated with implementing a behavior modification program for her son but the teacher the following year did not:

“That teacher did this behavior modification program where he had the instruction sheet on his desk. The third grade teacher refused to do that. In second grade, we had started meeting with the school psychologist and in third grade we did it again. Anyway, the third grade teacher refused to do any kind of behavior modification program with him because she said it wouldn’t be fair to the other kids.” ( Interviewee# 4)

Another advocate described a year of negative interactions and limited cooperation with one teacher:

“And so, that year I went to the principal a few times because I really felt that that teacher was very negative. And still to this day if I see that teacher in the hallway,



she does not say hi to me. There was a lot of negativity. And I still volunteered in her class, I still did Art Masterpiece in her class. I tried to be positive with her when we were having interactions that did not have to do with my son.” (Interviewee # 4)

The same advocate also said that she wished there was more consistency in cooperation with parent advocates between teachers, from year to year:

“I also wish there was more consistency across the board, like some teachers were more willing to do things in the classroom than others. I don’t think that’s fair. If you have a good program working well one year, why the next year teacher won’t do that. That’s scary as a parent. “What are we going to do next year if the teacher won’t do that program?” That’s how I felt going into the third grade when she refused to do it.” (Interviewee # 4)

Advocates have shared narratives of situations where there is limited or inconsistent cooperation between the advocate and the school which results in frustration, fear and disappointment. Following are advocate stories about situations where they experienced cooperation with the school.

### **Theme Fifteen: You’re Not Ready to Let All Your Joy Loose Because It’s Like, We’ll Wait and See, Is It Really True?**

One parent talked about how it felt to work at a high level of cooperation with a teacher:

“Again the difference with this teacher was that she was not negative. She would say, “Can we sit down together and re-evaluate what we are doing?” And I always got

the impression that she was going above and beyond to help him. It just meant the world to me. And I just think that because of her, and the way she was, that was his best year.

“(Interviewee # 4)

Another parent shares feelings of optimism, surprise and joy when reflecting on her experience in a school where there is cooperation:

“I would say I felt really optimistic. But it’s hard after you’ve gone along all these years. You’re not ready to let all your joy let loose because it’s like we’ll wait and see, is it really true? It’s a little hard to believe. They seem to be for real so far. They seem to be putting their money where their mouth is. They do seem to be providing the services and the support that they say they are going to. That’s kind of never really happened.” (Interviewee # 5)

One advocate described cooperation with high school teachers:

“In high school most of the teachers were very receptive to having conversations about it. Some of them recognized the issues themselves and would try to deal with it the best way they could. Some teachers didn’t want to deal with the extra work associated with providing the accommodations for somebody, particularly when they are not used to having to do that.” (Interviewee # 6)

An advocate described the experience of cooperation that occurred in a private school setting that was designed to support students with learning challenges:

“They give you very explicit instructions, particularly geared to kids with ADHD. Totally supported. It’s like night and day. Now we can see him feeling successful

probably for the first time ever. A lesson learned. It took us awhile but I think we may have gotten there.” (Interviewee # 5)

One parent talked about a positive experience where she requested certain teachers for her son:

“I hand-picked his teachers because I am very involved in the school, and I know who would be a good fit for him. Plus I had another child go thru the school so I know the teachers. I was dead on for him in fifth and sixth grade. I was really proud of that.” (Interviewee # 4)

The same parent also described her feelings about having frequent access to communication with her son’s teacher:

“And as far as being his advocate this year I sat down with the principal and his teacher. I’ve kept really close ties with the teacher. I’m very blessed this year to have a really great relationship with the teacher. He and I text things. He does that with other parents and not just me. When you have a teacher who you feel is on your side and understands and appreciates your child, it makes a world of difference.” (Interviewee # 4)

Another advocate talked about the experience of having cooperation from the school:

“Yet still pretty traditional but much broader than the previous school, the principal would be willing to work with us if we wanted to make suggestions for a particular teacher. That was very helpful. The teachers would be pretty receptive, for example, if we wanted him to have extra math or reading help, you know we could get

that help. They were just much more willing to work with you on a family by family basis. It wasn't like it or lump it, and if you don't fit our model you have to leave. They kind of fit more the public school model where they feel like they are going to teach everybody regardless of their ills or challenges." (Interviewee # 5)

Many advocates expressed feelings of relief, gratitude and optimism when they reflected on experiences where the school cooperated with advocates.

### **Theme Sixteen: It was Pretty Much a Closed Door**

Many parent advocates that participated in this story had the experience of moving their child to different schools depending on the age and need the student was having at the time. Below are narratives of advocate experience that reflect on when advocates move students to a different school and also when advocates stay with a school.

One advocate described making the decision to switch schools:

"That led us to have the assessment done but also led us to leave that school because we realized that it was not a school where we would be successful advocating for him, no matter what we did. So, it was pretty much a closed door. Actually the psychologist told us that we needed to switch schools. He was very unhappy there and to be that young, he was in first grade, and to be that unhappy was not good. That boosted our opinion about what we had to do. (Interviewee # 5)

The same advocate also talked about her experience when her son attended several different schools:

“Well, yeah that was the first couple schools. Now we have tried another couple of schools. (laughing) Whatever so briefly, he attended a typical middle school in South Minneapolis and immediately I could tell that was not going to work so we pulled him out. So all of the advocacy builds experiences for us so we know right away, ok, heads up. This is not going to work. We’re pulling him right away because we could see that we would not have the support at this school.” (Interviewee # 5)

The advocate also described the experience of having a 504 plan and the decision to move from a traditional school to a Montessori school:

“The experience was that they said they could support us. They had a 504 plan in place but in practice it was not happening. And maybe it was not to the fault of the teachers, because they had 36 kids in the class. There’s no way. They couldn’t even put a checkmark in his book to say whether or not he’d turned something in and that was the only thing we were asking them to do. So the slightest bit of support was not fulfilled so we just knew right away. Instead of beating our heads against the wall, we pulled him out and put him in a smaller school that appeared to be more supportive, a Montessori.” (Interviewee # 5)

The advocate also talked about the experience her son had at the Montessori school:

“But, you know, as far as advocating for him, in the end in that Montessori setting, you just don’t walk in the door. They don’t have parents there at all. Parents cannot walk around the hallway or the classroom. You can’t see how he’s doing. They don’t have parents there at all. You really know absolutely nothing about what they are

doing in the classroom. I told them at the end of the year, you know, it's not really working out. And then you learn, oh, that's unfortunate. You never really get a chance to advocate because that's not their protocol." (Interviewee # 5)

The advocate also described her feelings when she realized her son could not continue to attend the Montessori school:

"Well, you know there were a lot of aspects of it that we liked, like the farm school, the organic food, the whole love, peace and butterflies kind of thing. So there was that kind of aspect that we kind of gravitate toward. I found that personally, for me, maybe not my husband, that I would have loved to go there for school. So it was a hard separation. Well it would work for my but it would not work for [my son]. So that hard separation of feeling like, "Oh, wait, this is so wonderful! Why isn't it working for him?" So I had to come to that realization that this is not going to work for him at all. So that was an interesting lesson for me that this is not about me. It's about him and what he needs." (Interviewee # 5)

The advocate also talked about the experience of feeling uncertain about what her son would need in various schools or settings:

"You know, just to string families along when you know you can't provide what they need or the student needs is just prolonging agony. But nobody really knows when you go into a setting, are we going to need X, Y, & Z? You don't really know what you're going to need so as an advocate you don't know. I don't know, is he going to be able to turn his stuff in? Is he going to be able to make friends? That uncertainty is another challenge for an advocate. You just don't know what your kid's going to need

and when.” “So we did switch to a different school that did work for him. It was arts focused and they were more willing to look at the whole child and work with the family and not necessarily label him. And then that went well for most of second and third grade. We were constantly advocating for him, and we felt like the school was responsive to us.” (Interviewee # 5)

Another parent talked about her experience switching her daughter to a public charter school:

“So it was then that we decided to go to the charter school because it was smaller. There were only 20 kids in the classroom but it was a trade off because the public schools do have a lot going for them but the class sizes are really big. So when we went to the charter school, we went from the public school where the teachers were really seasoned but the class sizes were really large, and we didn’t feel like we had enough help for [her]. When we went to the charter school, the teachers were young and we had a lot of help but they were probably green. We had some behavior issue kids. In charter schools you get the catch-all. You get the kids who maybe aren’t making it in the public school for one reason or another. So we had a lot of loud boys and a lot of distraction but yes, the class sizes were smaller. The teachers did do a really good job of trying to tailor the things and were very energetic.” (Interviewee # 3)

One parent talked about having mixed feelings when deciding to switch to a different school:

“Of course it makes you terribly upset. You just want to pull him out. But then you know, all in all the school is good and next year is going to be a better year. It’s just

mixed. You're all over the board. You know, we want to stick with the school because all in all it was good but when you do have that time when it's not good. And if you have repeated years, like when we were at our first setting [in Minneapolis] in kindergarten and first grade, two not good years in a row, then you realize you've got to pull him. Just the stress and strain on the family and on your marriage, it's just immense. Trying to deal with it, you know, your energies are spent often times surviving rather than enjoying your child." (Interviewee # 5)

Advocates have shared narratives about situations where they have decided to move their child from one school to another. Following are advocate stories that describe situations and their feelings about schools they have chosen to keep their child in.

