The Family Experience with School When an Adolescent has ADHD

by
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ABSTRACT

TITLE: The Family Experience With School When An Adolescent Has ADHD

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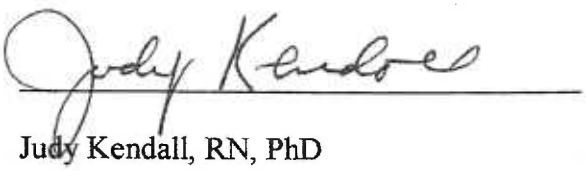
APPROVED: 

Judy Kendall, RN, PhD

The purpose of this qualitative study was to generate a theoretical understanding of the family experience with school when an adolescent had ADHD. The sample (N=40) included members of twelve families: 19 adolescents diagnosed with ADHD, one adult sibling, and 20 parents, twelve of whom had been diagnosed with or displayed strong characteristics of ADHD themselves. All participants were Caucasian, and all families were middle class SES. This study used grounded theory methodology. The research design included intensive interviewing and coding using constant comparative methods; reiterative data collection and inductive data analysis continued until one category emerged as the central phenomenon. Results indicated that the central phenomenon was the family focus on organizing cooperative efforts to manage ADHD in the family. Parents referred to ADHD as an "invisible disability" that made family life "a nightmare". Two patterns of adolescent behavior resulted from the combined effects of ADHD: difficulties accomplishing things and struggling with school. Because of these significant disabling patterns of behavior, parents took extraordinary measures with schools, community agencies, with the adolescents, and for themselves to manage the

effects of ADHD on the family. Outcomes from these actions included a range of family-school relationships, family costs and benefits, and adolescents gradually taking personal responsibility for their lives or prolonging their dependence on others.

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CHAPTER ONE

INTRODUCTION

Attention deficit hyperactivity disorder (ADHD) is the most common chronic behavioral disorder in childhood and adolescence, affecting approximately 3-5% of all children (American Psychological Association, 1994; Goldman, Genel, Bezman, & Slanetz, 1998), or as many as two million children (National Institutes of Health, 1996). ADHD is a chronic condition that continues to affect life into adulthood (Weiss & Hechtman, 1994). Diagnostic features of ADHD include inattention, distractibility, impulsivity and hyperactivity (American Psychological Association, 1994). Secondary problems associated with ADHD include social immaturity, low self-esteem, oppositional behaviors and depression (Cantwell, 1996). These characteristics can impact all aspects of growth and development and often negatively affect the experience at school and home (Levine, 1992; Lewis-Abney, 1993). This dissertation project involved the interactions between school and family when an adolescent had ADHD.

School is a significant setting where adolescents gain social, emotional, and academic competency. When school life is negatively affected by ADHD, adolescents fall behind peers socially, emotionally, and academically, and are less able to master developmental tasks (Lobar & Phillips, 1995). Adolescents with ADHD are at high risk for academic under-achievement and school dropout (Branch, Cohen & Hynd, 1995; Hinshaw, 1992a, 1992b).

ADHD is defined as a disability in legislation pertaining to education. Students with ADHD are covered by two civil rights statutes that guarantee the right to participate in public education, The Rehabilitation Act of 1973 and the Americans with Disabilities

Act (ADA) of 1990. The Individuals with Disabilities Education Act (IDEA) of 1990 required public schools to provide special education services to disabled students, including students with ADHD. Protections under these three federal statutes entitle students to accommodations to facilitate their success in school. Within the Amendments to IDEA (1997) Congress emphasized the importance of parent involvement and parental rights to participate in the educational decision-making about their children.

Families often are negatively affected when any member has a chronic condition (Rolland, 1999). Reflecting this chronicity, several family studies reported that negative effects of ADHD on the family increase when the child moved into adolescence (Hechtman, 1991; Kendall, 1998; Lewis-Abney, 1993). Kendall (1998) and Lewis (1992) identified school difficulties as a major source of family disruption. Shelton (1995) found that dealing with homework was among the top five "most problematic" behaviors in a study of parents of children with ADHD. Yet, parents of adolescents are still expected to prepare teens for a productive adulthood, even if they have a diagnosis of ADHD (Steinberg, Lamborn, Dornbusch, & Darling, 1992). This study focused on the family experience with school in order to examine this phenomenon in depth.

Statement of the problem

The literature on ADHD has carefully described the characteristics of ADHD that affect teens and their families, and its effect on school performance. However, there is little empirical research on the subjective experience of adolescents and their families regarding school, nor is there a study proposing a theoretical understanding of such experiences. Therefore, the purpose of this study was to generate a theoretical understanding of the family experience with school and to identify processes and

interactions that impact family functioning and school when a teen has ADHD. Findings are needed to generate relevant intervention strategies to alleviate family disruption and help families facilitate social, emotional, and academic competency in adolescents with ADHD.

Aims

The specific aims of this study were to:

1. Describe the family experience with school from the perspective of the parents and adolescents with ADHD.
2. Identify the following family processes when an adolescent has ADHD:
    - the context, interactions, and strategies that facilitate and/or interfere with family life as it relates to the experience with school,
    - the conditions which impact the family experience with school,
    - the basic social processes within families which are related to school.
3. Develop an initial grounded theory about the family experience with school when an adolescent has ADHD.

This study was designed to describe the family experience with school when an adolescent has ADHD. The purpose of this study was to elicit the complex relationships among family members and their activities regarding schooling. A grounded theory design was selected because its product describes the processes and meanings of a social phenomenon from the perspective of the participants and generates a conceptualization about a particular area of human interaction. A family perspective was sought to understand the experience of parents and teens with ADHD that may be very different from the perspectives of professionals in education, psychology, and medicine who work

with the parents and teens who have ADHD.

Significance to Nursing

As a discipline, nursing is interested in the human response and adaptation to health and illness. ADHD is a medical condition that requires a variety of interventions to improve the functioning and quality of life of those who have ADHD. There is no cure for ADHD; therefore, adaptation and amelioration of symptoms are the focus of treatment recommendations. Nurses are trained to provide many of the health services needed by families of children with ADHD. With 3-5% of all children diagnosed with ADHD, nurses will find these children and families in nearly every practice setting. In many cases, nursing interventions are cost effective because of the multiple functions performed by nurses: assessment and diagnosis, case management, family education and counseling, and medication supervision (Diacon, 1992; Kendall, 1998; Lewis-Abney, 1993).

Nurses in primary care clinics and schools need to be knowledgeable about how ADHD affects family functioning and academic work. Parents of ADHD children reported they needed information and advice about managing ADHD problems from their primary care providers (Shelton, 1995). Roles for school nurses and school-based nurse practitioners are expanding to provide specialized services to students with ADHD and other health impairments (Adams, Shannon, & Dworkin, 1996; Allensworth & Bradley, 1996; Francis, Hemmat, Treloar, & Yarandi, 1996; Fryer & Igoe, 1996; Resnicow & Allensworth, 1996). Nurses in mental health settings, juvenile facilities and prisons come in contact with many adolescents and adults with ADHD, and their families (Diacon, 1992). Knowledge about the experience with school from the perspective of the family is

prerequisite to the assessment and planning of successful family interventions. Findings from this study may be used by nurses in many settings where ADHD teens and their families appear for nursing services.

CHAPTER TWO

REVIEW OF THE LITERATURE

Attention deficit hyperactivity disorder (ADHD) is one of the most researched topics of child behavior, including its diagnostic criteria, incidence and prevalence, treatments, and outcomes. Children and adolescents affected with ADHD reside with families and attend school just like their peers. How ADHD affects learning has been researched extensively in the fields of medicine, education, and psychology. Clinicians working with this population know ADHD profoundly affects the family and school experience, yet very few empirical studies have examined this aspect of ADHD. Recent family studies about the family experience when a child has ADHD identified schooling as a major source of frustration and conflict in these families (Kendall, 1998; Lewis, 1992; Lewis-Abney, 1993).

This chapter contains a review of literature from three areas relating to the topic of study: ADHD, families, and school. For the purposes of this study, the literature review within each area is focused on research about interactions among families, school, and teenagers with ADHD. Literature on ADHD includes a summary of diagnostic criteria, treatment, how ADHD affects adolescent development, and teen behavior at home and school. Review of family literature is limited to research on family management styles when children have chronic health problems, and the impact of ADHD on family life. The third section of this chapter contains research regarding school law, parent participation in school, the establishment of the family-school connection, and the school experience of families with ADHD.

Literature Related to Attention Deficit Hyperactivity Disorder

Attention deficit hyperactivity disorder (ADHD) is a complex condition with a neuro-biological basis that presents in childhood, persists in adulthood, and is manifested behaviorally as inattention, distractibility, impulsivity, and hyperactivity. Secondary effects of these characteristics include egocentricity, poor impulse control, difficulty delaying gratification, hyperactivity, and poor rule-regulated behaviors (Barkley, 1990; 1997; Cantwell, 1996, 1997). Frequently, children with ADHD have comorbid conditions such as oppositional defiant disorder (ODD), conduct disorder (CD), anxiety, depression, and learning disabilities (Biederman, Newcorn, & Sprich, 1991; Shaywitz & Shaywitz, 1991). Comorbidities may exacerbate the effects of ADHD symptoms (Biederman, et al., 1995; Jensen, Martin, & Cantwell, 1997).

ADHD is a lifelong condition (Biederman, 1998) known to disrupt families and complicate daily living for all family members (Barkley, 1990; Kendall, 1998; Murphy & Hagerman, 1992). Prevalence is estimated to be 3-5% of all school age children and affects males 3:1 times more frequently than females (Goldman, Genel, Bezman, & Slanetz, 1998; Greenhill, et al., 1996). Prevalence rates have been reported in school literature as between 3-10% (Barkley, 1990); the wide range of estimates is explained by methodological difficulties (CDC Division of Birth Defects, Child Development, and Disability and Health, 2000). ADHD does not have a single cause, but is thought to be an interaction between various genetic and biological factors. Strong patterns of familial heritability have been established (Biederman, et al., 1992; Faraone, et al., 1993a).

Diagnostic criteria

The diagnosis of ADHD has undergone considerable revision over many years

but the primary defining characteristics of the disorder have remained constant over time. Historically, ADHD has been called the hyperkinetic syndrome, minimal brain dysfunction (MBD), hyperactivity disorder, and attention deficit disorder (Barkley, 1990; Cantwell, 1996; Hechtman, 1996). Regardless of the name given, the previous labels for ADHD have included inattention, distractibility, impulsivity, and overactivity as primary behavioral manifestations.

Diagnostic criteria has been revisited with each of the six editions of the Diagnostic and Statistical Manual (DSM) published by the American Psychological Association in 2000, 1994, 1987, 1980, 1968, and 1952. Research and discussion has accompanied each revision of criteria with the intent of refining categories and relationships among the subtypes (Barkley, DuPaul & McMurray, 1990; Cantwell, 1997; Cantwell & Baker, 1987; Faraone, Biederman, Sprich-Buckminster, Chen, & Tsuang, 1993). Two primary issues were addressed with each revision of the DSM: whether inattention and hyperactivity are distinctly different entities rather than manifestations of the same disorder, and how to distinguish features of ADHD from the comorbid conditions which have similar presenting behaviors (Biederman, et al., 1996). Barkley (1997) proposed a theoretical model of ADHD that separated the problems of inattention from disruptive behaviors. Meanwhile, clinicians and researchers both emphasize that careful consideration of the differential diagnoses during the initial diagnostic phase is necessary for diagnostic accuracy, and that periodic review of primary symptoms and treatment recommendations is essential for optimal outcomes (Biederman, 1998; Boyle, Offord, Racine, Szatmari, Fleming, & Sanford, 1996).

Diagnostic criteria from Diagnostic and Statistical Manual, 4th Edition (DSM-IV) (American Psychological Association, 1994) appear in Table 1.

Table 1
Diagnostic Criteria for Attention Deficit Hyperactivity Disorder

HISTORY

The history must include assessment of the following:

- Family: ADHD, neurological problems, learning difficulties, or psychological problems.
- Birth: Maternal health, medications, use of drugs, alcohol, tobacco, birth anoxia, difficult delivery, postpartum complications and postnatal history.
- General health: Consider especially neurological, vision, hearing, chronic diseases.

SIGNS AND SYMPTOMS

- Symptoms occur in more than one setting *and*
- There is significant impairment in social, school, or work settings *and*
- Symptoms have been present before the age of 7 *and*
- Symptoms have persisted for more dun 6 months *and*

At least six symptoms of inattention are present:

TRAITS OF INATTENTION

- Does not attend to tend to details, makes careless mistakes routinely in schoolwork.
- Has difficulty sustaining attention at work or at play.
- Does not seem to hear or pay attention when spoken to,
- Fails to follow instructions or fails to complete tasks.
- Has difficulty organizing activities and tasks.
- Frequently puts off doing off tasks requiring sustained mental effort,
- Often loses things necessary for accomplishing tasks,
- Is easily distracted by extraneous stimuli.
- Is often forgetful in daily activities.

At least six of the following symptoms of hyperactivity/impulsivity are present:

TRAITS OF HYPERACTIVITY/IMPULSIVITY

- Frequently squirms in seat or fidgets with hands or feet.
- Often leaves seat when remaining in seat is expected.
- Frequently climbs, runs, or moves restlessly in situations when it is inappropriate.
- Often has difficulty playing or enjoying quiet leisure activities.
- Is often described as "on the go" or "driven".
- Frequently talks excessively.
- Often answers before question is completed or "blurts out".
- Has difficulty taking turns.
- Often interrupts or intrudes in others' activities.

(Adapted from Diagnostic and Statistical Manual-IV, American Psychological Association, 1994)

Currently diagnostic criteria for ADHD includes three subtypes: predominantly inattentive, predominantly hyperactive, and combined type (American Psychological Association, 1994). Age of onset and presence of symptoms across settings are important factors in the diagnosis, in addition to the presenting behaviors of inattention, distractibility, impulsivity, and hyperactivity. Children displaying impulsive and hyperactive behaviors are more likely to be evaluated at a younger age than children displaying inattentive and distractible behaviors (Barkley & Biederman, 1997). DSM-IV (1994) criteria must be met and differential diagnoses ruled out to confirm the diagnosis.

Three factors complicate the diagnostic process: comorbidity, confusion with conditions whose presenting features mimic ADHD, and those who doubt the validity of the diagnosis. Each will be discussed briefly below. What confounds the diagnostic process is the fact that the primary signs and symptoms of the comorbid conditions often represent behaviors of ADHD along a continuum. However, ADHD and each of the comorbid conditions can and do exist without the other.

Comorbidity. Comorbidity refers to the frequent association between ADHD and other psychiatric diagnoses including Tourette's syndrome, oppositional defiant disorder (ODD), conduct disorder (CD), anxiety, depression, obsessive-compulsive disorder (OCD), bipolar illness, and learning disabilities. Of those with ADHD, approximately 60% have comorbid conditions. The process for differentiating ADHD from other comorbidities is based on time of onset of symptoms, frequency, severity, or intensity of symptoms, causes for exacerbation, and history.

Comorbidity has significant implications for treatment and prognosis. Accurate diagnosis of ADHD and comorbid conditions is important for selecting appropriate

treatment (Pliszka, 1998), to establish the basis for legal protection by federal education statutes, to identify prevalence rates and thresholds for measurement tools (Boyle, Offord, Racine, Szatmari, Fleming, & Sanford, 1996), and to further develop the diagnostic category (Barkley, 1990).

Each comorbid condition interacts differently with symptoms of ADHD; behavioral manifestations of ADHD present differently when influenced by comorbid conditions. The family experience with ADHD and comorbidities varies accordingly (Biederman, et al., 1995). For example, Barkley, Fischer, Edelbrock & Smallish (1991) found that in an 8 year prospective study of ADHD teens, ratings of home conflicts and maternal psychological distress were higher among teens who also were diagnosed with oppositional defiant disorder (ODD).

Confusion with other conditions. ADHD is sometimes confused with other diagnostic categories such as posttraumatic stress disorder (PTSD), child abuse, reactive attachment disorder, fetal alcohol syndrome/fetal alcohol effects (FAS/FAE), and children affected by congenital exposure to drugs or toxins other than alcohol, because presenting symptoms of these diagnoses often mimic those of ADHD. Famularo, Fenton, Kinscherff, &Augustyn (1996) studied the psychiatric comorbidity in childhood posttraumatic stress disorder and found significant correlations with ADHD. Glod and Theicher (1996) studied the relationship between early abuse, posttraumatic stress disorder and activity levels in prepubertal children. Findings indicated that abused children with posttraumatic stress disorder had activity levels similar to children with ADHD. In both studies, authors emphasized the importance of accurate diagnosis for presenting and comorbid conditions and the need for multimodal treatment for optimal

outcomes. Gardner (2000) studied the experience of living with children with fetal alcohol syndrome (FAS). Results indicated that aggressive and hyperactive behaviors of children with FAS occurred frequently and were disruptive to daily living.

The differential diagnosis is critical because the behavioral features of ADHD are similar to those of children and adolescents who have experienced physical, sexual, and emotional abuse, chronic neglect, significant losses, and other traumatic events. More importantly, personal safety planning and treatment recommendations differ significantly for this range of diagnostic entities; therefore, accurate diagnosis is essential for selecting effective interventions and for providing physical and emotional safety for children who have suffered abuse, trauma, and neglect. As with comorbidities of ADHD, elements of history, age of onset, and settings in which symptoms occur are factors that help differentiate ADHD from this group of diagnostic categories (Perry & Polland, 1998). A structured interview to assess abuse, neglect, trauma, and loss, as well as screening tools for depression, behavioral problems, stress, and family assessment tools are frequently used to discern the differential diagnosis.

Doubt about the validity of ADHD. Complicating the diagnostic process are those who doubt that ADHD exists at all, in spite of mounting scientific evidence. The media frequently fans the debate over the existence of the disorder by citing isolated or poorly designed research (Bacon, 1988; Baren, 1989; Bass, 1988; Docks, 1988). Others voice bias, ignorance, or malevolence in public arenas such as television and radio talk shows. It is a great disservice to those affected by ADHD when behaviors related to the disorder are characterized as flaws in character, irresponsibility, and immaturity, in a manner similar to those who misunderstand disorders like alcoholism and mental

illnesses, and malign sufferers of these conditions (Diller & Tanner, 1996).

Etiology and treatment

ADHD does not have a single cause, but is thought to be an interaction between various genetic and biological factors (Barkley, 1997; Cantwell, 1996). Strong patterns of familial heritability have been established (Biederman, et al., 1992; Faraone, et al, 1993b; Faraone, Biederman, Keenan, & Tsuang, 1991). The role of parenting requires maturity in social and emotional development, and mastery of life skills, all of which can be compromised when a parent has ADHD. Implications of familial heritability for this study include increased family stress and disruption when a parent also has ADHD. As with any chronic condition, family life is complicated when the parent has ADHD that interferes with his or her ability to parent and manage a household.

Recent advances in radiographic imaging techniques indicate that there is a biological basis for ADHD; differences in brain glucose utilization patterns, blood flow patterns in the frontal lobe, and size of anatomical structures in the brain have been documented in children with ADHD (Amen & Carmichael, 1997; Posner & Peterson, 1990; Zametkin, 1993). Other research suggests that there may be alterations in the biochemistry of neurotransmitters and neurological differences (Boutros, Fristad, & Abdollohian, 1998).

Medication. Treatment of ADHD in school age children frequently involves the use of stimulant medications (Greenhill, et al., 1996), behavior modification, and parent education and training (Dulcan & Benson, 1997; Goldman, Genel, Bezman, & Slanetz, 1998). Medication management has been researched extensively for many years (Barkley, McMurray, Edelbrock, & Robbins, 1990; Diller & Tanner, 1996);

psychostimulants continue to be the first line of pharmocologic therapy (Dulcan & Benson, 1997; Greenhill, et al., 1996). It is reported that two million children are currently being treated with stimulant medication for ADHD (Centers for Disease Control ADHD Conference proceedings, 1999). There is considerable debate as to whether use of stimulant medication increases the risk for substance abuse during adolescence and adulthood (Horner & Scheibe, 1997; Martin, Earleywine, Blackson, Vanyukov, Moss, & Tarter, 1994; Schubiner, Tzelepis, Isaacson, Warbasse, Zacharek, & Musial, 1995). It is unclear if stimulant medication predisposes adolescents to substance abuse, whether substance abuse is related to adolescent risk-taking behavior, or if a combination of factors is involved.

Since 1990, new preparations of dexedrine and methylphenidate have been used to increase compliance and efficacy with some success (Elia, Welsh, Gullotta, & Rapoport, 1993; Greenhill, et al., 1996; Swanson, et al., 1998). Use of medication to treat ADHD becomes more complicated when comorbidities exist (Greenhill, et al., 1996). Medication, however, only mitigates the intensity of symptoms; it does not "normalize" the pathophysiologic condition nor "treat" the disorder (Greenhill, et al., 1996).

Behavior modification. Behavior modification is an important treatment for ADHD and can be used in conjunction with, or without, medication. There are behavioral interventions for parents (Anastopoulos, Shelton, DuPaul, & Guevremont, 1993) and the child or adolescent who has the disorder (Cocciarella, Wood, & Low, 1995). Underlying all parent training interventions is the belief that parents need to be educated about ADHD and be willing to improve their parenting skills (Barkley, 1990;

Cantwell, 1996; Dulcan & Benson, 1997). A certain level of maturity is required to understand the need for parent education, practice the skills, and apply them consistently; this level of maturity is often compromised when parents themselves have ADHD. In addition, parent training programs require an investment of time and money, and presuppose the ability to incorporate the additional demand of the training on daily schedules. Parent training programs often may be doomed at the outset for certain parents due to lack of resources and level of family functioning.

The role of therapy in the management of ADHD is used most commonly to address issues of self-esteem, anger and frustration, and stress management for all family members. Ziegler & Holden (1988) developed a model of therapy for families with children who have ADHD and learning disabilities (LD). The model described five different types of families who have children with ADHD and LD: healthy families, fragile families, disorganized families, blaming families, and split families. They also outlined "family work" and "child work" for each family type. In healthy families, the primary stressor was the ADHD or LD; parents have displayed adequate parenting skills to deal with "normal" childhood. Fragile families were characterized as having marginal communication and parenting skills even before the ADHD/LD problems surfaced. The disorganized family was one with multiple problems and little structure to facilitate family functioning. In the blaming family, there was often disorganization, but in this family type, the child was seen as responsible for the family problems. The split family was composed of parents with very different and often conflicting ideas of how to manage ADHD/LD that significantly affected the rest of the family system. The model included individual and family therapy, which focused on child development and family

organization simultaneously, and the pressing needs of each family type.

Results from many studies indicate few interventions have had lasting effectiveness, although there is agreement that multimodal treatments work best (Barkley, 1997b; Greenhill, et al., 1996; Horn, Ialongo, 1988; Horn, et al., 1991; Ialongo, et al., 1993; Pollard, Ward, & Barkley, 1983). This is not surprising considering the complexity of the disorder and its effect on all aspects of daily living. This study aimed at exploring the complexity of behaviors within the family regarding school to guide future interventions.

Model of Behavioral Disinhibition

Barkley (1997) constructed a theoretical model of ADHD that incorporated the biological component and the behavioral manifestations of the disorder. He proposed that the core deficit in ADHD was behavioral disinhibition, which occurs in the executive function area of the brain. Executive functioning provides coordination and feedback to all other sections of the brain. For clarity, the model of behavioral inhibition will be presented first, followed by the model of behavioral disinhibition.

According to Barkley's (1997) model (Figure 1), behavioral inhibition provides individuals with the abilities to inhibit "first responses", to stop ongoing responses, and to manage "interference control" when presented with a stimulus. Four mental mechanisms combine to provide motor control, fluency of behavior, and a syntax of behavior: working memory; internalization of speech; self-regulation of affect, motivation, and arousal; and reconstitution. Each mechanism provides a cluster of skills that govern or regulate other functions.

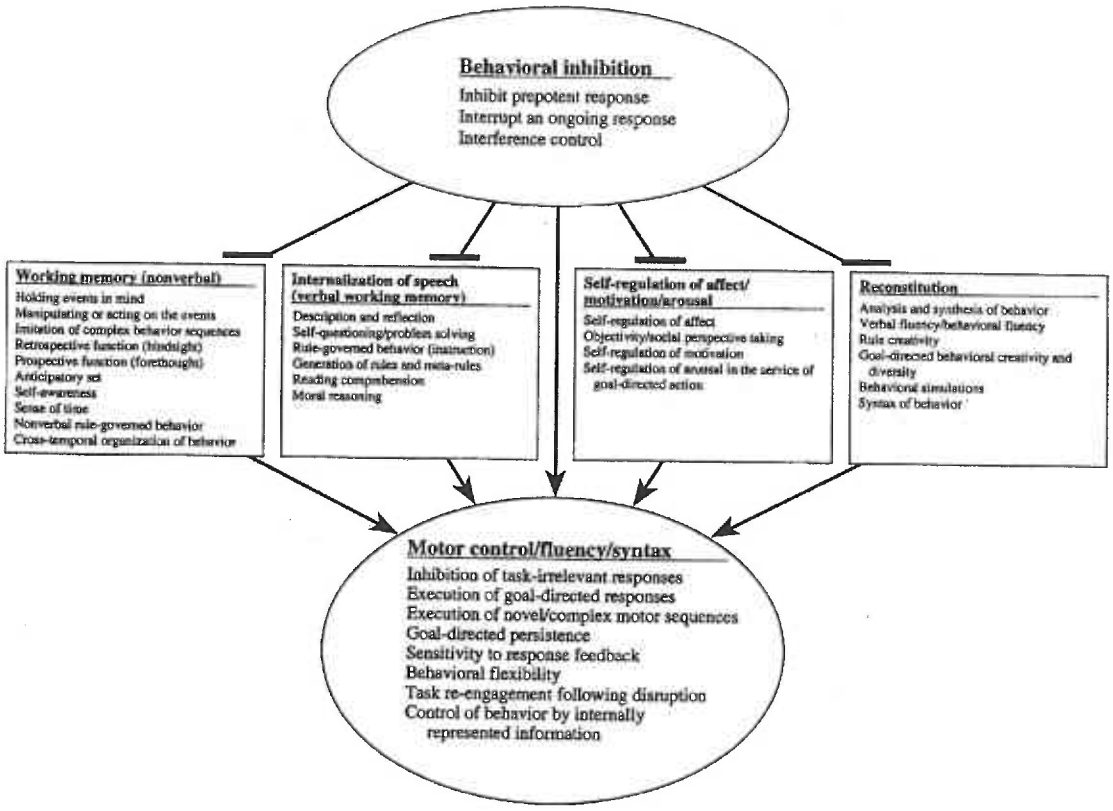

Figure 1. Barkley model of Behavioral inhibition. From ADHD and the Nature of Self Control, by R.A. Barkley, p.191. Copyright 1997 by The Guilford Press. Reprinted with permission.

The working memory is a non-verbal mental function that contains the ability for one to hold events in mind, and to manipulate and act on events and information mentally. The working memory provides useful hindsight, is important in creating forethought, and provides a sense of time and self-awareness when selecting a behavioral response. Internalization of speech guides rule-governed behavior, problem solving, and self-questioning. This mechanism is required for good reading comprehension and moral reasoning. Self-regulation of affect, motivation, and arousal provides emotional self-control and allows one to think objectively and consider the perspective of others.

Arousal to stimuli is regulated to form goal-directed behaviors. Reconstitution involves the processes of analysis and synthesis of behavior, it allows one to use behavioral simulations before selecting a particular behavioral action, and use of reconstitution allows for creative and diverse behavioral responses to stimuli.

Together, these four mental mechanisms yield motor control and behavior selection based on internally represented information, rather than impulsive, unthoughtful, or reactive behavioral responses to stimuli. In addition, use of the four mechanisms allows individuals to execute goal-directed responses, make complex motor responses, use flexibility in behavioral responses, and to re-engage in activities following disruption. The end result is behavior that results from reflection and complex consideration after inhibiting a "reflexive" or "non-thoughtful" response to a stimulus. This process of behavioral inhibition is an on-going developmental process throughout the lifespan, and is reflected as children move through stages of development to maturity.

In contrast to the process of behavioral inhibition, Barkley has proposed that the core deficit in ADHD is behavioral dis-inhibition. Despite chronological physical maturation, the developmental milestones that signal internalization of social behavior are delayed in children and adolescents with ADHD. Behavioral disinhibition results from the poor or absent coordination within and among the four mental mechanisms that regulate behavioral inhibition, and results in reduced motor control, decreased sequencing abilities, and decreased internal behavioral control (Figure 2).

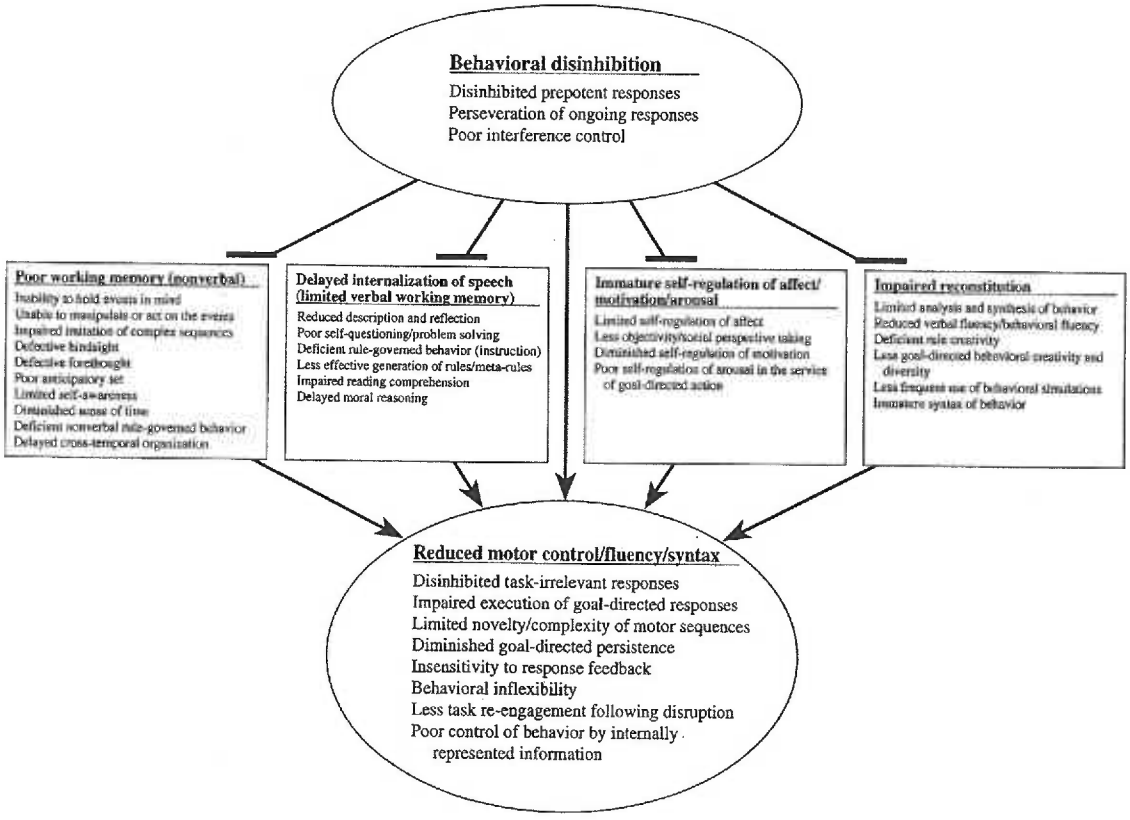

Figure 2. Barkley model of Behavioral disinhibition. From ADHD and the Nature of Self Control, by R.A. Barkley, p.237. Copyright 1997 by The Guilford Press. Reprinted with permission.

A poor working memory limits the ability to hold events in mind while considering options for behavioral response; it limits the ability to engage in hindsight or forethought before acting. Both the sense of time and awareness of self in relation to others are altered, which leads to a persistent egocentric perspective. Delayed internalization of speech results in reduced description and reflection within oneself, less effective problem solving, generation of rules and meta-rules, and impaired reading comprehension. Immature self-regulation of affect, motivation, and arousal leads to limited emotional self-control and less objectivity. Inability to take the perspective of others diminishes the capacity for empathy. There is a diminished self-regulation of

drive and motivation, resulting in difficulty in accomplishing goal-directed activities. Impaired reconstitution limits internal analysis and synthesis of information to form meaningful bases for behavior selection and less frequent use of behavioral simulations before selection of a behavioral response.

The result of behavioral disinhibition is reduced motor control and deficits in internal locus of control. There is more difficulty returning to tasks after interruptions, behavior is less driven by internally represented information and there is diminished goal-directed persistence. Behavioral disinhibition, then, ends in the primary behavioral characteristics of ADHD: inattention and distractibility, impulsivity, and hyperactivity.

ADHD and Development

ADHD is also viewed as a developmental disorder (American Psychological Association, 1994) characterized by behaviors which are seen in all children, but are significantly more intense and frequent, and persist beyond the time when the behaviors normally should have abated, thus interfering with the acquisition of normal developmental skills (Pisterman, et al., 1992). As early as age two, inattention and distractibility may interfere with the mastery of basic motor skills, cognitive development and language skills (Sonuga-Barke, 1994). Of preschoolers with ADHD, 30-50% of children diagnosed with ADHD also display oppositional behaviors that interfere with the acquisition of social skills (Barkley, 1990). These children often need constant supervision and they experience more frequent and sometimes more harsh discipline than peers (Hechtman, 1996; Stormont-Spurgin, 1995), causing self-esteem, confidence, and acceptance of rules to erode during preschool years when ADHD symptoms are moderate or severe (Sonuga-Barke, 1994). Once children reach school age, inattention,

hyperactivity and impulsivity interfere with demands of structured classroom settings, learning rules of social interaction and reciprocity in relationships (Atkins & Pelham, 1991; Cantwell, 1996). Academic work and social tasks not mastered during elementary years leave the adolescent with ADHD ill equipped to meet the challenges of adolescence (Biederman, et al., 1996b; Fischer, Barkley, Fletcher, & Smallish, 1993).

Some researchers view ADHD as an extreme variation in normal development and behavior (Gingerich, Turnock, Litfin, & Rosen, 1998; Taylor, 1995). These proponents do not discount the evidence of radiographic imaging associated with ADHD, but interpret the findings along a broad continuum. They argue that many persons with ADHD characteristics function well and do not deserve the stigmatizing label and stress associated with this diagnosis (Levine, 1992). Instead, they emphasize the importance of identifying strengths and limitations that affect daily life, capitalizing on the strengths of individuals and compensating for or mitigating the limitations imposed by ADHD (Coleman & Levine, 1988). Proponents of ADHD as a developmental variation do not hesitate to acknowledge, however, that there are those who suffer with the disorder to a much greater degree and they would consider those individuals as affected beyond "normal variation" at the extreme end of the continuum, often warranting the diagnosis of ADHD so as to receive adequate services to manage their symptoms.

Adolescent development and ADHD

Adolescence is the developmental stage of identity vs. role confusion and when teens emotionally separate from their family of origin in preparation for beginning their own nuclear family (Erikson, 1963; Havighurst, 1972). Cognitively, adolescents become able to think abstractly, solve complex problems, and mentally manipulate and synthesize

larger sets of information. Many teens develop abilities in music, athletics, and academics that provide sources for self esteem, recognition of peers and adults, and skills for adulthood. Normal adolescent development includes risk taking and rebellion to differing degrees. ADHD affects the nature of and timing of adolescent development.

Characteristics of ADHD, inattention, distractibility, impulsivity, and hyperactivity, can exacerbate "normal" teenage risk-taking and rebellion and put adolescents at higher risk than their peers for negative experiences during adolescence. Of adolescents with ADHD, 25-35% underachieve or fail in school, 75% experience more interpersonal problems than peers, 28% also were diagnosed with conduct disorder, 73% displayed oppositional behavior (Biederman, Faraone, Milberger, Jetton, Chen, Mick, Greene, & Russell, 1996a), and 50% have involvement with police (Barkley, 1990). Goldstein (1997) reported 39% of 16-23 year olds with ADHD had been arrested, 28% had been convicted of a crime, and 9% had been incarcerated.