### **Theme Seventeen: This is the First School Where I'm Not Pulled Out and I Don't Feel Odd**

In this section, advocates share their feelings and rationale for choosing to keep their child in a certain school. One parent talked about relief she felt and support that the school gave when they developed a detailed educational plan for her son:

"So I feel like we have a plan finally in place which we haven't really had before. So that probably helps with the advocacy too. You feel like you have a road map and kind of know what you need to do. And that adds to the stress too, when you don't know what to do when you are advocating for your kid because you don't know what's coming up and what their needs might be." (Interviewee # 5)



Another advocate talked about all the schools they've tried and share her experience and feelings about the school they choose to stay with:

“But when it came to her, we thought, “Big question mark, well, I don't know”. She was the one who was always at risk. It hasn't been easy education-wise. We've had public schools, we've had charter schools, we have private now, and it's just hard because most of the schools you're just sitting in the classroom, you don't have much wiggle time. They've taken physical education out a lot of the time, recess is short so there is not a whole lot of time for chit chat and moving around. I think that's been really hard. Groves Academy has been really good. They really seem like they understand kids with dyslexia and ADHD. They try to help them, I think to move a lot, break things down into pieces. I think it has been really good for her.” (Interviewee # 3)

The advocate also described her daughter's feelings about the school they chose to remain attending:

“She doesn't get too much homework but they do push her a little bit more. They seem to understand kids with ADHD and what they need. They have a lot of support, the self-esteem pieces. [She] likes it. The other day she told me, “This is the first school where I'm not pulled out and I don't feel odd.” And I never really thought about that. These kids from day one feel like they are different and they're not smart. Now she's in a school where everyone has something. I think she was blown away by how many kids have ADHD or other learning disabilities. Before she thought it was only the few that went to pull out with her at whatever school she was in.” (Interviewee # 3)

Advocates have shared their dynamic experiences interacting with school staff and selecting a school that best fits their child. In the next section, advocate narratives reflect on their experience working with the school and mental health professionals in developing educational plans for their child.

#### **Category Four: Advocates Struggle to Pave a Path for Success**

##### **Theme Eighteen: What are Accommodations Anyway?**

Advocates describe a range of experiences with regard to the identification and implementation of accommodations for their students and their narratives are below. One parent expressed extreme frustration with the very basic accommodations that a psychologist recommended for her son:

“But when we went back in to listen to the results, I was really upset because the accommodations that he gave me were so basic that I was like, how am I going to help this kid? The accommodations were like use an agenda. Every kid uses an agenda. Or prepare his backpack the night before. Really the recommendations were things that any good mom is already doing for their child. Making sure his backpack is ready. Making sure he is using an agenda. Making sure he has a calendar in his room. Making a to-do list. It was nothing out of the ordinary. And I really didn't mask my extreme disappointment because first of all it was a huge process to get him there and it took three days with two days of testing and two days to listen to results. And we had a huge co-pay with it but it was a huge disappointment. It was a big commitment and after all that all he could do was to tell us to use an agenda and check his back pack? I was furious! Especially as a therapist, these are things I tell my clients. This is not rocket science.

This is not something you need a Ph.D. to tell somebody about. So I was really disappointed and I don't think I masked that very well." (Interviewee # 4)

Another advocate talked about accommodations his daughter received in college:

"I would say once she got the diagnosis in college, all the teachers, it was very easy to accommodate her. She can take a little extra time on a test or she can go to an area where it's quiet. She doesn't have to do that but she can if she chooses that option is available to her. So once that was done, it was pretty easy." (Interviewee # 6)

Another parent described accommodations the teacher offered her son:

"So in 4<sup>th</sup> grade that teacher was really good because there was an empty classroom next to hers and she would encourage [him] to go in there to do his work so he wouldn't be distracted. She also changed his seating a lot to find best spot for him. He's a very social kid and like to talk to kids a lot so she tried to keep him away from kids that were distracting. So that was good." (Interviewee # 4)

The advocate also talked about the accommodation of preferential seating:

"Then in 4<sup>th</sup> grade, that teacher was really very kind and that teacher started moving him, doing preferential seating so he is closer to the teacher. We still do that to this day and he's in sixth grade. His seat is close to the teacher so the teacher can rap on his desk when he gets off task." (Interviewee # 4)

Overall, many advocates did not have very rich experiences with the accommodations that were developed for their children.

### **Theme Nineteen: Technology has been Wonderful for Her**

The main challenge that ADHD students have regarding performance in school is with executive function skills such as memory, organizing events and materials across time. In this section advocates share experiences with technology, specifically iPads, that have been used as accommodations. One parent talked about the experience of introducing an iPad into her daughter's learning at school:

“We also bought her an iPad about a year and a half ago so that she could download books and so that she could have all of her things in one spot. She downloads her webpages and puts in her ear buds and you know, it's cool to have an iPad at school. It's been good for her to do that. You know when she was at the charter school, we had to push to have her be able to bring the iPad. They didn't want her to bring that into the classroom because of all the what-ifs like if she would get on a website that wasn't appropriate with all the kids in class. What if somebody would steal it? So there were all these what-ifs so we had to draft up a letter saying she would not do that and if she would she would be suspended and just kind of laid everything out.” (Interviewee # 3)

The advocate also shared her experience about her daughter using technology to support her learning:

“iPads are becoming a huge part of learning. With all the applications it's wonderful. It's nice to have all those options. There's an application to organize her papers. There's a calendar, alarm clock, calculator, everything is just in one place. She doesn't lose anything. It's a one piece thing. I think technology has been wonderful for her. She uses it all the time, and not just for music but they do have applications with

songs for, you know, for fractions and how to do multiplication. It's just all these things that help them remember. She's doing great." (Interviewee # 3)

The advocate also talked about her daughter's executive function skill challenges and how the iPad can actually provide a depth of meaningful accommodations:

"She would get away with a lot because she's smart enough. She's very intelligent. She has a high IQ. It's just her dyslexia, her ADHD, her disorganization that makes everything so hard. It takes so long to do and she loses everything. And so, when she was at the charter school if papers did come home and she did them, I don't know, she'd lose them on the way. It was just so frustrating. We'd go from organization system to organization system and finally we had the iPad which worked really good because finally we didn't have this binder full of papers. You know asking is this paper due and did you turn it in? Or this one is graded, should we throw it out?" (Interviewee # 3)

### **Theme Twenty: I Don't Know If It's Considered Advocacy or Not**

Advocates discussed their experience in seeking atypical therapies to support their students. These approaches range from hypnotism to sports and music to getting a horse.

One parent talked about using a hypnotist as an alternative approach:

"The other thing we did with our youngest daughter is we sent her to a hypnotist to deal with it and that was actually very beneficial. I don't know if that's considered advocacy or not, but that's taking the issue into our hands and after seeing that that was very successful." (Interviewee # 6)

Another advocate emphasized taking a whole-person approach and shared the experience of the impact that sports and music has on her son:

“I think it’s really important because those are areas where he really shines and excels. He’s very athletic so he plays hockey and he’s on a hockey team so every week he has hockey practice and a game. And that’s fun for him. It helps to get his energy out. I think the pressure of all the gear helps to ground him. So that’s important. He also has piano lessons once a week and then he also, in the school band which is part of his day and not extra-curricular, plays percussion in the school band. And those are kind of, you know, music and athletics are very positive for him. You know, and like in third grade I feel like it was beating him down all day long, every day.” (Interviewee # 4)

Another parent described the experience of her daughter becoming involved with riding and caring for a horse:

“So she had a friend that said, ‘Why don’t you take some riding lessons with me?’” So she did, and she fell in love. She is really good with horses! We bought a horse about a year ago and she does a really good job of taking care of it. It’s kind of interesting because she has this need for speed and kind of throw caution to the wind. Now that she has this horse that she has to take care of it’s different and she’s got to be careful. It’s fun to see that she can manage and she can get along and she is maturing. So that’s been a good thing in her life and it’s been a positive thing. She loves horses and that’s helped her a lot in school. She’s always writing reports and it’s always on horses or animals. She spends a lot of time at the farm and it’s wonderful because it’s all girls and you don’t have to worry about the boyfriends. She always had all these boys hanging

around so I think this helped her self-esteem. You know, kids with ADHD, their self-esteem is low because they are always in trouble and when their grades aren't good, and when homework is hard. We just saw [her] doing this spiral downward and it was really hard as a mother to watch this. This passion just became this huge thing, and now she wants to go to college.” (Interviewee # 3)

Some parents place high value on the impact that alternative therapies have.

### **Theme Twenty-One: If Only I Knew Then What I Know Now**

In summary, many parent advocates reflected on several years of having advocated for their students. Below are their narratives of experience that describe those reflections.