Cantwell (1996) and Fischer, Barkley, Fletcher, & Smallish (1993) indicated that youth with ADHD are at higher risk than non-ADHD youth for creating teen pregnancy. Teens with ADHD are at higher risk than non-ADHD youth for motor vehicle accidents (Barkley, Guevremont, Anastopoulos, DuPaul, & Shelton, 1993; Barkley, Murphy, & Kwasnik, 1996); substance abuse (Horner & Scheibe, 1997; Martin, Earlywine, Blackson, Vanyukov, Moss & Tarter, 1994; Schubiner, Tzelepis, Isaacson, Warbasse, Zacharck, & Musial, 1995); depression and anxiety (Biederman, Faraone, Mick, Moore, & Lelon, 1996; Biederman, Mick, & Faraone, 1998), and school failure (Barkley, 1990; Hinshaw, 1992b), all serious social problems which often extend into adulthood. Poor school performance and social difficulties in an adolescent with ADHD was identified as

a significant precursor to underemployment, unsatisfactory personal relationships and antisocial behavior in adulthood, with only 11% having no psychiatric problems as adults (Barkley, 1990; Barkley, Fischer, Edelbrock & Smallish, 1990; Biederman, 1998; Hinshaw, 1992a, 1992b).

Each of these negative adolescent experiences tends to disrupt family life and increase stress in family members (Anastoupolos, Guevremont, Shelton, & DuPaul, 1992; Kendall, 1998; Lewis, 1992; Lewis-Abney, 1993). Increased family conflict interferes with a teen's ability to emotionally separate from his or her family of origin. Delayed development often leaves teens dependent on their family of origin beyond high school years (Barkley, Fischer, Edelbrock, & Smallish, 1991).

Conversely, adolescents who succeed academically, participate in athletics and extra curricular activities are less likely to be underemployed, socially isolated, or in trouble with the law (Biederman, Mick, & Faraone, 1998; Biederman, et al., 1996b). Clearly, there is a social mandate to intensify efforts to better understand this disorder in order to intervene more effectively with adolescents and their families before further morbidity and social difficulty occur. This study sought to understand adolescent development and ADHD as it related to school performance during middle and high school years.

In this section, literature related to ADHD was reviewed. ADHD is a behavioral disorder that affects approximately 3-5% of all children. Primary features of the condition include inattention, distractibility, impulsivity, and hyperactivity. Frequently, those with ADHD are diagnosed with other conditions such as depression, anxiety, oppositional defiant disorder, conduct disorder, Tourette's syndrome, and learning

disabilities. In addition, symptoms of ADHD are sometimes confused with those associated with abuse, trauma, loss, neglect, and congenital exposure to alcohol, drugs, and other toxins. ADHD is a developmental disorder that often interferes with normal adolescent development and puts teens who have ADHD at greater risk for negative outcomes than peers without ADHD. These negative experiences disrupt family life and increase stress for all family members. The next section will focus on research regarding ADHD and families.

Literature Related to Family

Development within Families

The family is an integral part of society. Human development unfolds within families where children are born, reared, and prepared for adulthood (Duvall & Miller, 1985; Hanson & Boyd, 1996). Developmental tasks for the adolescent stage include achievement of mature relationships with peers, establishment of a firm identity and a masculine or feminine social role, establishment and practice of an internal ethical system to guide social behavior, achievement of emotional independence of parents, and preparation for a career, marriage, and family of one's own (Erikson, 1963; Havighurst, 1972). Difficulty in future stages is encountered when previous developmental tasks are not met in previous stages. Parental tasks which facilitate adolescent development include loosening family ties; maintaining the couple relationship, parent-adolescent communication, and family moral standards; addressing risk behaviors associated with adolescence; and promoting success in school and social life (Aldous, 1996).

Chronic Health Problems and Families

Chronic health problems refer to illnesses, diseases, and conditions that do not

resolve within an anticipated time frame and cause prolonged impairment to normal functioning, in contrast to an acute illness that "runs its course". Although the terms "illness", "disease", "disorder", and "condition" frequently are used interchangeably, there are subtle distinctions. Illness and disease often refer to being sick; chronic illnesses and diseases are those where symptoms wax and wane, as in asthma, heart disease, and cancer. People look and act "sick" when the symptoms flare up. A "condition" refers to an alteration in health usually not associated with being sick. "Condition" is often used interchangeably with "disorder". Many "conditions" and "disorders" are not readily apparent as with an illness, or recognizable by a physical deformity or defect. ADHD is such a condition; that is, without a visible deformity, scar, or corrective appliance to alert observers to its presence.

Normal family functions and accomplishment of developmental tasks are impacted by chronic conditions, and significant adjustments must be made by families to accommodate chronic conditions (Deatrick & Knafl, 1990; Gedaly-Duff, Stoeger, & Shelton, 2000). Families of children and adolescents with chronic conditions are expected to perform normal family functions, learn how to manage the chronic condition, and live with the constant change, uncertainty, and additional caregiving tasks that are associated with chronic conditions (Corbin & Strauss, 1988).

Family Management Styles

Knafl, Breitmayer, Gallo, and Zoeller (1996) studied how families define and manage a child's chronic illness. Thematic analysis of qualitative data yielded two main categories: defining themes and managing themes. "Defining themes" related to how family members viewed the child, the illness, the parenting philosophy, and the nature of

the work associated with caring for a child with a chronic illness. "Managing themes" described the division of labor, the approach to illness management, and role satisfaction. Defining and managing themes in combination determined how families managed their child's chronic illness. Five specific family management styles of a child's chronic illness were identified: thriving, accommodative, enduring, struggling, and floundering.

Families of Adolescents with ADHD

There is little doubt that ADHD has a profound effect on family life. Parenting children and adolescents with ADHD is difficult and stressful. Children with ADHD exert a more powerful and more stressful effect on their family than do children without ADHD (Lewis, 1992). They often need constant supervision, mature more slowly, and become responsible for their own appropriate behavior at a later age than peers without ADHD (Barkley, Fischer, Edelbrock & Smallish, 1990, 1991). There is considerable research to support the bi-directional influence between child behaviors and parenting behaviors that continues throughout the childrearing years (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Anderson, Hinshaw, & Simmel, 1994; Breen & Barkley, 1988; Donenberg & Baker, 1993).

Parents have reported feeling blamed by extended family and friends as ineffectual when their children (Donenberg & Baker, 1993) and teenagers (Kendall, 1998) displayed ADHD behaviors. Many parents feel incompetent when dealing with professionals. Shelton (1995) studied the information and advice parents of children with ADHD wanted from their primary care provider. Qualitative data analysis indicated that parents wanted physicians to be supportive rather than critical of their parenting efforts and treat them with compassion.

Two studies indicated that prolonged stress and family dysfunction are related. Donenberg and Baker (1993) found that parental stress and family dysfunction result as a cumulative process over time when children exhibited externalizing behaviors. Kendall (1998) described a cycle where parents found themselves wearing out in the repetitive process of becoming discouraged, recharging to advocate and intervene once again for their child, only to find themselves burned out by the ongoing demands created by ADHD behavior that affected home and school life. Needs of other family members went unmet as time and energy were focused on the child or adolescent with ADHD and siblings without ADHD were frequently victims of the aggression and impulsivity of the child with ADHD (Kendall, 1999b).

In some cases, deleterious coping strategies were used by parents to alleviate their stress (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Breen & Barkley, 1988; Pelham, Lang, Atkeson, Murphy, Gnagy, & Greiner, 1997). Maternal depression and increased parental consumption of alcohol have been linked to increased stress resulting from parenting children with ADHD. Pelham et al., (1998) studied parents of boys with ADHD and found that in families with a positive history of alcohol use, alcohol consumption increased after negative interactions with boys displaying behaviors associated with ADHD, ODD, and CD. McCormick (1995) found a strong association between maternal depression and presence of a child with ADHD in the family. He concluded there is a need for primary care providers to routinely screen for maternal depression when a child is diagnosed with ADHD.

The range of family problems which result when a child or adolescent has ADHD includes negative parent-child interactions, increased stress, decreased coping, and

decreased family functioning (Anastopoulos, Shelton, DuPaul, & Guevremont, 1992; 1993; Anderson, Hinshaw, & Simmel, 1994; Barkley, Anastopoulos, et al, 1991, 1992; Barkley, Fischer, Edelbrock, & Smallish, 1991; Breen & Barkley, 1988; Brody, Stoneman, & Gauger, 1996; Gomez, 1994). These studies together identified several interactive factors that contribute to family stress and dysfunction: socioeconomic status, marital discord, parental psychopathology, age of the child, severity of ADHD symptoms in the child and other family stressors. Lewis-Abney (1993) found that severity of symptoms of ADHD and increasing age of the child with ADHD correlated with decreased family functioning and increased parental stress. Hechtman (1991) and Kendall (1998) reported that parent-child interactions and the emotional climate of the home became more negative during adolescence, and then improved when the young adult with ADHD left home.

Rutter (1975; 1977), in the classic Isle of Wight study, identified six risk factors within the family environment that correlated with childhood psychiatric problems: severe marital discord, low social class, large family size, paternal criminal history, maternal mental disorder, and foster placement. Biederman, et al. (1995) tested Rutter's six risk factors within the family environment with ADHD families. Findings revealed a positive association among Rutter's risk factors, risk for ADHD, and comorbid conditions. Both studies (Biederman, et al., 1995; Rutter, 1975, 1977) emphasized that the presence of a single risk factor does not predict psychiatric problems, rather the risk of poor outcomes increases with two or more risk factors. These studies are congruent with the findings of Donenberg & Baker (1993) regarding the cumulative effects of ADHD on families.

There is very little research on how families with ADHD manage the disorder successfully. Kendall set out to study how families do well when a child has ADHD. Participants in her study repeatedly stated they were not doing well (personal communication, 1998), although indicators such as socioeconomic status, marital status, and educational attainment of parents suggested an apparent level of family function. Instead, families reported that ADHD negatively impacted the family experience at home and with school.

To summarize, families are the social unit where children grow and develop skills to become productive members of society. Chronic conditions often negatively impact development and create stress on family members. ADHD, as a chronic condition, has a profound, often deleterious effect on family functioning. In the next section, literature related to ADHD and schools will be reviewed.

Literature Related to School

School is the central activity of children between 5-18 years of age; it is where factual information, thinking and communication skills, and socially acceptable behavioral skills are learned and practiced in preparation for a satisfying and productive adult life. Positive experiences at school are essential to a child's self esteem and ability to achieve mastery academically and socially. Furthermore, academic success is a predictor of a student's economic and social future (Barkley, Fischer, Edelbrock, & Smallish, 1990). Low self-esteem is one consequence of academic underachievement for the student with ADHD that is regularly reinforced by poor report cards (Kelly & Aylward, 1992; Levine, 1994). A second significant consequence is noted when ADHD students become less able to compensate for deficiencies in each successive grade until

failure in basic subjects begins to occur, particularly in middle school (Barkley, 1990; Levine, 1994).

ADHD Effects on Learning

ADHD directly impacts a student's ability to achieve academically (Levine, 1994; Faraone, et al., 1993b; Hinshaw, 1992a, 1992b). Inattention and distractibility prevent the student from gathering, processing, synthesizing and applying information presented for learning (Barkley, 1997). Distractibility interferes with thinking skills and memory retrieval; overactivity and impulsivity is disruptive to classroom activities (Barkley, 1990). Adolescents with ADHD often have difficulty distinguishing salient features from less significant detail and they suffer with problems of organizing thinking, prioritizing tasks and allocating time, which are essential skills in middle and high school (Cantwell, 1996; Levine, 1992). Failure to complete homework becomes a hallmark of the disorder (Weiss & Hechtman, 1994).

These descriptive characteristics of ADHD effects on learning correlate with Barkley's (1997) model of disinhibition (Figure 3). A poor working memory and delayed internalization of speech contribute to decreased ability to manage time, and impaired reading comprehension. Poor reading comprehension puts students at risk for underachievement or school failure. Immature motor control leads to hyperactivity, and the inability to make smooth transitions between classes and school activities or participate in quiet social activities at school. Deficits with internal locus of control contributes to difficulty delaying gratification, impulsivity, and the persistence of egocentricity, all of which often are associated with behavior problems at school.

With or without behavior problems in the classroom, many students with ADHD

have failed to master essential basic skills in reading, writing and math; 25-35% have experienced grade retention (Barkley, 1990). Remediation is necessary and discouraging to the student with ADHD; academic underachievement or failure may occur or students drop out of school completely (Levine, 1994). Barkley (1990) reported that 90% of students with ADHD were unable to produce the expected volume of school work, that 25-35% had learning disabilities, and 35% failed to finish high school. These problems are significant because dropping out of school often precludes adequate employment opportunities, and it denies the student of the social learning opportunities essential for satisfying personal and social relationships in adolescence and into adulthood.

The consequences of adult ADHD extend to all of society. Adults with ADHD are less productive in the work force, they consume costly social services, they perpetuate the cycle of academic underachievement and sub-optimal family functioning when inadequately prepared to parent their own children. They may pass on the genetic predisposition for ADHD without mastering the life skills necessary to mitigate the effects of ADHD on daily living (Weiss & Hechtman, 1994; 1986).

School Law and Students with Disabilities

Three federal statutes provide students with special education services and protection of civil rights accorded to persons with disabilities: the Individuals with Disabilities Education Act, or IDEA (Public Law 99-476); Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112); and the Americans with Disabilities Act, known as ADA (Public Law 101-336). Each of these statutes recognizes ADHD as a disabling condition. The Rehabilitation Act and the ADA are civil rights statutes that prevent discrimination against participation in public school based on disability. IDEA

requires schools to provide special education services to students with disabilities. Each law as it relates to students with ADHD will be discussed next.

The Rehabilitation Act of 1973, Section 504, provided that no "otherwise qualified handicapped individual" be excluded from participation in programs and activities receiving federal funding, including schooling. "Handicapped" in this statute was defined as having a mental or physical impairment that substantially limited one more major life activities, and ADHD was included within this definition. This civil rights law protected students' right to participate in public education. While schools are required to provide accommodations for children with disabilities under this Act, no funding is attached because this law does not require special education be provided. It merely provides the right to participate in public schooling. ADHD students who do not require special education services but who need other accommodations necessary for their participation in school have an educational plan written annually called a "Section 504" plan, in reference to this Act.

The Americans with Disabilities Act (Public Law 101-336) is another federal civil rights statute aimed at eliminating discrimination against disabled persons. The definition of "disability" in this Act is identical to that in the Rehabilitation Act of 1973 and prohibits denial of the right to participate in school based on disability. Most students who require special accommodations in the classroom (for example, extra time to complete tests) but not special educational services are served under the Rehabilitation Act of 1973, Section 504 rather than under the ADA. However, ADHD students with severe behavior problems cannot be denied the right to attend public schools based on their behavioral disability; protections under the ADA (rather than Section 504 of the

Rehabilitation Act) are usually invoked in these situations. Like its predecessor, the Rehabilitation Act of 1973, there is no funding for schools attached to the ADA and students do not receive "special education" services under this Act.

In 1975, Congress passed the Education for All Handicapped Children Act (Public Law 99-142) that did provide for special education services, referred to as "free and appropriate public education" in the Act. Funding was appropriated by this Act to help school districts pay for the special education costs. Thus, this statute required all schools to provide special education to disabled students who needed it. In 1990, the law was expanded and renamed The Individuals with Disabilities Education Act, also known as IDEA, (Public Law 101-476). Amendments to IDEA were passed in 1997 (Public Law 105-17) which included a stronger mandate for parent participation in educational decision making about their children through the individualized educational plan (IEP) process than the original Act.

Adolescents with ADHD qualify for special education services under IDEA in one of three categories of disability: severe emotional disturbance, specific learning disabilities, and "other health impairments". Students with only ADHD fit in the IDEA category, "other health impairments", however, students with comorbid conditions often qualify within the "severe emotionally disabled" or "learning disability" categories, depending on severity of ADHD symptoms and the presence of comorbid conditions. Those who qualify for IDEA must have an individualized educational plan (IEP) developed jointly by school personnel and parents to plan, implement, and evaluate the special education services plan to facilitate success in school for the adolescent with ADHD.

Family-School Connections

Most professionals agree that both home and school are involved in socializing and educating children. Family-school connections are important for all students as evidenced by studies linking parent involvement and school performance. Stevenson & Baker (1987) studied the family-school relationship and the child's school performance. The sample included 179 children, parents, and teachers from a large national database. Results indicated a positive relationship between parent involvement and school performance. Mothers with higher educational levels demonstrated higher levels of parent involvement, and involvement tended to be greater with younger children than older children.

In a more recent study, Grolnick & Slowiaczek (1994) studied relationships among academic achievement as measured by report card grades and three types of parent involvement with school: behavioral, personal, and cognitive/intellectual. Behavioral involvement included overt things parents do that are visible to the child and school personnel, as in attending open house and volunteering at school. Personal parental involvement included conveying positive feelings about school and the child, discussing school frequently and positively, and encouraging the child when doing schoolwork at home. Cognitive/intellectual parental involvement included providing stimulating educational experiences at home through books, visits to museums, reading together, etc. Results indicated that parent involvement in early elementary grades affected the child's motivation to learn, and that later in school, parent involvement and the student's own internalized motivation interactively fueled school performance.

Epstein and Lee (1995) reported on national patterns of school and family

connections in the middle grades. Corroborating the work by Stevenson and Baker (1987), results of the Epstein and Lee (1995) study indicated that parent involvement diminished as children moved from elementary to middle school, despite the ongoing need for parent involvement regarding course selection and transition from school to the work force.

Models of family-school connections. Although there are many models of family-school connections, the common elements in each include a collaborative relationship among parents, school personnel, and the student (Kampwirth, 1999; Levine, 1994; Thomas, Correa, & Morsink, 1995). One model of family-school connections emerged from data collected from parents, students, and principals in the National Educational Longitudinal Study of 1988 (NELS:88). The model (Epstein & Lee, 1995) is composed of overlapping spheres of influence in a child's academic life: school, family, community, and peer group interactions. Each sphere can be moved closer to another to overlap or be pulled apart, depending on forces within each environment. The external structure of the spheres is affected by behaviors (reflections of philosophy, practices, and background characteristics of each sphere) and time (changes in students with each successive grade, and historical information). Internal structure of the model included interrelationships among participants in school, family, and communities who work in partnerships.

Types of parent involvement. The model (Epstein & Lee, 1995) also described six types of parent involvement, including practices initiated by parents or school, and practices that occur at home or at school. Type 1 parent involvement is the basic obligation families have for parenting and creating an environment that supports learning.

Type 2 involvement is the school's basic obligation to communicate with parents regarding student performance and school programs. Type 3 involvement consists of parent volunteer work and attendance at school functions. Type 4 involvement regards home-based learning activities, parent participation in homework, which informs parents about curriculum and subject mastery, and encouragement to learn. Type 5 involvement includes parents' participation in school decision-making through parent organizations, and school committees. Type 6 involvement is community collaboration designed to enhance family-school connections through accessing services available and developing additional community services related to school. Although configured differently, parent involvement types 1, 3, and 4 in this study are similar to the three types of parent involvement described above by Grolnick and Slowiaczek (1994).

Results from Epstein & Lee's (1995) analysis of the National Educational Longitudinal Study of 1988 (NELS:88) indicated that nearly all parents were involved in their children's education and participated most often in type one and type three involvement. Parents also reported participating in community activities but not necessarily activities related to school. Conversely, parents reported that schools rarely contacted them about type two, type five, and type six involvement, except for sending report cards and rare notices about school functions. This study suggests that parents most often initiate the family-school connection.

Parent Involvement as a National Education Goal

Parent involvement in school is one of the National Education Goals (National Education Goals Panel, 1994) and was included as a major emphasis by Congress in the 1997 Amendments to IDEA. The Act specifically stated that parents have rights to

consent, notification, participation in the decision-making about their child's education and in educational policy-making.

In response to the Congressional emphasis on parent involvement in the Amendments to IDEA, the Office of Special Education and Rehabilitative Services (OSERS), an agency within the U.S. Department of Education, devoted an entire section on parent involvement in its Twenty-first Annual Report to Congress (U. S. Department of Education, 1999) using a model of the parent involvement process (Hoover-Dempsey & Sandler, 1995) to discuss current status of parent involvement and future directions.

Hoover-Dempsey & Sandler (1997; 1995) identified factors that influence parent decisions to become involved at school, which included how parents view their role in their child's education, the parent's sense of efficacy in helping their child to succeed in school, and the parent's response to invitations and demands for involvement from either school personnel or their child. Specific behaviors of school personnel were found to enhance parent involvement: establishing an ongoing relationship with family members, education of teaching staff to facilitate parent involvement, teaching families about their rights as parents, and using specialized strategies to improve parent involvement. These strategies included improving communication, tapping parent expertise, and involving families in community-based educational interventions. Behaviors found to impede parent involvement included staff not appearing to listen to parents, failing to attend meetings with parents or leaving early; failing to solicit parent information, using technical jargon, and failing to respect cultural differences.

Parent involvement in school when students have an illness or disability

Family-school connections are more important when students have medical,

learning, and behavior problems (Kampwirth, 1999; Levine, 1994; Thomas, Correa, & Morsink, 1995). Parental involvement at school is required when students with chronic medical conditions need their parents and teachers to share information and develop strategies to manage the illness at school. Zoeller (1996) studied the school experience of families with chronically ill children with insulin-dependent diabetes to understand family-school relationships from the perspective of the family. Three family-school relationship styles emerged from the data, satisfactory, guarded, and unsatisfactory, based on parents' involvement with school. Of thirty-one families with a child with insulin-dependent diabetes who participated in the study, a majority (60-70%) indicated a satisfactory family-school relationship style. However, 30-40% of parents reported a guarded or unsatisfactory relationship with school, despite parent-initiated ongoing contact with school to share information on the child's condition, provide supplies, educate teachers to manage health needs during school hours, and solve problems.

Dyson (1986) investigated the experiences of nineteen families of children with learning disabilities regarding parental stress, family functioning, and sibling self-concept. Parents indicated three problematic experiences with school: the length of time schools took for recognition, assessment, and identification of the learning disability, additional costs incurred by the family for the assessment and tutoring, the child's own problems with school (skipping classes, suspension, low self esteem, trouble adapting to mainstreaming, behavioral problems); and concerns regarding their children's academic experiences (poor grades, lack of appropriate teaching materials, reduced teacher attention to student). Parent involvement in school in this study was indicated by parents' reports of spending more time and energy on the child with

learning disabilities. Results showed that parental satisfaction with their child's school experience was related to reports that the student was "doing well".

Parent Involvement in school when students have ADHD

In contrast to Grolnick and Slowiazcek's (1994) findings that parent involvement had a positive effect on student grades, Kendall (1998) and Shelton (1995) reported that children and adolescents with ADHD frequently experienced academic underachievement despite strong parent involvement. Parents of school-aged ADHD students reported that parenting activities related to homework (such as dealing with students bringing home assignments or losing or failing to turn in completed work) rated as "most problematic" compared to other parenting responsibilities (Shelton, 1995). Only problems related to daily routines rated of higher concern than school problems; problems regarding behaviors, socialization, eating, medication, sleeping and dressing all were rated of lesser concern than problems with school.

Kendall (1998) conducted a grounded theory study about how families do well when a child has ADHD. Instead of discovering successful strategies for dealing with ADHD, family members revealed seven types of disruptive behavior that negatively affected the family: aggression, "out of control" hyperactivity, social and emotional immaturity, learning problems and academic underachievement, family conflict, isolation and rejection by extended family, and negative peer interactions. However, the primary pattern of disruption caused by ADHD was the frequently unsuccessful attempt to get the child with ADHD to do something that needed to be accomplished. As children entered adolescence, problems related to school escalated. Students often avoided discussing school at home and resisted parental efforts to create educational opportunities at home;

homework was major source of family conflict. For teens, motivation to try harder diminished with each passing year and a pattern of negative reinforcements to self esteem and academic achievement was established (Kendall, 1998). For parents, a cyclic pattern of getting stuck, giving up, recharging, burning out and getting stuck again was reported. Parents continued to put effort into talking with teachers and trying new medication, but over time, the pattern of getting stuck and giving up became more serious regardless of the degree of parent involvement in school (Kendall, 1998).

In summary, there is evidence to support the idea that increased parental involvement at school leads to improved academic performance in students. For children and adolescents with medical conditions and learning disabilities, often parental involvement is increased with the focus on helping school personnel to manage the illness or disability while the child is at school. Two studies with families of children and adolescents with ADHD, however, indicated that although parents are involved with school, students did not perform well as a result. This study aimed to discover the processes involved in parent involvement in school and to understand why that, despite parent involvement, students with ADHD have great difficulty with school.

Need for this study

Much of the medical and psychological research about ADHD is on diagnosis and treatment, with the major focus on medication management and behavioral interventions (Cantwell, 1996; Greenhill, et al., 1996; Hechtman, 1993; Nathan, 1992). Professional education literature contains research about classroom management and teaching techniques for ADHD children. These studies address the primary symptoms of ADHD and seek to remediate the effects of inattention, distractibility, impulsivity and

hyperactivity at school.

Family studies about ADHD trace genetic transmission, family stress and coping, and longitudinal outcomes (Biederman, et al., 1992, 1996b; Faraone, et al., 1993a, 1993b, 1995). Few studies were found which produced a theoretical understanding of family interactions and processes. Kendall (1998) used grounded theory method to study the experience of families when a child had ADHD, and findings indicated that school was one of seven significant sources of family disruption. Since school is the major activity of children ages 5-18, many daily family activities center on getting children to and from school and helping them with homework and other school-related tasks. No research has addressed how families experience school when a teenager has ADHD, highlighting the need for this study.

Summary

ADHD is a chronic, neurobiological condition that is characterized by persistent behaviors of inattention, distractibility, impulsivity and hyperactivity. Review of the literature documented that ADHD is known to negatively impact family life, adolescent development, and academic achievement, with significant negative costs for individuals, families and society. Research has focused primarily on diagnosis and treatment and secondarily on behavior management, educational strategies, and assessment of family functioning. There is no research specifically focusing on the family experience with school when an adolescent has ADHD. The purpose of this study was to generate a theoretical understanding of the family experience with school from the perspective of the parents and adolescent with ADHD. Findings can be used to plan interventions aimed at alleviating family disruption and facilitating social, emotional, and academic

competency in adolescents with ADHD.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

Grounded theory methodology was chosen for this study to generate a theoretical explanation of the family experience with school when an adolescent has ADHD. In this chapter, an overview of the methodology is presented, the historical and conceptual underpinnings of grounded theory will be discussed and variations of grounded theory methods will be compared. In addition, the rationale for selecting grounded theory for this study will be presented.

Overview of the Methodology

Grounded theory method is one approach to the study of human behavior and group life. It produces a theory developed inductively from data rather than deductively from pre-existent knowledge or theory (Glaser & Strauss, 1967). It is called grounded theory because all aspects of the final product are "grounded" in data, and although now in abstracted form, each part of the model can be traced back to specific instances of data. The philosophical roots of grounded theory come from symbolic interactionism, a perspective in which society is viewed as a complex system of interactions and processes about which individuals attribute personal meaning and construct social behavior (Blumer, 1969). Thus, grounded theory provides an in-depth description of a substantive area of social life and establishes relationships among concepts that offer theoretical explanation of complex social phenomena.

Historical Underpinnings of Grounded Theory

At the beginning of the 20th century, science was dominated by the positivists who held the philosophical position that there was a "reality" which existed and could be

known. Its aim was to produce explanation, prediction and control of the world in which humans lived. Physical and life sciences were the primary focus of investigation. Psychology was of great interest; most psychological research was based on biological models and employed laboratory methods used by animal scientists.

The positivists thought that objects of study and investigator were independent entities and that objects could be studied without being influenced by the investigator. They characterized science as unidirectional when the values and biases of the investigator were controlled by using rigorous procedures of research. Similar findings from replicated studies indicated findings to be "true" (Denzin & Lincoln, 1994).

The positivist view became modified as scientists grappled with criticism of positivistic "truth" claims and the intuitive conflict between rigid laboratory methodology and its applicability to the study of human behavior and social life. Therefore, post-positivists emerged with a somewhat tempered view that still aimed for explanation, prediction, and control through science, but claimed that hypotheses that were not proved false were "probable" facts or laws. This modified paradigm acknowledged that "reality" could be known only imperfectly. Those who subscribed to this tempered view of truth and reality were called contemporary empiricists. They recognized that using quantitative, experimental designs were not the most suitable methods for social science when researching topics not easily reduced to quantifiable dimensions (Denzin & Lincoln, 1994; Kegley, 1995).

Rapid change and deep social upheaval from the historical and economic realities of World War I and The Great Depression resulted in a need to develop sensitive research methods for use by academic scholars attempting to understand the current social

experience (Appleby, Hunt, & Jacob, 1994). Pragmatism, a philosophical movement most influential between the two world wars in Europe and America, offered scholars a perspective for understanding complex social phenomena (Shalin, 1986). Pragmatists emphasized that meaning and truth of any idea were functions related to its practical outcome; truth was what worked to solve problems and explain reality (Hoibraaten, 1991). Pragmatists rejected the notion of a single, knowable "reality" and simplistic, cause and effect explanations of social phenomena. Instead, Pragmatists promoted a view of pluralistic realities based on the meanings that people ascribe to particular situations (Kasper, 1995). The American Pragmatist Movement in the United States became closely associated with the emergence of the "Chicago School" of Sociology in the early 1920's. Scholars who held this view at the newly established Department of Sociology at the University of Chicago included Charles Horton Cooley, W. I. Thomas, John Dewey, George Herbert Mead, and Herbert Blumer. Blumer (1969) is credited with coining the term "symbolic interactionism" to describe what now is both a theoretical perspective on human society and a basis for methodological investigation of social phenomena, reflective of the pragmatist philosophical perspective.

The teachings of symbolic interactionism initially were an oral tradition, not committed to writing by the scholars themselves, but by students of the professors at the Chicago School. Two such students contributed works now considered classics in symbolic interactionism. Charles W. Morris (Mead, 1934) edited notes of many students to produce Mind, Self, & Society: The Works of George Herbert Mead (Mead, 1934). Blumer (1969) compiled a collection of his own essays and articles previously published between 1937 through 1959 into a single work describing symbolic interactionism as

both perspective and method that were useful for the study of social science. Grounded theory would be one of the methods to emerge to meet Blumer's challenge to develop research methods incorporating the symbolic interactionist perspective.

Conceptual Underpinnings of Symbolic Interactionism

A core assumption within symbolic interactionism is that human beings are thinking, acting, and creating individuals who respond to actions of others through a process of interpreting behavior of other humans (Blumer, 1969). Symbolic interactionists incorporated the idea of a person interacting with the self as the mediating activity in human behavior and group life (Mead, 1934).

There are three basic tenets of symbolic interactionism: 1) human beings act toward things (objects, people, ideas, situations, etc.) on the basis of the meanings that things have for them; 2) the meaning of such things is derived from, or arises out of, social interactions; and 3) these meanings are handled in and modified through an interpretive process used by the person in dealing with things he or she encounters (Blumer, 1969). These basic assumptions addressed the core of human behavior and social life and provided a mechanism for understanding the complexity of individual behaviors and group interactions. This is important because unlike physical and biological science which are governed by law-like regularity, human behavior and social life are comprised of infinite variety generated by the human interpretive process and the meanings ascribed to each human interaction. The basic assumptions of symbolic interactionism accounts for the complexity of social relationships.

Symbolic interactionism also contains concepts that are useful in understanding human behavior and social life. In particular, the notion of self is central to symbolic

interactionism. Cooley (1902) first described "the looking glass self" and characterized it as the ability of one to take the role of another. Mead (1934) extended this notion of self to include the ability to see oneself from the perspective of a particular "other", meaning a particular individual, and a "generalized other", the symbol of society and social values of group life. This consciousness of self and others takes place in the mind, where symbols are constructed, interpreted, and modified (Mead, 1934). This understanding of the "self" explains how one relates to self and others within oneself.

In contrast, the way one relates to another person or group is called "joint action", the interaction between groups and individuals which make up social acts (Blumer, 1969). Blumer (1969) described joint action as "the fitting together of the lines of behavior of the separate participants" (p. 70) and states that the life of a society constitutes the whole of joint actions. Joint actions are the result of the ongoing process whereby individuals assign meaning to symbols; act in response to those meanings; then observe and interpret the actions or symbols presented by others, assign new, different, or further meaning. They act again in response to further interpretation and interaction with the "self", but this time, act not only to the personal meaning constructed within the "self", but in "joint action" with another individual or group.

Two other essential concepts within the symbolic interactionism perspective are socialization and definition of the situation (Klein & White, 1996). "Socialization" is the process by which meanings of symbols are transmitted, learned, and understood; initially this occurs within the context of the family as development unfolds for all family members across the lifespan. After childhood, socialization still occurs within the family but is also influenced by the wider social context. When seeking understanding about

meanings attributed to symbols in a person's life, it is necessary to consider not only the meanings that were taught and learned within the family, but also the processes and context used to transmit such meanings. "Definition of the situation" refers to how perception of reality impacts human behavior (Mead, 1934, Klein & White, 1996). This concept helps account for meanings that are incongruent with others' reality, or the "obdurate world" (Blumer, 1969) which exist outside of, and apart from, individuals' perceptions.

Thus, symbolic interactionism provides a philosophical and conceptual basis for the study of group life and human behavior. Grounded theory was developed to generate theory of substantive social phenomena and was philosophically congruent with the basic tenets of symbolic interactionism, incorporating the concepts of mind, self, socialization, and the definition of the situation into the methodology.

History and development of grounded theory

Barney Glaser, a demographer who studied at Columbia University, was trained in quantitative methods but became attracted to the rich contextual knowledge produced by the emerging qualitative methods lodged in the interpretive paradigm of scientific inquiry. Anselm Strauss was trained as a sociologist at the University of Chicago where he had been influenced by Herbert Blumer. Strauss moved to the University of Indiana to teach and conduct qualitative research (Strauss, 1965); here he worked with Leonard Schatzman (Strauss, Bucher, Ehrlich, Schatzman, & Sabshin, 1964). In 1964, Strauss and Glaser were invited by Dean Helen Nahm at University of California San Francisco School of Nursing to promote the use of qualitative research by nurses. Schatzman later joined them at UCSF. His area of expertise was field research (Schatzman & Strauss,

1973). All three colleagues worked together at UCSF, collaborated on books (Glaser & Strauss, 1967; Schatzman & Strauss, 1973), facilitated graduate qualitative methods seminars and served on dissertation committees.

Glaser and Strauss published The Discovery of Grounded Theory in 1967 and both men used the method in their own research (Glaser & Strauss, 1964; 1965) and while mentoring graduate nursing students. As interest in the method grew, so did the need for further explication of the method. Glaser responded by publishing Theoretical Sensitivity in 1978 wherein he emphasized the need for the theory to emerge from the data by remaining sensitive during data collection and analysis. Strauss later published Qualitative Analysis for Social Scientists in 1987.

Supporters of grounded theory requested more detailed information about processes and procedures to instill confidence in the investigator and rigor in the method. Critics of the method cited the lack of clearly articulated procedures as a primary weakness and challenged grounded theorists to clarify their analytic strategies (Sandelowski, 1986; Lincoln & Guba, 1986). In response to both the critics and supporters, several publications provided an ongoing dialogue about the purpose and procedures of grounded theory. Strauss and Corbin, a colleague of Strauss at UCSF, wrote Basics of Qualitative Research: Grounded Theory Procedures and Techniques in 1990. Schatzman (1991) published an essay describing dimensional analysis, a similar qualitative method resulting in a grounded theory, which Schatzman developed as a result of mentoring students struggling with qualitative data analysis. Glaser (1992) responded to Strauss and Corbin's 1990 book with Basics of Grounded Theory Analysis to further the discussion and development of grounded theory methods. By the mid-1990's, it

became apparent to supporters and critics alike that variations of grounded theory were emerging to address a variety of research questions and philosophical perspectives regarding the study of human behavior and group life.