One advocate reflected on how a daily program might have been helpful:

Interviewee # 6: “But I wonder about the coping skills that they might have learned had they been in a better program through the school on a daily basis versus just going to see a psychologist on the side.”

Another advocate reflected on wishing to have acknowledged ADHD earlier:

“I wish I would have started sooner. As a father, I wish we would have started sooner accepting that there were some issues and there was something that we could have done better, a little earlier. And I don't say that with regrets, but we could have acknowledged that the drugs would have been a benefit a little earlier particularly for our oldest daughter.” (Interviewee # 6)

A parent talked about realizing that things change frequently:

“One lesson I’ve learned from all of this: One day at a time. You just have to take it one day at a time because it could change, literally overnight.” (Interviewee # 5)

Another parent described the qualities of the teacher and the impact that can have:

“I think that kindness really goes a long way. You have that teacher that reaches out to you and you feel like understands and supports you as a parent, it just means the world when your child is struggling. I just wish there was more consistency across the board with that.” (Interviewee # 4)

One parent reflected on having learned a lot through the years of advocating for her daughter:

“I think I’ve learned a lot. You know, at the beginning, [she] was diagnosed so young. I felt like I was walking in the forest and I didn’t know which way to go and where the path was. I just wished somebody would tell me what to do because I was so confused. And now I feel like I’ve walked the path. I know how things work. I know what to do. I understand more about ADHD. I understand more about my daughter. I think my daughter is more able to verbalize her needs as well which is very helpful to me. So I don’t feel like I have to advocate as much or be the cheerleader. I just encourage her to keep going, you know, ‘You got an A, good job!’” (Interviewee # 3)

The same advocate also expressed these hopes for her daughter:

“Just because she has ADHD, I hope that won’t define her. And I hope to be helpful to other people who are going through similar issues. I hope I can help them find their way through the woods and it doesn’t have to be such a struggle. People are talking



about it more now and that makes it a little bit easier. You learn so much from other people's experiences."(Interviewee # 3)

In summary, three categories and twenty-one themes evolved to describe advocate experience.

## CHAPTER 5

### Discussion and Recommendations

Advocacy, the act of pleading or arguing in favor of something such as a cause or a policy, occurs today in the school system for students with ADHD. In this study, advocates are parents of students with ADHD in school. Parent advocates broadly impact student lives by deciding whether or not to seek a medical diagnosis and by choosing how a student diagnosed with ADHD will be treated, whether with or without medication. More specific to the school setting, advocates call on federal education laws that guarantee student rights to identification, qualified special education services, and public education with the goal of improving student opportunities for education and achievement. This section discusses the major findings of the phenomenological analysis of the experience of parent advocates of students with ADHD. The analysis of participant interviews generated four categories and twenty-one themes. The four main categories are: 1) Identifying and Treating ADHD in the School Context, 2) ADHD Advocates Need More Support from Schools, 3) Advocate Experience with the School is a Swinging Pendulum and 4) Advocates Struggle to Pave a Path for Success. Parent advocates for students with ADHD in school who participated in this study shared experiences about diagnosis and treatment, needing more support from schools, strong reactions both positive and negative to interactions with the school, and their struggle to help their child be successful in school. Each category and major themes are discussed below with themes condensed for the purpose of discussion.

#### **Category One: Identifying and Treating ADHD in the School Context**

Parent advocates typically share a path to student ADHD diagnosis and treatment that includes receiving and reacting to information from the school about their child's behavior in the classroom and about achievement. Some advocates acknowledge that challenges exist when their child is very young and some realize it over years when their child is older. Challenges for ADHD students can exist from kindergarten through college years. Once the student is diagnosed, parents are faced with the task of negotiating with themselves, partners and the school regarding whether or not to medicate their child as a treatment for ADHD. The rationale that favors medication as a treatment focuses on the student and the belief that medications such as Ritalin or Adderall give the student the behavioral effect of increased attention and self-control and the academic effect of increased achievement. Following are two themes that illustrate parent advocate experience regarding ADHD diagnosis and treatment.

**Theme One: That Year Sat Very Heavily on my Heart.**

Parent advocates shared two different experiences related to how they realized that their child has challenges, specifically ADHD. Some sensed that the student was having trouble early on in elementary school but were conflicted regarding when to seek a diagnosis. Others talked about having determined that the student had challenges with behavior and attention in school right out of the gate. Parents in both situations shared strong feelings of concern, worry, hopelessness and frustration regarding their experience with the school and initial steps toward advocating for their child. The feelings that parents shared in this study were similar to feelings that parents of ADHD children shared in a study conducted by McIntyre and Hennessy (2012):

“Other concerns included those about specific symptoms, social and academic difficulties, medication and the transition to secondary school. Such dedication to their child can leave parents feeling depressed and overwhelmed. One parent illustrated this when she said: ‘You do get down, get really sad and when you think of it, [it] just seems like such a huge . . . it’s like a mountain in front of you sometimes’ (Mother of 11-year-old boy).”

A recommendation related to the theme of the parental emotional experience of advocating for an ADHD child is to develop a resource guide for advocates. The guide could be organized in the way that ADHD is identified. For example, the symptomatic behaviors of impulsivity, distractibility and hyperactivity could be explained using narratives of students and advocates. In addition to typical information about ADHD such as steps to diagnosis, a checklist of what to consider that may be influencing the student to express these behaviors could be developed including topics such as gifted students with over-excitabilities, physiological effects on behavior such as omega-3 and ferritin, and pediatric sensory issues. (Hartnett et al, 2004; Oner et al, 2010; Richardson, 2006; and PT in Motion, 2011)

### **Theme Three: A Good Thing and a Bad Thing.**

Once parents have obtained a medical diagnosis of ADHD, they have the opportunity to decide whether or not to use medication to treat the student for ADHD. Parent advocates consider multiple factors when deciding whether or not to medicate the student. They contrast time on and off medication to obtain behavioral information from their student that they use to determine whether or not to medicate, (Brinkman et al,

2009). In addition, parent advocates also experience pressure from the school to medicate students diagnosed with ADHD.

In order to further understand the social and educational landscape regarding ADHD diagnosis and treatment that parent advocates make decisions in, it is helpful to look at Connor's (2011) article titled, "Problems of Overdiagnosis and Overprescribing in ADHD: Are they legitimate?" Connor (2011) states:

"Once the diagnosis of ADHD is established, treatment planning depends on symptom severity and pervasiveness of functional impairment, tempered by the wishes and concerns of the patient and his family. Treatment should be individualized for each patient. Not all children with ADHD require medication. Behavioral therapy can be helpful for many. Patients with very mild ADHD may initially receive psychosocial therapy and educational support without medications."

This perspective offers a rationale for why parent advocates are conflicted when deciding whether or not to medicate their student.

Brinkman, et al (2009) conducted a focus group study parents with the goal of better understanding how parents make decisions about treatment for their student with ADHD and summarize that,

"Parents in our study made decisions about treatment for their child with ADHD in the midst of experiencing a variety of emotions as they witnessed child functional impairments at home and at school. In addition, parents felt stress as a result of their daily efforts to manage their child's struggles."

The literature review includes a section on ADHD and Misdiagnosis which provides a foundation for the legitimate concerns that advocates have when feeling conflicted about whether or not to medicate their student as a treatment for ADHD. One resource is Haber's book, *ADHD: The Great Misdiagnosis* (2003), which offers advocates information about influences that affect the expression of ADHD behaviors as well as co-existing disorders that impact diagnosis and possibly misdiagnosis. Another is the Johnson-Gros (2007) article that reviews the Haber book and she says Haber "describes 'the real thing' and the 'imitators' of ADHD. Haber's attempt to place ADHD in context with other possible disorders is refreshing. The book gives a good but brief review of the 'imitators' that need to be considered when a comprehensive assessment is conducted."

A recommendation targeted at addressing the conflict that advocates face when deciding whether or not to medicate their student is to develop a more fully fleshed out resource that describes how misdiagnosis occurs, what the confounding aspects are, what alternative therapies exist and how to access alternatives to medication. Such a resource would acknowledge the reasons advocates feel conflicted when making a decision to medicate their children and would offer alternatives to medication as well as narratives about the benefits of medicating students.

#### **Theme Four: I Think We've Found a Good Fit.**

Although parent advocates struggle with the decision of whether or not to have their child diagnosed for ADHD, and then whether or not to medicate the student to treat ADHD, it is also the case that advocates have a range of reactions to the effect of medication on their students. In some cases, advocates in this study expressed relief

because the medication had such a positive effect on the student. One advocate described an emotionally volatile experience where her daughter tested several medications which had extreme behavioral effects that seemed to decrease her ability to cope and act like herself. Finally they settled on a medication that worked well and had positive effects with minimal side effects. Similarly, a recent focus group and interview study of medicated ADHD youth by Singh, et al (2010) reports that:

“Young people were positive about taking medication, feeling that it reduced their disruptive behaviour and improved their peer relationships. Young people experienced stigma but this was related more to their symptomatic behaviours than to stimulant drug medication. The study's findings helped to inform the NICE guideline on ADHD by providing evidence that young people's experiences of medication were in general more positive than negative.”