The Variations of Grounded Theory

There are three main variations of grounded theory method: the traditional method as originally described by Glaser & Strauss (1967), an adaptation developed by Strauss and Corbin (1990), and dimensional analysis which was developed by Leonard Schatzman (Schatzman, 1991). Variations of grounded theory arose as Glaser, Strauss, Schatzman, and Corbin mentored students in the use of grounded theory for different kinds of research projects that required clarification of existing procedures or the development of additional analytic strategies (Glaser, 1992, 1994; Schatzman, 1991; Stern, 1994; Strauss & Corbin, 1990;). In addition, the philosophical perspectives of the developers of grounded theory changed over time and are reflected in variations that now exist. Each variation has strengths and is applicable to particular types of research questions (Annells, 1997; Robrecht, 1995) and analytic challenges (Kendall, 1997).

Traditional grounded theory. Traditional grounded theory is best described in the original work by Glaser and Strauss (1967) and subsequent writings of Glaser (1978, 1992). In addition to his writings about the method, Glaser collected the works of others and published examples of traditional grounded theory to further illustrate the method (Glaser, 1993, 1994, 1995). According to Glaser (1992), the hallmark of traditional grounded theory is the belief that the theoretical understanding of a phenomenon will emerge as abstraction of ideas occurs to the researcher. Analytic strategies called theoretical sensitivity, theoretical saturation and theoretical memoing will produce a

theory that is relevant, grounded ("fits" the data) and "works" to explain the phenomenon of interest (Glaser, 1978; 1992).

The research question in a qualitative study represents a general area of interest or concern to the researcher or to a group of participants. The goal of traditional grounded theory is to discover the basic social process that is of primary interest or concern to the participants (Glaser & Strauss, 1967). Initial interviewing of participants begins with broad, open-ended questions, which become more focused as results of early data analysis indicate what is relevant. Use of the literature is reserved for later in the research process to reduce preconceived understanding.

Reiterative data collection and data analysis are used during the data expansion phase of traditional grounded theory. Coding instances of data is the first step in conceptualization and theorizing. Initially, coding includes the naming of ideas generated by the data and by comparison with other data. Comparisons are made between separate segments of data (which then are coded conceptually), between segments of data and concepts or codes, and between concepts as the theory emerges from the data (Glaser, 1978). Codes provide an abstract, distilled description of a phenomenon. The coding process is more than just a labeling task; it is a vehicle for theoretical sensitivity when ideas occur to the researcher as the data are analyzed.

Open coding is the process by which the researcher labels what the data indicates and what is happening in the data. This process quickly moving from beyond mere labeling to more fully describing the aspects suggested by the codes: the dimensions, properties, variations, etc. Open coding also verifies and saturates individual codes through constant comparison of data, and categories (clusters of codes) emerge.

Theoretical relationships among codes may be discovered by using the "families of codes" (Glaser, 1978) that aid the researcher in densifying the categories in preparation for selective coding. Selective coding is the search for a core category that best explains the data. Each level of coding becomes more abstract. Finally, a core category is selected during the data limitation phase that is central to the problem, related to almost all of the other categories, it recurs frequently in the data, and is completely variable. The core category represents the main concern of the participants and the attendant basic social process. The core category is then centralized in the writing of the traditional grounded theory.

Glaser defined basic social processes as "theoretical reflections and summarizations of the patterned, systematic uniformity flows of social life which people go through, and which can be conceptually 'captured' and further understood by the construction of basic social processes theories (Glaser, 1978, p.100). These processes occur over time and change over time. Frequently, basic social processes address the solution to the concerns of the participants. Therefore, a grounded theory helps to explain and interpret social phenomena and provides a transcendent view of related, individual instances, which would unlikely be understood in isolation.

Theoretical sensitivity is both an analytical process and a personal quality developed in the grounded theorist. The process refers to the activity of data analysis during which the researcher takes a particular instance of data and renders it as a theoretical notion by comparison with other data and by employing analytic strategies of theoretical sampling and theoretical memoing. The quality in the researcher refers to the personal ability to be open and flexible as ideas occur during coding activity and

comparative analysis. It is assumed that theoretical sensitivity increases in both aspects as the research project proceeds.

Theoretical sampling is the analytic strategy used during data collection and analysis to determine what data to collect next and where such data might be found. The process of theoretical sampling is guided by the emerging theory from the data rather than from a preconceived plan suggested by the literature or some other logic. According to Glaser and Strauss (1967), the basic questions in theoretical sampling are what groups does one turn to next for data collection and for what purpose? The answers to these questions provide direction for next round of data collection. Theoretical saturation is the point in data collection and analysis where no new information is forthcoming and the properties of categories appear complete, even after deliberate sampling attempts to fully explore the properties by using comparison groups yield nothing new.

Theoretical memoing is the recording of decisions made about data collection and analysis and to track the thinking and development of the grounded theory. Using techniques of theoretical sampling and memoing, a conceptual understanding arises. Theoretical memoing also contributes to the evaluative process by which a grounded theory is judged. Criteria for the critique of a grounded theory includes an assessment of its relevance and fit with the data, its ability to explain what has happened, and its interpretation of the data, or how the theory "works" (Glaser & Strauss, 1967), and its ability to be modified over time (Glaser, 1978).

Strauss and Corbin Variation. A variation of traditional grounded theory has been developed by Strauss and Corbin that resulted in their book, Basics of Qualitative Research (1990). Their aim was to provide basic information and procedures to those

new to qualitative research. They clarified meanings of terms and developed several analytic procedures to demystify the emergence of theory from data: axial coding and the use of a paradigm model.

Coding is the act of analyzing data. In this variation, open coding is the process of breaking down data into "bits", comparing it to other "bits", conceptualizing and categorizing these "bits". Concepts are conceptual labels named by the researcher to describe discrete instances of the phenomenon. Categories are classes of concepts that emerge through comparing one code with another to look for similarities or variation. They represent more highly abstract ideas. Categories include codes describing properties (attributes) and dimensions (location of properties along a continuum) of concepts.

Axial coding occurs during the data limitation phase and involves making connections between categories and their subcategories. Axial coding involves specifying the conditions, context, actions, and consequences (subcategories) of a category about a phenomenon. This process uses the Paradigm Model that serves as a structural process to link subcategories. Its purpose is to help the researcher think systematically about the data and to see complex relationships.

Paradigm model

Conditions → Phenomenon → Context → Intervening conditions →

Action/Interaction strategies → Consequences

An additional procedural strategy called the conditional matrix is an analytic aid to distinguish and link levels of conditions and consequences within the paradigm model.

This model of concentric circles locates the level of social interaction along the individual-social continuum (i.e., interpersonal interaction vs. community or national level of interaction) and can be used to designate specific conditions about a particular phenomenon and help define the scope of the grounded theory.

Selective coding is the process of selecting the core category or the central phenomenon that serves to integrate all other categories. There are five steps used in selective coding: 1) explicating the story line, 2) relating subsidiary categories around the core category, 3) relating categories at the dimensional level, 4) validating the relationships against the data, and 5) filling in categories needed to refine or fully develop the theory.

In step one, the story is dense description of the phenomenon, now called the core category. The story line is a conceptual explanation of the story. Relationships in steps two and three result from the use of the paradigm model. Step four consists of writing statements of relationships and then returning to data for validation and illustration. Step five reviews the overall theoretical relationships and returns to data or seeks specific new data to complete conceptual density and specificity. The final product of this version is a written grounded theory about the social phenomenon explained in terms of the core category. This study was based on the Strauss and Corbin method of grounded theory (Strauss & Corbin, 1990).

Dimensional analysis. Dimensional analysis is a third variation of grounded theory, developed by Leonard Schatzman (Kools, et al., 1996; Schatzman, 1991). Dimensional analysis uses the process of "natural analysis" systematically to understand "what all is going on here" (Robrecht, 1995). According to Schatzman, natural analysis

is the way people naturally "figure things out", that this process is learned at a very early age, and grows more sophisticated with maturity (Kools, McCarthy, Durham, & Robrecht, 1996). Dimensional analysis is a variation of grounded theory that is useful when researching decision making and problem solving aspects of human behavior because it explicates how people "figure things out".

The Common Research Process. Although a debate exists (Annells, 1997; Kendall, 1999; Robrecht, 1995) regarding the philosophical and methodological issues involved in these three variations of grounded theory, there is a research process and research design common to all grounded theory studies. There are two main phases in the research process in grounded theory. The first is the data expansion phase, the second is the data limitation phase. Data collection and analysis occur reiteratively throughout both phases and continue until no new categories are forthcoming from the data.

Data expansion occurs as data is collected and analyzed initially. For descriptive purposes, phases are described here in a linear progression, but in practice, the process is not linear but recursive. Coding of data is the primary analytic strategy that fractures the data into its smallest units of ideas. Initial coding may be merely a process of labeling an idea or it may begin the process of abstracting an idea from a specific instance. The primary goal during data expansion is to identify as many ideas and examples about the phenomena as possible. Codes are grouped or clustered together according to similarities into larger code units or more abstract categories. The deliberate search for relationships between categories is reserved for the second phase of analysis (data limitation) but potential relationships may begin to emerge as the researcher ponders the data and explores clustering of codes together.

At a point during the data expansion phase, a "critical mass" of categories is reached when no new categories emerge through the process of theoretical sampling (Glaser, 1978; Schatzman, 1991). It is emphasized that data collection and analysis continue simultaneously throughout both phases of the research process until theoretical saturation has been reached and the writing of the narrative grounded theory is undertaken.

The data limitation phase begins when categories are grouped and placed in a tentative theoretical form to explain the subject under investigation. At this point each variation of the method employs its own procedures for discovering relationships among the categories to form a theoretical understanding of the phenomenon.

The final product is a grounded theory about human behavior and group life. The grounded theory may be presented as a written narrative or a theoretical statement of propositions and hypotheses. One category is selected as the perspective from which all other categories are described and explained. These categories are organized according to the structural procedure associated with the particular variation selected for the study. The procedures used during data limitation and writing of the grounded theory distinguish one variation from the others.

Evaluation in Grounded Theory Method

There are two sets of criteria by which qualitative research is judged: trustworthiness and authenticity (Sandelowski, 1986; Denzin & Lincoln, 1994). In addition, grounded theory has its own criteria (Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss & Corbin, 1990).

Trustworthiness includes an assessment of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Strategies used to establish credibility of data include persistent observation, peer debriefing, and member checks (Denzin & Lincoln, 1994). Persistent observation results from the ongoing process of theoretical memoing, or recording one's thinking about the data. Peer debriefing is the practice of discussing the data with professional colleagues; member checking is the act of taking conceptualized data back to participants for clarification, confirmation, or revision. These strategies are intended to probe for bias, explore meaning extracted from data, and clarify the basis for interpretation of data with trained qualitative researchers and with participants. Dependability and confirmability are judged by the use of an inquiry audit which examines both the process used in the study and the product which is evaluated at each step of the research process (Lincoln & Guba, 1985; Rodgers & Cowles, 1993). Authenticity criteria include a more subjective approach that reflects the interpretive position more closely and examines ontological, educative, catalytic, and tactical authenticity (Denzin & Lincoln, 1994).

Specific criteria for judging grounded theory include judging the final product by its "fit", ability to "work", its relevance, modifiability, and its parsimony and scope of explanatory power (Glaser & Strauss, 1967). "Fit" means that the categories emerge from the data directly and are not forced; and "work" is defined as categories that are relevant and able to explain the phenomena being studied (Glaser & Strauss, 1967). A grounded theory should be modifiable as new data emerges in later studies. Parsimony and scope of the theory are achieved via theoretical saturation.

Morse (1994) extended the criteria for judging qualitative research to include an assessment for adequacy and appropriateness of data. These criteria address questions about sufficiency of data to achieve theoretical saturation and selection of data and sampling techniques that remain congruent with the research question and methodological procedures. These criteria evaluate theoretical sampling and saturation techniques described by Glaser & Strauss (1967) and Glaser (1978).

Use in Nursing

Grounded theory is a useful method for nursing research because it aligns easily with the disciplinary interest in interactional responses to health and illness. Nurses can use grounded theories in similar contexts to explain or anticipate outcomes of certain behaviors to clients. As clinicians, nurses interact with clients in complex social ways to explore solutions to health problems. Artinian (1998) described the application of grounded theory knowledge into clinical practice as a way to transcend the experience of single instances to understanding patterns of behavior in health and illness. Thus, the philosophical perspective of symbolic interactionism and knowledge produced using grounded theory methods becomes integrated with the praxis of nursing (Lutz, Jones, & Kendall, 1997).

Research Design

The design of this study was based on grounded theory method as described by Strauss and Corbin (1990). This method includes theoretical sampling, intensive interviewing, simultaneous data collection and inductive data analysis, and the development of a grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Data collection and analysis continue until no new information is forthcoming and a

theoretical understanding of the phenomena has emerged from the data (Strauss & Corbin, 1990; Chenitz & Swanson, 1986).

Rationale for use of grounded theory in this study

A qualitative, grounded theory method was selected to study the family experience with school when an adolescent has ADHD. Choice of the method was based on which method would best answer the research question (Polit & Hungler, 1995), was congruent with the author's philosophical perspective on the problem (Annells, 1997), would be a logical choice to extend a previous study on family experiences when children have ADHD (Kendall, 1998), and be recognized by the primary audience of the study.

Answering the research question. The research question is, what is the family experience with school when a teenager has ADHD? A qualitative approach was selected because there is a paucity of research regarding family experiences and interactions between school and home when teenagers have ADHD. Qualitative designs often are used to explore and describe previously unresearched topics and to identify concepts relating to a particular phenomenon.

Attention deficit hyperactivity disorder is one of the most researched disorders of childhood, and nearly all of the research about ADHD is quantitative. A great deal is known about the social and learning problems of adolescents with ADHD (August, Realmuto, MacDonald, Nugent, & Crosby, 1996; Barkley, Anastopoulos, Guevremont, & Fletcher, 1991; Branch, Cohen, & Hynd, 1995; Carter, Krener, Chaderjian, Northcutt, & Wolfe, 1995; Denckla, 1996; Faraone, Biederman, Lehman, Keenan, Norman, Seidman, Kolodny, Kraus, Perrin, Chen, & Tusany, 1993; Goldstein, 1987; Hinshaw, 1992a, 1992b; Lazar, & Frank, 1998; Marquis, 1983; Marshall, Hund, Handwerk, & Hall, 1997),

and family problems related to ADHD have been extensively researched (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Anderson, Hinshaw, & Simmel, 1994; Barkley, Anastopoulos, Guevremont, & Fletcher, 1992; Barkley, Fischer, Edelbrock, & Smallish, 1991; Biederman, Milberger, Faraone, Kiely, Guite, Mick, Ablon, Warburton, & Reed, 1995; Dyson, 1996; Eccles, Flanagan, Lord, Midgley, Roeser, & Yee, 1996; Fletcher, Fischer, Barkley, & Smallish, 1996; Hechtman, 1996; Johnston, 1996; Lewis, 1992; McCormick, 1995; Murphy & Barkley, 1996; Pelham, Lang, Atkeson, Murphy, Gnagy, Greiner, Vodde-Hamilton, & Greenslade, 1997; Reid, Hertzog, & Snyder, 1996). This body of literature cited in Chapter Two indicates that teens with ADHD do poorly in school and that their families experience increased stress when teenagers underachieve academically. These studies identified objective factors that contribute to school failure and family stress: student inattention, distractibility, poor impulse control, hyperactivity, aggression, immature social skills, lack of organizational skills, comorbid condition, maternal depression and psychopathology, and family history of ADHD in family members. What is missing from the existing literature is an understanding of the subjective family experience with school that explains the personal meanings of the experience and offers a theoretical explanation of the interactions between school and families when a teenager has ADHD. This study was designed to investigate this gap in the literature.

Symbolic interactionism is an appropriate conceptual framework for studying family experiences because of its basic tenets regarding meanings, behavior, and interactions with self and others. Blumer (1969) explained that within symbolic interactionism, "joint actions" between groups and individuals are the ongoing social acts

that constitute daily living and social life. The interactions between families, students and schools are examples of the complex, ongoing "joint actions" described by Blumer (1969). Grounded theory, which is based on symbolic interactionism, provided a method for describing and explaining joint actions. Therefore, grounded theory was selected for its potential to explain theoretically the complex interactions and subjective meanings involved in the family experience with school when an adolescent has ADHD.

Author's philosophical perspective. The second reason for selecting grounded theory for this study is reflected from my philosophical perspective on clinical practice and research. During my 22 years of practice as a pediatric nurse practitioner, I have come to believe that to be an effective health care provider, one must understand the perspective and situation of the clients and address their concerns when offering treatment recommendations. When at work, adolescents with ADHD and their parents frequently told me I "didn't understand" their problems. For example, they told me that many interventions we discussed didn't address things of concern to them. Family members told me that a particular, research-based intervention I suggested wouldn't work or the results did not work after a period of time.

In fact, most intervention studies indicate that no treatment has long lasting effects on symptoms of ADHD (Barkley, 1990, 1997; Greenhill, 1996; Nathan, 1992). Most discouraging of all are the findings about interventions to improve family life and social functioning of those diagnosed with ADHD (Kendall, 1998; Lewis-Abney, 1993). The perspectives of parents and adolescents with ADHD was sought because a recent family study on ADHD indicated that both parents and adolescents felt that the interventions offered to them by professionals did not correspond with family-identified

problems (Kendall, 1997, 1998). Grounded theory, rooted in symbolic interactionism (Blumer, 1969), contained the methodological tools to explore and conceptualize the perspectives of family members and to provide a theoretical understanding of the meanings of their experiences that are embedded in social behavior.

According to symbolic interactionists, these meanings develop over time through socialization at home, work, and school. "Socialization" is the process by which meanings of symbols are transmitted, learned, and understood; initially this occurs within the context of the family during a child's early years, and later at school and at work (Mead, 1934). When seeking understanding about meanings related to experiences with school, it is necessary to consider not only the meanings that were taught/learned within the family, but also the processes and context used to transmit such meanings.

"Definition of the situation" refers to how perception of reality impacts meanings and human behavior (Klein & White, 1996; Mead, 1934). This concept helps account for meanings that are incongruent with others' reality, or the "obdurate world" (Blumer, 1969) that exist outside of, and apart from, individuals' perceptions. A study seeking to explain a phenomenon from the point of view of its participants must also seek to understand the individuals' definition of the situation to explain the individual's perspective in contrast to other perspectives. Grounded theory was selected for this study because of its link with symbolic interactionism, the methodological strategies to represent the participants' perspective, and to understand the socialization and definitions of the situation that are embedded in the family experience with school when teenagers have ADHD. Thus, grounded theory has the potential to inform clinicians of the client perspective, which is essential when aspiring to provide effective health care solutions to

complex conditions.

Extension of previous research. A third rationale for selecting grounded theory was related to a previous study of ADHD and families. Kendall (1998) investigated the effects of ADHD on families using grounded theory methodology. Since this study was intended to extend Kendall's study by focusing primarily on the family experience with school when a teenager has ADHD, it was a logical choice to employ the same method as long as the selection was also compatible with the research question.

Matching method to the audience. The final rationale for choosing grounded theory method for this study was to select a method that would be easily understood, recognized as scientifically rigorous, and adaptable to professional practice by members of the audience I wished to address: nurses and other health care providers, mental health specialists, and educators. Grounded theory is recognized by members of these disciplines as a scientific method for studying human behavior and group life and has been used by members of these disciplines when researching social phenomena (Kendall, 1998: Lewis, 1992; Reid, Hertzog, & Snyder, 1996).

In summary, grounded theory was chosen for this study because it had the potential to answer the research question and was compatible with the author's philosophical perspective and clinical experience with families of children and adolescents with ADHD. Since this study was designed to extend a recent family study of ADHD that used grounded theory for its methodology, it was a logical choice to use a similar method in this study. In addition, the method was chosen for its recognition and use by the audience I wished to address: nurses, other health care professionals, mental health specialists, and educators.

Sample

Adolescents with ADHD aged 12-18 and their parents were included in the sample. Eligibility criteria for the study participants were: a) parent participants must be the legal parent or guardian of an adolescent diagnosed with ADHD, b) the adolescent must have been diagnosed with ADHD by a medical professional able to make such a diagnosis, and be a student in middle school or high school; c) all participants must be willing to take part in at least one individual interview, and d) all participants must be fluent in English. Participants were asked for permission to return for a second interview for clarification and/or expansion on topics identified in the first interview.

An initial sample of 15 adolescents and at least one of their parents or guardians was planned. Sample size was determined when information redundancy and theoretical saturation was reached. Parents and adolescents were to be interviewed separately. Additional interviews were conducted to reach conceptual saturation (Glaser, 1978) with the emphasis on adequacy of data rather than numbers of interviews. The final sample consisted of 19 adolescents and 21 adults. In addition, observational data were obtained and recorded as theoretical memos.

Purposive sampling techniques were used initially to obtain the richest information about the phenomena. Subsequent theoretical sampling was guided by concepts that emerged from the data to obtain maximum variation and fill in conceptual understanding of the phenomena under study (Glaser & Strauss, 1967; Glaser, 1978).

Ethnic representation in the sample was expected to reflect the minority population in the Portland, Oregon, metropolitan area in 1998 (African-American, 5%; Hispanic, 9%; Asian-American and Pacific Islander, 1%; Caucasian, 84%, Native

American, 1.2%; and other, 1%). However, given the small sample size of this study, it was anticipated that all minorities probably would not be represented. Since males are affected approximately three times more often than females, it was expected that there would be more males than females in the adolescent sample. An attempt to oversample females was made when it appeared that gender affected a particular concept.

Recruitment

Participants were recruited through self referrals and referrals from health care providers in pediatric and family practice clinics serving adolescents with ADHD within the Kaiser Permanente system, whose large, heterogeneous membership includes minority representation similar to the Portland metropolitan area. Posters announcing the study were placed in clinic waiting rooms and a health organization newsletter to facilitate self-referral. Health care providers at Kaiser gave prospective participants an announcement about the study or participants took an advertisement from the clinic posters. The researcher's phone number was on the advertisement for the study; potential participants contacted the researcher if interested in participating in the research. During the initial telephone contact, potential participants were given a verbal explanation of the nature and extent of the study. After having any questions answered and a willingness to participate was indicated, an individual appointment with the parent(s) and adolescent with ADHD was arranged at a place convenient to the participant that allowed for privacy.

Midway through the data collection phase, recruitment strategies were expanded (and approved by the OHSU Institutional Review Board) to include publishing the study advertisement in the newsletter of a second large health system to increase the pool of

prospective participants. Ten families responded to advertisements of the study and two families on the Kaiser health plan were recruited through physician referral.

Data collection

At the first appointment, consent forms for parents and assent forms for adolescents (Appendix A) were read and explained to participants. After participants signed the appropriate forms, demographic information (Appendix B) for all participants and medical/diagnostic data on the adolescent with ADHD was collected orally at the beginning of the first interview. The format of the interview was described and the interview begun. Initial interview questions were broad, intended to obtain the participants' perspective on interactions and processes involved in the topic under study and to elicit personal meanings. Initially, open-ended questions were used to explore the full range of the phenomena of interest. As data collection progressed, questions became more specific to obtain in-depth understanding and analyzed data were offered to participants for confirmation or revision (Glaser, 1978; Glaser & Strauss, 1967). Lincoln & Guba (1985) asserted that this form of member checking was necessary for establishing credibility of research findings.

Interview Guide. The initial interview guide was developed from topics identified in the literature, Kendall's (1998) ADHD family study, and the researcher's clinical experience spanning 25 years (Chenitz & Swanson, 1986). The initial interview guides are found in appendices C and D.

Issues in interviewing adolescents. When interviewing adolescents, certain considerations about access and cooperation were necessary (Deatrick & Faux, 1991). Accordingly, the researcher sought to establish rapport, used interviewing skills

appropriate to adolescents, showed respect and interest in the adolescent's point of view, established self as an experienced researcher, clinician and interviewer, attempted to allay anxiety by providing privacy and confidentiality, gave the adolescent control over the interview setting, and was sensitive to adolescent issues. This sensitivity included understanding the vulnerability of adolescents and being able to detect signs of distress requiring adjustment or termination of the interview if that was in the best interest of the adolescent.

Data analysis

All interviews were audiotaped, transcribed, and analyzed using the constant comparative method of data analysis used in grounded theory. Observations were written as theoretical memos. According to the grounded theory method, data was analyzed while additional data collection was occurring. Coding was the process by which conceptual categories and their properties emerged from the data (Strauss & Corbin, 1990). The coding scheme was refined as similarities and differences in the codes became more clearly conceptualized and were clustered together to form categories. Categories were then analyzed for relationships until a core category emerged. An initial grounded theory was generated from relationships discovered between categories. Theoretical memos were kept during the analytical process to track decisions made about codes, categories and relationships. NUD.IST computer software (Qualitative Solutions and Research, 1994) was used for data management.

During the data analysis process, the researcher addressed the aims of this study. The first aim was to describe the family experience with school when an adolescent has ADHD. The process for data analysis used to describe experience involved identifying

common themes of family life that provide context to meanings, situations and events related to school when an adolescent has ADHD. By comparing, conceptualizing and categorizing data, the phenomena were labeled and described in terms of properties (characteristics such as intensity and frequency) and dimensions (location of a property along a continuum). For example, an adolescent described dread about going to school because homework was not completed. Data were compared and categorized into codes according to their properties and dimensions, i.e., how frequently dread was experienced and to what degree. Further sampling was used to fill in any conceptual gaps. When no new codes emerged from the data, conceptual saturation was reached. Once properties and dimensions defined all codes, codes were analyzed in terms of their relationship to one another, clustered into mutually exclusive categories and subcategories that provided description of the family experience with school when a teenager has ADHD.

The second aim of the study was to identify the following family processes when an adolescent has ADHD. These processes included the contexts and interactions which contributed to or mitigated family disruption as it relates to the experience with school; the conditions which impacted the family experience with school, and the basic family processes within families which were related to school. The analytic process was similar to the description above, except it was anticipated that the context, conditions, and consequences within the family experience when an adolescent has ADHD would emerge as antecedent, concurrent, and consequent factors. It was anticipated that a full conceptual description of processes and interactions would emerge if teen participants represent the range of ages and grades across middle and high school years. An attempt to clarify any contradictions was one strategy used to illuminate properties and

distinguish one category from another.

The third aim of this study was to develop an initial grounded theory about the family experience with school when an adolescent has ADHD. Selective coding of the core category was used in the final step of analysis to develop the grounded theory. This occurred once categories identifying factors involved in the family experience with school were sufficiently dense, conceptually saturated, and the core category selected, using the paradigm model. After the theory had been developed, it was compared with previous work and available literature to validate or identify differences and gaps in the literature.

Strategies for Handling Limitations in the Data

Naturalistic, qualitative research is judged according to its credibility, transferability, dependability and confirmability as described by Lincoln and Guba (1985), in contrast to evaluation criteria for quantitative research such as validity and reliability (Campbell & Stanley, 1963; Polit & Hungler, 1995).

Three techniques were employed to establish credibility of the data: persistent observation, peer debriefing and dissertation committee supervision, and member checks. Persistent observation included observations of study participants during the individual interviews recorded as theoretical memos. Peer debriefing, the process of presenting data analysis to experienced qualitative researchers to probe for biases, explore meanings and clarify the basis for interpretation of the data, was obtained regularly at a biweekly advanced qualitative research seminar and from a selected group of professional colleagues. Member checking, the practice of returning to participants with the data analysis for confirmation or revision (Lincoln & Guba, 1985), also was employed to

establish credibility of the data.

No attempt was made to generalize findings from this study to any other setting. Characteristics of the setting and participants in the study have been included with the results so readers can determine for themselves if the findings are relevant to other settings. Dependability and confirmability were established by the technique called inquiry audit (Lincoln & Guba, 1985). An audit was made of processes used for conceptualization and theory generation by reviewing the researcher's journal. Dissertation committee members monitored these processes regularly to help insure that the resultant theory was grounded in and emerged from the data.

Protection of Human Subjects

Both adolescents and parents had the study explained to them before they were asked to participate. Parents were asked to sign a consent form for their own participation and for their adolescent child. Adolescents were asked to sign an assent form. Potential participants were given ample opportunity to ask questions about the study. At the end of the study all tapes were destroyed, but transcripts with identifying information removed were kept. During the course of the study, all tapes and transcripts were kept in a locked cabinet accessible only to the primary investigator and her sponsor. Personal identification of participants was kept secure and separate from the data. Only identification numbers were used to link data to participants. All participants were assured they were free at any time to withdraw from the study without consequence.

Risks from participation in this study were minimal. However, previous clinical and research experience working with families dealing with ADHD sensitized me to the possibility that sharing personal experiences regarding difficult family experiences may

result in some emotional discomfort. Referral to a mental health specialist was available should this situation have arisen. Parents were to be notified if information was forthcoming regarding the adolescent's intent to harm him or herself or others; no parents of adolescent participants needed to be notified of any information thought to be deleterious to their child's health. Adolescents were aware of this provision. Confidentiality was explained to parents and adolescents with emphasis on the need to maintain confidentiality to preserve validity of the data and to protect human rights. Both parents and adolescents were informed of mandatory reporting laws regarding the disclosure of child abuse, which were binding on this researcher.

All study participants received a copy of the study's results. There were no other direct benefits from participation in this study but an indirect benefit may have been gained from contributing to a better understanding of the family experience with school when an adolescent has ADHD.

Summary

The grounded theory method of qualitative research was selected for this study. Historical and conceptual underpinnings of grounded theory were discussed and variations of grounded theory methods were compared. The rationale for selecting the Strauss and Corbin variation of grounded theory for this study was explained. The philosophical perspective, conceptual underpinnings, and methodological issues of grounded theory method provided the best fit between the research question and the methodological variations available. The sample, recruitment plan, and strategies for data collection and analysis were outlined. Actual procedures used and study findings appear in the following chapter.

CHAPTER FOUR

RESULTS

The purpose of this study was to generate a theoretical understanding of the family experience with school and to identify processes and interactions that impact family functioning when an adolescent has ADHD. Grounded theory methodology was used to analyze data from interviews with families that had at least one adolescent diagnosed with ADHD. Results indicated that the central family experience with school when an adolescent had ADHD was about parents organizing cooperative efforts to manage ADHD in the family. Although participant families were not always successful in organizing these cooperative efforts, the aim and the intent of these parents was to seek organized cooperation among various health and education services in an attempt to manage their child's ADHD. This experience was central to all families in this study.

In this chapter, the sample will be described and expansion of the recruitment and data collection procedures will be explained. The remainder of the chapter will include a presentation of the initial grounded theory, and an explanation of the categories and codes contained therein.

Sample

The sample for this study consisted of twelve families with at least one adolescent family member diagnosed with ADHD. Twenty parents and one adult sibling, and nineteen adolescents were interviewed at least once; seven parents and three adolescents were interviewed twice. The in-depth interviews lasted between one to three hours. Those who were interviewed a second time were contacted by the researcher to obtain

further information on a topic covered during the first interview and to clarify emerging topics.

Demographic information for the nineteen adolescent participants is presented in Table 2. Fifteen males and four females between the ages of twelve and twenty were interviewed. Ten adolescents were in middle school (grades 6-8), six were in high school (grades 9-12), and three were in college. Of the college students, two were freshmen attending college full time; the third was working full time and attending a community college on a part time basis.

The age criteria for participation were originally established for adolescents between the ages of 12-18. However, a twenty-year-old college student with ADHD requested to be included in the study after learning that her siblings were being interviewed. The decision to include her as a participant was based on the fact that two male eighteen-year-old participants who had transitioned to college were also participants and it was thought her participation in the study might add breadth to the analysis of the developmental and gender aspects of the study.

Seventeen of the nineteen adolescent participants currently or previously had been on an Individualized Educational Plan (IEP) or a "Section 504" Educational Plan that outlined accommodations or special services provided at school because of difficulties related to ADHD. All nineteen adolescents had taken medication for ADHD at some time since their diagnosis; seventeen were currently taking medication daily at the time of the initial interview. Although all nineteen students had been diagnosed with ADHD by their pediatrician, only six were managed by the pediatrician alone. Nine adolescents from 5 families attended a multi-disciplinary ADHD clinic for evaluation,

Table 2
Characteristics of the Adolescents in the Sample

Demographic characteristic	#Cases	%Cases
Gender		
Male	15	78.9
Female	4	21.1
Grade		
6	4	21.1
7	3	15.8
8	3	15.8
9	1	5.3
10	3	15.8
11	1	5.3
12	1	5.3
Attending college	3	15.8
Does the teen have an Individualized Educational Plan (IEP)		
Yes	17	89.4
No	2	10.5
Has the teen ever taken medication for ADHD?		
Yes	19	100
No	0	0
What type of medication is/has been used?		
Ritalin	3	15.8
Dexedrine	6	31.6
Adderall	4	21.1
Concerta	3	15.8
Clonidine	3	15.8
Antidepressant	2	10.5
Other	1	5.3
Who made the initial medical diagnosis of ADHD?		
Pediatrician	19	100

parent education, family counseling, and ADHD management classes for adolescents. Three adolescents were treated by a psychiatrist who managed medications for ADHD and comorbid conditions; one adolescent received medication management from a psychiatrist and counseling from a licensed medical social worker.

Three adolescents in the sample had Tourette's syndrome and four had obsessive-compulsive disorder (OCD). Three adolescents had been treated for depression, and parents of several others had concerns their adolescents were depressed but had not sough a formal diagnosis. None of the adolescents in the study had been diagnosed with oppositional defiant disorder (ODD) or conduct disorder (CD) but parents of three of the older adolescent males described incidents of frequent rebellious or resistant behavior at home.

Nine of the adolescents had been involved in fighting at school on more than one occasion, primarily during elementary and middle school years, and three other adolescents had been involved in "playground misbehavior" on more than one occasion. Many of the adolescents had behavior problems while riding the school bus. One mother said of her son, "He had difficulty with kids on the bus. It was very easy for kids to push his button and he was always the kid who slugs first and asks questions later." School officials reporting misbehavior of the adolescents frequently called many parents at work; one father said he dreaded being called by the principal and never knew when a call would come. Six of the adolescents had been to detention and three were suspended at least one time during middle school or high school years. All the boys who were suspended had been fighting at school; two girls who received detention during middle

school were penalized for forgetting gym clothes on numerous occasions and speaking in a disrespectful manner, but not for fighting.

Although the three oldest adolescents in this sample had graduated from high school and were attending college, the next oldest adolescents had a different school experience. One senior and two juniors were in danger of not graduating due to course failures. All parents reported that their adolescents were not working to the level of their potential even when the teenager was getting passing grades.

Twenty parents of the adolescent participants and one adult female sibling were interviewed for this study: 12 mothers and 8 fathers. Demographic information about the parent sample is found in Table 3. The study proposal did not include adult siblings as participants; however the adult sibling was included in the study at the request of her parents because of her advocacy and mediation roles within the family. The ages of parents in this study ranged from 35-61 years with the majority of parents being in their forties. Fifteen participants were married to their first spouse, 4 participants had been divorced and were remarried, and one parent was divorced and remained a single parent. Two couples were adoptive parents, one father in the study was a stepfather to an adolescent participant, and 15 parent participants were biological parents of adolescents in the study.

The educational level of parents in this study was quite high. All parents were high school graduates, three parents completed two or three years of college, 7 parents had baccalaureate degrees, 7 had master's degrees, and one parent had a Ph.D. One father was retired, one father semi-retired, and all other fathers were employed full time in a position commensurate with their education.

Table 3
Characteristics of the Parents in the Sample

Demographic characteristic		#Cases	%Cases
Parent participants, total		20	
Mothers		12	60
Fathers		8	40
Adult female sibling participant without ADHD, attending college		1	100
Age of parents			
35-39		2	10
40-44		5	25
45-49		4	20
50-54		2	10
55-59		2	10
60-64		1	5
Missing		4	20
Marital status of parent participants			
Married to first spouse		15	75
Remarried, previously divorced		4	20
Divorced		1	5
Ethnicity			
Caucasian		20	100
Education level of parent participants			
2-3 years of college		3	15
Mothers	1		
Fathers	2		
Baccalaureate degree		7	35
Mothers	6		
Fathers	1		
Master's degree		7	35
Mothers	5		
Fathers	2		
PhD degree		1	5
Mothers	0		
Fathers	1		
Employment Status of Father Participants		8	100
Full time		6	75
Semi-retired		1	12.5
Retired		1	12.5

Of the twelve mother participants in the study, 4 were employed full time in a position equivalent to their education, 4 worked part time at jobs that offered flexible work schedules and two mothers were not employed in order to accommodate the need to respond to calls from school, transport adolescents to school, medical, and counseling appointments (see Table 4). The two mothers who did not work had two and three children diagnosed with ADHD, respectively. One mother was retired and one mother had recently left full time employment due to a disabling medical condition.

Characteristics of the families in the study are found in Table 5. The size of families in this study was relatively large with eight families having three or more children: six families had 3 children and two families had four children. Only one family had one child, three families had two children. Seven families had more than one child diagnosed with ADHD and four of the twelve families had three children diagnosed with ADHD.

Nine of the twelve families had at least one custodial parent who had been diagnosed with or displayed strong characteristics of ADHD; six families had one parent afflicted and three families had two parents affected. Of the six families with one parent afflicted, four fathers and one mother had ADHD. In one family, a non-custodial parent had ADHD. Eleven families had at least one member of the extended family with ADHD.

In summary, the sample of participants in this study represented twelve families and included nineteen adolescents diagnosed with ADHD, one adult sibling, and 20 parents, twelve of whom had been diagnosed with or displayed strong characteristics of ADHD themselves. All of the parents were well educated; all parents had attended

Table 4
Characteristics of Mothers' Employment

Demographic characteristic		#Cases	%Cases
Employment Status of Mother Participants		12	
Full time		4	33.3
#Children with ADHD at home (including teens)			
1	2 families		
2	2 families		
3	0 families		
Part time to accommodate ADHD demands on family		4	33.3
#Children with ADHD at home (including teens)			
1	2 families		
2	1 family		
3	3 families		
Unemployed to accommodate ADHD demands on family		2	16.6
#Children with ADHD at home (including teens)			
1	0 families		
2	1 family		
3	1 family		
On disability		1	8.3
#Children with ADHD at home (including teens)			
1	1 family		
Retired		1	8.3
# Children with ADHD at home (including teens)			
1	1 family		

Table 5
Characteristics of the Families in the Sample

Demographic characteristic	#Cases	%Cases
Number of children in the family		
1	1	8.3
2	3	25.0
3	6	50.0
4	2	16.7
Number of children in the family with ADHD		
1	5	41.6
2	2	16.7
3	4	33.3
4	1	8.3
Number of families with at least one parent diagnosed or Displaying ADHD characteristics	9	75.0
Number of families with one custodial parent diagnosed or displaying ADHD characteristics	6	50.0
Mothers affected	1	20.0
Fathers affected	4	80.0
Number of families with two custodial parents diagnosed or displaying ADHD characteristics	3	25.0
Number of families with neither custodial parent diagnosed nor displaying any ADHD characteristics	3	25.0
Families with a non-custodial parent diagnosed/ or displaying ADHD characteristics	1	8.3
Number of families with extended family members with ADHD	11	91.7

college for at least two years, fifteen had graduated with an undergraduate degree and eight parents had completed advanced degrees. All fathers were employed full time or had retired; six mothers were not working full time in order to be able to meet the demands on the family created by adolescents having ADHD. Eleven of the families had two or more children; seven families had more than one child diagnosed with ADHD.

Results of the Study

Six major categories emerged from the analysis of data: (1) juxtaposition of parental expectations with reality of the ADHD disorder, (2) disrupted family climate, (3) organizing cooperative efforts, (4) parents taking extraordinary measures, (5) family values and family characteristics, and (6) family outcomes. Each category has many sub-categories and sub-codes depicting the depth of the data set (see Codelist, Appendix E). The findings of this study are presented as a conceptual model (see below) that depicts the interacting patterns between the concepts that explain the core process, Organizing Cooperative Efforts. Organizing Cooperative Efforts was identified as the core category because of its pervasive and centralizing focus on the conditions that influence the family experience with school when an adolescent has ADHD. Selective coding of the core category through the process of theoretical sampling rendered an empirical pattern of how organizing cooperative efforts influenced family outcomes.

The Conceptual Model:

Organizing Cooperative Efforts to Manage ADHD in the Family

The central family experience with school when an adolescent had ADHD was aimed at organizing a cooperative relationship with teachers, schools, the adolescents themselves, clinicians and other community professionals, and nuclear and extended

family members. Parents discussed the experience of having to "go beyond", i.e., to take "extraordinary measures" to parent their children beyond that which was required for children without ADHD. This involved continually confronting ADHD and compensating for the "invisible disability" of ADHD. Parents discussed the difficulties of there being no visible outward physical sign that their adolescent had a disability (no scar, deformity, or corrective appliance) to remind others or themselves that the disability existed. Because there was no visible evidence of ADHD, "you can't see what is wrong with them," as one mother explained, "what you see is what they cannot do". Yet, parents found themselves confronting the disability on a moment-by-moment basis, with ADHD constantly interfering with every aspect of family life. It was always "in your face wherever you turned" according to one mother.

The primary symptoms of ADHD combined into two disabling patterns of behavior that were confronted continually: "difficulty accomplishing things" and "struggling through school". Adolescents had trouble accomplishing things because they were plagued by procrastination, distraction, daydreaming, resistance and avoidance, relying on others, and giving up. This pattern, difficulty accomplishing things, affected life at home and at school; adolescents were unable to complete activities of daily living, chores, or schoolwork on a consistent basis, and it interfered with their school and social activities. "Struggling through school" was a pattern of intending to do well at the beginning of a term or school year, keeping up initially, performing unevenly, falling behind, getting to "crunch time", compensating with extra credit, and either "pulling it out of the fire" or failing. This pattern of behavior was repeated every school term and school year.

These two patterns of behavior interfered with all activities of daily living at home and school so that adolescents with ADHD and their family members were constantly confronting the invisible disability. Families referred to the ongoing confrontation with ADHD as a nightmare. One father described, "the problem is when you start something, things go and fall apart so fast, messes happen, things break, kids get hurt, that all of a sudden what was joyful fun has turned into a nightmare. It's almost like you're in some Felini play or it's like, 'God, how did we get here?'"

The constant confrontation with the two ADHD behavioral patterns was a result of the reality of living with an adolescent diagnosed with ADHD. This reality was a sharp contrast to the expectations parents had for a "normal" family life. The juxtaposition of these expectations and the reality of living with an adolescent with ADHD led to a disrupted family climate.

The context for this ongoing confrontation with ADHD was a disrupted family climate created by the clash between adolescents living with ADHD and parents using ordinary parenting strategies to raise their adolescents with ADHD. Ordinary "good parenting" strategies were ineffective to manage ADHD in adolescents. The clash between the reality of living with an adolescent with ADHD and the constant realization that "ordinary good parenting" was ineffective produced frustration, anger, and escalating behaviors in all family members on a regular basis. Homework and grades were frequent triggers for the disrupted family climate.

Symptoms of ADHD included inattention, distractibility, impulsivity, hyperactivity, a poor concept of time, problems remembering, organizing, and connecting things, and being aware of others. These symptoms created an "inner chaos" that

permeated the adolescent's social, emotional, and cognitive experiences and affected all activities of daily living. A paradox emerged when adolescents displayed significant talent and accomplishment in a certain area, yet were unable to complete mundane and usual activities of daily living.

Six factors influenced the actions parents took to organize cooperative efforts to compensate for their adolescent's disability. These factors were: family values, ages of family members, socioeconomic status, knowledge of ADHD, extended family support, and presence or absence of family risk factors such as family violence, poverty, access to health care services, drug or alcohol abuse, etc. In particular, parents used their family values about the role of parents, the value of children, how to live as a family and member of the community as a template for the extraordinary parenting strategies they developed to mitigate the effects of ADHD on the family.

Over time, parents developed four sets of actions aimed at organizing cooperative efforts to help their adolescent succeed in school and life. These actions were extraordinary parenting measures that included advocating in the community, working with the schools, investing in their adolescent, and advocating in the community.

The consequences of this continual confrontation with the invisible disability of ADHD and parents needing to take extraordinary measures to manage their adolescent's ADHD resulted in significant costs and some benefit to the family, a range of family-school relationships, and uncertain futures for the adolescents. Family costs included large financial expenditures associated with ADHD, parental depression, marital stress, and family disruption. Family routines were constantly interrupted, households were disorganized and messy, communication was poor, and there was an ongoing tension

between meeting the needs of individuals versus the family unit. The family benefit was the increased time parents and adolescents spent together and the satisfaction they shared as they worked each school term or school year to "pull it off" and complete schoolwork and projects. The uncertain future for the adolescents included the hope and possibility of high school graduation and a smooth transition to college, work, and adult responsibilities as well as the threat of prolonged dependence on parents and persistent immaturity. Family values, ages of family members, socioeconomic status, extended family, and knowledge of ADHD were variables that influenced these actions and outcomes.

This section described the conceptual model of Organizing Cooperative Efforts to Manage ADHD in the Family (Figure 3). It included explanations of the links between the major categories of data in this study. The next section describes the major categories of data in detail.

Explanation of Categories of Data

This section focuses on the major categories of data and describes the codes contained within categories. The section is organized using the framework of a grounded theory as described by Strauss and Corbin (1990) which includes the core category, antecedents or causal conditions, context, intervening conditions, actions and interactions, and outcomes. The core category, Organizing Cooperative Efforts to Manage ADHD in the Family, is presented first, followed by antecedents, the context, actions and interactions, intervening conditions, and outcomes. Conceptual links between the major categories were presented in Figure 3.

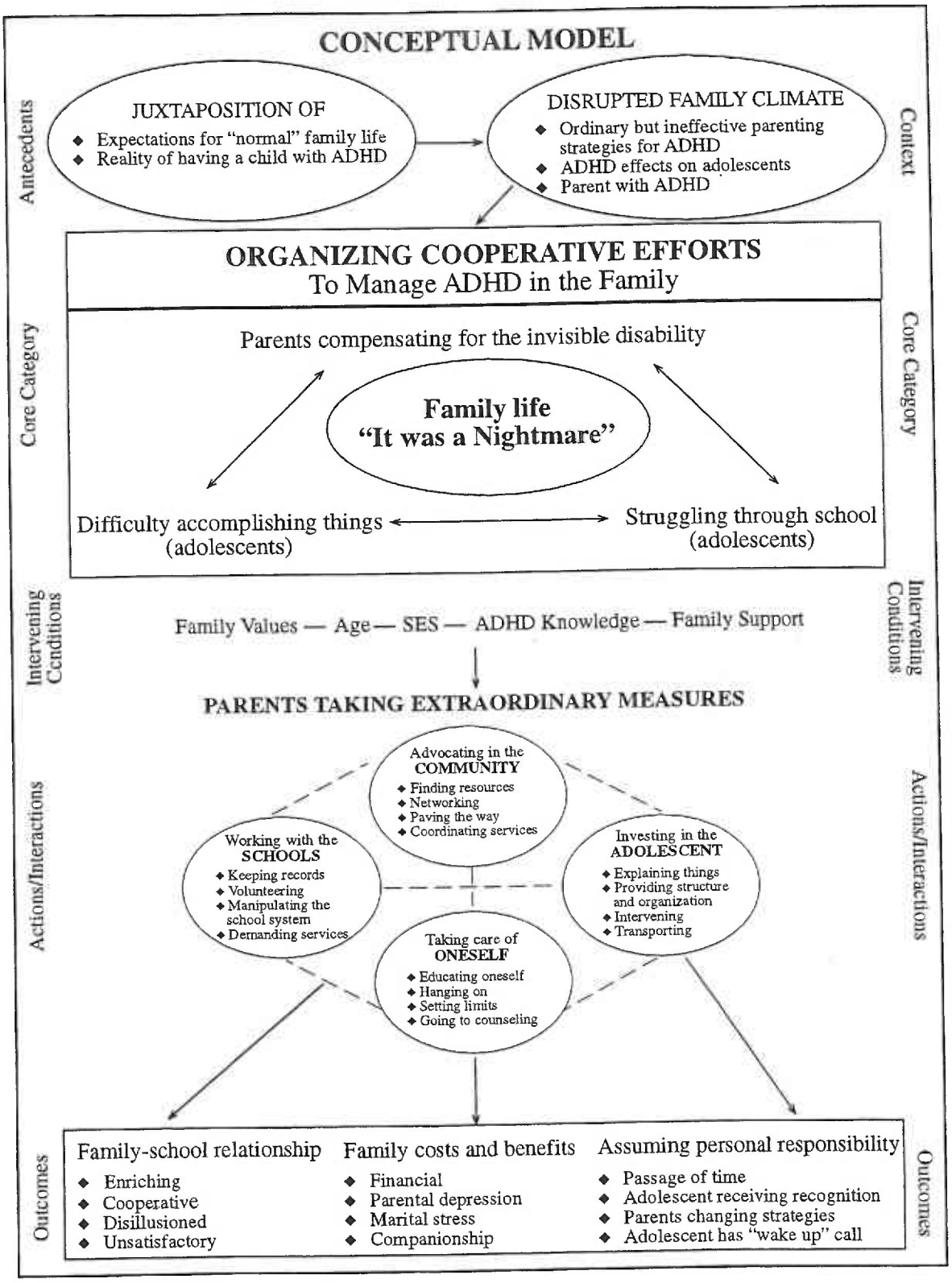

Figure 3. Conceptual Model: The Family Experience with School When an Adolescent has ADHD

The Core Category: Organizing Cooperative Efforts

The core category in a grounded theory is the central phenomenon (an idea, event, or situation) for which a set of actions is taken to manage or handle the phenomenon. It is the result of the antecedent factors and exists within the described context. Actions and interactions are undertaken to manage or respond to the central problem or situation, and there are outcomes that result from actions taken. The core category of data in this study was Organizing Cooperative Efforts to Manage ADHD in the Family.

There were four categories of data within the core category: adolescents having difficulty accomplishing things, adolescents struggling through school, parents compensating for the invisible disability of ADHD, and the family nightmare. The combined effects of ADHD symptoms on adolescents led to two patterns of behavior: difficulty accomplishing things and struggling through school. Parents called these two patterns of ADHD behavior a "nightmare" for the family. They regarded these patterns of behavior as an "invisible disability" and realized that as parents, they had to develop compensations for the disabling conditions on the adolescent and the family. They did this by organizing cooperative efforts to manage ADHD (see Figure 3). Each of these categories will be described below. The categories, difficulty accomplishing things and struggling through school will be described first because an understanding of the behavioral patterns is prerequisite to understanding the how and why parents compensated for the invisible disability and the family nightmare that resulted when adolescents used the patterns of behavior.

Difficulty accomplishing things

The first major category of data in Organizing Cooperative Efforts was called "difficulty accomplishing things". Adolescents in this study had great difficulty accomplishing tasks at home and at school. Six factors interfered with accomplishing things (see Figure 4): procrastinating, distracting, checking out or daydreaming, resisting or avoiding, giving up, and relying on others' reminders to do things.

Procrastination. Procrastination was the act of putting off doing something until a future time. Procrastination involved the intention to accomplish the task at some time but not in the present. Sometimes adolescents described procrastination as a passive event, something they did without awareness, rather than it being a deliberate attempt to put something off. Adolescents also reported that procrastination occurred when tasks were unchallenging. Adolescents with ADHD used procrastination much more frequently than peers or siblings without ADHD. As one adolescent explained, "This happens approximately two times a day. Mom says I need you to do the dishes. And you can see that they are still not done (gestures toward sink). She says, do it right now. So I say, okay...I think about it but say to myself, I'll do it in a couple of minutes, or I'll do it before she gets home. And when she gets home, she asks, why didn't you do the dishes?" All parents in the study reported that this was a significant problem for their family, affecting school work as well as activities of daily living, because it happened so many times every day.

Procrastination also was related to the ADHD adolescent's poor concept of time. An adolescent explained how her perspective on procrastination differed from her mother's. "From mom's point of view I procrastinate and don't always put forth what I

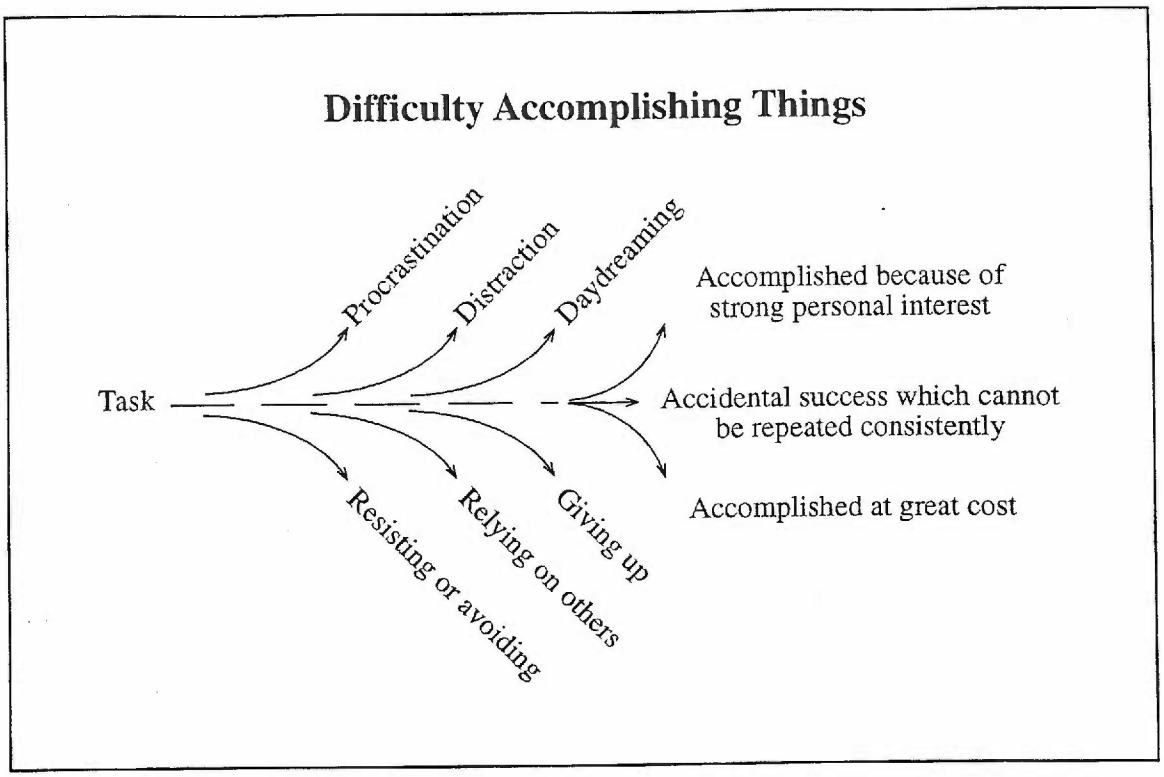

Figure 4. Model of Category: Difficulty Accomplishing Things

can even though she knows I can do it. I see it like I have more time than I do and she sees it like I have less time than I do.

Parents suggested that procrastination actually might be a processing style while ideas percolate, or the result of not knowing how to attack a task, break it into smaller tasks, and begin. Poor organization and mess also interfered with accomplishing things and contributed to adolescents inability to begin a task. Adolescents searching for assignments, books, and supplies needed for homework often appeared as procrastination. Procrastination often led to crunch time when a deadline was near and work was incomplete.

There were consequences for procrastination for both the adolescent and the family. Adolescents suffered anxiety about the deadline and their inability to complete a project or pass a course. They also experienced lower self-esteem as a result of the frequent negative interactions with family and school when they procrastinated. One adolescent stated that if he didn't have ADHD he would be able to get projects done with ease, rather than waiting until the last minute. In order to cope with feeling badly about procrastinating regularly, he thought of himself as "the best procrastinator because I get things done at the last minute a lot."

Consequences to parents when adolescents used procrastination involved parents giving up personal activities in order to find supplies for the projects, providing organization and support to the adolescent, helping with editing and typing, etc. in an effort to help the adolescent accomplish the school assignment. When adolescents procrastinated about chores, there were family consequences: frustration, conflict and other family members having to perform the tasks. For example, a 16 year old described a common exchange with his mother. "She'll ask if I have fed the animals yet. I'll say not yet. Then she'll yell, you have to do that right now. I'll say, yea, in a second...Usually mom will end up feeding them. Or sometimes she'll feed them before I get a chance to." Another adolescent described treating family members better after the stress and tension generated by looming tasks disappeared when the task was accomplished. Parents acknowledged that some of these behaviors were typical of all adolescents. What was different with their adolescent with ADHD was the degree to which things were left undone and the degree of chaos and anxiety that resulted; it was much greater than what they observed in adolescents without ADHD.

Distraction. While appearing to be similar, procrastination and distraction were actually different. Procrastination was the intention to do something at a future time. Distractions were interruptions while working toward accomplishment. A sixteen-year-old adolescent described distractions as "...a giant force field. I can't ever get to [my chores]. If I was ever to actually start doing them it takes like five minutes to do."

Distraction prolonged activities and interfered with accomplishing things. Like procrastination, parents acknowledged that distraction is a common human experience but occurred so frequently in adolescents with ADHD that it regularly and significantly interfered with their ability to accomplish things.

There were several types of common distractions reported by adolescents: thoughts that disrupted concentration on a task, environmental distractions, or over-involvement in activities. Environmental distractions such as the radio playing, the dog walking through the room, or somebody whistling downstairs, provided constant threats to staying focused. One mother characterized distractions as "too many irons in the fire" and attributed difficulty accomplishing things as a result of not setting priorities.

Distraction affected family life. It contributed to household mess and disorganization, and disruption of family routines when schoolwork and chores were not done. Distractions made simple activities like dressing in the morning a complicated routine. Adolescents felt tense and moody when tasks were not accomplished in a timely manner, and experienced increased stress when deadlines loomed and distractions interfered with finishing assignments or projects.

Daydreaming. Daydreaming or "checking out" was another of the characteristics of ADHD that interfered with accomplishing things. It was the antithesis of maintaining

focus to accomplish things. Like procrastination and distraction, it was the frequent recurrence and duration of daydreaming that distinguished it from "common" daydreaming and significantly hindered adolescents with ADHD from accomplishing things in a manner similar to adolescents without ADHD. There were many labels for daydreaming or checking out; it was also referred to it as spacing out, vegging, and being in "lalaland". In all cases, the label referred to the experience of being physically present in a particular place but being mentally absent to the point of being unaware or under-aware of one's surroundings and missing important interactions and information which were needed for understanding and functioning. As one mother said, "his body was here and his head was somewhere else."

Adolescents said daydreaming resulted from fatigue or boredom, or as a coping mechanism when adolescents were not able to remain focused on the classroom or family activity. They developed strategies to engage when they were "caught" daydreaming at school: "I'll make a joke and then I'll look at the board and realize in my head what is going on while I'm making the joke and then I'll say what is going on." Another adolescent similarly relied on cues from classmates and the environment to rejoin the class. Other adolescents alluded to humor, hyperbole, and word games when trying to deal with boredom. One adolescent was bored working on a science worksheet and played a mental guessing game: "it's not moving, it's not funny, it's not a lizard, it's not running, it's a piece of paper!"

Checking out or going to "lalaland" was described as a recuperative strategy for dealing with stress. Lalaland was described as "being in her own little world" or "playful...write stories...make things up...just in a different world and was very content

and very happy". An adolescent explained that "vegging" was like going to "lalaland" and occurred when he was "tired, tuckered, and my brain just can't do it any more. I need to just sit down and take a break". He also said that he "vegged" when he felt very low or when he needed to "get away from life as it is". Another adolescent talked about needing more sleep or a lazy day or weekend for "vegging". Parents and adolescents said daydreaming and checking out happened many times a day and significantly interfered with accomplishing things.

Resisting and avoiding. Resisting and avoiding were intentional acts not to do something, in contrast to procrastination where there was intention to do something at a future time. This intention to not accomplish something was either a neutral or oppositional act. An example of neutral avoidance was when a adolescent simply did not want to do chores because something of greater interest was competing for time and attention: "I came home and didn't really want to do my work. I just wanted to watch TV and put photos in an album." In contrast, resistance to accomplishing something was usually an act of opposition or rebellion against someone trying to get the adolescent to accomplish a task. It was the element of interpersonal struggle that distinguished resistance from avoidance.

When adolescents used avoidance and failed to accomplish a task, there were minor consequences to the family such as disappointment, other family members having to complete what the adolescent avoided doing, etc. However, there were almost always negative consequences to the family when adolescents used resistance to not accomplish things because of the added level of tension and discord attached to the parent/adolescent

contest of wills. Frequently families reported that this negative climate was more disruptive to the family than the fact that a task or project was not completed.

Adolescents used avoidance when the task was difficult, when the fear of failure and threats to self-esteem were attached to a task. Sometimes avoidance looked like procrastination, in which case it was not a matter of doing something at a future time, rather, adolescents used avoidance when they did not know how to go about a task and felt uncomfortable about having to ask for help with what peers seemed able to do without effort. Avoidance was used more frequently by younger adolescents than older adolescents, reflecting a maturing understanding that some things just had to be accomplished.

Both adolescents and parents reported that sometimes resistance to doing homework or accomplishing tasks was more related to emotional contesting between parent and adolescent than it was about the task itself. Several families talked about accomplishing the task of taking medication. Even though adolescents agreed that medication was helpful, frequent conversations about the daily medication routine reflected the adolescent's resistance to parents' reminders (telling them what to do) rather than an intention to not take the medication.

Giving up. Giving up occurred most often when adolescents were under stress and when they could not see any chance of success. It happened most often during "crunch time" when adolescents were faced with completing many worksheets that had not been turned in. Because of parental support and encouragement, adolescents did not use giving up when large projects were due. Younger adolescents were more prone to giving up than adolescents who were juniors or seniors in high school.

In summary, difficulty accomplishing things was a category of data about the central phenomenon that described a pattern of behavior that developed from ADHD symptoms. While the pattern of behavior was observable, the underlying causes of the behavior or ADHD symptoms were not visible. Because of adolescents' difficulties with accomplishing things, parents had to compensate for the invisible disability of ADHD and organized cooperative efforts to manage the effects of ADHD in the family.

Struggling through school

Struggling through school was the second major category of data in the core phenomenon, Organizing Cooperative Efforts to Manage ADHD in the Family. Adolescents and parents reported a predictable cycle that occurred at the beginning of each new term or school year, ran its course, and repeated itself yearly with little variation unless actions on the part of school, adolescents, and parents coalesced into a pattern of adolescents assuming personal responsibility for their school performance. Struggling through school consisted of seven stages (see Figure 5) that occurred in a predictable order: intending to do well, keeping up initially, performing unevenly, falling behind, getting to crunch time, compensating with extra credit, and pulling it out of the fire.

Struggling through school had macro and micro meanings. In the larger sense, this process described the long term pattern of adolescents' performance that deteriorated as school years went by, as the effects of ADHD accumulated and the adolescent's ability to compensate failed to keep up with the increasing demand of schoolwork. Struggling through school as a micro event involved the process of keeping up with work during a single term or school year.

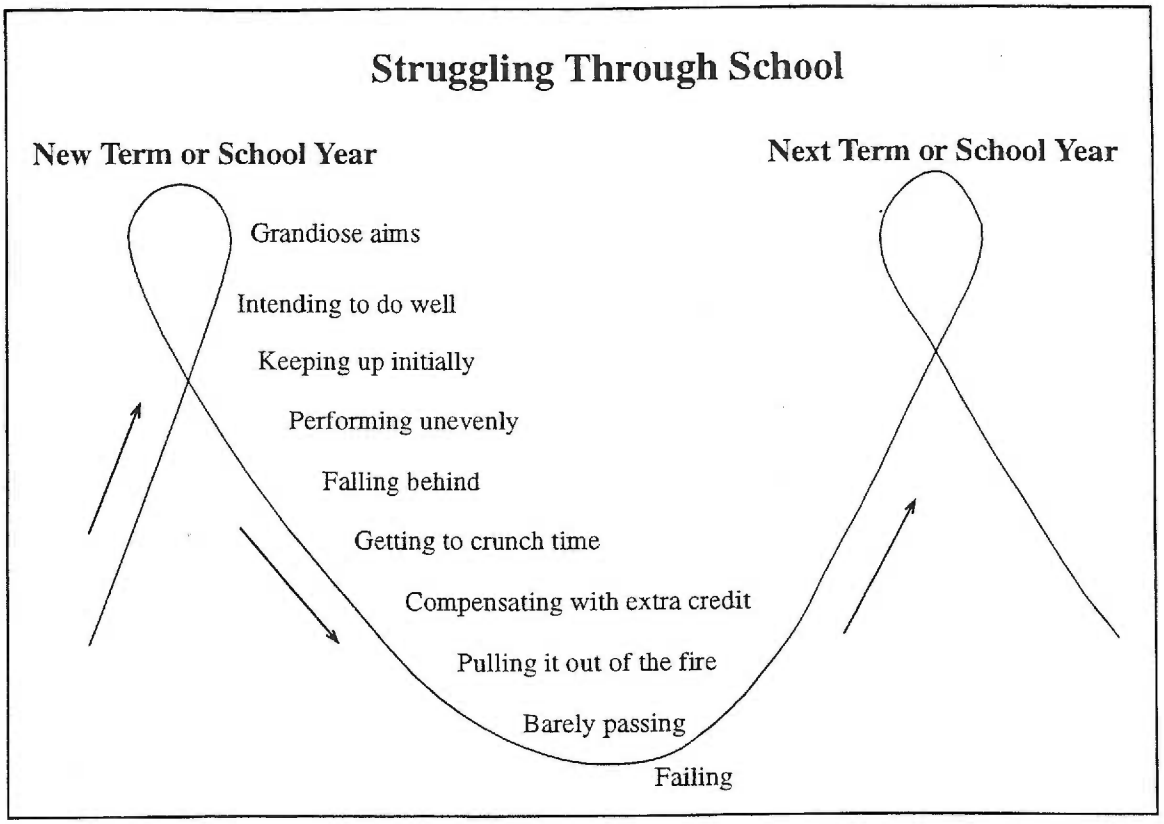

Figure 5. Model of Category: Struggling Through School

Intending to do well. At the beginning of a term or school year, adolescents intended to do well. A junior in high school stated his intentions: I ve been thinking I m going to do a lot better this year than last year. For adolescents it meant they would complete assignments, study, and pass tests to demonstrate mastery of the subject material. A related component of intending to do well was a grandiose vision of things to be accomplished. For example, one adolescent hoped to be elected class president; other examples included scoring the maximum on an achievement test, or rising to first chair in the orchestra section. While the envisioned goal was not beyond the reach of the adolescent, the likelihood of achievement was doubtful as long as this cycle persisted.

Keeping up initially. Next in the cycle was the period of keeping up initially during which time students completed and turned in assignments on time, and parents and schools provided necessary support. A stepfather described his freshman adolescent: "The first six weeks of school she will stay right on, trying to get as much in as she can, stay on task, and give it her best effort." Parents provided organization and structure and the adolescent was receptive to help and encouragement. He explained how the emotions of success initially energized his stepdaughter: "She'll really feel elated about it. She'll really be upbeat and pumped. She gets a euphoric feeling about being ahead of her class, ahead of her assignments, having everything turned in."

Performing unevenly. As the days and weeks of the school term passed, the adolescent began performing unevenly, which consisted of keeping up with some assignments in some classes, doing well on some tests, but here and there missing an assignment, performing poorly on a test, or failing to comprehend a concept. For one adolescent, the euphoria of success was soon replaced by anxiety: "She is anxious about doing well and staying on top of it and she just can't keep that momentum up. The steam goes out and things start piling up..." An adolescent explained that it was hard to keep up on daily work, and assignments brought home didn't always get finished or turned in at school.

Another aspect to performing unevenly involved the inability to maintain passing grades in all classes. As a father explained, "what happens is, one of her grades is low, so we meet with her special ed teacher, we work really hard to bring up that grade, and another grade will fall. It can never be (consistent), there is no evenness in her grades".

Falling behind. Soon a pattern developed where the student found himself or herself falling behind. What was an irregular occurrence of missed work or a poor grade earlier in the term or year quickly turned into a trend where many assignments were missing, more than one test score was unsatisfactory, and larger portions of course material were unmastered. One mother commented that as the school year wore on and the workload got heavier, her daughter started missing one or two, then five or six, "and the snowball starts rolling".

Getting to crunch time. Crunch time was the period during a term or school year when the possibility of failure loomed because of missing assignments or several poor test scores, and a crisis was identified. Usually crunch time was identified when a parent realized progress reports were not coming home and it was close to the end of a term or school year.

Suddenly aware of the looming failure, despite the best of intentions, adolescents and parents engaged in a flurry of activity to save the day, usually creating a huge disruption in the family's evenings. One adolescent described feeling like he had to stay up past his bedtime typing the paper that had to be turned in the following morning. A parent talked about driving "all over town" to purchase materials for an art project due in the morning.

Crunch time sometimes presented dilemmas for parents when they had to decide whether to let their adolescent experience the natural consequences of falling behind. "There have been times with the big crunch on them, I'm going to try and help if it's like my son is showing clear, large stress over it. But if it is a practice sheet, and they haven't

got it done, and there is one of those every week, that's where your logical consequence is going to come up."

Compensating with extra credit. During crunch time, one strategy that was offered by teachers, accepted by students, and dreaded by parents was the opportunity for compensating with extra credit. A compensatory project was agreed upon by parents, adolescents, and teachers that, if completed, allowed the student to pass the class or school grade when it became apparent that there were too many missing assignments to make up, or test scores were unsatisfactory.

Pulling it out of the fire. In most cases, the pattern of struggling through school resulted in underachievement. Parents and adolescents both described the suspense before report cards arrived; "I don't know what or how she is going to pull it off in terms of what her grades are going to look like. I'm always prepared for the worst because I know what hasn't been done and I know that even if she gets all this work done that she is only getting partial credit for it. So it is kind of like for her, why bother? If she is only getting a half or quarter credit, then it is a lot of work and stress for her to try to make it all up, get it turned in, and my philosophy is half points is better than none." Many of the adolescents had failed individual courses during their middle and high school careers but managed to do very well in other classes. Two adolescent participants, a junior and senior in high school were in danger of failing for the year, and for another, a senior, graduation was in doubt.

The repetition of struggling through school had negative effects in the long term. Adolescents, parents and school personnel felt that the worry and effort expended during crunch time and pulling it out of the fire was not justified, even when a satisfactory grade

was achieved at the end of a grading period. Over time, the repetitious cycle of struggling through school eroded commitment and confidence in the adolescent's ability to be successful in school. One parent talked about the effect of pulling it out of the fire. "I don't know what her grades are going to look like. I usually just take a deep breath and let it happen because there is nothing I can do about it. We get progress reports so we know what we are working with, and if she pulls it off in the end, and usually she does, and she surprises herself, then we're all going, cool, this is good. However, what can we do so we aren't always doing this? It just drains us. I felt drained." The repetition of this cycle also eroded the resources available that adolescents, families, and schools had to invest in future school terms and years.