Once a good fit with medication for treatment of ADHD in youth is identified, advocates in this study and qualitative research located in the literature indicate their experiences are positive.

A recommendation is to develop a broader set of qualitative research that describes the effects of medication on students that have experienced improvement as well as crisis as a result of using medication to treat ADHD. This would be helpful to advocates because it would give them access to a range of experiences that other advocates have had, both positive and negative, to compare to their experience of medicating their student.

**Theme Five: They wanted him to be medicated.**

The issue of medicating students has been a concern for parent advocates because ADHD diagnosis has increased to millions of students in the country and the main treatment for ADHD is stimulant medication. Between 2003-2008 a bill called the Child Medication Safety Act was in the legislature, and it was an effort to legislate safety for children so that the school could not require ADHD students to take medication in order to maintain their attendance in school. Although the bill eventually died, the topic is still in the forefront for parent advocates. An opinion article published by Dr. Diller in 2001 gives his perspective on the situation some parents have faced in being pressured by the school to medicate their ADHD children:

“As a doctor with a practice in behavioral pediatrics--and one who prescribes Ritalin for children--I am alarmed by the widespread and knee-jerk reliance on pharmaceuticals by educators, who do not always explore fully the other options available to deal with learning and behavioral problems in their classrooms. Issues of medicine aside, these cases represent a direct challenge to the rights of parents to make choices for their children and still enjoy access to the public education they want for them--without medication. These policies also demonstrate a disquieting belief on the part of educated adults that bad behavior and under-performance in school should be interpreted as medical disorders that must be treated with drugs.”

A recommendation that relates to the teacher and school and their influence on parent advocates regarding medicating ADHD students is that at minimum a teachers should obtain professional development on the topic of ADHD including boundaries that exist where clinicians diagnose and discuss medicating the student and teachers do not.



Confusion can easily exist for teachers regarding the boundaries for ADHD diagnosis and treatment because teachers often make the referral for diagnosis and also participate in assessment by submitting a teacher evaluation. (Conners, 2000) A clear distinction should be made that teachers make the referral, clinicians do the assessment and diagnosis and parent advocates make the decision regarding how to navigate the treatment for ADHD students.

### **Category Two: ADHD Advocates Need more Support from Schools**

Parents described their experiences interacting with the school, engaging staff for support and determining where the student will attend school. This category details a variety of situations where parents have experienced a wish for more resources to support themselves as advocates as well as a need for school staff such as principals, teachers and counselors to have more training about ADHD in the school setting and how to collaborate with parent advocates to support students.

### **Theme Six: The Schools Didn't Do Much of Anything.**

Parent advocates in this study shared their reactions to interactions with various school staff including teachers, counselors and the principal. Parents experience a range of emotions when advocating for students because they are often embarrassed and frustrated by their child's behavior. Parents in this study shared strong negative and positive experiences. They experienced negative reactions in situations where advocates feel like teachers do not like their child or when teachers say or do things that result in the child not wanting to go to school, feeling stupid or feeling disliked. Another negative experience was that of loneliness and isolation when advocates felt like the school was

not supporting the student and not on the side of the parent. Participants felt disappointed when they did not feel that the school teamed with them to support the student and when staff at the school mostly wanted the student to be diagnosed and medicated. They also felt disappointed when the school seemed to refer the student for ADHD assessment which the parent has to pay for and find resources for while at the same time not offering any behavioral or educational support. Furthermore, parents felt helpless due feeling like a lone advocate who had to spend so much time and energy taking the student to tutors, counselors and even fighting within the family to get the student to attend school daily. Parents also experienced shock when teachers implied that, although their student had a diagnosis of ADHD, the student's behavior was the parent's fault. Similarly, parents of ADHD students interviewed in the McIntyre and Hennesy (2012) study also felt others blamed them for their child's behavior:

“Linked with the general ignorance surrounding ADHD, the majority of parents in the

present study felt they were being blamed for their sons' ADHD. Family members, school staff and total strangers were all perceived as quick to 'point the finger' at parents. In the words of one mother:

‘I was told by somebody in the school . . . that I was a really bad parent . . . a lot of people just thought we were dreadful parents and it wasn't that at all but that's very hard to take . . . that's the hardest thing. (Mother of 9-year-old boy)’”

Parents experienced positive reactions to interactions with the school when they feel like the teacher understands their student and sees him/her as a whole person, likes the student and communicates positively about the student. Parents also felt incredibly

positive about their experiences when they interpreted the school staff as working with them as a team to support the student. Participants also described positive reactions to interactions with the school when they were able to team with teachers to implement meaningful behavior modifications as well as educational plans.

**Theme Seven: If I Was the School, I Would Have a List of Resources.**

This theme includes discussion about the ADHD information gap that exists for and between school counselors, teachers and parent advocates regarding supporting ADHD students and parent advocates in the school setting. Parents described the need for school counselors to define their role in supporting ADHD students and parent advocates. They also identified a need for more consistency between teachers in supporting ADHD students and advocates and also a need for schools to develop and offer more meaningful resources for parent advocates of students with ADHD. More meaningful resources would include lists of assessment and diagnosis referrals and lists of accommodations and effective interventions that can be used in the classroom to support ADHD students. Participants seem to lament that often the school identifies ADHD type behaviors in a student and sends the parents in search of a diagnosis but then does not have consistent information or a policy for how the school will go about supporting the ADHD student.

A recommendation that would improve the ADHD information gap for the school and for parent advocates is that teachers and counselors should receive training on ADHD and on the other conditions that influence ADHD behaviors. For example, Hartnett et al (2004) and Rinn and Nelson (2009) report on their studies where both counselors and teachers who received information that Gifted students can demonstrate

overexcitable behaviors that mimic ADHD were likely to consider giftedness as a reason for the student behavior and not only to consider ADHD. In addition, as mentioned before, the school should develop and communicate a clear policy whereby the school will adhere to when working with parent advocates and their ADHD students.

### **Category Three: Advocate Experience with the School is a Swinging Pendulum**

This category describes parent experience of engaging staff for support with results swinging between very negative to very positive. Most parents shared negative experiences regarding what it was like when teachers and schools limited cooperation with advocates and also shared positive experiences about what it was like when collaboration occurred between the advocate and the school. Parents describe limited cooperation with the school as occurring in situations where the school has not acknowledged the student has special needs due to ADHD or when teachers have declined to implement behavior modification programs that have worked for the student in other classrooms.

### **Theme Fourteen: I Wish there was More Consistency Across the Board.**

Another parent shared a wish that more consistency between teachers would occur so that year by year accommodations that work could be relied upon to be implemented rather than hopefully implemented depending on the teacher's interest or lack thereof in collaborating with parent advocates.

In contrast, parents described very positive experiences of collaboration with teachers and the school that had the effect of supporting their ADHD student. Collaboration occurred when teachers interacted with advocates in a positive way and

when teachers did not blame the parent advocate but instead asked the parent to work together with the teacher to support the student. Parents also described collaboration as having their requests for behavior modification programs or specific academic supports well-received and honored by teachers and principals.

An article published in 2013 by Pfiffner, et al, discusses the evaluation of a collaborative school-home intervention, a collaborative life skills program, for students with ADHD symptoms. The results are described below and the study offers great support for using a collaborative approach between school and home to support ADHD students in school.

“Significant pre-post improvement was found for all measures, with large effect sizes for ADHD symptoms, organizational skills, and homework problems, and medium to large effects for teacher-rated academic skills, report card grades, academic achievement, and student engagement. Improvements in organizational skills mediated the relationship between improvement in ADHD symptoms and academic skills. Significant improvement in both ratings and objective measures (achievement testing, report cards, classroom observations) suggests that improvement exceeded what might be accounted for by expectancy or passage of time. Findings support the focus of CLS (Collaborative Life Skills) on both ADHD symptom reduction and organizational skill improvement.”

A recommendation for schools and teachers that would generate more support and consistency in collaborating with parent advocates is to develop a school-based ADHD policy for interacting with parent advocates of students with ADHD. Such a policy could

include expectations for school-advocate engagement and definitions of what a collaborative partnership looks like between advocates and the school. The teachers could receive professional development training in the form of workshops to learn how to collaborate with parent advocates.

### **Theme Sixteen: It was Pretty Much a Closed Door.**

Participants talked about the journey their students took through elementary school, junior high, high school and even college. Many shared experiences where they had moved their student from one school where the student was not supported and not achieving to another school so that the student had a better chance to be successful.

Parents described the experience of deciding to go to a different school as a result of a psychologist assessing the student and then recommending that the student move to a different school. Most other situations were clearly where the student was not supported and not achieving. An article published by Comfort (1994) offers the following opinion about how teachers can collaborate with the student thus promoting the student's success:

“A dichotomy for both these students and their teachers is that, on the one hand, they need structure and routine, but, on the other hand, they need to be given a fair amount of independence and choice. This takes a teacher who can be flexible and understanding--one who will work with the child rather than set up a no-win battle.”