Parents compensating for the invisible disability

ADHD affected the adolescents' experiences at school profoundly but because of its invisibility, the difficulties were not always attributed to ADHD. This section describes the disabling and invisible aspects of adolescents' experience at school first and is followed by a description of parents compensating for the invisible disability.

Experiences at school. ADHD affected adolescents' experiences at school and contributed to difficulties organizing their thinking and doing schoolwork. Adolescents in the study had great difficulty with school regardless of the grades they received. All adolescents had tested at above-average intelligence and many displayed talents in art, music, science, writing and theater, yet all of the adolescents and their parents reported that it was difficult to do well in school. Actual performance on schoolwork varied widely in individual classes and over the years.

Despite the struggles with school, seven adolescents were in honors programs and three adolescents were getting very good grades, roughly equivalent with their potential. Seven adolescents were performing "unevenly" with good grades in some subjects and failing grades in others. Two adolescents failed courses regularly or barely passed, although each had had classes in which they excelled. One of two seniors in the study was in danger of not graduating, despite his ability to maintain good grades during the months he played sports.

ADHD altered adolescents' perceptions of school difficulty, affected the grades they earned, the quality of work they produced, and how they managed school projects. Adolescents took advantage of opportunities to learn outside of school that helped them in school. Six factors were involved with adolescents' performance on schoolwork: the student's perceived level of difficulty, meaning of grades, quality of work, the management of schoolwork, fatigue, and learning outside of the classroom.

Perceived level of difficulty. Adolescents with specific learning disabilities often reported schoolwork was difficult in that area; however, the perceived level of difficulty did not necessarily correspond to their performance. For instance, one mother commented on a part of her son's interview with me: "he talks about struggles with math, well, he is in freshman algebra and he is in eighth grade. He is getting B- or C+."

Meaning of grades. Adolescents reported a range of meanings of grades, from important to irrelevant. The meaning ascribed to grades often correlated with the grades they received in a class. One middle school student described his effort to get good grades because that was important to him: "Motivation and rewards? I don't look for so much, you know, pizza, candy, pop, I look for kind of my future. I look, oh no, I have a

B, and it's a very low B. I need to get myself on task. Now I have an A, now I can pat myself on the back, I'm closer to my goal of, you know, getting good grades kind of a thing."

In contrast, poor grades often related to boredom and perceived irrelevance. Adolescents with ADHD suffer from boredom when they do not find a task or assignment intrinsically interesting, thereby limiting long term goal achievement. One student explained why he wasn't able to complete class work satisfactorily: "Um, it just gets boring, 'cause we have like...I don't want to make it seem like I'm not interested, but after a while, after nine lessons that are each eight pages long, taking detailed notes for a really important test, it just wears you out." Several parents described their adolescents as not understanding the importance of grades nor sharing the family value of doing well in school, leading to poor performance; one parent said, "he gets real defensive and we have gotten into real heated discussion at the end of last year because his grades weren't where they could have been. So I would have the discussion, what is it going to take to get you to work to your potential? How do you overcome the choice to do it or not do it? And his discussion, my grades aren't about who I am as a person. They are just a letter that is thrown on a piece of paper. Just because I get a C in a subject doesn't mean I'm not going to pass school..." Another mother reported her son's experience in algebra. "He flunked Algebra II because he was bored and didn't like to do the homework...I know that he has a strong feeling of wanting something to be relevant in order to become engaged in it. And a lot of his schoolwork doesn't seem too relevant to life."

Management of schoolwork. Adolescents continually struggled with managing schoolwork, including estimating time needed for assignments, maintaining the quality of

work, and turning work in on time. Because adolescents with ADHD had difficulty with the concept of time, they often misjudged the amount of time a project or assignment would take and how long it would take with the inevitable distractions. One mother explained, "she needs more time. There is no way that that kid can put out that stuff. It is like her brain does not allow her to do a project from beginning to end in eight hours. It takes her a longer... it takes her three days and that is if she stays focused on the activity." A father talked about the trouble his sons have estimating the time needed for a project: "I would say that things like how much time it takes to get ready to do something, is a big problem. Mis-estimating how long it will take to complete an academic project...they might think that an hour is enough time. Well, after they've been at it four hours, and it's about two-thirds done..."

Mismanaging the temporal aspects of schoolwork often contributed to increased stress and lost opportunities for other activities when schoolwork piled up. A mother called it a "domino effect": "all of a sudden she is struggling to make sure she gets this stuff done and she doesn't know how she is going to manage her time to get all this stuff done, and all of a sudden she can't do the things she wants to do because she has all this other stuff she needs to attend to."

Quality and timeliness of work affected the grades adolescents got on schoolwork, but quality of work was not related to the level of difficulty of work. Adolescents often approached schoolwork impulsively, trying to get it finished as quickly as possible while parents struggled to get adolescents to improve the quality of their schoolwork because they believed in "doing your best". A mother described a typical scenario: "Can you do this to better it? I don't want to. It'll be good for you. But, I've done what is required.

You really should (improve it). I don't want to. Would you please do it? Groan groan. Oh, okay. Oh, that doesn't look very neat. But you said I could if I wanted to...I'm doing this for you. Well, honey, if you want good grades, do it good."

Adolescents with ADHD often were not motivated to improve the quality or timeliness of schoolwork by the threat of negative consequences or the enticement of rewards. The quality of their schoolwork often was not related to the level of difficulty of the course. Adolescents performed unevenly at school, sometimes excelling in one class and failing in another. Stimulant medications were helpful in improving school performance and moderating social and emotional behavior but did not eliminate the negative effects of ADHD entirely. Both parents and adolescents could tell when medication had been taken and when it had not.

Poor grades were often a result of missing work rather than work poorly done or not completed: "that is the thing, it is always missing work. Often times it is work that is completed and lost somewhere in her mess. Her grades in testing are great. Her grades on projects are great. But her overall class school grade has dropped two or three points because her daily assignments aren't turned in. So we come along with As and Bs and come out of the class with a D, threatening to fail because she doesn't get her daily assignments in." Even when parents sat with their adolescents, saw that the work was completed and put in the backpack in the proper folder, adolescents had great difficulty getting work turned in. One mother explained that despite her best efforts to help her son his grades still suffered because of lost work: "I have to talk to his teacher. My son has a problem with that because he forgets to turn things in. That is a part of his grade, why he

doesn't have better grades. He has A's and B's but instead of doing better, because he loses them and forgets them."

Fatigue. Physical and cognitive fatigue negatively affected the adolescents' experiences at school. It was a frequent complaint and contributed to adolescents' inability to accomplish things. Adolescents had great difficulty getting up in the morning and being awake enough to function well. All families in the study reported this was a problem and characterized it as more than "just fatigue" from being up late the night before, but a frequent and pervasive type of fatigue that interfered with the adolescent's ability to function. One adolescent explained that cognitive fatigue was different from physical fatigue: "I get mentally tired out of it after, you know, homework, homework, homework. I won't if I'm liking it or if it doesn't require thinking and that's also when I'm depressed and I don't want to think, I just go down and "veg", because I don't want to do any thinking." Another adolescent talked about fatigue he related to homework: "when I'm mentally fatigued, I feel like I'm tired, and my mood, I try to stick out of people's business when I'm mentally tired. I mean, when I get mentally fatigued from all the homework, I want to be happy…but that's homework, I'm sorry, I just can't make myself do that."

The adolescents often spoke of being tired more than their peers. One girl in the study had difficulty staying awake in school: "Most of the time she is just really tired. She will come home and say, oh, I am so tired. I slept during such and such a class." Another adolescent who complained of feeling tired at school tried to schedule his more difficult classes for later in the day when he would be more aware and ready to learn: "I'll ask if I can get it at a later time and then they want to know why. I'll have to tell them I

won't be awake then…I am really tired during first and second period and then I kind of wake up around lunch." Adolescents also described feeling fatigued at home after school, one parent described it as "shutting down": "When she gets home she can manage just a little bit more time of studying and that's it. It is almost like she is burned out and it is time to shut down. And she really does just literally shut down. It is like her brain cells check out."

The paradox. Parents described a paradox regarding the adolescents' abilities and disabilities. Many adolescents taught themselves complicated things of personal interest like trigonometry, computer programming, or they developed special talents in art, music, and athletics. Despite these abilities, they struggled with subject matter in other areas and had great difficulty accomplishing things, especially mundane tasks, at home and at school. The incongruity between the high level of performance in certain areas and very low levels of performance in other areas was confusing. One mother described her confusion: "If these adolescents are so bright, so talented, and do so many extraordinary things, why can't they do seemingly littler things like get themselves up in the morning, organize themselves, and do little chores daily? When you have kids who are obviously bright and capable to begin with, and I think 90% of kids with ADHD kids are, it is hard to reconcile, if they can do this, why can't they do that? My son can tell you what he had for breakfast and what pajamas he was wearing on March 3, 1985, but he can't tell you what tomorrow's algebra is. He can recite full dialogue of a television program or a movie, but if you ask him to repeat what I just told you, he can't."

The paradox was created when symptoms of ADHD interfered with an otherwise bright adolescent being confronted with the invisible, disabling, and pervasive effects of

ADHD had trouble with many mundane tasks that make up daily living. These were tasks that people with lesser ability seemed to master with relative ease. However, adolescents had great difficulties with time, difficulty accomplishing things related to difficulties remembering, connecting, organizing, and being "aware" experienced by adolescents with ADHD. Teachers were faced with a dilemma when the paradox appeared because they wanted to recognize the extraordinary work in some areas and yet not tolerate the lack of performance of daily tasks. One mother explained: "I remember these teachers saying, I don't know what to do. I look at my grade book and I have got F, F, F on all the worksheets. And then he turns in a project that would be an A in high school and he is in sixth grade. So I can't flunk this kid. I said, so give him an A. They say, how can I give him an A when he hasn't turned in any worksheets? So, he tended to get B's from those kinds of teachers."

Parent compensations. Parents had to first recognize and accept ADHD as a disability before they could begin to compensate for the invisible disability in their adolescents. Parents debated with themselves and others about whether the individual symptoms of ADHD they observed in their adolescents and if the two patterns of behavior, accomplishing things and struggling through school, were attributable to "normal" adolescent behavior. They concluded that some problematic behaviors were similar to other adolescents, but the frequency and intensity of the behaviors for adolescents with ADHD were much greater. Parents also felt that after years of observing these behaviors and finding nothing that helped with remembering, organizing, or accomplishing things, they began to realize that their adolescents were not "not doing" these things, but that they "could not" do them. Parents began to accept these behaviors

as part of the disability of ADHD. One mother said, "I don't know if you have seen the commercial for granola bars. The high school kid comes running down the stairs to the bottom and says, oops, forgot my books and runs up. Then he comes down again, and remembers his hat, does it again, and remembers his lunch. The first time we saw that we said, on my God, that's our son. He couldn't get a series of things. You could say, go get your jacket. Fine. No problem. Close the door, turn off the light; pick up your jacket and backpack, not going to happen. He couldn't do a series of things." Another example of a disabling aspect of adolescents with ADHD was described: "...he couldn't think past the end of his nose. You couldn't get him to understand that if you don't do A, you can't do B and C, and here is the result. He can't make the connections."

Once parents accepted the diagnosis of ADHD as a valid medical condition and that, in fact, their adolescent with ADHD, had an invisible and disabling disorder, they were able to understand that the "family nightmare" was a consequence of the disability and devoted significant family resources toward organizing cooperative efforts to manage ADHD in the family. Parents spoke highly of the benefit of services from a multi-specialty ADHD clinic although they still struggled to manage behavior and daily routines. One mother compared her experience before and after her family received comprehensive family services at an ADHD clinic. "There were lots more conflicts before we knew what was happening...It was much harder before he was diagnosed, because if you can't put your finger on what is wrong...But once you can say, one of the symptoms of ADHD is... impulsivity, and you can put it in a context that makes sense so you aren't blaming yourself, each other or your kid, really, you are trying to figure out strategies that will work."

The family nightmare

The family nightmare was the result of the interaction of three factors: adolescents' difficulty accomplishing things, adolescents struggling through school, and parents trying to compensate for the invisible disability of ADHD. Families called this interaction "a nightmare". There were three aspects of the nightmare for parents, dealing with school personnel, dealing with the adolescent about school at home, and dealing with personal emotions resulting from the nightmare.

The family nightmare emerged when the child first began experiencing difficulties in school or when the parents experienced difficulties when communicating with school personnel. Parents' frustration level was already high after trying without success to help their child with school, prior to enlisting help from schools. When communication and school relationships were unsatisfactory, parental frustration increased, leaving parents wanting more from school. Several parents thought teachers perceived students with ADHD as a nightmare to have in the classroom. When teachers were unsympathetic to the adolescent's disability and unwilling to make accommodations to facilitate success, it became a nightmare for the adolescent, as well: "Algebra was a complete and total nightmare for him; it was just awful and his teacher was, 'this is how we do it, and if you can't keep up, tough.'"

Often the family nightmare was exacerbated during middle school, when there were increased academic expectations for students, and adolescents with ADHD struggled through school because of the effects of ADHD and the delays in development related to ADHD. Having to deal with multiple teachers who frequently were unaware of homework being assigned in other classes, plus the increased volume of schoolwork

expected in higher grades contributed to the adolescent's experience of inner chaos and family disruption.

Parents described a frequent scenario where the family would start something, often homework, and things would deteriorate quickly. "The problem is when you start something, things go and fall apart so fast, messes happen, things break, kids get hurt, that all of a sudden what was joyful fun has turned into a nightmare." The nightmare was made worse when adolescents misunderstood assignments and directions, which often led to conflict with parents who interpreted assignments differently.

The emotional aspects of family life as a nightmarish experience related to the reality that parenting ADHD adolescents was more difficult than parenting adolescents without the disability; and resulted in parental feelings of confusion, inadequacy, and lack of support. Several parents stated they felt parenting children with ADHD was more difficult than parenting children without ADHD. "You've got to understand as a parent that you've got a much tougher row to hoe than everybody else, and if you want to bear your cross, and you know what, honest to God, we've got a cross to bear. This is a lot harder than it is for other families." Lack of support and understanding from extended family, friends, and the community often resulted in isolation. "When you feel like you're all on your own, and you've go no resources behind you, I think that's when people get desperate, and people get depressed. The more negative energy you have going, the more that feeds on itself...Talk about a nightmare; I could easily see this turning very unpleasant for the parents who aren't getting what they want. When their needs are never met, the kids needs aren't being met, and that feeds on itself."

The nightmare of parenting children with ADHD was worsened when meeting the demands of more than one child with ADHD decreased the time and energy available for parents to meet other family and personal obligations, as well as their own needs. "Not only was one of my children falling apart, all three were. At the same time. So as a family, it was very chaotic. It was very explosive at times, very confusing. It was a nightmare because I didn't know at that time what I needed to be doing." Over time, parents learned strategies to manage some aspects of the chaos but the nightmare continued as the younger children went through school, despite parental experience with the older siblings.

To summarize, the core category of data for this study was about the parents interest and intent to organize cooperative efforts to manage ADHD in the family. Parents were becoming more and more aware that "ordinary good parenting" was not enough to manage the ADHD disability. Parents in the study desired a more organized and cooperative resolution to their nightmarish experience. They felt depressed, isolated, and out of control. This was a major family focus intended to minimize the very difficult family situation that families called a "nightmare" which had resulted from adolescents having difficulty accomplishing things and struggling through school, and parents expending tremendous family resources on compensating for the invisible disability of ADHD. The next section contains explanations of the antecedents, context, actions and interactions, intervening conditions, and outcomes related to parents organizing cooperative efforts to manage ADHD in the family.

Antecedents: The juxtaposition of expectations vs. reality

Antecedents or causal conditions in a grounded theory are the events or incidents that lead to the development or occurrence of a social phenomenon (Strauss & Corbin, 1990). The categories of data that emerged as antecedents to the family experience with school when an adolescent had ADHD included expectations of parents for a "normal" family life juxtaposed against the reality of having a child with ADHD.

Expectations of a "normal" family life

Expectations of a "normal" family life was a category of data that were antecedents to the core category. Parents reported developing early expectations about their future family life during their adolescence and young adulthood. They expected to obtain the higher education necessary for the career they hoped to pursue, find a position that would bring personal satisfaction and would provide an adequate family income. They looked forward to getting married and raising a family.

In this study, all of the parent participants were bright, graduated from high school and attended college. It was their expectation that their children would also have above average intelligence to succeed in school and go to college. Those parents who experienced difficulties in school hoped for an easier time in school for their children, and subconsciously thought and planned how to help their children have fewer difficulties in school.

Expectations for a "normal" family life were constructed during the parents' own adolescence and arose from the family life they experienced as children. Those who came from families with rigid rules, oppressive religious beliefs, or problems with violence, alcohol abuse, or child abuse made conscious decisions and took steps to live

differently; they educated themselves and chose partners and careers that supported the expectations of family life they envisioned. Parents who came from families that were relatively happy included many of the aspects of their childhood into their early expectations of their future family life.

When envisioning having children, only one couple reported seriously considering the possibility of having a disabled or medically fragile child. This consideration arose because there was a child with a congenital disability in the extended family. Other couples expressed hope that their children would be "normal" but did not belabor the consideration of having a child with a disability or medical condition.

Even though 12 of the twenty parent participants in the study had ADHD, none of the parents considered the possibility of having a child with ADHD. Only one of the parents with ADHD, the youngest participant, had been diagnosed with the disorder during childhood. All other parents were diagnosed in adulthood since ADHD was not commonly recognized and diagnosed during the 1960s and early 1970s when many of the parents in this study were children. In fact, most of the parents with ADHD in this study were diagnosed only after their child with ADHD had been diagnosed.

Reality of having a child with ADHD

The second category of data antecedent to the core category was "reality of having a child with ADHD". The early expectations of creating a family and raising children in a loving, peaceful, nurturing household were challenged when the children with ADHD were young. For many parents, they identified very early that "there was something different" about the child who eventually was diagnosed with ADHD. As the child grew, more behaviors related to ADHD became apparent. Most concerning were

behaviors of stubbornness, aggression, and difficulty following rules. In many cases, parents attributed the early ADHD behaviors to precocious development, while others outside the family more often attributed the negative behaviors to poor parenting.

Some parents acted on their concerns about the emerging ADHD behaviors and sought medical attention on their own for their child. Other children were diagnosed after teachers observed behaviors associated with ADHD and shared this information with parents. Two of the adolescents were not diagnosed with ADHD when parents first responded to the school's suggestion that a child be evaluated; these children were initially evaluated by a counselor or psychologist who did not think the child had ADHD.

The discrepancy arose when the criteria used in school district testing focused on the severity of behaviors related to learning rather than the more global perspective of the medical diagnosis. At this stage in their lives, parents did not have enough information about the disorder nor skills in advocating for their children and they trusted the judgment of school professionals. However, parents were frustrated by the inconsistency in the professional opinions and the difficulties their children were experiencing at home and at school. Several years later the parents sought a second opinion from their pediatrician after a different teacher suggested to parents that a medical evaluation might be helpful. The child's pediatrician then did diagnose the child with ADHD.

All the adolescents in this study were diagnosed by their pediatrician during the elementary school years. Seven of the twelve families (12 adolescents) were referred to a specialist, such as a developmental pediatrician, psychiatrist, psychologist, or a multidisciplinary team at an ADHD clinic. The adolescents also received testing through the school districts for educational planning purposes. All nineteen adolescents had taken

medication for ADHD at some time during elementary school and middle school years. At the time of the study, seventeen were taking medication daily, two were not. One adolescent who was managing his own medication said he "often forgot" to take it.

Once diagnosed with ADHD, all parents acknowledged relief to learn that something was "wrong" with their child and they became hopeful that things would improve as they complied with the treatment recommendations. They gratefully anticipated an end to feelings of blame for their children's misbehavior and inability to succeed at school. One mother compared her experience before and after her family received services at an ADHD clinic: "there were lots more conflicts before we knew what was happening...It was much harder before he was diagnosed, because if you can't put your finger on what is wrong, you don't know if it is me? Is it lack of consistency? Is this kid just whacko? Just what are we doing wrong? What can we fix? You go back and forth and it is a never-ending struggle."

In most cases, the primary treatment recommendation was a stimulant medication that was effective in curbing the intensity of the problem behaviors. However, the euphoria they experienced initially when the medication improved some behaviors evaporated as the core deficits of ADHD were not corrected, and the negative effects of ADHD persisted: problems with the concept of time, completing tasks, oppositional or avoidant behaviors, and egocentricity. Parents who did not have the benefit of services from multidisciplinary professionals still struggled most to manage behavior and daily routines with the child with ADHD.

In summary, it was the juxtaposition of parents' expectations of a "normal" family life set against the reality of living with a child with ADHD that set the stage for

the context of this study, disrupted family climate. This disrupted family climate occurred despite the level of education and mastery of life skills attained by these parents during young adulthood and their aspirations and diligent efforts to be good parents. The context that emerged from these antecedents is described next.

The Context: Disrupted Family Climate

The context in a grounded theory contains the set of conditions that pertain to the central social phenomenon and under which the actions and interactions occur in an attempt to manage or carry out the social phenomenon. The context for this study was a disrupted family climate. Categories of data that are included as context for this study were: disrupted family climate, ADHD effects on adolescents, and ordinary, but ineffective, parenting strategies. The disrupted family climate resulted from the clash between adolescents struggling because of ADHD symptoms and parents finding that ordinary but ineffective parenting strategies did not always work with ADHD adolescents, even though most parents practiced good parenting skills with diligence.

Adolescents in this study manifested the symptoms of ADHD, which included inattention, distractibility, hyperactivity, egocentricity, poor impulse control, problems with short term memory, organizing, and making mental connections, difficulty delaying gratification, altered concept of time, and poor rule-regulated behavior. They were unable to pick out salient information and often "missed the point" in social situations and academic work. Many of the adolescents in this study also had diagnoses or features of oppositional defiant disorder, anxiety, depression, obsessive-compulsive disorder, Tourette's syndrome, and learning disabilities, all of which are common co-morbid conditions with ADHD. All of these symptoms had the potential to disrupt the family

climate. These additional diagnoses are typical and are characteristic of the disorder. It is very unlikely one would have ADHD without other secondary difficulties. In this sense, this sample of adolescents is typical of the larger ADHD population.

Disrupted family climate

The major category of data that provided the context for this study was a disrupted family climate. A disrupted family climate resulted when parents used ordinary, but ineffective, parenting strategies for raising adolescents with ADHD which clashed with the realities of ADHD effects on adolescents. The disrupted family climate was episodic rather than pervasive and occurred most often when the adolescent needed to perform a task (such as a household chore or a homework assignment) and the ordinary parenting strategies (like asking or reminding the adolescent of a chore or homework assignment) were not sufficient for getting the task done.

The disrupted family climate was felt both internally and externally. Internally, adolescents and their parents felt powerless and frustrated much of the time because they were unable to mitigate the effects of ADHD on life at home or school. Externally, ADHD affected interactions between adolescents and their parents more frequently and more intensely compared to the level of family conflict commonly associated with adolescence.

Homework. Parents reported that trying to get adolescents to do homework was a major source of conflict and a regular trigger for the disrupted family climate. There were typical and predictable family scenarios when tension rose and behaviors escalated as one mother described: "it was like mixing oil and water. That was a very difficult time. It was one of those situations of 'I don't get this'...And he would think he was

getting it and his dad would say, well, if this is this, and this is this, then what is this? And he would say, that. And dad would say, No! Wrong! And that is what I mean by...WWIII going on in the kitchen with the two of them trying to do math. So sometimes I would just have to say, okay, round two. Everybody back in their corners."

One mother said, "and one of the problems that I am sure you know is getting into these power struggles. And after awhile it seems like all your life is about is homework. You never have fun with your kids anymore. You are just always at each other, power struggling over homework, getting it done, getting it turned in, is it done well enough, is it done right, and your whole life becomes about this."

Another mother talked about the family disruption that occurred when adolescents did homework: "it creates for us a horrendous parental child dynamic, a negative dynamic that resulted in nightly tears, and crying, and slamming doors, and arguing, and begging, and bartering, trying to get things accomplished but didn't. When that became so volcanic, we over and over again we decided it would be best to take that pressure off the family unit and bring in a tutor."

Adolescent ADHD behavior. The adolescents' impulsive and egocentric behaviors also contributed to a disrupted family climate. Parents described disruptive impulsive outbursts like screaming, stomping, slamming doors, and yelling "I hate you" to parents when they were upset or confronted about grades or unfinished chores or school assignments. Adolescents' moods frequently invaded or pervaded family life and upset the family climate. One father said it made him wonder who was in charge of the household: "You know, who sets the mood around this household, is it your household or are your mother and I in charge? Well, we experienced this a lot...I didn't feel like I

had any, oh, like control, or anything to do with my mood having anything to do with the mood in the household. It was what (she) was up to. How her life was going. If her social life was going well, well then everything was happy go lucky. But if she was having a problem with something, she saw to it that we all had hell. To join in with her hell...if she is having a bad day she wants everyone else connected with her to have as bad a day as hers."

The disrupted family climate was a frequent but not constant element for the families in this study. It was considered highly problematic, however, because parents had envisioned family life as peaceful and harmonious most of the time. The disrupted family climate resulted from the clash between ADHD effects on the adolescents and parents using common, but ineffective strategies to parent their ADHD adolescents.

ADHD effects on adolescents

ADHD had a profound effect on the daily life of adolescents in this study because the symptoms of ADHD permeated every aspect of daily living. They had difficulties with waking and sleeping, and increased fatigue; they struggled with maintaining any kind of daily schedule or routine. Their concept of time was altered, they had great difficulty organizing and accomplishing things, modulating their social and emotional experiences, and performing in school at the level of their potential. They were unaware of the level of disruption ADHD created for them at home and school, and were confused about why their lives were so difficult. In short, they lacked a gestalt about daily routines, rules that structured social, emotional, and cognitive experiences.

One mother characterized the lack of gestalt due to ADHD as "inner chaos". She said it was "unlike clutter and mess that can be cleaned up or organized. It is an internal

chaos thing that is like the plague. It affects everybody and everything. It is not like just a wet towel on the bed. It is not like you can just pick up that towel off the bed and then it is gone. It is chaos that travels physically from place to place everywhere, but it is also internal and you can't change it. The chaos that happens inside, you can't just pick it up. It is still there."

Another mother added to the explanation of "inner chaos": "That is a great definition. For my older son, I think inner chaos is right on the nose. And I think the inner chaos is that they are so smart and they have so much going on, that for some reason, other smart people can compartmentalize, and they can say, now I'm going to think about buying a car this weekend, and then I'm going to think about changing jobs, and then I'm going to think about painting the living room. For an ADHD kid, all those things are all mixed up and they can't sort them out and they can't figure out a starting place or stopping place, and they become immobilized because they can't get the "noise" to stop to have a second to think. I think that is where the distractibility and impulsivity comes in-when you can't stop and organize your thoughts, you lash out and do the first thing that comes to your head. I think that inner chaos is a really good definition of what it feels like my son does."

The chaos also affected the family. According to a mother, "It is this uncertainty; it is going to come up everywhere and you can't predict it and you don't know what is going to happen next" since ADHD affected every area of an adolescent's life: daily routines, social and emotional experiences and experiences at school.

Daily routines. Adolescents found daily routines at home hard to follow and often resisted the routines followed by other family members. Adolescents with ADHD had

difficulty completing chores at home and organizing their own belongings, which led to very messy bedrooms and areas of the house where adolescents spent time. Parents perceived that chores frequently were not completed because of forgetfulness, a poor concept of time, and an immature avoidance of personal responsibility. However, the avoidance was not necessarily rebellious or oppositional; it was a manifestation of the "invisible disability".

One mother offered her explanation about why her son was unable to keep his room clean: an inability to know how to organize the project and where to begin. She talked about how she figured this out: "I honestly think it was because he wasn't quite sure about how to start and what to do because ...when I said, wait a minute. Just this corner, what about this, what about this? And that allowed him to make the first cut...I think he was just kind of overwhelmed by it and so he just didn't... When it becomes too much and he doesn't know what to do or where to begin, he will just avoid it rather than do it."

Morning family routines were particularly stressful during middle school years. Adolescents had difficulty waking up and moving through morning routines without stressing themselves and their family members. Because they struggled with a concept of time, they frequently moved slowly, were late, kept family members waiting, and began their school day feeling rushed and having to deal with consequences of being late. Afternoon and evening routines were similarly affected by the adolescent's poor concept of time. Getting to and from school was often complicated because adolescents were late, missed the bus, or misbehaved and were not permitted to ride the bus.

Social and emotional experiences. Adolescents displayed normal adolescent behaviors as well as impulsive, rebellious, and risk-taking behaviors related to the effects of ADHD. For example, they went through periods of disputing everything parents said or they withdrew into their rooms for hours and days at a time. Boys were frequently in arguments or fights with peers, and those with driver's licenses had been involved in more than one auto accident. No parents reported drug or alcohol use by the adolescents in the study, but several parents worried that it might occur.

Socially and emotionally, the adolescents in this study functioned at a level several years behind their age mates; the impulsive and egocentric behaviors they displayed were more characteristic of younger adolescents. Their social experiences frequently involved misbehavior at school and difficulty getting along with classmates and teachers. Adolescents had difficulty following school rules and routines when inattentive, distracting, impulsive, and hyperactive behaviors reigned.

The social abilities of adolescents seemed related to their age. Younger adolescents had much more difficulty making and keeping friends. In many cases, their friends were older or younger than they were because of the developmental differences compared to their own age mates. Parents of younger adolescents reported making greater efforts to facilitate friendships than parents of older adolescents.

Emotionally, many of the adolescents suffered from low self-esteem, feelings of being overwhelmed much of the time, and depression. They reported, as did their parents, that they struggled with more daily living than their siblings or peers and often displayed immature behaviors for their age. One 14-year-old adolescent in the study said he wished he didn't have ADHD because he would be able to get along with people

better and not have impulsivity. He said as a result of his impulsivity he was often not included in social activities with his friends. At school he said he would be able to work on things and get projects done. Another boy said it was difficult when his friends' parents didn't believe in ADHD; he lamented that he wanted people to know "how hard it is to focus and how easy it is to get off task. I'd tell them about the different problems that I have, like things like hyperactivity and stuff. I just think that people don't understand what, how hard it is to have it."

Ineffective parenting strategies

The second category of data related to the disrupted family climate was about parents' use of ordinary, but ineffective parenting strategies to raise adolescents with ADHD. Parents found that raising adolescents with ADHD was much more difficult than raising their other children without ADHD. Ordinary, but ineffective parenting strategies included loving their children, taking pride in adolescent accomplishments, having aspirations for their children, preparing for their future, worrying, and empathizing with their adolescents during painful and stressful times. Ordinary parenting strategies also included showed interest in school activities, shared activities with their school friends, and established rules and routines that were considered a moderate approach. The highly recommended "good parenting" practices were not effective enough to manage the effects of ADHD. Parents felt unprepared to manage symptoms of ADHD in their adolescents. In many cases, they isolated themselves socially to protect themselves and their adolescents from the criticism of others.

When parents did use common parenting strategies, they had to use them in the extreme, and then with only limited success. For example, a common parenting strategy

was to show an interest in the adolescent's school life. However, parents of adolescents with ADHD were not able to take a casual interest in school, as in attending a few school functions, providing occasional monitoring or helping with homework. Instead, they had to regularly provide structure, organization, and even physical presence while adolescents did homework. One parent recalled, "it used to be a nightly thing that we would have to sit down with him and work with him EVERY NIGHT, every night, every night, every night."

Many parents said they began doubting their competence as a parent when so few things worked. Mothers in particular, expressed feeling totally overwhelmed trying to parent an adolescent with ADHD. One mother said, "I just, I came to think that I must be lazy and selfish because I couldn't keep up with it. I was convinced that I was the problem. If I would stay on top of it better, and I just couldn't seem to stay on top of it better... I look back on it now and realize that I was up against a lot more than I could handle, or that most people could handle." Many parents internalized the blame when others attributed the characteristics of ADHD to poor parents and feelings of inadequacy about parenting adolescents with ADHD mounted because the common parenting strategies didn't seem to work. Parents also felt responsible for the difficulties their adolescents experienced, thinking if they only knew what to do or were better parents, life for the adolescents and the family would be much improved. One parent explained, "You can't put your finger on what is wrong, you don't know if it is me? Is it lack of consistency? Is this kid just whacko? Just what are we doing wrong? What can we fix? You go back and forth and it is a never-ending struggle."

Parent with ADHD

The third category of data in the disrupted family climate was parents with ADHD. Family life was affected profoundly when a parent had ADHD. Twelve parents in this study had been diagnosed with or showed strong characteristics of ADHD, reflecting the strong heritability factor within ADHD families. Despite their apparent success in college and the work place, these parents, like their adolescent children, struggled daily with accomplishing things and cyclic performance of tasks and projects. They had difficulty organizing self and others, poor household management skills like cooking, cleaning, and shopping; and having difficulty making transitions to other tasks, and becoming overly focused on something to the exclusion of all other activities. Spouses without ADHD had to be willing to accept a disproportionate amount of parenting and household activities when married to someone with ADHD.

There were three different scenarios when a parent had ADHD: when the mother had ADHD, when the father had ADHD, and when both parents had ADHD. In most cases, when fathers had ADHD, their wives expressed frustration sometimes but worked to lessen the effects of paternal ADHD on the family. A mother who did not have ADHD commented, "I also have a good friend who is not ADD but her husband is, and a couple of her kids are, and when I talk to her…I get frustration. 'My husband was supposed to do such and such and it never got done and now what am I supposed to do?'"

Mothers talked about the increased responsibility and burden they felt when their spouse had ADHD: "it gets really regimented for me because I'm stuck in all the schedules I have to make for them so they can be functional individuals. I used to have to do that for my husband and he has gotten much better but he still has trouble. He has

learned to keep a calendar...My life was a matter of organizing everybody else's schedule so that everybody could be functional. That is hard to do and still get time in to clean the house, do the shopping, laundry, and oh, by the way, go to work." Another mother said, "The bottom line is, that as the mother, I'm expected to structure five ADD people's lives, and I just can't do that. That has overwhelmed me."

Family life was more negatively affected when mothers had ADHD. Mothers with ADHD had a more difficult time parenting and managing a household than fathers with ADHD. Mothers frequently are expected to be the family organizers and nurturers; mothers without ADHD report being overwhelmed with so much responsibility for other family members. Mothers with ADHD report a constant feeling of inadequacy, shame for not being able to function like other mothers, and experienced depression and guilt.

One mother without ADHD explained: "I don't know what it is about sex roles in our society, but women are supposed to be the glue that holds the family together. I think I have a very good friend who is ADHD and although nobody has diagnosed her, she is! And her family is just a disaster. Nice kids, but damn, it's a disaster. (Her husband) doesn't step in and he is not the glue and everything just crumbles. I think there is a big difference between families when the woman brings the ADHD and the man is ADHD because I think you can function if it is the guy who has ADHD because that is just the way our society is built. I think it is a lot harder the other way."

A mother with ADHD was tearful and spoke with angst in her voice, "It is just a constant feeling of inadequacy...I never could clean house completely anyhow before I, well, I never could do it my whole life...So, for me, I had always had difficulties taking care of my own little life and I couldn't do that very well or consistently. I kept beating

myself up because I wasn't disciplined enough or I wasn't consistent enough. So, bringing that into a family setting gets back to the nightmare issue because I am supposed to be able to work, this is the women's movement thing, a woman can do all these things and it doesn't matter if she has ADHD, because in our society it is still really expected that the mom has a priority, a tremendous amount of the nurturing, parenting simply because that is the way it has always been. Yet, I wanted to fit into that picture because a lot of my friends were doing that quite well. But, so when, before we had kids, I wasn't able to keep the house clean or have meals, I don't even think I have developed a habit in nineteen years of getting a meal on the table for six weeks."

Mothers more than fathers expressed feeling guilt, shame, and depression about having ADHD, passing it on to their children, and not being able to structure family life to meet the needs of their children with ADHD. One mother said she was taking medication for ADHD and depression but hadn't told her husband because she was so ashamed. Mothers said they took on a double amount of guilt: a generalized guilt about how their ADHD negatively impacted the family and their inability to provide consistency as a parent.

The struggles of parents with ADHD, particularly mothers, also contributed to the disrupted family climate. A mother with ADHD talked about the constant feeling of inadequacy when she had difficulty managing her own ADHD in addition to the ADHD symptoms in her husband and family: "I feel like, as the mom, I'm expected to do it all. And I'm sick and tired of it and desperately wish we could find an outside person who would come in and be in charge of telling people what they are responsible for and having them answerable for it instead of me. I feel it is totally unfair that everybody's

problems have become my problems, instead of just my problems.... and a large share of your problems being mine. I really resent that, and I now there is a lot of anger in me."

In summary, the frequently disrupted family climate provided the context in which three elements interacted to produce the chronic family situation families called "a nightmare": adolescents having difficulty accomplishing things, adolescents struggling through school, and parents compensating for the invisible disability. This situation created the need for parents to devote huge amounts of time, energy, and other family resources to organize cooperative efforts to manage ADHD in the family. The next section describes data related to the extraordinary actions parents took in response to this negative family climate to organize cooperative efforts with schools to compensate for the invisible disability of ADHD.

Actions and Interactions: Parents Taking Extraordinary Measures

Actions and interactions in a grounded theory study are the strategies that are devised to manage or handle the central phenomenon; the actions and interactions occur under certain intervening conditions. In this study, parents had to take extraordinary measures when organizing cooperative efforts to manage ADHD in the family. These actions were necessary because of the powerful and disabling effects of ADHD on daily family life which parents called the family "nightmare". Parents developed four sets of actions to implement the cooperative efforts needed to manage ADHD in the family.

Extraordinary Measures

Most of the extraordinary measures were needed because of the invisible but disabling qualities of ADHD. Parents said that because there was no visible scar, deformity, or corrective appliance, they spent considerable time and energy explaining

and in some cases, trying to convince others that ADHD was a valid medical condition, not an excuse for poor parenting, or bad behavior and laziness on the part of adolescents.

There were four subcategories of data in Parents Taking Extraordinary Measures: advocating in the community, working with the schools, investing in the adolescent, and taking care of oneself. All of these strategies evolved over time, and were frequently the result of trial and error, suggestions from other parents of children with ADHD, and too infrequently, the result of formal education and training by professionals who were knowledgeable about ADHD. Parents said that most of the strategies that worked well had been developed or discovered during a crisis, rather than implemented as a preventive measure. The strategies were not implemented in any specific order.

Parents also created a pattern for the development and implementation of extraordinary measures: they would develop an idea, test and evaluate it before "going public" with it. For example, when parents developed a strategy to be used at school, they would first try it in one classroom with a supportive teacher before requesting widespread implementation or inclusion on the educational plan. Each group of extraordinary measures is explained below.

Advocating in the community. Advocating in the community was about extraordinary measures parents took to find resources, establish networks, pave the way for their adolescent, and coordinate services. Parents had to learn how to advocate and became more skillful as years went by. Finding resources was complicated because services were often unadvertised and proscribed or embedded within organizations such as school districts, health maintenance organizations, or county agencies. Parents spent considerable time establishing networks with other parents and professionals in the local

and regional area. They later served as community educators about ADHD whenever they sought services or support for their family.

Working with the schools. Parents used extraordinary measures when organizing cooperative efforts with schools to manage ADHD. There were four main activities involved in working with schools: keeping records, volunteering, manipulating the system, and demanding services. These activities were a hierarchy of assertive and demanding behaviors parents used to gain cooperation and educational services for their adolescent.

Communication with school personnel was the key to organizing cooperative efforts. Parents used many means to stay in touch with teachers and staff: regular visits or volunteering at school, email, Internet sites, weekly progress reports, phone calls, and parent teacher conferences. In most cases, the parents' assessment of their relationship with school was directly related to how well school staff communicated with parents. Good communication between parents and school staff was characterized by feelings of mutual respect, contacts initiated by both parties, and timely follow up by both parties.

Keeping records was a low-level assertive strategy that parents used to stay organized themselves, help keep staff on track, and could be accomplished even when schools did not cooperate. Keeping records involved logging medical information at doctor's visits, counseling and educational appointments, and gathering educational materials to share with others who needed to understand and cooperate with the family plans to manage ADHD. Parents also kept records of annual report cards and educational plans as well as records such as phone messages, emails, letters, and progress reports. One mother explained that keeping records was helpful when her son changed schools:

"It helped in terms of communicating with the woman who was in charge of the program. I asked if she wanted documentation or do you want us to wait. I forget what she said, but if I had one thing to tell parents, it is document, document, document. And keep it current...If we had not done that, I don't think he would have been accepted."

Parents, especially mothers, volunteered many hours at school for several reasons: 1) to be able to observe their children and adolescents at school, 2) to be present often enough to get well acquainted with and to build credibility with teachers, and 3) to be able to interact informally as well as formally with teachers. Parents felt volunteering at school contributed to the cooperative efforts they tried to maintain with schools and improved communication with teachers. Several mother talked about the invaluable "sidebar" conversations they could have in the halls with teachers about their adolescent while volunteering.

A mother described her volunteer experiences: "every year I go in and am just the nicest person I can think of being and I try to buy their attention. I bake the cookies for the class. I come and sharpen their pencils every week, whatever scutwork that needs to be done I do. I copy papers and correct tests. I ... up until this year I have done that in everybody's classroom and at all times have tried to give at least a half a day to each teacher each week. I made contact with them at least once or twice a week."

One of the reasons mothers chose not to work full time was to be able to volunteer because it was a valuable strategy for maintaining a cooperative relationship with schools, and these mothers recognized the advantage they enjoyed. "So many parents don't have the flexibility in their workweek to do that. I don't know. I feel sorry for most parents who don't have the resources or flexibility to deal with it. A lot of people have to

take a day off from work to deal with it and they can't afford to take a day off of work. I can, and that comes first."

Parents spoke of manipulating the school system only when teachers or staff were resistant to providing necessary accommodations to their adolescents or were overwhelmed with competing responsibilities. Mothers said that physical presence in the school at times other than for meeting about problems was one way to be assertive: "When they were both at the private school, I was at that school and I mean INSIDE that school, in the front office, in the halls, and classroom. It was my way of saying, you aren't going to get rid of me so you better figure out how to work with me because I won't go quietly."

Sometimes parents demanded services from the schools after exhausting all other means of organizing cooperative efforts. Parents demanded services only as a last resort and resented being put in the position of having to act so demonstratively. A frequent complaint of parents was that there had been an initial cooperative effort but schools failed to follow through on their part of the plan. One mother talked about her frustrating experiences which ended in demands for service: "We have developed these little plans that they would call me and let me know how things were going but I wouldn't get calls. I would call teachers, they would call me back. I said, I thought we had a plan that said if this and this were happening, you would let me know. Oh, yea. I would think, who has ADD here? So, that was what I went through with her in middle school. I was the one notifying the school, calling the teachers, finding out where are the progress reports, calling the vice principal and say I need progress reports in all of her classes NOW." One family demanded serviced through litigation with the schools. This was undertaken only

as a last resort because the adolescent desperately needed services the school was not providing.

Investing in the adolescent. The extraordinary measures parents took to invest in their adolescents included explaining things, providing structure and organization, intervening, and transporting. Because of the inability adolescents with ADHD had in making connections or extracting saliency from situations, parents had to explain many things to their adolescents. Parents found it a challenge to explain things in a neutral, non-threatening way when adolescents had learning disabilities, processing difficulties, and low self esteem. Explaining things was a strategy that evolved as parents became better educated about ADHD themselves and understood the underlying causes of ADHD behaviors they observed. Providing structure and organization meant that parents often sat with adolescents every night while they did homework or projects, they helped the adolescent to deconstruct large tasks into smaller ones and order the sequence for completing the smaller tasks. Organizational help included such things as establishing or sequencing daily routines, making lists or reminders, calling the adolescent after school each afternoon, and providing files, binders, computers, and other equipment.

Intervening was a parenting strategy used more often with younger adolescents, and less as adolescents moved into high school. Adolescents in middle school needed parents to intervene when problems arose in school, on the school bus, and in friendships. Parents frequently chose to intervene in situations where the problems developed because of the invisible nature of ADHD. Older adolescents preferred to deal with problems themselves; when parents did intervene, interpersonal conflict between the adolescent and parent often resulted.

Mothers invested many hours in their adolescent children by transporting them to private schools, to frequent appointments, and to activities parents thought were enriching or helpful in managing ADHD. Transporting was a significant undertaking for mothers with more than one adolescent with ADHD. Two mothers said they drove approximately 30,000 miles per year transporting their adolescents.

Taking care of oneself. Taking care of oneself is a subcategory about what parents did to educate and protect themselves from burnout when organizing cooperative efforts to manage ADHD in the family. Educating themselves was a formidable task without formal instruction. Parents educated themselves by reading, searching the Internet, interviewing medical and school personnel about the disorder, and by using that knowledge with the knowledge they had about their own children to develop strategies to minimize the effects of ADHD on the family. Parents also "learned the hard way" using trial and error, and spoke of deep regret for things they did before they understood the nature of ADHD and how to manage it. One mother explained, "I knew nothing about ADHD. Zero…And I swore he was doing it just to spite me. And we were always having these battles and tug of wars, and I will regret till the day I die the way I treated my son because I didn't understand what was going on with him and he didn't have a way to explain it."

Taking care of oneself included self-preservational activities. Going to counseling, setting limits or personal boundaries, and hanging on through tough times by finding personal support were activities parents used to recharge so they could continue to take the extraordinary measures necessary to help their adolescent and family manage ADHD.

To summarize this section, parents took four kinds of extraordinary measures to organize cooperative efforts to manage ADHD in the family. These parenting activities were beyond what was expected or needed to parent "normal" children and adolescents. Parents in this study regularly took extraordinary measures to parent their teens with ADHD when they advocated in their community, worked with the schools, invested in their adolescent children, and took care of themselves. The next section includes categories of data about intervening conditions that influenced both the actions and interactions parents took to organize cooperative efforts and also the outcomes of those actions.

Intervening Conditions

Intervening conditions in a grounded theory are the structural conditions that facilitate or constrain the actions taken to handle or manage the phenomenon. They also influence the outcomes resulting from the actions taken. In this study there were six categories of data that provided structural conditions that mediated the actions parents took to organize cooperative efforts to manage ADHD in the family: family values, ages of family members, socioeconomic status of the family, ADHD knowledge, extended family support, and the presence or absence of family risk factors.

Family values

"Family values" was the largest category of data about intervening conditions that influenced how parents organized cooperative efforts to manage ADHD. Family values were the beliefs and principles about how people should live and behave, and how parents should raise children; they provided organization and structure to family life. Parents tried to instill these values in their children by teaching them in the course of

daily living and by example. Parents hoped their children would embrace these values as guides for their own lives, and that they, too, would pass them on to the next generation. There were five types of family values: rules and routines for daily living, the role of parents and children, principles about how people should live, beliefs about a social ecology, and aspirations for future generations.

Family values provided social stability, bound generations of families together, and provided the structural and organizational framework for family life. Family values held by families in this study were tied to those of previous generations and revised when parents were constructing their early expectations for family life. ADHD presented challenges to family values and sometimes required parents to decide between adhering to the value and altering it to fit their situation of living with ADHD. Some parents considered the revision of family values an additional stressor, other parents felt the process provided the impetus and often sustenance to parents to persevere in the extraordinary actions they took to manage ADHD effects on the family.

Rules and routines for daily living. Beliefs about daily living were the organizing structure for family life and included rules and routines about mealtimes, bedtimes, schedules, chores, care of personal belongings, and pets; rules and routines were patterns that were supposed to simplify family life, eliminating the need to "reinvent the wheel" about how, when, and why certain activities of daily living would be accomplished.

Mealtimes, a primary family activity in most homes, consumed a large amount of family time spent together, and were the focus for much family interaction and teaching and learning of social skills. ADHD had a profound impact on family mealtimes. Adolescents on medication often had poor appetites and were picky eaters, which led to

limited variety on family menus and provided ample opportunity for complaining and/or arguing about types of food and routines about mealtimes.

Several parents stated that one family belief was the importance of a good breakfast to get the day off to a good start but found that adolescents were unable to move quickly enough through morning routines to have time for breakfast. The parents who spoke of the importance of a good breakfast gave examples of what they did to get their adolescent to eat. One dad said to get his son to eat a decent breakfast and make mornings go smoother, he tried to entice him with lunch money, fifty cents more if he came down on time. He also described cooking a variety of breakfast foods hoping to entice his son to eat at least one of the items before leaving for school. One mother described mornings as not going well at all when her sons don't eat.

Another family belief regarding mealtimes was the importance of eating meals together to enjoy the social aspect of mealtimes. One father explained that mealtimes were a social thing, the time that families spent together. He said in his childhood everybody ate together, and when the first two children were still at home, mealtimes were a big deal. Everybody had to be home for dinner.

Parents listed some of the deviations and modifications of these beliefs regarding mealtimes which ranged from tolerating unusual eating behaviors or positions, allowing adolescents to leave before or after the rest of the family were finished, to focusing menus and mealtimes on the adolescent with ADHD, and tailoring mealtimes to the whim of the adolescent with ADHD rather than expecting the adolescent to conform to mealtime routines which reflect a particular family value. One adolescent explained his perspective on mealtimes: "sometimes I won't end up eating dinner because I won't be

hungry. We just come to dinner and I'll try to eat something but if I can't eat anything, then I'll get up. It's not too important to me. Mom and dad think so."

Beliefs about bedtimes were especially important when raising adolescents with ADHD because of their difficulties with waking and sleeping, and the fatigue they experienced. Parents tried to structure bedtimes to allow for adequate hours of sleep, however, adolescents regularly stayed up beyond the "bedtime", either because they could not fall asleep, they wished to continue activities of personal interest, or as an act of opposition to family rules.

Adolescents with ADHD challenged these rules and routines almost continually which contributed to family disruption. Family members could not depend on daily schedules being followed on a regular basis. In households where a family member had ADHD, rules and routines did not provide the same kind of structure and in fact, rather than simplifying family life, complicated it by becoming a focal point for conflict. Routines needed to be broken down into individual tasks and constant parental reminding and monitoring was needed for adolescents to follow rules and complete routines. One mother described the constant struggle her daughter posed regarding rules. "Whatever it is, there is going to be an argument and it is this she being female and her age, adolescent, ADHD, all rolled up into one, it is this constant, who is going to win. And I've already told her, you aren't going to win. I'm the mom..." Other parents adjusted expectations about following rules they held for children without ADHD after learning through trial and error that ADHD severely impacts a child's or adolescent's ability to follow rules.

What was a common sense rule or a routine taken for granted in ordinary families became a focal point for energy and activity in families with ADHD members. A mother described the extraordinary process of getting ready to take her adolescents with ADHD skiing. She could not just tell her sons to get their things ready for skiing: "so for us to get out of the house, it has to be a staged event. It has to come in pieces. For instance, we have all four of them skiing this year. It is an event that starts the night before you go skiing and it starts with two hours of everybody getting all their clothing and putting the clothing they are going to wear home from skiing in the bag, then we line it up across the floor..."

The role of parents and children. Parents in the study identified the roles of parenting, which included establishing rules and routines for the household, teaching children how to master activities of daily living, and providing the necessary nurture and support while children were growing up to be productive, responsible adults. One father described a technique called "nudging", a gentle approach to setting boundaries within which the adolescent could succeed and learn necessary lessons about life in a relatively safe environment.

Sometimes family values were in conflict with one another. For instance, one of the beliefs about family roles voiced by several parents was that "grades belong to the student", meaning that schoolwork was primarily the responsibility of the adolescent. When adolescents did not have ADHD, parents held to this value; the parenting role had clear boundaries and responsibilities for parents and students that included parents providing minimal support to have their adolescent succeed in school. Sometimes it was in the act of letting a non-ADHD adolescent experience a poor grade that stimulated

personal responsibility for schoolwork in an adolescent. For parents of adolescents with ADHD, however, this was not the case. Many adolescents in the study required their parents to continue to provide structure and support for schoolwork long past the time parents of age mates did.

Principles about how people should live. Parents had values about living in peace and harmony, sharing companionship with family members, being honest, doing your best, not giving up, setting goals, and having faith in God.

Two values that were commonly challenged regarded living in peace and being honest. Adolescents with ADHD regularly challenged the peace and harmony with family members. One father described how problems at school caused disruption in his family life: "when you talk about the ADHD family, it is hard to have peace and harmony and that was part of my values for family. Part of my picture is peace and harmony. I find it is sometimes frustrating nowadays in this household there is just us and this dog living here, why is there stomping and storming going on upstairs and slamming of doors, raising of voices. There should be peace and harmony at all times...or at most times. So what is the impact or is there a relationship between ADHD and problems at school that impact the peace and harmony at home? Oh, gee, it is brought right home. Sometimes the very next day one of us has to go down to the school to meet with a teacher..." In contrast, the same father talked about the benefits of traveling together as a family" "even if her grades suffered somewhat, when it is something that we can all benefit from, she gains. There is companionship with us, we share experiences."

Honesty about completing schoolwork and chores was a problem for many adolescents in the study. Parents frequently were distressed about their adolescents lying about schoolwork being completed when it was not: "Another thing that has to do with values, I think, that we have dealt with, is this issue of honesty. With my children I do lose it when my kids lie to me, especially when it is repeated and to me, it is a sign of disrespect. It is like saying, I hate you."

As parents struggled with the lying, however, they began to make a distinction between lying that seemed to be an impulsive, unthoughtful response and lying that was intended to deceive: "I will always go back to her and say, excuse me, every day I ask you if you have homework and you say no. Every day I ask you if you have turned in your assignments, and you say yes. This report says you are not turning in your assignments, so why am I bothering to ask you and why are you always lying to me? The lying is a big question. I've got a theory on this lying thing. I don't think when her mother asks her, did you do this or that work, I don't think she is calculating, no I didn't but I am going to lie about it. I don't think she does that. I think her mind is off school. She's home, and loves being home...and I hear my mother over there asking me something about school, I'll just tell her automatically what she wants to hear, yea, I got it done. She hasn't actually listened to the question. That is a completely different category of lying and that is what I was trying to explain before. I don't just flip out anytime she lies to me. It is when I know it is a decision to be deceitful to me that, like it is predetermined, premeditated." These parents devised different consequences for impulsive lying they felt was related to ADHD and lying that was not related to ADHD.

Two mothers linked the family values of setting goals, doing your best, and not giving up together and felt that pursuit of these values could mitigate the negative effects of ADHD. As one mother said, "in regards to, it is very important to me that the boys have goals. Whether it is in sports or academics, or what they like to do, because with people or kids who have ADHD or LD, the chances of a person giving up are pretty high. That is why one of my values is not giving up."

The second mother saw the pursuit of these family values as protective, as well, and worked hard to instill them in her son: "I just don't want to see him get in a place where he is going to be at risk for mental health issues, substance abuse issues, all of those things that go along with it, can go along with people who are distractible and inattentive, impulsive. So, yea, it is real important for me that he has strong goals and that he succeeds in school...(to protect) against bad things that could happen like drug abuse, poor self-esteem, depression, suicide, bad things. I don't want bad things. I want people with positive self-images and goals...I think they came from us. But I think he has internalized them. I think that now they are his goals."

Most of the parents stressed "doing your best" as a family value. Despite their own high academic achievements, the aspirations they held for their adolescents' future, and their high appraisal of their adolescent's intellectual abilities, they often stated that high grades were not the expectation, rather that adolescents did their best: "I've always maintained the consistent philosophy, school is your job. It is a full time job and you give it your best. When you bring home Cs because you didn't turn work in because you didn't work up to your potential, that is not okay. I can give them that piece of information and they are the ones to figure out what to do with it. It is about their grades,

their graduation, their college and some of the consequences are going to become natural consequences down the road."

Beliefs about social ecology. Family values also contained templates for how individuals related to each other within the family and to the community beyond the family. Parents worked hardest to impart the idea that each member of the family had to contribute to the family unit to help it function and that there were benefits to individuals and the family group when this kind of cooperative effort existed. A mother described how she helped her sons understand their relationship within the family and the community: "And we have discussions regularly about the fact that it is not just them, they are not the only people on the face of the earth, this whole unit has to function together as a collection of individuals and in order for that to happen, everybody has to meet certain expectations. For instance, come home, do your homework as soon as you walk through the door because otherwise things fall apart. You can't begin doing it when we are taking people to Scouts or soccer practice. It has to happen right then... You gotta do it now so the whole unit can function."

Adolescents were able to verbalize this concept during the middle school years but most of the high schoolers still had not gotten to the place where they could dependably contribute to the reciprocal relationship without strong parental input: "because if things don't go well for my family, then things won't really go too well for me, and so, you know, I'm interested in them succeeding and me succeeding...When I stay on schedule in the morning, the family functions very well because if I'm not, I'm pretty ditzy, and I can drag the family behind and it's kind of hectic every now and then...but if we have a good day, which is, you know, one out of three..."

Aspirations for future generations. Aspirations parents had for their children's futures were an extension of the early expectations they had for family and included the children growing up, getting a good education and enjoying a satisfying life. These aspirations were fueled in part by their own educational and professional success. Parental aspirations for their adolescents were still high but parents were slowly coming to terms with the possibility that their adolescents may not do as well in life as they had hoped. One father said, "I went into the Marines soon after high school and had worked at the manufacturing plant and other jobs. I figured out that if I wanted a better job I would have to go to school. What college means to me is that it opened the door. You get to start that way. I expected that all our children would go to college. I think that we have given up. Mom and I skip around like this about him ever getting a college degree or any kind of college work. I'm afraid it won't mean anything to him so I'm hoping he will get a high school degree and find some kind of skill at one of these skill centers or something like this that he can enjoy doing and make a living."

Another parent still had hope for his daughter's future success but acknowledged the possibility that launching this adolescent to independence would take much longer: "It is not just to survive, but to have a good quality of life. So, what we find at our age, both of us around middle age, we do have our concerns with some of her special problems, that we have to keep ourselves healthy so that we can be there to help her get on her way. The other two kids appear that they are going to be okay...But that is a basic family value, to teach their young how to live, not just how to survive, but how to live."

As parents grappled with the effects of ADHD on their adolescents' lives, they began thinking of higher education as a protective factor for their adolescent's future.

One father said that the hope of going to college after high school also has to do with imagining the worst; he thought that going to college somehow protected kids from the worst. A mother said, "so, yea, it is real important for me that he has strong goals and that he succeeds in school...it is my insurance policy. Definitely. That is what it is. Insurance. I am trying to buy a lot of it!"

Parents reported that as a result of having a adolescent with ADHD, they had to make some philosophical decisions when their early expectations of family and school and family values were challenged by the effects of ADHD on the family. Parents reported gradual and thoughtful revisions of the early expectations they had as a young couple that later raised a child with ADHD. This exercise was more complex than that experienced by other couples as they moved through adult and parenting experiences. Revising early expectations included an element of grieving the child and family they imagined and accepting the child and family they had.

Thus, family values were the beliefs and principles about how people should live and behave, and how parents should raise children; they provided organization and structure to family life. They provided the template and motivation for the extraordinary measures parents took to organize cooperative efforts to manage the effects of ADHD on their adolescent children and family. Five smaller categories of data were also included in the major section called intervening conditions: ages of family members, socioeconomic status, knowledge of ADHD, support from extended family, and family risk factors. Each will be described below.

Ages of family members

The ages of family members impacted how families dealt with ADHD. For example, older parents of adolescents spoke of having less energy to deal with the disrupted family climate and meet the demands of extraordinary parenting. Older parents also had more concern for the future of their adolescent. Parents of younger adolescents invested far more energy into providing structure and organization for homework than parents of older adolescents.

In this study, adolescents in middle school had the most difficulties in school. As adolescents moved into high school they were able to select coursework in areas of personal interest or mastery. At the same time, parents grew more knowledgeable about services available and more skillful in advocating for their adolescents as they progressed through grades.

Adolescents aged 12-20 participated in this study. Both adolescents and parents described delays in assuming personal responsibility compared to age mates. Signs of personal maturation were more commonly noticed in the junior and senior years and reflected the adolescent's emerging ability to think of the future, plan, and act accordingly. Parents reported feeling pessimistic about their adolescent's future during grades 7 through 10 when common signs of persistent immaturity included simplistic thinking, and avoiding personal responsibility. These were discouraging years for parents who saw the developmental gap widening between their adolescent and non-ADHD schoolmates. One father described occasional glimpses of maturing behaviors which gave him hope that his son could "make it": "If we can keep him here in the house

without him running off or doing something stupid or getting thrown out of school till he graduates, maybe he will start to mature."

Socioeconomic status

Socioeconomic status profoundly affected how families were able to cope with ADHD. Parents in this study were highly educated and employed at a level commensurate with their training. Most families had health insurance benefits that allowed parents to procure necessary medical and educational services needed by their adolescents with ADHD. Health insurance in managed care programs, however, did not always cover services at free-standing, multidisciplinary ADHD clinics; families without additional financial resources were limited to obtaining services from their pediatrician frequently. Parents with managed care plans reported difficulty in obtaining referrals to psychiatrists and for counseling, especially when professionals with expertise in ADHD were not members of the managed care plan. Families with financial resources paid for comprehensive assessments and ongoing treatment, hired tutors, paid private school tuition, and were able to live without a second income when the mother did not work in order to manage the effects of ADHD on the family.

Knowledge of ADHD

Knowledge of ADHD was a factor in how families confronted the effects of ADHD because the level of knowledge parents, adolescents, and school personnel possessed constrained or facilitated the actions taken to manage ADHD. Most families began with little information about the disorder and were not educated in a formal or organized manner. Instead, parents often found their own resources and educated themselves. Several families benefited from parent education classes offered by

counselors or ADHD clinics that provided services to the adolescents. Other families availed themselves of information in libraries, on the Internet, and from national ADHD organizations as one parent described, "I think that there are external supports available...a counselor, it can be CHADD [national parent support group for ADHD] membership, it can be your reading, it can be your listserve, whatever it is, there's all these other resources that are out there, and I think that you better start there in getting those things in place and learning about it. It's so important to know about it... You thought you were trying hard before you discovered your kid had ADD, you didn't know squat. Now, you're really going to have to try (to educate yourself)."

When school personnel were not well educated about ADHD, parents had a more difficult time obtaining necessary accommodations to mitigate the effects of ADHD; parents and adolescents spent much of the time with school personnel educating school personnel. In contrast, when school personnel were knowledgeable about ADHD, more time and energy were directed toward making accommodations for the student to improve school performance. More positive interactions between family and school resulted when school staff were receptive to learning about ADHD.

Support from extended family members

Support from extended family members eased or complicated the process of living with ADHD. Two families received considerable support from extended family members. One set of grandparents provided financial help for the expenses related to ADHD and a grandmother came to live with the family to help manage the household during a very stressful year. Parents also reported that it was helpful to be able to share the angst of living with the disabling aspects of ADHD when extended family members

understood and accepted the disability. In other cases, families chose to have less contact with extended family that did not understand or support the parents. This was a protective measure to conserve parental energy and limit frustration.

Family risk factors

Family risk factors included variables that were known to impact family functioning such as inadequate social and financial resources, inadequate housing and transportation, access to medical and mental health services, family violence, drug or alcohol abuse, child maltreatment, and unemployment. Families in this study did not present with any of these family risk factors but several parents spoke of the difficulties these factors would impose on the family already struggling with the effects of ADHD.

In summary, six categories of data were included as intervening conditions: family values, ages of family members, socioeconomic status, knowledge of ADHD, support from extended family members, and family risk factors. These data influenced the actions parents took to organize cooperative efforts to manage ADHD. The next section describes the categories of data about outcomes.

Outcomes

Outcomes in a grounded theory are the results or consequences of actions taken or interactions that occurred because of the central phenomenon. In this study, parents took extraordinary measures to manage the effects of ADHD on their adolescents and families. This section is about the outcomes of those extraordinary parental measures; the major categories of data about outcomes were family-school relationship, family costs and benefits, and adolescents assuming personal responsibility. Subcategories in family-school relationships included enriching, cooperative, disillusioned, and unsatisfactory

relationships. Subcategories in family costs included financial costs and benefits, parental depression, marital stress, family disruption, and changing philosophies. The adolescent outcome category was assuming personal responsibility and included subcategories of passage of time, adolescent receiving recognition, parents changing strategies, and adolescents' having a "wake up call".

Family-school relationship

Family-school relationship was one of three major categories of data about outcomes. Relationships between parents and schools represented a continuum of experiences ranging from enriching for both parents and school staff, to cooperative, disillusioned, and unsatisfactory. The quality of the relationship was most dependent on the nature of the interactions between parents and school staff, regardless of the outcome for the adolescent. The parents who reported enriching and satisfying relationships with the school had been treated with respect, were recognized for their dedication to their adolescent's success, and appreciated by staff for the collaborative spirit, hours of volunteering, educating staff, etc. Parents appreciated school staff taking the initiative in planning accommodations and providing professional educational services.

One mother summarized her enriching experience of working with staff to help her oldest son succeed: "So, we wanted more from the school, we got what we needed with a sense of teamwork. That is the thing I remember. So with our son, was that I always had a sense that the teachers and I were a team. That we were on the same side. I didn't feel like it was a tug of war or a battle; it was this sense that we were on the same team. This is a neat kid. This is a smart kid. Boy, we really want to see him succeed. There is a legitimate reason that he needs some accommodations. Let's see what the best

way to make those accommodations is and let's celebrate the victories. You know, when a problem would come up, it was much more a sense of, either I'm concerned about this because I'm seeing this, or I'd get a call and they would say, this has happened, what do you think? Then we would brainstorm together, and sometimes that would include him."

Cooperative family school relationships were characterized by mutual respect, mutual investment in the adolescent's school experience and shared goals. School staff in these relationships were knowledgeable about ADHD or were receptive to being educated about the disorder. They had an organized approach for communicating with parents and followed through on communication plans. Often parents had to take the lead in arranging IEP meetings and educating the staff, but parents found the staff cooperative. A mother talked about her experience with staff at a small, parochial school: "I have to give them credit. They certainly are not on the cutting edge of anything anymore but they were very cooperative and very helpful in the initial stages. We, at the end of fourth grade (when he was diagnosed), the teachers he was going to have for fifth grade, because it was a team taught thing, there was a class coming up and we offered these two teachers, we'll pay for it if you will attend the class to try to help and understand our son. And they did. It made a tremendous difference. Those teachers were instrumental in encouraging him, and tried to undo all the damage that had been done up until then. Getting him to believe in himself, and survive in a school atmosphere that is not geared for kids with ADHD."

Disillusioned family school relationships were tenuous relationships where parents had to take the initiative and be responsible for following through on the educational plan. Teachers maintained communication on an irregular basis and had to

be asked or reminded for progress reports to be sent home. Parents felt that if they did not follow through that their adolescent would "fall through the cracks" as long as the student was not creating a behavior problem in the classroom. Staff members did not convey a personal interest in the adolescent or parent in a disillusioned family school relationship. A mother described her approach in a disillusioned relationship: "What we did whenever we thought it would make a difference was to politely but firmly, whether it is the principal or the academic dean, or whoever, and say, look, here is the deal. This is what we are hoping you can do, or a teacher. And here is what we are willing to do in return. Again, that is one of those situations where if you have the documentation, it makes all the difference in the world. If you don't, it is your word against theirs. If you have the documentation, you can take the SAT untimed. You can get accommodations for testing, for finals, for all kinds of things that you can't if you just say, my kid has attention deficit. They say, prove it. Provide the scientific evidence. And so we did that."

Unsatisfactory family school relationships resulted from rigid, inflexible, and insensitive responses by school staff to parents' attempts to help their adolescent succeed in school. Parents wanted the respect of school personnel. They did not want staff to run or avoid conversations with parents when they appeared with concerns for their student. Parents did not expect schools to know exactly how to work with adolescents with ADHD but they did expect school staff to be willing to learn and collaborate with them. Several parents reported that sometimes a teacher or staff person was also struggling with ADHD in their home and thought that frustration from that situation was transferred to the parent's student. One mother gave this example, "I can't remember her exact words,

but she suddenly became just irate, and said, why I know what he is like, I have a son just like him. If they would just... I said, oh, my goodness; she has a son who has the same problem that she can't get to do what she wants to... I realized at that point that he was not going to succeed with her. There wasn't going to be much I could do."

To summarize, there were four types of family-school relationships parents experienced. Their assessment of the type of relationship was based on the quality of the parent-teacher interaction, not on the academic success of the adolescent. The second major category of outcome data is presented next.

Family costs and benefits

Family costs and benefits was a category of data that described the family outcomes that resulted from the extraordinary measures parents took to manage ADHD. There were seven subcategories of data within family costs and benefits: financial costs, parental depression, marital stress, family disruption, changing philosophies, and family benefits.

Financial costs. Parents reported that there were significant financial costs involved in taking extraordinary measures to manage ADHD. Financial costs included private or out-of-district school tuition and tutoring; costs of adolescent medical and educational assessments, counseling, and parent education; lost wages when mothers did not work in order to advocate, volunteer, drive to appointments and school meetings; medication, transportation to school, appointments and meetings; costs of litigation with the schools, and replacing the multitude of coats, clothing, and school supplies adolescents with ADHD lost. Only one family reported that grandparents were financial contributors; all other families used family income and health insurance to obtain

necessary services. Four families obtained diagnostic assessments at an ADHD clinic in the city but were unable to partake of its educational and therapeutic services because of the prohibitive costs, while acknowledging that the services they did receive were "worth every penny ".

Eight of the nineteen adolescents attended private schools and parents paid the tuition. In addition to the extra family expense of tuition, two mothers gave up lucrative employment in order to meet the demands ADHD imposed on the family. "I knew my husband wanted me to (work) to help with tuition, which I was glad to do but not only was one of my children falling apart, but all three of my boys were, all at the same time." Another mother of three sons all affected with ADHD said she "had come close to working full time just advocating for these kids. Between doctor's appointments, psychiatrists' appointments, learning specialist, IEP meetings, volunteering in schools, talking to teachers, keeping track of them at home, keeping track of medications...getting refills at the right time, making sure each child gets the right medication at the right time...it is just crazy, so I am sure we have lost an income's worth of time." Another mother of two boys with ADHD left full time employment for a part time position "so I have more time to advocate for them, volunteer in school, be available, do all the running back and forth to the appointments and all that." Yet another mother explained, "I chose to cut back on work. We chose to go into debt because I wasn't working much to keep our family income where it needed to be so that I could be home to do these things that needed to be done.

Transportation to and from appointments was expensive and time consuming, in addition to the lost wages because mothers worked part time. A mother of two boys,

one with ADHD, explained, "we used to have to drive to all the way across the city. I rearranged my work schedule so I started working a shorter work day, 32 hours instead of 40 hours, so I could leave and get from one side of the city to my son's school, pick him up, take him to the opposite side of the city, and get back. He was going there twice a week, then once a week, then every other week. Yea, the time, stress, traffic, the whole thing. I wish the clinic had been closer."

Only one family did not ever pay for tutoring; most families reported paying for tutoring for many years. Parents paid for tutoring when their child/adolescent did not fall far enough below the cutoff to be covered by school district funds or services. Several parents also elected to pay for private tutoring when school services weren't adequate. "He had tutoring at his grade school, but the resource room was a pullout and it wasn't a good match. Pulling kids out of class who are not challenged in all areas is very demeaning, so we just stopped. If we didn't have any other resources, what would have happened?"

Parents talked about the great expense involved in raising a child with ADHD: "there was a tremendous financial toll", "getting wiped out if you don't have good insurance", "thousands of dollars that had been spent..." and how many families just don't have those kinds of resources. Parents were grateful for services that were covered but lamented that insurance did not cover enough.