Advocates decide to keep their student in a school when they feel supported and when they see that a plan that includes a roadmap is in place to support the student. Participants also valued situations where the school or teacher seemed to understand kids

with ADHD and their needs both academically, intra-personally and socially. Although advocates experience both negative and positive reactions to interactions with the school, most of the positive reactions stem from situations where the advocate feels like a participative team member with the school staff in developing and implementing positive behavior modifications and meaningful educational plans.

A recommendation for advocates regarding selecting the school fit for their student would be to interview staff at a school prior to enrollment and ask what is their policy for collaborating with parent advocates of students with ADHD? And what are examples of collaborative interventions that lead to success for ADHD students. In addition, interviewing other parent advocates whose students attend this school would be helpful in determining the landscape that may lend support to the student with ADHD.

#### **Category Four: Advocates Struggle to Pave a Path for Success**

##### **Theme Eighteen: What are Accommodations Anyway?**

Students diagnosed with ADHD most do not qualify for special education services because they do not often meet the criteria of lagging 2 years behind their age in ability. When ADHD students do not qualify for special education services, schools can be approached to endorse a 504 plan for the student which could make the student eligible for accommodations that can support the student's achievement. A civil rights law, The Rehabilitation Act of 1973, includes Section 504 which is defined as follows:

An individual with a disability that has a physical or mental impairment that substantially limits major life activities, either currently or in the past. Major life activities may refer to self-care, performing manual tasks, walking, seeing,

hearing, speaking, breathing, learning and working (United States Department of Health and Human Services, 2006; Rehabilitation Act, 1973).

Students that don't qualify for special education services under IDEA generally seek to qualify for services using Section 504. Depending on student needs, Section 504 may offer a quicker more flexible opportunity for obtaining services. This law is often used to qualify students with ADHD for services such as accommodations that allow the student extra time to complete tests, a reduction in homework, a reduction in penalties for lost work, and accommodations that support student need to move around the classroom. Parents in this study described their experiences with 504 plans and identifying accommodations for their students. Some parents described accommodations as helpful but not really anything unique or unconventional. Accommodations described were seating the student closer to the teacher or giving students a private place to take a test.

**Theme Nineteen: Technology has been Wonderful for Her.**

One parent talked about her student's experience using an iPad and that it positively affected the student's learning because it took the place of the executive function skills that the student is challenged with due to having ADHD. In the literature a recent article published by McClanahan, et al (2012) also describes the positive effect that using an iPad had on a student's achievement:

“The subject was a fifth grade struggling reader with Attention Deficit Hyperactivity Disorder. The device not only helped the student focus attention, it facilitated his becoming much more metacognitive in his reading. Comparisons of pre- and post-assessments showed that the student had gained one year's growth



in reading within a six week time period. The student also gained in confidence and sense of being in control of his learning.”

A recommendation that evolves from this theme is that resources and even school level policies can be developed to determine what accommodations for ADHD students look like, how to go about determining what to implement and further, how to use technology to accommodate ADHD student deficits in executive function skills such as organizing work, submitting work on time and retaining learning tools such as notes, etc. Although medication can reduce the distractible and hyperactive behaviors that ADHD students demonstrate, accommodations in the learning environment are most meaningful if they help the student adapt and perform in spite of having executive function challenges.

**Theme Twenty: I Don’t Know If It’s Considered Advocacy or Not.**

Parents of children with ADHD are often given by the medical and educational communities medication as the quickest, most cost-effective treatment of ADHD. In the context that parents are decision-makers and consumers who ultimately shape the pattern of therapeutic approach to treating ADHD, Edwards and Howlett (2013) recently conducted a study of parents and published an article titled *Putting Knowledge to Trial: ‘ADHD Parents’ and the Evaluation of Alternative Therapeutic Regimes*. Edwards and Howlett comment that,

“Parents have had to fight for services in a resource-scarce environment and the dominance of traditional biopsychiatry has led to medication becoming a primary treatment route. Although alternatives such as neurofeedback (a type of biofeedback in which sensors are placed on a person's head to provide a display of

brain activity, or ‘brainwaves’, that can be monitored and, so it is suggested, retrained) and behavioural interventions are available, many of these are only offered in the private health sector. Parents can pay therefore pay heavily for their experiments with alternative interventions, and are critical of the health service for its failure to provide treatments other than medication.” (Edwards and Howlett, 2013 and Hough, 2011)

The position that alternative therapies to medication or alternative therapies that can be used in combination with medication was also interest to parent advocates in this study.

In addition to parents discussing their experiences with alternative therapies, another article in the literature by Johnson-Gros (2007) who reviewed Haber’s book, *ADHD: The Great Misdiagnosis*, said that, “Haber devotes an entire chapter (chapter 8) to alternative therapies, but it is disappointing that other psychological and behavioral interventions were not given more attention. This is not to say that Haber does not discuss these topics; however, when the issues are sprinkled throughout the text, they do not appear to be cohesive or important.”

A recommendation that would improve resources and support for advocates is the development of a set of alternative therapies that by definition are not medication but other therapeutic approaches that reduce the behaviors symptomatic of ADHD and increase attention and achievement.

### **Theme Twenty-One: If I Only Knew Then What I Know Now.**

Participants reflected on several years of advocating for their students and generally said that they wish they would have started sooner accepting that there were

some challenges for their student. They also they wished for a daily program or intervention in the school that would support the skill development that ADHD students need and not to receive that support mainly when visiting a psychologist outside of the school. Some also said they wished they had had someone available to guide them and tell them what to do with regard to how to support the student and how to develop a collaborative team-based approach to working with the school to support the ADHD student.

### **Conclusion**

In conclusion, although this study is qualitative and is not generalizable, several of the themes of experience of parents in this study relate to the need for advocates to feel supported by the school, to feel as a collaborative team member with the school and to see their child succeeding in school. Recommendations for practice included creating teacher and counselor professional development that includes defining ADHD and the professional's role in the school regarding supporting parent advocates in learning about ADHD in the school setting. In addition, a broad recommendation for practice is to develop a school policy for ADHD that includes protocol for interacting with parent advocates in a way that is collaborative, school-based and likely to implement meaningful accommodations that support student learning.

### **Implications**

“When the 1990s began, most schools across the country had only a handful of (if any) children diagnosed with ADHD and using stimulants. By 2000, every classroom in the United States had, on average, at least 1 to 2 such students treated for the disorder.

Currently, almost 8 percent of youth aged 4 to 17 years have a diagnosis of ADHD, and approximately 4 percent both have the diagnosis and are taking medication for the disorder.” (Mayes, et al, 2007). In addition, Mayes et al (2007) describe the growth of the diagnosis and treatment of ADHD students as:

“Growing political movements advocating for children's welfare and mental health consumers, along with the decreasing stigma associated with mental disorders, led to three seemingly minor changes to disability, special education, and Medicaid policies in the early 1990s that helped trigger the surge in ADHD diagnoses and related stimulant use.”

The magnitude of the growth in numbers of students with ADHD in the classroom has changed the social and political nature of how high energy and distractible student behavior is interpreted and managed in the classroom, and this major change has a significant effect on student learning and their parents. As a result of this shift, parents are increasingly being pulled by the momentum of ADHD diagnosis and stimulant treatment to act as advocates for their children in school to support their student in learning and achieving. A major implication of this study is that because advocates value collaborative, positive working relationships with the school that promotes them feeling like a member of the team working to support their student, schools should develop an ADHD Policy. The policy should include educational information about ADHD for school staff and parent advocates which would include assessment and school-based interventions such as meaningful accommodations and 504 plans. Such a policy would lay the foundation for expectations regarding professional development, parent advocate education and educational planning for the student. An effect would be more consistent

programming for the student over the years in school, increased satisfaction of parent advocates due to the effects of collaboration and increased student retention at schools as well as increased student achievement.

### **Recommendations for Future Research**

The recommendations for further research are generated from the following four categories: 1) Identifying and Treating ADHD in the School Context, 2) ADHD Advocates Need more Support from Schools, 3) Advocate Experience with the School is a Swinging Pendulum and 4) Advocates Struggle to Pave a Path for Success.

Recommendations for further research are discussed below as questions that were inspired by the results discussed in this thesis. The recommendations are not focused on practice.

Research related to identifying and treating ADHD in the school context is targeted at developing a deeper understanding of what the parent advocate's level of knowledge is on this topic. Parents in this study shared their experiences regarding identifying and treating ADHD which included feelings of conflict and trepidation due to the idea of labeling and/or medicating their child. They also shared positive and negative experiences regarding medicating their child. Research questions that evolved when reflecting on this advocate experience are:

1. What do parent advocates who have been advised by the school that their child needs an ADHD assessment know about ADHD?
2. What do advocates consider the ADHD assessment process to be and what diagnostic behaviors indicate ADHD?

3. Do parents know they have a choice regarding whether or not to have the child assessed for ADHD?
4. In addition to ADHD assessment information, what do parent advocates know about special education services, 504 plans and the school's influence regarding student medication and what their student's rights to education are?
5. What contributes to advocates having a positive or negative experience when medicating their child?
6. Furthermore, what is the ADHD knowledge level for advocates from diverse backgrounds?

Identifying and quantifying advocate knowledge about ADHD identification and treatment can steer practitioners toward advocate needs with the goal of developing meaningful support for advocates.

Research related to advocates needing more support from school could produce answers to the following:

1. What do advocates want schools to do, especially if their experience is “the schools didn't do much of anything”?
2. What resources would advocates like to receive from the school?
3. What interventions can schools and teachers develop that would be meaningful and helpful to students and parent advocates?
4. What types of policies could be developed that would improve the rate of effective outcomes such as increased student achievement?

Understanding what advocates expect from schools and teachers and what they are looking for in a set of resources would guide practice in developing programs to support advocates.

Category Three, Advocate Experience with the School is a Swinging Pendulum, focuses on the experience of advocates with a certain teacher or school as having been very positive or very negative. A common experience was that effective collaboration such as described in Theme Thirteen, A Strong Triangle Between Parent, Student and School, resulted in a very positive experience for advocates. Negative experiences resulted from a lack of consistency between teachers in collaborating with advocates. Additionally, negative experiences resulted when parents felt blamed for their child's problem behavior and when students feel like the teacher does not like them. In contrast, advocates had positive experiences when the advocate felt that the teacher was interested in their child, liked their child and understood the child as a whole person who has ADHD. Further research could seek to answer questions that identify and further understand the underlying influences that have an effect on whether parents have a positive or negative experience. Following are potential research questions:

1. What qualities or behaviors do teachers who successfully collaborate with parent advocates demonstrate?
2. What does a teacher do to express that he or she likes a child and is interested in the whole child?
3. What do teachers or administrators do to result in not collaborating with advocates?

4. What behaviors occur that contribute to establishing a strong triangle between parent, school and student? What does this triangle look like and what attributes are required to establish this triangle of collaboration?
5. What is the experience like for a teacher who “gets my child”?
6. What do parent advocates identify as reasons for pulling their child out of a certain school? And what reasons exist for retaining a child in a certain school?

By using the positive and negative experiences of advocates as a guide, future research can dig deeper to discover the reasons and influences regarding both positive and negative collaboration with advocates. Further research that seeks to determine what qualities and behaviors contribute to effective collaboration between advocates and schools can also investigate the effect that collaboration has on student retention and achievement in school.

Research related to Category Four, Advocates Struggle to Pave a Path for Success, can be conducted to further understand specific challenges that advocates have related to personalizing support for students. Research can use the education laws that give students rights to education such as Individuals with Disabilities Education Improvement Act (IDEA) of 2004, Section 504 of the Rehabilitation Act of 1973, and the Assistive Technology Act of 2004 as a foundation from which to develop research questions. Advocates in this study expressed not fully understanding the Section 504 of the Rehabilitation Act of 1973 and what accommodations for ADHD students can or should be. They also mentioned that technology such as iPads offer their students support but did not see the school as offering technology to ADHD students as



accommodations. Finally, advocates were not fully aware of how to define their interactions with the school as advocacy or not. Research questions that can be answered with further investigation are:

Accommodations:

1. What do effects do accommodations have on ADHD students?
2. What are typical accommodations for ADHD students? What is the rationale for recommending each accommodation?
3. What do school counselors and/or teacher recommend as ADHD accommodations?
4. What qualities do teachers that implement effective accommodations have?
5. What is the outcome of school achievement when ADHD students who utilize accommodations to ADHD students that do not are compared?

Technology:

1. What assistive technology is used to support ADHD students?
2. What are the effects of using technology such as an iPad on the achievement of ADHD students?
3. What are the qualities of schools and teachers that facilitate the use of technology to support ADHD students?

Advocacy:

1. What activities to parents of ADHD students engage in that they consider advocacy?
2. What effect does parent advocacy have on ADHD student achievement in school?

In summary, the recommendations for future research have evolved from the description of parent advocate experience. The recommendations are questions that seek to obtain information about how issues such as identification and treatment of ADHD, resources for ADHD advocates, collaborative relationships between parents and the school, use of 504 Plan accommodations and assistive technology can be further understood, and how they affect the outcomes of ADHD student achievement.

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## APPENDIX A

### Invitation to Participate in Interview Study Sample Letter

*Department Letterhead*

University of Minnesota

Date

Dear *(insert participant's name)*:

This letter is an invitation to consider participating in a study I am conducting as part of my doctoral degree in the Department of Organizational Leadership, Policy and Development at the University of Minnesota under the supervision of Professor Rosemarie Park. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

The purpose of the study is to obtain a deeper understanding of the experience that parent of students diagnosed with ADHD have. The study will, through the process of interviewing, focus on hearing the experience that parents have and the contexts that parents describe as they have experienced being parent advocates of students who are diagnosed with ADHD. I believe that because you are a parent of a student diagnosed with ADHD, you are suited to talk about your what your experience has been like.

Participation in this study is voluntary. It will involve an interview of approximately 60 minutes in length to take place in at the University of Minnesota. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising the researcher. With your permission, the interview will be audio recorded to facilitate

collection of information, and later transcribed for analysis. All information you provide is considered completely confidential. Your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. Data collected during this study will be retained for up to two years in a locked office in my home office. Only researchers associated with this project will have access. There are no known or anticipated risks to you as a participant in this study.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at 651-442-6082 or by email at male0039@umn.edu. You can also contact my supervisor, Professor Rosemarie Park at (612) 625-6267 or email at parkx002@umn.edu.

I would like to assure you that this study has been reviewed by the Institutional Review Board at the University of Minnesota. However, the final decision about participation is yours.

I hope that the results of my study will be of benefit to parent advocates of students diagnosed with ADHD, as well as to the broader research community.

I look forward to speaking with you and thank you in advance for your assistance in this project.

Sincerely,

Melissa Malen

## **Consent Information Sheet**

I have read the information presented in the information letter about a study being conducted by Melissa Malen of the Department of Organizational Leadership, Policy and Development at the University of Minnesota. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded and video recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through, the Institutional Review Board at the University of Minnesota. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the project supervisor, Dr. Rosemarie Park at (612) 625-6267.

Completion of this interview implies my consent to participate in this study. If you choose to withdraw your consent to participate at a later time, please notify Melissa Malen at (651) 442 6082.



## **APPENDIX B**

### **Interview Analysis Themes**

Category One: Identifying and Treating ADHD in the School Context

Theme One: That Year Sat Very Heavily on my Heart

Theme Two: She was Always the Naughty One

Theme Three: A Good Thing and a Bad Thing

Theme Four: I Think We've Found a Good Fit

Theme Five: They Wanted Him to be Medicated

Category Two: ADHD Advocates Need more Support from Schools

Theme Six: The Schools Didn't Do Much of Anything

Theme Seven: If I Was the School, I Would Have a List of Resources

Category Three: Advocate Experience with the School is a Swinging Pendulum

Theme Eight: Mom, My Teacher Doesn't Like Me

Theme Nine: We are the Only People who Understand this Kid

Theme Ten: We Wanted Him to Succeed There so Badly

Theme Eleven: It's the Parent's Fault

Theme Twelve: She Gets My Child!

Theme Thirteen: A Strong Triangle Between Parent, Student and School

Theme Fourteen: I Wish There was More Consistency Across the Board

Theme Fifteen: You're Not Ready to Let All Your Joy Loose Because It's Like, We'll Wait and See, Is It Really True?

Theme Sixteen: It was Pretty Much a Closed Door

Theme Seventeen: This is the First School Where I'm Not Pulled Out, and I Don't Feel Odd

Category Four: Advocates Struggle to Pave a Path for Success

Theme Eighteen: What are Accommodations Anyway?

Theme Nineteen: Technology has been Wonderful for Her

Theme Twenty: I Don't Know If It's Considered Advocacy or Not

Theme Twenty-One: If Only I Knew Then What I Know Now

APPENDIX C

UNIVERSITY OF MINNESOTA

Research Exempt from IRB Committee Review

Category 2:

SURVEYS/INTERVIEWS, STANDARD EDUCATION TESTS & OBSERVATIONS

Empty rectangular box for Category 2 selection.

OF PUBLIC BEHAVIOR

Submission Instructions:

E-mail a copy of this application and any other materials required to the Research Subjects' Protections Programs Office: [RSPPeRev@umn.edu](mailto:RSPPeRev@umn.edu)

Electronically submitted protocols must be sent from a University of MN e-mail account. Original signatures are not required. U of M x.500 IDs have been deemed by the University of Minnesota to constitute a legal signature.

Academic Advisors and Co-Investigators should be carbon copied (Cc) on the submission e-mail.

For help with this form and to download additional appendices: see <http://www.research.umn.edu/irb/download/> or call 612-626-5654

1.1 Project Title (Project title must match grant title. If different, also provide grant title):

Doctoral Dissertation: The experience of parent advocates of students diagnosed with ADHD: A phenomenological study

1.2 Principal Investigator (PI)

Table with 2 columns: Name (Last name, First name MI) and Highest Earned Degree. Name: Malen, Melissa Peterson; Degree: M.A.