All of the adolescents were initially diagnosed by their pediatrician and all had received specialized services for parent education, further assessment, or counseling at some time. Assessment services obtained at a specialized ADHD clinic was "prohibitively expensive" if parents did not have good insurance. One mother discussed

the expense of reevaluations: "the school said he needed to be evaluated again because the last evaluation was too long ago. At the time, I wasn't working and we had zero money, and it was going to be very pricey to do that, but we decided to…go through an abbreviated process, and they said not only does this kid have ADHD, but also he is now profoundly depressed on top of everything else because he has been struggling." Another mother reported that the adolescent's grandparents paid for tutoring for four years and the initial diagnostic assessment.

Treatment costs were also expensive. All but two of the adolescents were on medication for ADHD. Health insurance covered a portion of prescription medication costs and "natural" medications for ADHD that cost $100 per month were not covered at all by insurance. Parents reported that weekly counseling fees ran between $65-100 per session, many of which were not covered at all by insurance. Despite the fact that all the families in this study had health care insurance, all families reported spending significant amounts of money on services related to ADHD.

Parents also reported the high cost of replacing lost coats, clothing, and school supplies; one boy lost 13 coats in one winter, one girl lost three of her own and one of her mother's winter coats. Other parents stated they frequently replaced lost gym clothes and other garments.

Parental depression. Raising a child and adolescent with ADHD created feelings of sadness and depression in parents. Most of the mothers talked about feeling depressed on occasion and four mothers had been diagnosed with depression and were treated with medication and therapy. Fathers did not talk about feeling or being depressed; instead

they talked about the sadness they felt about their adolescent's struggles or worries they had for the adolescent's future.

Depression was debilitating and a significant family stressor. Maternal depression was particularly concerning since mothers in this study were responsible for so much when dealing with adolescents, the school, and other family business. One mother explained: "I continue to struggle with depression and I am now on, and have been for two and a half years, medicine for depression. I think a lot of that is from years and years of the toll of struggling and failing. If you work hard at something and you succeed, I think it pays for itself but when you struggle and fail, it is just... I don't know how many times I have literally cried, locked myself in my room and cried, thinking that my son might have to be institutionalized someday because he is never going to survive on his own." Mothers clarified their feelings of failure as a parent of an adolescent with ADHD. Mothers acknowledged they had experienced feeling of success and competence in other areas of their lives; the feelings of failing as a parent were heightened because these were their children, they cared most about them and they were unable to affect change in this most important area.

There was a cyclical pattern to the depression as reported by several mothers. When there was a school crisis or family life was particularly difficult because of ADHD, things would get worse and mothers withdrew from the situation temporarily: "when it gets to that point for me, then there aren't any options for a while because I've given up. I can't go any further." Withdrawal provided a brief respite but ongoing confrontation with the effects of ADHD eventually wore mothers down again: "if sometimes, you break a cycle if you recharge and try something new and do get some

success, then you don't burn out. But the more times you have been around, the harder it is to break away and maybe you get off a little but then you are back again."

Several mothers reported that an additional cost to depression was when mothers worked so hard to provide organization and structure for others, they lost their own personal structures and began questioning their own identities. Mothers talked about how the experience of raising an adolescent with ADHD had impacted their own self-esteem: "I think the toll for me has been depression and poor self-image. I have really struggled with feeling like a failure... One of the things that is so hard is that in trying to make structure for them, you lose your own structure... And because of the time, energy, emotional energy, and stress of trying to deal with the kids and their education, the things I used to be successful at, I started to fail at. There wasn't enough of me left to succeed. And I still haven't come out of it; haven't come out on the other side of that. I am still struggling with that even though a lot of the situation at school is much much better now. I wonder sometimes, after the kids are grown and left, will it take me a year, two years, a decade, will I ever really recover emotionally and functionally?"

Mothers also described the things that mitigated their depression and sustained them, such as receiving affirmations from others, sharing with understanding friends, and pursuing activities of personal interest: "thank goodness there have been some people in my life who said, you are doing great. You ARE doing great. This is not YOU. Don't berate yourself. Don't put yourself down." Mothers also said affirmations they received from their own counselors, their adolescent's therapists, and school personnel were equally uplifting, and very necessary because of the chronic nature of ADHD.

The effects of ADHD on the family created marital stress on the couples in the study. The increased stress stemmed from disagreements about the diagnosis of ADHD, differing parenting styles, allocating resources to manage ADHD, emotional burden of raising an adolescent with ADHD, and difficulties when a parent had ADHD. In most cases, the increased marital stress was more related to the degree of disruption to the family than because of actual conflict between parents.

Many of the couples in the study alluded to the fact that their marriages remained intact because they were able to share the parenting; when one parent was discouraged or no longer able to deal with the effects of ADHD, the other parent could step in and provide a brief respite for the distressed partner. Four families had not sought counseling or parent education to alleviate family and marital stress; eight families had availed themselves of professional resources to help them cope with the depression, stress, and disruption to the family. Families who took advantage of resources for family counseling appreciated the help and speculated that without such support, families were vulnerable to breaking up: "weekly calls from teachers and administrators, he is very high maintenance. I have talked to other parents who have struggled with similar kinds of things who are just at the end of their rope, it is affecting their marriage, and that in turn affects the dynamics of the kids and family and it is a vicious cycle. And it can just destroy families if you don't find the kind of resources that we were lucky enough to find…I sent a thank you note to the staff and said, you gave us back our kids, and if it weren't for you, we would never be here. Because there was always somebody there to help us with what we needed…and I know that not everyone is lucky enough to have something like that."

Family benefits. Several parents talked about the importance of finding joy when parenting adolescents. Parents took pride in the special abilities their adolescents displayed and several commented on the unique brand of humor they enjoyed with their adolescent. Often parents developed new interests because of the interests of their adolescent. One mother talked about the rewarding relationship she now enjoyed with her son once she let go of struggling with him to do homework: "But the change in our relationship, we are absolute buddies now. We have this incredible, deep, philosophical world, ethical, religious, even gourmet discussions, and we cook things and eat together." Another mother chose to make the additional time she spent with her adolescent with ADHD a positive thing; she reframed the "need" to be present to supervise and monitor activities to make that a family benefit.

Parents did not say that the benefits outweighed the costs to the family; they did make a conscious choice to see the positive side of things. This was both a coping mechanism and a way to reap some reward for the extraordinary measures parents took to help manage ADHD effects on the family.

Family disruption

Family disruption was the category that described the combined effects of financial costs and parental depression before adolescents began assuming personal responsibility for themselves. This was different from the contextual disrupted family climate that occurred when parents used ordinary, but ineffective parenting strategies for raising adolescents with ADHD. Family disruption was a major and pervasive disturbance to the very core of family life that families attributed to ADHD effects. Often family life was centered on ADHD and other family members' needs went unmet

because of the time, attention, and resources devoted to helping the adolescent with ADHD get through school. Families missed vacations because of the need for tutoring in the summer. Daily routines were often chaotic as a result of the combined affects of ADHD on the adolescent and family.

Parents reported that adolescents with ADHD were powerful contributors to family disruption. One father described the disruption caused by a niece with ADHD who lived with his family for a period of time and " was literally trashing to quality of life in this household" by her behavior and attitude. A mother talked about the calm that existed when her son with ADHD was away on a trip and the sudden change when he returned: "The house was clean, it was quiet. The refrigerator stayed three quarters full. There was suddenly an extra four hours in the day and it was like we were waiting for the other shoe to drop. It was like, what is wrong with this picture? What is missing? And then I realized, our son was away. That is what is missing. And that is the difference. And I never realized how much he affected the dynamics of the family. When he came home, in two days the house looked like a bomb hit it, we were, sentences were being interrupted and five people were talking at once and there were only four people in the house. And it was just nutsoid. And I thought, it wasn't my imagination. It really is him. It is him. No one has raised their voice in this house... by the time he was home a week, he and his dad were at each other's throats. The tension level rises..."

Another mother described the family disruption as a circus that she could not manage: "Because at the same time the middle son was having trouble controlling anger and impulsiveness. I put him on Adderal but I was trying, I was doing this with three hats in the air. It was like a circus, you are trying to balance everything. Not only was

one of my children falling apart, but all three of my boys were. At the same time. At different levels, but at the same time. So, as a family, it was very chaotic. It was very explosive at times, very confusing. For everyone. For all of us... All three of the boys needed my help, I was so confused. I was so far over the edge that I didn't even see the edge passing under me. (Laughs, then has tears, followed by a long silence.)"

Parents reported two situations that were particularly chaotic to the family: doing homework, and when more than one person in the family had ADHD. Parents frequently devoted their entire evenings to helping with schoolwork, to the point that one parent stated, "And one of the problems that I am sure you know is getting into these power struggles. And after awhile it seems like all your life is about is homework. You never have fun with your kids anymore. You are just always at each other, power struggling over homework, getting it done, getting it turned in, is it done well enough, is it done right, and your whole life becomes about this."

There was another type of disruption that occurred when parents helped with homework: inability to plan or schedule activities other than homework. A mother described this type of family disruption: " If you are trying to make sure their homework gets done, it means that anything else you may have planned to do that evening, you don't know whether you will be able to do it or not because they might come home and have no homework, or not brought the book home, or they might come home and have six or seven hours of homework and I am not only not going to be able to get the dishes washed or the phone calls, you won't even get a decent night's sleep."

Family disruption increased when there was more than one person with ADHD in the family; only one family in the study had only one person, an adolescent, with ADHD.

Disruption increased even more when at least one parent and one adolescent had ADHD. Only three families in the study did not have a parent affected with ADHD; seven families had one parent affected, and three families had both parents affected with ADHD. A mother with ADHD described the increased impact as more family members have ADHD: "if one person in the family unit had ADHD, it is a big deal. When two people have it, it is a bigger deal. When three people have it, it is a bigger deal and when (laughs), and the added factor having any other kind of learning disabilities, that makes it even a bigger deal. So it is like three strikes you're out. I am constantly pushing the rock up the hill. Everybody in our family is constantly pushing the rock up the hill."

Adolescent outcomes: Assuming personal responsibility

During late adolescence, particularly during the junior and senior years of high school, the oldest adolescents in this study began assuming more personal responsibility for themselves and engaging compensatory mechanisms on a regular basis to mitigate the effects of ADHD on daily living and school performance. However, these adolescents still relied on support from parents and school personnel as they began assuming personal responsibility for accomplishing things, getting through school, and activities of daily living.

Three interactive factors contributed to the adolescent's gradual assumption of personal responsibility: maturation related to the passage of time, adolescent recognized for competence, and parents changing strategies. Each factor is described.

Maturation related to passage of time. Some maturation occurred with the passage of time. Parents often used elaborate schedules, routines, and reminders posted around the house to provide external structure for activities of daily living and to help

manage schoolwork. Developing habits and maintaining daily routines was helpful to one family: "they have learned or been trained over the course of years that when they don't know what to do they have to look for their list and that works pretty well."

Parents of younger adolescents reported that while the adolescents had acquired some skills in organization and mastery of curriculum during elementary school, the transition to middle school was complicated by parents and adolescents having to interact with multiple teachers and staff, increased school workload, changes in school location, transportation, and scheduling, and the onset of puberty. Even when adolescents were able to manage the more advanced curriculum, they were not prepared to manage the increased demands for organization, timeliness, and volume of work expected in middle school. Both parents and adolescents agreed that reading comprehension and writing skills had improved during middle- and early high school years.

Adolescents reported that after the first year of middle school there was less "crunch time" needed to complete missing assignments but parents did not agree with this assessment. In fact, parents reported that both boys and girls in middle school often cried at home while doing homework. One mother lamented, " I don't know, there were many times when he cried and told us he felt so stupid...why don't I get this?" She said she hoped her son wouldn't remember how much he cried."

Parents explained that some of the delays in maturation were evidence of "late bloomers" and that they expected the adolescent to catch up eventually. One father said "every once in a while I see something that makes me say, damn! He has a chance. Maybe he can make it." This father reported that he first experienced a change in conversations with his adolescent about automobiles and how things work; changes in

behavior and the ability to act on intentions mentioned in conversations came a year or two later.

Recognition of competence. The second factor that impacted an adolescent's maturation was the recognition of teachers, peers, and parents of competence or some meaningful accomplishment by the adolescent, such as a school play performance, academic or athletic achievement. The recognition served to boost the adolescent's self esteem and self-confidence, and provided motivation to pursue other achievements. One mother described her son's recognition as a dramatic turning point: "he got one of the leads in the play and it is as though he found something he excelled at, something for which he gained the respect of his peers, that people obviously enjoyed because everyone complimented him, and he turned into a big man on campus. That was a turning point for him. It made a big difference for him to be able to find a creative outlet for expression. We said if you are going to do this, you have to keep your grades up. You got to survive. You can't flunk everything else. Not only is that the school's rule, but it is our rule. His teachers were very accommodating and stretched things out until after the play was over. He just matured tenfold overnight. He had this presence, and poise, and confidence that he had never had before."

This recognition did nothing to alter the effects of ADHD on the adolescent's life nor did it change the amount of effort and work required for the adolescent to get through school. It did change the perceptions of the adolescents, teachers, and peers and altered the interactions to more cooperative and productive relationship. This was important because it was a sharp contrast to the perception that the child/adolescent had disabilities and were unable to perform in certain areas, perceptions that frequently were generalized

beyond the specific areas of disability. Parents who were good advocates for their child and adolescent may have inadvertently reinforced this perception as they worked to convince school personnel that the adolescent had a disability requiring accommodations.

Parents change strategies. During grade school many parents educated themselves about ADHD and learned how to provide adequate support and structure for their child. They used schedules, routines, and reminders in an attempt to develop habits to help accomplish activities of daily living. Because of the child's age and inability to manage the demands of school, parents took on much of the responsibility for keeping track, organizing, completing and turning in schoolwork. However, over time, parents realized that they needed to change to amount and type of assistance they offered their adolescent during high school. The extraordinary parental actions that were helpful and necessary for the school age child interfered with the adolescents' maturation. "As he got older, we were always aware of how involved we were, trying to walk the line between helping and rescuing. About the end of his sophomore year...it was okay, the kid is two years from being out of the house, and he needs to start taking his lumps. That is one of the reasons his junior year was so hard for him."

Parents began to use strategies they hoped would help adolescents grow up: letting go, allowing adolescents to experience negative consequences of their behaviors, and planning for the adolescent to leave home after high school. Parents learned to shift the burden of planning and problem solving back to their adolescent by asking questions rather than noting a project was due and begin to make decisions, organize, schedule, and supervise the work for the adolescent. Letting go was hard for parents and sometimes involved risk of danger or serious consequence. A mother talked about having to

relinquish the conflict over her son taking his medication: "okay, if you think you can do this without medication or without something else, go ahead and try it." Before this adolescent began taking his medication regularly of his volition, he was involved in several motor vehicle accidents and nearly missed the opportunity to attend the private school he wanted to attend due to poor grades.

One father with ADHD commented on the lifelong consequences when parents don't shift the burden of responsibility to adolescents for organizing their own belongings and space: "In a lot of ways I think my dad took any kind of ownership I had of trying to do it myself, took it upon himself and I never, somehow never managed to learn it."

These three interacting factors set the stage for the adolescents to make a significant move toward maturity: the older adolescents began to "wake up" to the fact that high school was nearly over and that they had to formulate a plan for the future.

The "wake up" call. Regardless of the recognition of competence adolescents received and the strategies parents used to facilitate maturation, the adolescents came to realize his or her responsibility for one's life, as one adolescent said, "I'm thinking I'm almost done, I better not mess this up. 'Cause I have gotten this far I don't want to ruin it." Similarly, a father with ADHD reflected on his senior year: "I realized that high school was almost over and I've got to do something here" and improved his grades so he could go on to college. This realization often came after parents changed the nature of their support and structuring of the adolescent's life. There was a necessity for the adolescent to take actions since parents were no longer providing certain things, like transportation and allowance.

Following the "wake up call", adolescents began to assume increasing personal responsibility by integrating three kinds of behaviors: figuring things out for themselves, thinking of the future, getting organized, and following through. They put into practice external structures and supports to use as compensatory mechanisms to offset or mitigate the effects of ADHD on their lives. Often, these compensatory mechanisms included the extraordinary measures parents had provided when the adolescent was younger but now were relinquishing as parents changed strategies and began letting go. When adolescents began to accept personal responsibility for themselves, they were more able to accomplish tasks that permitted them to live more independently. Figuring things out for themselves, thinking of the future, getting organized, and following through functioned as antidotes for some of the behaviors that hindered them from accomplishing things. For example, figuring things out for themselves minimized the behaviors of relying on others.

Figuring things out. Figuring things out by the adolescents themselves included identifying and accepting one's own strengths and limitations, developing one's own adaptations to deal with limitations, seeing the need for action on one's own, having the desire, and making an effort on one's own. A mother talked about her son meeting with the college counselor: "he actually has come up with enough adaptations, and is secure enough in himself now to not want anything changed. And if that means he doesn't get quite as good a grade as he might, that's okay with him. He knows he is going to succeed, he knows he is good. He has found what he is good at and knows he is good at it and he doesn't want adjustments. He wants to plow forth on his own strength."

Adolescents still needed and appreciated help and support from parents and others, but figuring it out demonstrated an internal action or desire that was

uncharacteristic of younger adolescents with ADHD. A mother talked about her daughter's improvement over last year, "maybe part of it was just checking in with her, trying to keep her on task, but she had the desire and momentum to see that she got these things turned in."

Younger adolescents were influenced by teachers in some instances of "figuring it out". One adolescent reportedly sized up her teacher and decided she was going to do her best for that teacher and managed to perform well in that class. A middle school adolescent was negatively influenced by his teacher when "she didn't give me challenging material and didn't make me feel the need to strive to excel."

Thinking of the future. Thinking of the future was necessary for adolescents who were assuming personal responsibility. Adolescents who had thoughts of the future were able to engage in planning and scheduling more realistically than those who did not. Thinking about the future provided motivation to work in the present. For example, one adolescent talked about rewards for motivation: "I don't look for so much, you know, pizza, candy, pop. I look for kind of my future. I look, oh, no, I have a B, a very low B. I need to get myself on task…I'm closer to my goal of getting good grades." In contrast, adolescents who don't think of the future engage in simplistic thinking, "it doesn't bother him to not make more money than what he needs for to pay for a car and insurance."

Getting organized. Getting organized as an element of assuming personal responsibility included "unpacking" or deconstructing projects into individual tasks, planning and scheduling, setting priorities, taking charge, and creating an environment for accomplishing things. Unpacking projects was difficult for adolescents with ADHD and was a skill learned over time. An 8th grader stated "sometimes I just break off into

trying to do everything at once. But that doesn't work, really. So then I break things down. Like I do the paper first and then I work on the visual stuff later." A father gave a more graphic illustration of the difficulties adolescents have unpacking projects into manageable tasks: "there is a dramatic difference right there, between kids that don't have ADD....they start on a project and it's like they can see the end of the tunnel. I think with ADD kids, they start down the tunnel, they see the light shining behind them, like the great light of inspiration is still shining over their shoulder showing them the first ten feet, but they get in there and it is 'I don't know what I am doing' and they go back outside and get some other inspiration."

Adolescents were often able to organize themselves if there were external structures in place at home. A fourteen-year-old adolescent managed her schoolwork best when parents maintained consistent mealtimes and bedtimes. Medication also provided an external support as one mother described the routine after school: "they come home and immediately before anything else happens, they go to the table and do homework before the Ritalin is gone." Another external structure that helped an adolescent with organization was a special environment for doing homework. One set of parents gave their son a laptop computer and organized his bedroom so it was conducive to studying. A high school graduate stated she suffered because she did not have a quiet, organized place to work. She had to do homework at the dining room table where her siblings were also working, providing ample distraction and opportunity for disorganization.

Following through. Following through included overcoming inertia, persisting and staying focused, trying harder, and tolerating boredom and irrelevance or marching to

a different drummer. One adolescent described his difficulty beginning to practice his music: "making myself do it is hard, but if I do go down there and do it, I have the time of my life. But just getting down there is hard enough."

Parents often helped with persisting until a task was completed by offering their presence. One mother said, "I would literally sit here with her, making sure she did it." Another mother gave an example of her adolescent's improvement with following through: "really what has changed last year and this year, the huge change is the amount of time we spend on his homework. It used to be a nightly thing that we would have to sit down with him and work with him every night, every night, every night."

Adolescents talked about having to try harder to stay focused. "I have to try harder to focus and try harder not to have impulsivity and stuff. It is just really hard to get my mind straight and in one spot at one time." Another adolescent stated it was easier to try harder when he was interested in something.

Adolescent outcomes were still largely unknown since all but three adolescents had not completed high school. Three participants had graduated, two were beginning college studies in schools with special services available to ADHD students; a third student was working full time and taking classes part time at a community college.

Prolonged adolescent dependence on family. An alternative outcome to adolescents gradually assuming personal responsibility was a prolonged dependence on family by adolescents. This was the case with the next oldest group of adolescents in the study, those who were in their junior and senior years. Although one student was recognized by teachers and peers for his abilities and performance in one academic area, he was still failing courses in that area and had not experienced a "wake up call" nor had

begun to engage the strategies of figuring things out, thinking of the future, getting organized, and following through. One other student had begun to make plans for a career requiring a graduate degree but had not taken steps necessary to move toward that goal. Most of the participants in this group of the sample were exhibiting a prolonged dependence on their families to provide the external supports and reminders for both activities of daily living and for school. Parents of this group of adolescents also recognized the lack of movement toward maturation and continued the extraordinary parental activities without beginning the letting go process exhibited by parents of adolescents in the oldest group.

Also, there was a marked difference in the level of maturity between the youngest participants in middle school and those in the junior and senior high school grades. Parents described a parent-child relationship characteristic in elementary grades that persisted into middle school. It was not until the adolescents were in their sophomore and junior years that parents realized the time was short when the teens would be old enough to leave home and be expected to assume much more personal responsibility. This seemed to be a parental "wake up call" signaling the need for engaging letting go strategies and allowing the adolescent to experience the consequences of the ADHD behavioral patterns with the hope that it would trigger maturation on the part of the adolescent.

Whether or not adolescents had reached the point of assuming increased personal responsibility, parents and adolescents both reported that maturation did occur over time but at a slower rate than for their age mates. The maturation was uneven and adolescents

still required structure and support from parents and school as they continued to confront the hidden disability of ADHD.

In conclusion, this chapter described the results from a study entitled The Family Experience with School when an Adolescent has ADHD. The core category of data was Organizing Cooperative Efforts to manage ADHD in the family. Parents compensated for ADHD, an invisible disability, but taking extraordinary parenting measures to help their adolescent do well in school. Antecedent factors included the juxtaposition of parental expectations and the reality of having a child diagnosed with ADHD. The context for the core category was a disrupted family climate resulting from the clash between the ADHD effects on adolescents and parents using ordinary, but ineffective strategies to parent adolescents with ADHD. Intervening conditions included family values, ages of family members, socioeconomic status, knowledge of ADHD, parents with ADHD, and support from extended family.

Parents took extraordinary measures to organize cooperative efforts to manage their adolescent's ADHD. They worked diligently with school personnel to obtain the necessary accommodations for their adolescent to have the best chance to succeed in school. Four types of family school relationships resulted: enriching, cooperative, guarded, and unsatisfactory. The quality of the relationship did not depend on the student outcome but on the nature of the interactions between parents and school staff, regardless of the outcome for the adolescent. The outcomes for the study included family disruption, adolescent outcomes, and the family school relationships. Discussion of the results follows in the next chapter.

CHAPTER FIVE

DISCUSSION, RECOMMENDATIONS, AND SUMMARY

The purpose of this study was to generate a theoretical understanding of the family experience with school and to identify processes and interactions that impact family functioning when an adolescent has ADHD. Grounded theory methodology was used to analyze data from interviews with families that had at least one adolescent diagnosed with ADHD. Results indicated that the central family experience with school when an adolescent had ADHD was about parents organizing cooperative efforts to manage ADHD in the family. The conceptual model and categories of data were detailed in chapter four.

This chapter contains a discussion of the findings in light of related research and to recommendations for clinical practice and future research. This section also contains a discussion of the criteria by which qualitative research is judged and limitations of the study.

Discussion

Findings of studies generated from grounded theory methodology must "fit" with existing literature and be examined in light of related research. "Fit" means that the categories emerge from the data directly and are not forced; and work is defined as categories that are relevant and able to explain the phenomena being studied (Glaser & Strauss, 1967). Results of this study will be considered in light of current research with ADHD and adolescents, development, families, and the family-school relationship. The purpose of this section is to connect the findings of this study to relevant work in the

literature in order to shed light on the family experience with school when an adolescent has ADHD.

Research about ADHD and adolescents

Barkley's model of behavioral disinhibition. Barkley (1997) proposed that the core deficit in ADHD is behavioral disinhibition, which results from poor or absent coordination of executive functions in the brain. The lack of adequate executive functioning affects four types of mental processes: 1) a poor working memory that limits the ability to engage in hindsight or forethought, and affects one's sense of time, 2) delayed internalization of speech that affects personal reflection before acting, 3) immature self-regulation of affect, motivation, and arousal that affects the ability to be objective, empathetic, engage emotional self control, and maintain drive and motivation necessary to accomplish goal-directed activities, and 4) impaired ability to reconstitute events and situations needed to make meaningful behavioral selections. Poor executive functioning coordinating these mental processes results in limited motor control and fluency in modulating behavioral responses to stimuli in all activities of daily living. In short, behavioral dis-inhibition interferes with self-regulated behavior.

Barkley's theoretical model was developed to integrate the emerging physiological scientific evidence with the behavioral manifestations of ADHD. The theory looks beyond the visible behavior to what caused, created, or influenced the behavior. Deductive reasoning about how people without ADHD manage self-regulation helped explain why people with ADHD had difficulty with self-regulation. This current study aimed at understanding the behavioral manifestations from the perspective of adolescents with ADHD and their parents, and used inductive methods of reasoning. The

two patterns of ADHD behavior that emerged in this study, difficulty accomplishing things, and struggling through school, are consistent with Barkley's model of disinhibition. Both patterns of behavior are by-products of problems with self-regulation.

The underlying explanations of the six factors that interfered with accomplishing things (procrastination, distractions, daydreaming, resisting and avoiding, relying on others, and giving up) are also consistent with Barkley's model. For example, Barkley suggested that a poor working memory causes difficulties maintaining a sense of time. Adolescents in this study explained that underlying procrastination, the intention to do something "in a minute", was the inability to know or sense how long a minute was. Avoidance, another factor interfering with the accomplishment of tasks, was explained as a coping mechanism covering the adolescent's inability to deconstruct a task into smaller segments, organize them sequentially, and carry them out to complete the larger task. Two elements of behavioral disinhibition in Barkley's model, delayed internalization of speech/limited verbal working memory and impaired reconstitution/immature use of verbal working memory result in difficulties in problem-solving and analysis and synthesis of behaviors that contribute to goal-directed responses, in other words, difficulties deconstructing and reconstructing tasks in order to accomplish things.

The difference between the two patterns of behavior, difficulty accomplishing things and struggling through school, is explained as a micro/macro relationship. Difficulty accomplishing things is a micro pattern of behaviors about individual tasks to be accomplished while struggling through school is a macro pattern of fitting together multiple instances of smaller tasks to produce a complex end product. In this study, individual chores or school assignments were micro-level behaviors while daily living,

and grades and learning over the school term or school year represented the macro-level of behaviors. When adolescents were unable to accomplish the individual tasks of daily living and schoolwork, family life was chaotic and the pattern of struggling through school became a predictable, recurring experience.

The aims and methodologies used to construct Barkley's models were very different from those used in this study. Because of these differences, results from this study cannot be said to parallel the model developed by Barkley, but it is possible to appreciate the similarities of conclusions from both deductive and inductive reasoning about ADHD behaviors.

Adolescents in this study. While high school graduation is certainly an important outcome marker for any study about school, it is not the only outcome possible. More importantly, when looking at the developmental trajectory of adolescence into adulthood, the ability to manage satisfying personal relationships, activities of daily living, transition to the workplace, establish an economic independence from parents, and become a good citizen are equally important adolescent outcomes. In addition, avoiding problems with drugs and alcohol, safe driving, abiding by the law are social outcomes to be evaluated when examining the developmental trajectory of adolescents.

The oldest three adolescents in the study sample graduated from high school and went on to college. They had begun to engage external strategies to mitigate the influence of ADHD and were able to succeed in school. However, they still struggled greatly with performing boring routines and activities of daily living. The next oldest group of adolescents who were juniors and seniors in high school did not share such an optimistic future, despite the extraordinary measures taken by their parents to manage

ADHD symptoms. One senior was in doubt of graduating and the juniors were failing in required classes and were experiencing behavioral problems at home and at school. Thus, adolescents in this second oldest group in the sample were not yet using the strategies the first group of oldest adolescents had employed to enable them to graduate and continue their education (figuring things out, thinking of the future, getting organized, and following through). This group of adolescents had not experienced the same degree of recognition by teachers and peers, nor were parents letting go since the adolescents did not seem ready to assume more personal responsibility.

This suggests several interpretations. The first is that when adolescents with ADHD begin to use behaviors associated with assuming personal responsibility, they have less difficulty with accomplishing things and struggling through school. This is reasonable if the strategies associated with assuming personal responsibility (figuring things out, thinking of the future, getting organized, and following through) are external mitigators of behaviors that interfere with accomplishing things. Second, behaviors related to assuming personal responsibility are not applied in a universal way, but rather to specific tasks assigned a priority because of interest, ability, or other reason of import. Thirdly, development is a complex phenomenon and does require the interactions of many factors for maturation to occur. It may be that an appropriate emphasis at home and school should be on recognizing the things adolescents do well to stimulate the cascading effects of adolescent recognition, parental letting go, and adolescents acknowledging a "wake up call" to then begin engaging the strategies necessary to mitigate the effects of ADHD on adolescent development.

Research about ADHD and development

Maturity for all adolescents occurs in fits and starts, and for adolescents with ADHD, maturity is not only delayed, but is also uneven. Maturity is observed as adolescents complete high school, assume personal responsibility for activities of daily living, participate in their communities and establish families of their own. ADHD complicates the maturational process throughout the life span.

According to Barkley, behavioral disinhibition in adolescents with ADHD is evident despite physical and chronological maturation and manifests the delayed developmental milestones of internalized social integration of rule-governed behavior and one's place within a larger social context. Barkley argued that the diagnostic criteria for adult ADHD does not adequately reflect the disorder among adults and proposed that a more accurate paradigm for describing adult ADHD should be similar to that for adults with mental retardation. Neither diagnosis is outgrown over time and both are described according to the developmental delays experienced during childhood and adolescence. However, mental retardation in adulthood is not seen as a set of cognitive or behavioral criteria, but an assessment of the cognitive and behavioral items within the set compared to age mates. Some developmental achievement in many categories is possible and sometimes expected; however, the level of achievement in adults with ADHD, as with mental retardation, should be in comparison with other adults of the same age.

Findings in this study also indicated that there was significant delay in acquiring the social and organizational skills necessary to accomplish activities of daily living and succeed in school compared to peers and siblings without ADHD. For the three adolescents in the study who were successful in going on to college, it is important to

note that they did not "outgrow" their ADHD; they still struggled compared to other college freshman, despite the accommodations the colleges provided for two of the students. Although each was doing satisfactorily in their academic pursuits in areas of personal interest and talent, they did so by working harder than peers to manage time, stay organized, and maintain in school. They also were less able to manage activities in their personal lives compared to their age mates. Again, it was the intensity and frequency of difficulties with daily tasks that set them apart from other adolescents making the transition to college and life away from their families.

In this study, the adolescent outcome of assuming personal responsibility explained how some of the factors which interfere with accomplishing things are mitigated or diminished so adolescents were able to accomplish things. When they were able to engage certain strategies, (figuring things out, thinking of the future, getting organized, and following through), they were able to subvert or overcome in that instance, behaviors of procrastination, distraction, daydreaming, resisting or avoiding, relying on others, and giving up. However, since ADHD is a lifelong condition, it is not anticipated that adolescents and adults with ADHD will not be bothered by these factors again. In fact, it is quite the reverse. A great deal of effort is needed to mitigate individual behaviors that interfere with accomplishing things. Assuming personal responsibility was a set of behaviors that were costly in terms of energy and other activities, and were not evident across settings, that is, at home, at school, at work, within personal relationships. Parents with ADHD in the study who were successful at school and work, demonstrated that when they engaged a rigid set of external supports, they were able to be successful in obtaining college degrees and were able to be employed in

setting where their strengths were valued and they had the ability to design positions according to their personal strengths and weaknesses. However, each of the parents with ADHD in the study were forthcoming about how the disorder continued to affect other areas of their life, particularly family life and their ability to parent with consistency and provide organizational structure for their children with ADHD.

Adolescents and adults with ADHD don't "get better" even when they begin to assume personal responsibility. They continue to need extraordinary external supports to help them accomplish things and to persevere through cycles or seasons of life that require ongoing macro-level engagement of strategies to deconstruct and reconstruct large projects and repetitive aspects of daily life, as in keeping records throughout the year for income taxes, and later, helping their own children through school terms and school years.

Research about ADHD and families

Results from this study add to the growing body of literature regarding families and ADHD. Findings about family disruption and maternal depression in ADHD families will be compared with other research.

Family disruption. Kendall (1998) studied 15 families with a child with ADHD using grounded theory method. Results included seven types of disruptive behaviors to family life, and three processes used by parents to outlast the family disruption. The seven disruptive behaviors were: aggression, hyperactivity, social and emotional immaturity, academic and learning problems, family conflict, negative peer interactions, and isolation and rejection from extended family. Parents struggled to manage the effects of ADHD on the family and outlasted the family disruption by making sense of the

ADHD behaviors, recasting biography of their own lives, and relinquishing the "good ending" of managing the ADHD effects on the family by reinvesting in the themselves, the children without ADHD, and the "real" child with ADHD.

The parental processes of making sense, recasting biography, and relinquishing the "good ending" in Kendall's study paralleled the extraordinary parental actions described in this study: advocating in the community to find resources to help manage the ADHD effects, working with the schools to provide accommodations to minimize the disabling ADHD effects on learning and the family, investing in the adolescent to facilitate the teen assuming personal responsibility, and parents taking care of oneself to limit the costs to the family created by ADHD.

There were striking similarities between this present study and Kendall's study: both parent samples were well educated and predominantly middle class or above, the level of family disruption was significant despite extraordinary parental efforts to manage ADHD, over time parents were frequently overwhelmed and worn out by the demands on the family created by ADHD, and eventually began transferring responsibility to the adolescent for his or her life.

The most significant difference between findings of Kendall's study and this research regarded the adolescent and parental outcomes, and the quality of the maternal/child relationship. There were three adolescents in this study who had graduated from high school and were in college with the full support of their parents. Mothers had "let go" as their adolescent left the home for college. The mothers spoke with pride of their adolescent's maturity, tempered with some fear, realizing the physical distance between them precluded any "rescue" on a regular basis. They were able to "let go"

emotionally because of the adolescent's relatively recent assumption of personal responsibility. This difference can be accounted for partly because the adolescents in the current study were older than those who participated in Kendall's study. The mothers who had emotionally separated from their adolescents also had experienced enriching and cooperative family-school relationships that fostered confidence in educators the adolescents would encounter in the future.

In Kendall's study, the older adolescents were not successfully graduating and transitioning to higher education. Kendall reported that the parental process of letting go when adolescents failed to succeed in school and faced a bleak and uncertain future was painful. Kendall reported that highly enmeshed mothers of sons who had behavior problems protected their sons from the natural consequences of their behavior into the high school years, and in retrospect, wondered if that strategy was a hindrance to the son's maturational process. It seems likely that the enmeshment created a delay in the mothers' processes of individuation, and contributed to feelings of guilt, exhaustion, and depression.