Mailing Address:  <b>1978 Nature View Lane</b>  <b>West St. Paul, MN 55118</b>	Phone Number:  <b>651-442-6082</b>
	Pager or Cell Phone Number:  <b>651-442-6082</b>
	Fax:  <b>None</b>
U of M Employee/Student ID:  <b>1775198</b>	Email:  <a href="mailto:melissamalen@yahoo.com">melissamalen@yahoo.com</a>
U of M x.500 ID (ex. smith001):  <b>Male0039</b>	University Department (if applicable):  <b>OLPD</b>
Occupational Position:  <input type="checkbox"/> Faculty Staff <input checked="" type="checkbox"/> Student <input type="checkbox"/> Fairview Researcher	
Human Subjects Training (one of these must be checked--refer to training links at the end of this section):  <input type="checkbox"/> CITI , <input type="checkbox"/> Investigator 101, <input type="checkbox"/> NIH training (EXCEPT for 5/8/06 to 2/29/08), <input type="checkbox"/> UM/RCR (between 1994-2003)  XX Other - Indicate training received, when and from which institution: Course WCFE 8915, Ethics and Responsibility in Research, Summer 2003 at the University of Minnesota.	HIPAA Training (Required if Data Contains PHI):  <input type="checkbox"/> HIPAA

**As Principal Investigator of this study, I assure the IRB that the following statements are true:**

The information provided in this form is correct. I will seek and obtain prior written approval from the IRB for any substantive modifications in the proposal, including changes in procedures, co-investigators, funding agencies, etc. I will promptly report any unexpected or otherwise significant adverse events or unanticipated problems or incidents that may occur in the course of this study. I will report in writing any significant new findings which develop during the course of this study which may affect the risks and benefits to participation. I will not begin my research until I have received written notification of final IRB approval. I will comply with all IRB requests to report on the status of the study. I will maintain records of this research according to IRB guidelines. The grant that I have submitted to my funding agency which is submitted with this IRB submission accurately and completely reflects what is contained in this application. If these conditions are not met, I understand that approval of this research could be suspended or terminated.

Melissa Malen	5-6-2012
x.500 of PI	Date

**Training Links:**

FIRST (Fostering Integrity in Research, Scholarship and Training): <http://cflegacy.research.umn.edu/first/humansubjects.htm>

HIPAA: <http://www.research.umn.edu/first/AdditionalCourses.htm>

- "UM/RCR" includes all human subjects protection training offered in-person or online at the University of Minnesota from 1994-2003.

- The online NIH tutorial offered during the period May 8, 2006-February 29, 2008 is NOT acceptable to meet this requirement.

- If you completed a version of this training not included on the list provided, provide details as indicated


- The University of Minnesota uses two methods to verify records about completion of human subjects protection training: 1) training registration online, or 2) researcher must provide copy of completion certificate. To check your online training record, go to <http://www.research.umn.edu/first/Reports.htm>

**1.3 Department, Division Head, or Dean Information**

*Please note as the researcher, you are responsible for confirming and following your departmental standards and requirements for research.*

Dr. Rebecca Ropers-Huilman, OLPD Department Chair
Name of Department Head, Division Head, or Dean

**1.4 Are there additional Co-Investigators and Staff?**

Yes. Download an [extra personnel sheet](#) and include it with your application. 

**No.** Continue to 1.5.

**1.5 Is the PI of this research a student?**

**Yes.** . Include [Appendix J.](#) 

*Electronically submitted protocols must be carbon copied (Cc) to their advisor.*

**No.** Continue to 2.

<b>Academic Advisor to the Student Investigator</b>	
Advisor's Name (Last name, First name MI): <b>Park, Rosemarie</b>	University Department: OLPD
Mailing Address: Room 410E WullH 86 Pleasant Street S E Minneapolis, MN 55455	Phone Number: 6126256267
	Email: Parkx002@umn.edu
	U of M x.500 ID (ex. smith001): Parkx002

**2. Funding**

**2.1 Is this research funded by an internal or external agency?**

**Yes.** Include [Appendix A.](#) 

**No.**

**If no,** explain how costs of research will be covered:

There are no costs.

**3. Institutional Oversight**

**3.1 Is this research proposal being reviewed by any other institution or peer review committee?**

**Yes.**

It is the responsibility of the PI to secure the appropriate approval from these committees and document that approval to the IRB. Attach a copy of documentation of approval, if

**No.**

**4. Conflict of Interest** received, and indicate committees below.

**If yes,** please list which committees will review this proposal:

Federal Guidelines emphasize the importance of assuring there are no conflicts of interest in research projects that could affect the welfare of human subjects. Reporting of financial interests is required from all individuals responsible for the design, conduct or reporting of the research. If this study involves or presents a potential conflict of interest, additional information

will need to be provided to the IRB. Examples of conflicts of interest may include, but are not limited to:

- A researcher participating in research on a technology, process or product owned by a business in which the researcher or family member holds a significant financial interest or a business interest
- A researcher participating in research on a technology, process or product developed by that researcher or family member
- A researcher or family member assuming an executive position in a business engaged in commercial or research activities related to the researcher's University responsibilities
- A researcher or family member serving on the Board of Directors of a business from which that member receives University-supervised Sponsored Research Support
- A researcher receiving consulting income from a business that funds his or her research
- A researcher receiving consulting income from a business that could benefit from the results of research sponsored by a federal agency (i.e. NIH)

**"Family Member"** means the covered individual's spouse or domestic partner, dependent children, and any other family member whom the covered individual reasonably knows may benefit personally from actions taken by the covered individual on behalf of the University.

**"Business Interest"** means holding any executive position in, or membership on a board of a business entity, whether or not such activities are compensated.

For additional details and definitions, please refer to the appropriate policy:

University of Minnesota Researchers, please refer to:

<http://www.policy.umn.edu/Policies/Operations/Compliance/CONFLICTINTEREST.html>

University of Minnesota Researchers involved in clinical health care in the Academic Health Center, also refer to:

[http://www.policy.umn.edu/Policies/Operations/Compliance/CONFLICTINTEREST\\_APPA.html](http://www.policy.umn.edu/Policies/Operations/Compliance/CONFLICTINTEREST_APPA.html)

Fairview Health System Researchers, please refer to:

<http://www.fairview.org/Research/index.htm>

Gillette Children's Specialty Healthcare Researchers, please refer to:

**4.1 Do any of the Investigators or personnel listed on this research project have a business interest or a financial interest of \$10,000 or more (\$5,000 or more if involved in clinical health care with an appointment in the Academic Health Center, AHC) associated with this study when aggregated for themselves and their family members?**

X No.

Yes.

If yes, identify the individual(s) and complete section 4.3:

**4.2 Do any of the investigators or personnel (when aggregated for themselves and their family members) listed on this research have:**

**Ownership interests less than \$10,000 (\$5,000 if in clinical health care with an appointment in the AHC) when the value of interest could be affected by the outcome of the research?**

X No.  Yes.

**Ownership interests exceeding 5% interest in any one single entity?**

X No.  Yes.

**Compensation less than \$10,000 (\$5,000 if in clinical health care in the AHC) when the value of the compensation could be affected by the outcome of the research?**

X No.  Yes.

If yes, identify the individual(s) and complete section 4.3:

**4.3 Has the business or financial interest been reported?**



X No.

**If you are a University of Minnesota researcher**, please report your business or financial interest online via the Report of External Professional Activities (REPA) at:

[http://egms.umn.edu/quickhelp/EGMS\\_Instructions/prepa.html](http://egms.umn.edu/quickhelp/EGMS_Instructions/prepa.html)

**If you are a Fairview Health System researcher**, please complete the Fairview Health Services Conflict of Interest Disclosure forms at:

<http://www.fairview.org/Research/BusinessOperations/ConflictsofInterest/index.htm>

and submit the completed forms to the Fairview Office of Research.

**If you are a Gillette Children's Specialty Healthcare researcher**, please contact the Director of Research Administration, at 651-229-1745.

Yes.

**If yes, have you been informed that a Conflict of Interest Review Committee is reviewing the information you reported on your REPA?**  No.

Yes.

The IRB will verify that a management plan is in place with the Conflict of Interest (COI) Program. If the COI Program does not have an approved management plan in place for this research, they will contact the individual(s) listed in question 4.1 for additional information.

**Final IRB approval cannot be granted until all potential conflict matters are settled. The IRB receives a recommendation from the Conflict of Interest Review Committee regarding disclosure to subjects and management of any identified conflict. The convened IRB determines what disclosure language should be in the consent form.**

## **5. Summary of Activities**

***Use lay language, do not cut and paste from or refer to a grant or an abstract.***

### 5.1 Briefly state your research question.

Following are the main two questions will be used to guide the interview:

1. As a parent, what is the experience like of advocating for your child who is diagnosed with ADHD?
2. What are contexts or situations have affected your experience of advocating for your child who is diagnosed with ADHD?


Follow up questions will include reflective interview questions that encourage the participant to share more details about his or her experience such the following:

1. " You mentioned \_\_\_\_\_, tell me what that was like for you."
2. " You mentioned \_\_\_\_\_, describe that in more detail for me."

### 5.2 Describe the tasks subjects will be asked to perform.

Describe the frequency and duration of procedures, psychological tests, educational tests, and experiments; including screening, intervention, follow-up etc. *Reminder:* No personal or sensitive information can be sought under exempt guidelines. (If you intend to pilot a process before recruiting for the main study please explain.)

Participants will be adults and each will be interviewed one time.

Attach all surveys, instruments, interview questions, focus group questions etc. 

### 5.3 Describe what non-participants will do during this period (activities and supervision if applicable):

*If your subjects will be students, it is important that the study design not penalize students who will not be participating if not all students will be participating.*

There will not be any non-participants.

### 5.4 How long do you anticipate this research study will last from the time you are determined to meet the criteria for exempt research?

Exempt research is generally considered short-term in nature. This office routinely inactivates exempt applications after five years from the time it was determined to meet the exempt criteria. If you think your project will extend beyond five years, contact the IRB office (612-626-5654 or [irb@umn.edu](mailto:irb@umn.edu)).

This project will not extend beyond 3 years.

## 6. Participant Population

### 6.1 Expected Number of Participants: 6

# of Male: Up to 6	# Female: Up to 6
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### 6.2 Expected Age Range

Please confirm subjects are at least 18 years old, checking all that apply (you may not conduct research with subjects younger than 18 under exempt category two, if you would like to include subjects younger than 18, you must complete the full IRB application requesting expedited review if appropriate):

- 18-64  
 65 and older

### 6.3 Describe the criteria for inclusion and exclusion of subjects in this research study.

#### Inclusion Criteria:


A participant will be included if he/she is an adult parent of a student who is diagnosed with ADHD. Participants will be invited to participate by a third party such as an organization or a school.

#### Exclusion Criteria:

Non-parents and parents of students who are not diagnosed with ADHD.

### 6.4 Location of Subjects during Research Data Collection

Check all that apply:

- Elementary/Secondary Schools (include Appendix M) 
- Community Center, specify: \_\_\_\_\_
- University Campus (non-clinical), specify: Wulling Hall in an OLPD office
- Subject's Home, specify: \_\_\_\_\_
- International Location (include Appendix K): \_\_\_\_\_
- Other special institutions, specify: \_\_\_\_\_

## 7. Compensation

### 7.1 Will you give subjects gifts, payments, compensation, reimbursement, services without charge or extra credit?

- Yes.  
 No.

If yes, please explain:

## 8. Recruitment

### 8.1 Are subjects chosen from records?

- Yes. Complete 8.1a-c  
 No. Continue to 8.2

#### 8.1a What type of records:

- Medical  
 Educational  
 Employment  
 Other: \_\_\_\_\_

#### 8.1b Are the records publicly available?


- Yes. Proceed to question 8.2  
 No. Proceed to question 8.1c

**8.1c Do you already have permissible access to the private records? (i.e. through your job, volunteer work, internship, etc.)**

**Yes.** Describe how you have permissible access.

**No.** You must ask the custodian of the record to make initial contact for you (describe how they will do this in question 8.2) and let the potential subject contact you if they are interested. Attach a letter of cooperation from the custodian of the record indicating that they will make initial contact on your behalf. Please note that even if the custodian is willing to give you the private list, if you do not have permissible access to the records, the fact that the custodian will give you the list does not create permissible access. The custodian will still have to make initial contact.

**8.2 Describe the recruitment process to be used:**

*Attach a copy of any and all recruitment materials to be used e.g. advertisements, bulletin board notices, e-mails, letters, phone scripts, or URLs.* 

A letter inviting parents to participate in the study by sitting for an interview will be distributed by a third party such as the Pacer Center or Groves Academy **or any other public or non-public K-12 school**. Participants will volunteer to participate and will meet the criteria of being an adult parent of a student who is diagnosed with ADHD. The invitation letter is attached.

**8.3 Explain who will approach potential subjects to take part in the research study and what will be done to protect individuals' privacy in this process:**

Initial contact of subjects identified through records search must be made by the official holder of the record, i.e. primary physician, therapist, public school official.

A designee from an organization such as Pacer Center or Groves Academy will invite parents to participate. In the invitation letter, participants will be notified that none of their private information, including the name of their student and his/her school records and medical records, will be shared with the researcher.

## **9. Confidentiality**

See [Protecting Private Data Guideline](#) from the Office of Information Technology (OIT) for information about protecting the privacy of research data.

**9.1 Describe provisions that will be taken to maintain confidentiality of data (e.g. surveys, video, audio tape, photos):**

Interviews will be audiotaped and videotaped only with consent of participants. Participant names and identifying information will be kept confidential. The fact that participant confidential information will not be shared will be explained to the participants before beginning interviewing. Participants will be interviewed in a private space **or on a password-protected phonecall**. Participants will be notified that they have the right to stop the interview or retract permission for use of audio or video tape at any time without repercussion. After the live interview, participant audio and video files will be stored on a digital voice recorder or a video camera

which will be locked in a file cabinet or **in a password-protected internet cloud file**. The audio and video files will be destroyed after data analysis occurs.

**9.2 Describe the security plan for data including where stored and for how long, noting that you may not keep identifiable data indefinitely:**

Audio, video and text transcripts of interview data will be kept in a locked file cabinet and participant names will not be included. Interview data will be logged as “participant 1, participant 2, participant 3, participant 4, participant 5 and participant 6.” Interview data will be destroyed upon completion of the dissertation project or 2 years, whichever comes first.

**9.3 Will the PI have a link to identify subjects?**

- Yes.  
 No.

**9.4 Will identifiable data be made available to anyone other than the PI?**

- Yes.  
 No.

**If yes, explain who and why they will have access to the identifiable data:**


## **10. Informed Consent Process**

*Reminder: If you are mailing a survey to subjects and asking them to return it to you, or doing a phone interview, you must send or read a consent statement which includes the same information as the consent form but is not signed.*

**10.1 Describe who will conduct the consent process with subjects and how consent will be obtained:**

The participant will be given consent information in the invitation letter. The researcher will also read and explain consent information to participants immediately prior to beginning the interview. Participants will sign the consent to participate agreement after the researcher reads it to participants immediately prior to beginning the interview.

**10.2 Recognizing that consent itself is a process of communication, describe what will be said to subjects to introduce the research:** Do not say “see consent form”. Write the explanation in lay language.

*If you are using telephone surveys, attach telephone scripts.* 

Prior to beginning the interview, I will say to participants that they have the opportunity to be informed about the study and then to give consent (or not) to participate in the study. Participants will also be told they have the right to decline answering any questions and may end participation in the interview at any time. Participants will be told that the study will use recorded interviews to gather the

participant's answers to interview questions that are designed to hear the participant's experience that he/she had and/or is having as a parent advocate of a student diagnosed with ADHD. The study will seek to understand the essence of the experience of participants. The results will be reported in a written doctoral thesis and in a presentation for an oral defense of a doctoral thesis. In addition, the research may be shared in articles or other types of forums such as an exhibit, poster presentation or meeting. The participant information will be confidential meaning that participant names and other identifying information will not be included in any way when sharing the results. I will then share the Consent Information Sheet.

**10.3 Prepare and attach consent forms for review. For exempt category two research, it is not necessary to obtain signed documentation of consent (i.e. a signature). Please submit a 'consent information sheet' which does not include a signature line. The IRB office reserves the right to require that you obtain signatures, but in most cases it is not necessary.**

Even though the IRB may determine that some research is exempt from the federal regulations, adequate provisions still need to be in place to protect research participants.

In making its consideration of exempt status, the HRPP/IRB office still has to determine that:

- a) The research involves no more than minimal risk to participants
- b) Selection of participants is equitable
- c) If there is recording of identifiable information, there are adequate provisions to maintain the confidentiality of the data
- d) If there are interactions with participants, there will be a consent process that will disclose such information as:
  - that the activity involves research
  - a description of the procedures
  - that participation is voluntary
  - name and contact information for the investigator
- e) There are adequate provisions to maintain the privacy of participants.

[Information Sheet for Research](#)

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**This regulation does not apply to FDA regulated research.**

*You have reached the end of this form. Please make sure that you have responded to every question on this application (even if your response is “not applicable”).*

## **APPENDIX D**

### **Interview Question Guide**

Sometimes a general interview guide, or topical guide, is used when the researcher has not tapped into the participant's experience qualitatively and with sufficient meaning and depth. Broad questions, such as the following, may also facilitate the obtaining of rich, vital, substantive descriptions of the experience of the phenomenon. The language and timely way in which the questions are posed facilitates full disclosures of the participant's experience.

1. How did the experience affect you?
2. How did the experience affect significant others in your life?
3. What feelings were generated by the experience?
4. What thoughts stood out for you?
5. What bodily changes or states were you aware of at the time?
6. Have you shared all that is significant with reference to the experience?