Kendall's study focused broadly on how families coped with an ADHD child and findings identified school problems and homework as a significant source of family conflict. Building on Kendall's work, this study focused primarily on the family experience with school and explicated two patterns of behavior that contributed to school problems and homework as sources of family conflict. Both studies also corroborated Lewis (1992) and Lewis-Abney (1993) studies of family functioning when a child has ADHD that indicated ADHD children have a profound and often negative effect on

family functioning and that family conflict increases as children with ADHD move into adolescence.

Maternal depression. Maternal depression, a significant finding in this study, is the second common topic to emerge in family studies about ADHD. In this study, mothers attributed their depression to the cumulative fatigue they experienced as they raised their "high maintenance" children and adolescents with ADHD. Mothers also described depression as a result of being so involved in structuring and organizing the lives of their children that they lost their own sense of personal structure and identity. Some voiced concerns about whether and when they would regain the confident sense of self they had lost while parenting a child with ADHD. These data were similar to the introspective parent trajectory in Kendall's study (1998) that included experiencing, remembering, grieving, individuating, and restoring as parents tried to make sense of their experience of parenting a child with ADHD.

Other research has linked maternal depression with the experience of parenting a child with ADHD (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Barkley, Anastopoulos, Guevremont, & Fletcher, 1992; Barkley, Fischer, Edelbrock, & Smallish, 1991; McCormick, 1995). With the evidence of maternal depression mounting in family research about ADHD, clearly there is a need to incorporate screening for maternal depression periodically when providing family services to parents of ADHD children.

This study corroborates research about family disruption and maternal depression as common findings in family research about ADHD. The next section focuses on research about the chronicity of ADHD.

ADHD as a chronic illness

Knafl, Breitmayer, Gallo, and Zoeller (1996) studied how families define and manage a child's chronic illness. Five specific family management styles of a child's chronic illness were identified: thriving, accommodative, enduring, struggling, and floundering. This body of literature was about how families of children with other chronic conditions attempt to "normalize" family life by making daily adjustments to compensate or accommodate the disabling aspects while maintaining many patterns and routines common to most families. These structural, functional, and organizational routines frequently included morning, evening, and bedtime routines, patterns for mealtimes, household chores, division of labor, childrearing, leisure activities, etc.

In contrast to the literature on normalizing family life when children had chronic illnesses, Kendall's study indicated that families found it nearly impossible to "normalize" family life because of the pervasive characteristics of ADHD: difficulty accomplishing daily routines and activities of daily living, and managing the child's educational experience. There was continual disruption to the patterns and routines in households with ADHD family members; this was the "norm" for daily living. Parents' coping strategies in Kendall's study did not fit into one of the family management styles, instead, parents had to "stop trying" to manage ADHD, accept the limitations of the children and adolescents with ADHD, and refocus on themselves and the other children without ADHD.

Results of this current study identified two primary disabling patterns of behavior, difficulty accomplishing things, and struggling through school, as the antithesis of routines that structured and defined "normal" family life and school life, even when

children had chronic conditions such as diabetes or asthma. The chaos created by ADHD, which can only be modified slightly by external structural and organizational supports, distinguished ADHD from other chronic conditions where "normalization" processes were possible. These two patterns of ADHD behavior represent the essence of a disabling condition. The results of this study again confirm Kendall's results that "normalization" (Knafl, Gallo, Zoeller, & Breitmayer, 1994) does not occur in families with ADHD children, thus differentiating the family experience of ADHD from that with other chronic illnesses. The results indicated the chaos in these families is significant and these families are in need of additional illness specific educational, medical, social, behavioral, and community services to help them manage ADHD in the family.

Family-school relationships

Family school relationships are the result of parent involvement in school. Parent involvement in schools is one of the National Education Goals (1994) and three federal educational laws give parents rights to participation in educational planning when children have disabilities or other health impairments (Public Law 99-476; 93-112; 101-336). Research has demonstrated that parent involvement in their children's education had positive effects on student learning and grades, and a variety of models and categories of parental involvement have been linked to improved student outcomes (Grolnick & Slowiaczek, 1994; Stevenson & Baker, 1987; Epstein & Lee, 1995; Hoover-Dempsey & Sandler, 1997, 1995). Parent involvement in school was secondary to the student-teacher relationship, but nonetheless a positive factor.

Results from this current study indicate that increased parent involvement with school does not necessarily improve student outcomes. Parents in this study reported

they participated actively in each type of parent involvement recommended by researchers (Grolnick & Slowiaczek, 1994; Stevenson & Baker, 1987; Epstein & Lee, 1995; Hoover-Dempsey & Sandler, 1997, 1995), but often without improvement in their adolescent's academic performance. All families reported regular, uneven performance and grades below the child's potential, even when the grades were good. Parents also reported that despite their extraordinary efforts of helping with homework and projects, adolescents had received D's and F's at some time during the child's school career. For ADHD children, parent involvement alone is not enough to compensate for the difficulties with school created by ADHD.

The National Educational Goals (1994) and family-school connection models (Epstein & Lee, 1995; Hoover-Dempsey & Sandler, 1995, 1997) proposed collaborative relationships that inferred a more equal partnership between parents and schools than the parent involvement model. However, parents in this study suggested that sometimes school personnel did not desire, and actively avoided collaboration with parents. Parents perceived that some teachers regarded students with ADHD as undesirable to have in the classroom because of the extra work involved in teaching them and working with parents collaboratively. Parents also had experienced teachers misinterpreting parents' hypervigilence about progress reports as overinvolvement in the student's life, not understanding the difficulties adolescents with ADHD had nor being interested in learning about ADHD. It becomes important, then, for parents to learn how to collaborate with teachers in a non-threatening way and develop a family-school relationship with each teacher that will be beneficial to the adolescent, parents, and

teachers. Similarly, educators need to be willing to learn about ADHD and work cooperatively with parents to facilitate the family-school relationship and student success.

For families of children with special needs, the family school relationship takes on greater importance because the quality of the relationship often is related to the quality of services provided to the child as perceived by parents. Zoeller (1996) studied the family school relationship when children had diabetes. Results indicated three types of family school relationships as identified by parents: satisfied, guarded, and unsatisfactory. A majority of parents (60-70%) were satisfied with the family school relationship and 30-40% rated the relationship as guarded or unsatisfactory, despite parent attempts to educate teachers, provide supplies, and be available for consultations with school personnel. The level of knowledge a school employee had about diabetes and the interest to learn influenced parent satisfaction with the family-school relationship. Parents were willing to be helpful and patient, but were unsatisfied when they encountered resistance to parental input about the illness management.

For ADHD families, parental dissatisfaction is probably higher than results reported by Zoeller because ADHD is a constant condition that affects students day in and day out. Zoeller's study suggested that parental dissatisfaction was linked to lack of judgment of school personnel during a crisis or period of illness exacerbation. Because ADHD is not a condition that waxes and wanes, adolescents, parents, and teachers must deal with the effects of ADHD every day so the family-school relationship needs to be ongoing and flexible to deal with changes over time.

ADHD is recognized by federal statute as a disability but is not generally accepted as a disabling condition by the general public. Parents in this study attributed

much of the difficulty with obtaining school services to the fact that ADHD was an "invisible" disability. Several parents compared their experience to that of parents of a physically disabled child, reasoning that if ADHD were recognized by a disfigurement, scar, or brace, parents would have much less difficulty obtaining school accommodations for their adolescent.

A second consequence of the invisibility of ADHD as a disabling condition is that it is easier for some to question the validity of the diagnosis of ADHD. Parents reported that "disbelieving" school staff was often a problem when seeking accommodations for their adolescent at school. This study highlights the need for more education of educators about ADHD and training on how to develop collaborative family-school relationships. National and state statutes designed to protect the civil rights of students with ADHD are of little value unless local educators are adequately trained and required by their districts to engage in cooperative, collaborative family-school relationships.

A new paradigm for educating students with ADHD. Results from this study regarding the significant difficulties ADHD students have completing and turning in homework and projects is consistent with other research about ADHD and school performance (Barkley, 1990; 1997; Hinshaw, 1992a; 1992b). This suggests that the challenge to schools is greater than proposing accommodations to help students complete and turn in schoolwork. Instead, the challenge schools face is to "think outside the box" to develop alternative instructional and measurement of mastery strategies that go beyond helping the student fit into the present educational paradigm. Universal designs for learning represent one approach for thinking outside the box and provides a model for educating all students, not just students with disabilities (Meyer & O'Neill, 2000).

Just as architects and product designers have employed principles of universal design to improve access and livability for disabled and non-disabled persons alike, the field of education is beginning to develop universal designs for learning (Meyer & Rose, 1998). This new paradigm includes strategies for teaching, learning, and assessment, and incorporates emerging knowledge from brain research and media technologies to respond to individual differences among students. Like architectural universal designs where adaptability is incorporated subtly into the design, universal designs for learning increase usability of curricula for all students.

Universal designs for learning reflect the spirit of federal legislation on education and disabled students (ADA, IDEA) and represent one approach to providing equitable educational opportunities for all learners, not just the divergent needs of students with disabilities. In particular, universal designs for learning change the assumptions of teaching and learning in several ways: 1) teachers see students with disabilities along a continuum of learner differences, not a distinct category of learners; 2) providing accommodation occurs for all students, not just those with disabilities; and 3) curriculum materials are varied and diverse, includes a wide variety of technological resources rather than worksheets and textbooks.

Although this particular paradigm within education offers great hope to students with ADHD, major policy and procedural changes are needed to implement this emerging approach into the daily school experience of students with ADHD. Teacher education programs in universities must adapt their professional educational curricula to embrace this paradigm shift. State departments of education will have to adjust the methods for measurement of subject mastery. School board members and district

administrators will have to adopt the principles of universal designs for learning or other similar perspectives and continuing education is needed for teachers already in practice.

This systemic change in education can be spearheaded by national organizations like CHADD (Children and Adults With Attention Deficit Disorders) and the National Academy for Child Development, but the major burden of creating this type of change for individual students most likely will fall to parents who continue to take extraordinary measures to help their own children and adolescents through school. The family-school connection is a mechanism that can and should be employed by individual parents and teachers until systemic changes are made in teacher education programs, state departments of education, and local school districts.

In summary, findings from this study were discussed in light of other research on ADHD and families, ADHD and chronic illness, and the family-school relationship. These results corroborate research about family disruption and maternal depression as common findings in family research about ADHD. "Normalization" of family life does not occur in ADHD families, thus differentiating the family experience of ADHD from that with other chronic illnesses. The findings of this study indicate the chaos in ADHD families is significant and these families are in need of additional illness specific educational, medical, social, behavioral, and community services. Finally, a new educational paradigm is needed to meet the learning needs of students with ADHD rather than provide accommodations to help ADHD students "fit into" the existing model of education that is inadequate for educating students with disabilities. The next section discusses the criteria used to judge qualitative research.

Criteria for judging qualitative research

The two sets of criteria by which qualitative research is judged are trustworthiness and authenticity (Sandelowski, 1986; Denzin & Lincoln, 1994). Trustworthiness includes an assessment of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Strategies used to establish credibility of data include persistent observation, peer debriefing, and member checks (Denzin & Lincoln, 1994). Persistent observation results from the ongoing process of memoing one's thinking about the data. Peer debriefing is the practice of discussing the data with professional colleagues; member checking is the act of taking conceptualized data back to participants for clarification, confirmation, or revision. These strategies are intended to probe for bias, explore meaning extracted from data, and clarify the basis for interpretation of data with trained qualitative researchers and participants. Dependability and confirmability are judged by the use of an inquiry audit that examines both the process used in the study and the product that is evaluated at each step of the research process (Rodgers & Cowles, 1993; Lincoln & Guba, 1985.

In this study, the researcher wrote theoretical memos to track thinking about concepts and questions about the data. The practice of memoing reflected the interactions of the researcher with the data and was used as an integral part of generating grounded theory (Glaser, 1978). Notations about discussions of the data with the dissertation advisor, professional colleagues and members of an advanced qualitative research forum for doctoral students were also recorded as memos regarding peer debriefing, and were useful for clarifying interpretation of data and identifying potential sources of bias or alternative explanation. Memos about regular meetings with the

dissertation chairperson recorded the emergence of theoretical relationships. Conceptualized data was reported back to participants during later phases of data collection for clarification and confirmation. The researcher used analytic strategies of memoing, peer debriefing, and member checking to enhance the trustworthiness of the data in this study.

No attempt was made to generalize findings from this study to any other setting. Qualitative, grounded theory studies are not designed to produce results that are "final" or generalizable to the larger population of families with ADHD children and adolescents, but are, instead, intended to produce a theoretical understanding of a social process or phenomenon as experienced by the study participants, embedded within that context. As the number of studies of qualitative and quantitative research increases and produces results that are consistent, corroborative, and illuminate different aspects of a complex phenomenon, confidence in findings is increased. This grounded theory should be modifiable as new data emerges in later studies.

An audit trail composed of memos, journal entries, field notes, dated conceptual maps and summaries of categories was made to establish dependability and confirmability. Dissertation committee members monitored these processes regularly to help insure that the resulting theory was grounded in and emerged from the data.

Limitations of the study

Limitations of this study included the disproportionate number of educated and high socioeconomic families than what is typical for the general ADHD population. In addition, the three high school graduates in the sample were all enrolled in college and doing well, which may not be typical of most adolescents with ADHD. However, what is

typical for adolescents transitioning from high school to young adulthood has not yet been documented sufficiently to chart a likely trajectory.

Conceptual saturation may not have been reached regarding adolescent outcomes since the sample did not include adolescents with moderate to severe behavior problems, nor a broader sampling of socioeconomics adolescent intelligence, and family risk factors. Further research is needed to fully understand the adolescent outcomes of the family experience with school when adolescents have ADHD, as well as the transition of adolescents to work and higher education.

The families in this study had available and took advantage of health care, ongoing tutoring, counseling, and training resources to help them manage ADHD in their families. Yet, in spite of the relatively high level of SES and IQ in these families, and the fewer behavioral problems these adolescents had compared to the general ADHD population, these parents still called their family life a nightmare. For families with more difficult adolescents, environmental and educational supports need to be even greater, and services need to be matched with specific needs and coordinated across agencies to be effective and timely.

A second limitation of the study regards the perspectives represented in the study. This study was focused on the family experience with school when an adolescent had ADHD from the perspective of the parents and adolescents. The analysis included an explanation of the family-school relationship, but only from the perspective of the family. Although several parent participants in the study were educators by profession, the family-school relationship cannot be fully explained without understanding the perspective of teachers, school staff, administrators, and other multi-disciplinary school

professionals. However, findings from this study help illuminate the complex relationship and contribute to the expanding interdisciplinary fund of knowledge about the family school relationship.

Recommendations

Two types of recommendations can be made in light of the study findings: clinical implications and recommendations for future research. ADHD is a medical condition that requires a variety of interventions to improve the family experience and quality of life of those who have ADHD. There is no cure for ADHD; therefore, adaptation and amelioration of symptoms are the focus of treatment recommendations. Nurses find adolescents with ADHD and families in nearly every practice setting. Knowledge about the experience with school from the perspective of the family is prerequisite to the assessment and planning of successful family interventions.

Clinical implications

The primary implications to be made from the results of this study are in the area of clinical practice for nurses and other health care professionals. The recommendations reflect an underlying philosophical assumption of the grounded theory method, that a social phenomenon is best understood from the perspective of those who experience the phenomenon. The clinical implications may be used by nurses and other professionals in many settings where adolescents with ADHD and their families appear for health care services.

The first clinical implication from this study regards the sensitization of professionals to the struggles families face when an adolescent has ADHD. Parents expressed the wish to be respected as a parent who loved their children and were trying

diligently to be good parents, but admitted that without information, guidance and support from professionals, their best efforts were frequently inadequate. Parents also expressed profound appreciation when professionals acknowledged their efforts and worked cooperatively with parents.

Parents characterized sensitized professionals as caring individuals who inquired about other family members and family issues related to ADHD. For instance, parents reported feeling supported by their primary care physician who asked during an office visit for medication refills how the student was doing in school, or how the family was coping with ADHD. From the parents' perspective, being a sensitized professional did not necessarily require expertise about all aspects of ADHD but did include a willingness to make referrals to clinicians or resources that might be helpful to the family. In some cases, making referrals means professionals must become advocates for services for families outside of a managed care panel or health care plan. Sensitivity to the level of family disruption created by ADHD can empower professionals to assume roles of advocacy and community leadership for ADHD families.

A second clinical implication of this study is the challenge to make accurate diagnoses for ADHD during the early elementary school years and tailor treatment recommendations to reduce the amount of family disruption due to ADHD. Data suggested clearly that the family costs from ADHD (parental depression, marital stress, and family disruption) increased over time and that the negative family climate had a cumulative effect on all family members. Support and interventions for family disruption need to be implemented as soon as school problems begin to affect family life in order to minimize the cumulative effects of ADHD on families.

A final clinical recommendation resulting from this study regards the scope of initial and ongoing assessment of adolescents with ADHD and their families. Assessment of the adolescent should include examining the behavioral patterns of accomplishing things and struggling through school to ascertain the level of difficulty these patterns create for the adolescent and family. Parents reported a decrease in the negative family climate once parents understood the nature of the behavioral patterns. Parent education about these behavioral patterns and ongoing support are needed to promote parental actions to compensate for the effects of ADHD and protect the self esteem of the adolescent that is vulnerable when accomplishing things and struggling through school is so difficult.

The scope of family assessment needs to be broadened because of the complexity of effects ADHD creates in individuals and families. Family assessment should include screening parents for ADHD characteristics, depression, parent/child enmeshment, identifying family values, family resources, and the degree of family disruption caused by ADHD. It is important to screen parents for ADHD because adults with ADHD are often undiagnosed until one of their children is diagnosed, but they struggle and are frequently in need of services themselves. In addition, parents should be evaluated periodically for signs of depression, marital stress, and enmeshment with the ADHD adolescent to intervene before these conditions create further morbidity in the family. An assessment of family values and family resources are needed to identify sources of motivation, inspiration, and support to sustain parents as they organize cooperative efforts and take extraordinary measures to manage the effects of ADHD on the family. Assessing the level of family disruption from ADHD is important not only to plan for interventions and

services, but also to detect clues to understanding the patterns of difficulty accomplishing tasks and struggling through school. This is important because parents report that they responded less negatively when they understood the underlying causes for unfinished chores and homework and were more able to manage the negative family climate.

There are also implications for educators based on data about the family experience with school when an adolescent has ADHD. The first implication for educators involves the need for adequate training about ADHD. With 3-5% of all children of school age diagnosed with ADHD, teachers and other school staff need to be knowledgeable about the condition, understand the patterns of ADHD behavior that impact school performance and social behavior, and how to manage ADHD behaviors while students are at school. Educators also need training about creating and managing the family-school relationship so that enriching and cooperative partnerships are achieved among students, parents, and educators.

A second implication for educators arising from this study involves the management of homework. Since doing homework at home is a source of great family disruption, teachers and parents have an opportunity to develop collaborative strategies that will assure adequate practice for mastery of schoolwork without causing significant disruption to the family.

A third implication for educators involves the adoption of a new paradigm of universal designs for learning in the classroom, across the curriculum, at the state level in departments of education and public instruction, and in teacher training courses at the university level.

Fourth, while awaiting systems changes needed to implement universal designs for learning, schools need to strive for positive family-school relationships to fulfill the mandate of federal legislation and professional practice standards by making necessary accommodations for students with ADHD.

Implications for future research.

There are numerous avenues for future research arising from this study. Recommendations for future investigation follow:

1. The conceptual model needs to be tested with a larger, more diverse sample of adolescents with ADHD and their families to see how ethnicity, socioeconomic status, and family risk factors impact the model. In particular, further research is needed to study the relationships between greater diversity of adolescent and parent participants and adolescent outcomes.
2. An assessment tool to measure the degree and type of family disruption to aid in family-tailored interventions needs to be developed and tested.
3. The behavioral patterns of difficulty accomplishing things and struggling through school need to be developed further by identifying selected measurable variables to expand the understanding of the underlying disabling components.
4. A correlational study on the relationship between family values, parental extraordinary measures, and parental depression is needed to further understand how parents manage their personal energy and optimism over time.

5. A longitudinal study is needed to further explore the phenomenon of adolescents experiencing a "wake up" call and gradually assuming personal responsibility.

6. The family-school relationship needs to be studied from the perspective of schoolteachers, administrators, ancillary and professional school staff members. The family school relationship is a complex social interaction that takes place over many years because schooling is a primary activity of childhood. Future research is needed to map the complexity of the interactions among parents, students with ADHD, and school personnel.

7. Further research is needed to identify similarities and differences in the family-school relationship across other chronic conditions of childhood and adolescence.

8. A collaborative demonstration project among adolescents with ADHD, parents, and school personnel needs to be developed to model components of enriching and cooperative family-school relationships when an adolescent has ADHD. One such project could be developed to assist with the transition between elementary school and middle school, middle school to high school, and high school to work or further education since transitional periods are stressful for parents and adolescents.

Summary

The purpose of this study was to generate a theoretical understanding of the family experience with school when an adolescent had ADHD. Grounded theory methodology was used to analyze data from interviews with families that had at least one adolescent diagnosed with ADHD. Results indicated that the central family experience with school when an adolescent had ADHD was about parents organizing cooperative efforts to manage ADHD in the family. The primary focus of the organizing efforts were directed toward school since school is the central activity of adolescents.

This study adds to the knowledge about how families experience the effects of ADHD, how ADHD affects the family-school relationship, and how families manage a lifelong chronic condition. It corroborates findings from three previous family studies about ADHD and contributes to the ongoing dialogue about parent involvement in their children's schooling.

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APPENDIX A

CONSENT FORM
ASSENT FORM
STUDY ADVERTISEMENT

OHSU IRB# 4873
Approved: 6/22/99

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form

TITLE: The Family Experience with School when a Teenager has ADHD (Attention Deficit Hyperactivity Disorder)

PRINCIPAL INVESTIGATOR: Kathleen C. Shelton, RN, PNP, MS
Doctoral Student, School of Nursing
503-494-1141

PURPOSE: You have been invited to participate in this research study because you are a teenager with ADHD or a parent of a teenager with ADHD. The purpose of this study is to learn how families experience dealing with school (homework, conferences, etc.) when a teenager has ADHD in order to provide improved services to families with ADHD teenagers. Your participation in the study will involve meeting with the principal investigator on two occasions, 4-6 weeks apart, for approximately 2-3 hours at the first visit and one hour for the second visit.

PROCEDURES: The teenager with ADHD and at least one of his or her parents will be asked to participate in the study. At the first meeting, you will be asked to complete a set of questionnaires and participate in one private interview. You will be asked questions regarding your family experience with school, what happens at school, and how school affects family life. Questions will include some sensitive issues. With your permission, all interviews will be tape recorded. During the second meeting, each parent and teenager will be asked to participate in a similar, but much shorter interview, to obtain any information that might have been overlooked at the first meeting.

RISKS AND DISCOMFORTS
You might find it upsetting or painful to talk about how ADHD affects teenagers and family life. In the unlikely event that information is discovered regarding abuse or neglect of a child, I am legally required to report that information to the State Office for Services to Children and Families in Oregon. I will be available to provide you with support and referrals if requested.

BENEFITS
You may or may not personally benefit from participating in this study. However, by serving as a participant, you may contribute new information, which may benefit teenagers and families in the future. Participating in this study may provide some benefit to you in that some parents and teenagers report that talking to someone about their situation is helpful.

ALTERNATIVES
You may choose not to participate in this study and may withdraw from the study at any time.

CONFIDENTIALITY

All information you provide will be kept confidential. All information obtained from minors will be ensured the same right to confidentiality as adults, with two exceptions: 1) according to Oregon law, suspected child or elder abuse must be reported to appropriate authorities, or 2), when a teenager might be physically or psychologically harmed if information were kept secret, such as suicidal thoughts, significant physical or psychological illness, or risk of injury.

Neither your name nor your identity will be used for publication or publicity purposes. Research records may be reviewed by a funding agency but no identifying information will be provided. Information you provide will be identified only with a code number.

COSTS

There are no costs to you for participating in this study.

LIABILITY

It is not the policy of the U.S. Department of Health and Human Services, or any federal agency funding the research project in which you are participating to compensate or provide medical treatment for human participants in the event the research results in physical injury. The Oregon Health Sciences University, as a public corporation, is subject to the Oregon Tort Claims Act, and is self-insured for liability c claims. If you suffer any injury from this research project, compensation would be offered to you only if you establish that the injury occurred through the fault of the University, its officers or employees. However, you have not waived your legal rights by signing this form. If you have further questions, please call the Medical Services Director at 503-494-6020.

PARTICIPATION

Kathleen Shelton, or her faculty advisor, Judy Kendall (503 494 3890), have offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at 503 494 7877. You may refuse to participate, or you may withdraw from this study at any times without affecting your relationship with or treatment at the Oregon Health Sciences University. The person signing this consent will be given a copy.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

_____ _____

Signature of Participant Date

_____ _____

Signature of Witness Date

_____ _____

Parent and/or Guardian Date

OHSU IRB# 4873
Approved: 6/22/99

OREGON HEALTH SCIENCES UNIVERSITY
Assent Form

TITLE: The Family Experience with School when a Teenager has ADHD (Attention Deficit Hyperactivity Disorder)

PRINCIPAL INVESTIGATOR: Kathleen C. Shelton, RN, PNP, MS
Doctoral Student, School of Nursing
503-494-1141

1. I, _____, state that I am _____ years of age and wish to participate in a research study being conducted by Kathleen Shelton, RN, PNP, MS, at Oregon Health Sciences University, in Portland, Oregon.

2. The purpose of the research is to learn more about attention deficit hyperactivity disorder (ADHD) and the family experience with school.

3. The study involves participating in two interviews that ask questions about what it is like having ADHD and dealing with school. With my permission, the interviews will be recorded.

4. No one, including members of my family will know the information I give, or see the answers to my questionnaire. If problems are revealed which could be dangerous, Kathleen Shelton may speak with my parents, or in the case of abuse or neglect, with the proper authorities.

5. No one is making me do this, and I can refuse participation at any time.

6. If questions arise about this research, I can ask my parents, Kathleen Shelton (503) 494 1141), or Judy Kendall, who is Kathleen's faculty advisor (503 494 3890).

7. The information will be used to help nurses and doctors learn about how families deal with school when a teenager has ADHD.

Participant signature: _____

Research signature: _____

Date: _____

KP CPHS approved 12/22/99 as revised

SEEKING PARTICIPANTS

FOR A RESEARCH STUDY ENTITLED:

The Family Experience with School when a Teenager has ADHD (Attention Deficit Hyperactivity Disorder)

PRINCIPAL INVESTIGATOR: Kathleen Shelton, RN, PNP, MS
Doctoral Student, School of Nursing
Oregon Health Sciences University
503-494-1141

This study is about understanding what it is like for families dealing with school when a teenager has ADHD. The researcher is interested in learning about how the family deals with doing homework, report cards, school meetings, behavior problems at school, etc. The study will involve two meetings from 1-3 hours in length at your home or a place convenient for you.

Teenagers with ADHD and their parent(s) are eligible to participate in this study if:

1. at least one teenager in the family, age 12-18, has a diagnosis of ADHD
2. parent participants must be the legal parent or guardian of the teenager with ADHD, and currently living with the teenager,
3. the teenager with ADHD and at least one parent are willing to participate in 2 individual interviews and complete a questionnaire, and
4. the teenager and parent speak English.

There will be no cost to you for participating in the research.

Call Kathleen Shelton for further information at 494-1141.

APPENDIX B

DEMOGRAPHIC INFORMATION SHEET

DEMOGRAPHICS

About the adolescent with ADHD:

Age:

M/F

Grade

Medication: Y/N
Type & dose

When diagnosed: (age/grade)

Diagnosed by: Pediatrician Family physician Nurse practitioner

About the adolescent's parent:

Age:

M/F

Highest grade completed:

Number of children:

Number of children with ADHD:

Have you ever been diagnosed with ADHD?

Has either parent ever been diagnosed with ADHD?

Other family members diagnosed with ADHD? Y/N What relationship:

APPENDIX C

INITIAL INTERVIEW GUIDE FOR PARENTS

Sample Questions for Parents in Individual Interviews

1. Please describe a typical day at your house.
   - What things go well in your family? What things don't go well?
   - How do people get along in your family?
   - How do school mornings go?
   - How do chores get assigned and completed at your house?
   - How does ADHD affect a typical day at your house?

2. Tell me about ADHD in your family.
   - What is it like for you to have an adolescent with ADHD?
   - How does ADHD affect the teen who has it?
   - How does ADHD affect the family members who don't have it?
   - How has ADHD affected your family over time?
   - What things does your family do to manage ADHD?

3. What factors about school affect how your family functions?
   - When your teen with ADHD does well at school, how does that affect the family?
   - When your teen with ADHD doesn't do well at school, how does that affect the family?
   - How do you participate in your teen's school life?
   - What kind of relationship do you have with your teen's school?
   - How does the "school and family connection" work in your family?
   - How does homework get done at your house?
   - What about school affects your family functioning most/least?

4. What factors about how your family functions affect your teen with ADHD at school?
   - How do "good days" or "bad days" at home affect school for your teen with ADHD?
   - Which family functions most/least affect your teen with ADHD at school?

APPENDIX D

INITIAL INTERVIEW GUIDE FOR ADOLESCENTS

Sample Questions for Adolescents with ADHD in Individual Interviews

1. Would you please describe what a typical day at school is like for you?
   - Describe a typical day, what happens first at school, order of classes, etc.
   - What sorts of things go well for you at school? What things don't go well at school?
   - Does ADHD cause any difficulties for you? How?

2. What is it like for you to have ADHD?
   - What is ADHD?
   - What characteristics of ADHD do you have?

3. How does ADHD affect you at school?
   - What things are easy for you at school?
   - What things are hard for you at school?
   - What is it like for you in class?
   - Tell me about keeping up with school work.
   - What kinds of grades do you get?
   - What kind of effort is required for you to do well in school?
   - Who is helpful or not helpful at school and what do they do?

4. How does ADHD affect you at home?
   - Tell me what happens at home when you are getting ready for school in the morning?
   - Tell me about doing homework at your house.
   - Describe how well your family functions (gets along, gets things done, etc.)
   - Are things better or worse at home since you've become a teenager?

5. What things at home affect your work at school?
   - What things do your parents to that are helpful or unhelpful with your school work?
   - How do your parents participate in your school life?
   - How does how people get along at home affect your school work?
   - What things about your family make school easier or more difficult?

6. What things about school affect you at home?
   - Do your grades affect how things are at home?
   - How does doing homework affect your family?
   - Is family life different or the same during school vacations? How?
   - What privileges and penalties at home are connected to school work?

APPENDIX E

FINAL CODELIST

REVISED CODELIST

CAUSAL CONDITIONS: Juxtaposition of:

- Early expectations
  - Getting an education
  - Getting a good job
  - Starting a family
  - Having an enriching family life
- Diagnosis of ADHD
  - Who initiated
  - The diagnostic process
  - Emotional responses of parents

CONTEXT: DISRUPTED FAMILY CLIMATE

(Results from the interactions bet. ineffective parenting strategies and teen's inner chaos)

- Frustration
- Struggling
- Escalating behaviors
- Really blowing it, Wanting more
- Hovering
- ~~Homework/schoolwork activities~~
- Ordinary good parenting strategies don't work with ADHD
  - Raising teens
    - Loving
    - Yelling
    - Pride in kids
    - Facilitating friends
    - Investing self in kids
    - Helping with school
    - Sharing the parenting
    - Giving benefit of doubt
    - Aspirations for teens
    - Monitoring,
    - Worrying
    - Organizing
    - Providing structure
    - Hoping
    - Letting go
    - Empathizing
    - Preparing for the future
    - Feeling responsible
    - Helping with homework
    - Providing other educational opportunities
    - Casual involvement
- ADHD effects on adolescents
  - Teen ~~behavior: Normal and ADHD~~
    - ~~Rules and routines at home~~
    - ~~Concept of time: waiting, moving slowly, feeling rushed, late, absent~~
    - ~~Fatigue, difficulty sleeping, waking,~~
    - Getting to and from school
  - Emotional experiences (developmental level?)
    - Worries, attitudes
    - Feeling bad, stressed, overwhelmed, depressed
    - Struggles, hard things
    - Personal teen aspirations, philosophies, perspectives, ideas
  - Social competencies (developmental level?)
    - With friends, interactions & communications with school, life skills
    - Rules and routines at school
    - Behavior problems, acting up
    - Sibling interactions
    - With teachers, staff
    - Related to family resources
    - Awareness, clueless

Cognitive experiences: School
- Like or don't; good days, bad days
- School work
  - Level of difficulty: easy, hard, don't like subject, boring, notetaking
  - Grades, consequences, ownership, motivators
  - Quality of work-well done
  - Managing, planning, completing, turning work in
  - Factors affecting school: fatigue, time of class
  - Learning outside of class/school
  - Difficulties at school

The paradox
- Mindworks
- If they can do this, why can't they do that?

PHENOMENON: Organizing Cooperative Efforts to Manage ADHD in the Family

Parents compensating for the invisible disability
- You can't see what is wrong with them
- Forgetting Connecting Organizing Being aware Timing
- Teen experience
  - Experience at school
  - Perceived level of difficulty
  - Meaning of grades
  - Management of schoolwork
  - Fatigue
  - The paradox

Difficulty accomplishing things
- Procrastinating
- Distracting
- Checking out
- Resisting/avoiding
- Giving up
- Relying on others
- Accidental success
- Related to level of interest

Struggling through school
- Intending to do well
- At the beginning
- Uneven performance
- Falling behind
- Crunch time, mustering up
- Compensating with extra credit
- Pulling it out of the fire

The family nightmare
- Constantly dealing with ADHD
- What am I doing wrong?
- The nightmare

INTERVENING CONDITIONS

Family values

Daily living: mealtimes, pets, rules and routines

Role of parents

Value of children — Nudging, setting example

How to live

Being honest, living in peace & harmony, enjoying companionsing, sharing, doing your best, not giving up, setting goals, having faith in God

Social ecology

Own family, individual vs. family unit, extended family

Community involvement

Aspirations: college, good job, school success, life success

Ages of family members

SES

Knowledge of ADHD

Parents with ADHD

Strengths

Personal difficulties

Household management

Parenting

Gender differences

Emotional responses

Needs for support

ACTIONS: PARENTS TAKING EXTRAORDINARY MEASURES

Feeling

Feeling grateful — Accepting — Feeling relief

Setting limits for self — Dealing w/ disability — Hanging on

Resigning oneself — Aligning family values

Thinking

Figuring it out — Evaluating — Lowering expectations

Normalizing — Balancing — ID strengths, limits

Preparing for the worst — Making choices — Revising expectations

Acting

Advocating in the community

Educating educators — Finding resources

Networking — Paving the way

Working with the schools

Keeping records — Going to meetings — Communicating with school

Volunteering a lot

Manipulating the system

Demanding services

Investing in the adolescent

Explaining things — Providing structure & organization

Intervening — Transporting

Taking care of oneself

Educating oneself — Hanging on

Setting limits — Going to counseling

Getting support

OUTCOMES

- Relationships with school
  - Enriching
  - Cooperative
  - Disillusioning
  - Unsatisfactory
- Family costs
  - Financial
    - Tuition, tutoring, evaluations, treatment, medications
    - Transportation, lost wages, replacing lost items, clothing
    - Lack of resources
  - Parental depression
    - Marital stress
  - Family disruption
    - Daily routines: mornings
    - Mess, organization
    - Family communication
    - Family as unit
    - Intergenerational relationships
    - Contrast between ADHD, non-ADHD sibs
- Teens assuming personal responsibility
  - Delayed development
  - Passage of time
  - Facilitating factors
    - Parents change strategies
    - Teen received recognition for competence
    - Teen wakes up, takes hold
      - Figuring things out
      - Thinking of the future
      - Getting organized
    - Marching to a different drummer