CHILDREN WITH ADHD IN A RURAL COMMUNITY

by

Debra Joan Miller

A thesis submitted in partial fulfillment
of the requirements for the degree

of

Master

of

Nursing

MONTANA STATE UNIVERSITY
Bozeman, Montana

December 2005

APPROVAL

of a thesis submitted by

Debra Joan Miller

This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

Karen Zulkowski, DNS, RN, CWS
Committee Chair

Approved for the College of Nursing

Elizabeth Nichols, DNS, RN, FAAN
Dean

Approved for the College of Graduate Studies

Joseph J. Fedock, PhD
Graduate Dean

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Debra Joan Miller

December 2005

Dedicated
to
ROBERT LELAND, M.D.

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ABSTRACT

Children with ADHD experience a myriad of chronic behavioral and academic difficulties. If attributes among rural children are similar to those described by studies conducted on the urban population, educators and health care professionals may have grossly underestimated the public health impact of ADHD

Research does not provide adequate descriptive data of children with ADHD in rural communities and until more is known about actual attributes of these children, there will continue to be disparities in identification, access to treatment, and reports of the manifestations of ADHD and its co-existing conditions. Levine's Conservation Model-Nursing Process in the Community provides the theoretical framework for the study.

A Descriptive Correlational study is conducted to gain information on the demographic attributes; to identify the distribution of ADHD subtypes; and to explore the comorbidity associated with ADHD in rural children. The sample consists of 88 children seen at a pediatric outreach clinic located in a rural community in southern Wyoming. Secondary data analysis makes the study exempt from IRB review.

Descriptive statistics are used to organize and analyze the data. Because of the small sample size, results may only indicate potential trends. Findings may not be statistically significant but clinically they assisted the community in proposing systems for establishing family-centered, community-based care.

The gender ratio is similar to those of larger studies with more boys than girls diagnosed. This raises the continued concern that ADHD may be under-diagnosed in girls in rural communities. Caucasians are diagnosed more frequently, raising the concern that minorities are under-diagnosed or underrepresented in research. Findings on the distribution of subtypes is somewhat ambiguous when compared to other studies. Most of the children were diagnosed during school transition times (1st and 3rd grades). Psychological comorbidities were diagnosed in 27.3% and 55.7% were identified with learning disabilities. Sleep disturbances were frequently associated with the diagnosis of ADHD and depression was found to contribute substantially to sleep disturbances.

ADHD can be characterized by heterogeneity and ambiguity, and confounded by comorbidity. Nurse Practitioner strategies should include: collaborative assessment; case planning; advocacy; management; and building systems to provide a multimodal approach to interventions.

CHAPTER 1

INTRODUCTION

Attention Deficit Hyperactivity Disorder (ADHD) has become one of the most frequently encountered childhood developmental disorders in primary care (Brown et al., 2001). ADHD is now recognized as a chronic disorder that can continue into adulthood with symptoms persisting in one third to two thirds of the children diagnosed (Glod, 1997). The disorder is recognized as pervasive in its impact to the individual's domains of function which include academics, peer and family relationships, and self esteem. The high rate of comorbidity associated with the diagnosis has become a confounding factor of ADHD and has been identified as one of the most common reasons for referrals to mental health services and psychiatrists by primary care providers (Hazelwood, Bovingdon, & Tiemens, 2002). Clinicians, educators, and parents are challenged with deciphering ADHD from other disorders or from the upper limits of normal behavior. Diagnosis holds far-reaching implications not only for the child, but for the family and community as well (Primary Care Practice: A Peer-Reviewed Series, 2000).

As research of ADHD has grown and been more widely published, the public has become more accepting of the concept and validity of ADHD as a public health crisis. Early recognition, assessment, and management of this condition can redirect the educational and psychosocial development of more children with ADHD (Cantrell, 1996). A thorough, systematic evaluation can validate ADHD diagnostic criteria or differentiate ADHD from other conditions with similar patterns of presenting symptoms (Goldman, Genel, Bezman, & Slanetz, 1998). Inconsistencies in the diagnosis, treatment,

and follow-up of children with ADHD present a major public health problem. Children, who present with ADHD-type symptoms often receive an inconsistent level of health and educational services that are fragmented, ineffective, and costly (Magyary & Brandt, 2002).

The fact that children with ADHD experience a myriad of chronic behavioral and academic difficulties further necessitates an expanded focus on community-based research. Multiple studies document high rates of prevalence, as well as describe the characteristics of children from inner city elementary schools. If attributes among rural children in the U.S. are similar, educators and health officials may have substantially underestimated the public health impact of ADHD.

In a rural setting, Advanced Practice Nurses are in a key position to help promote community awareness of ADHD and its co-existing conditions and to enhance the comprehensive and systematic nature of the assessment process for the child suspected of ADHD. Family Nurse Practitioners can enhance the comprehensive and multimodal nature of the intervention plan and augment collaboration among various community agencies providing care to the child and family. Strategies can be implemented to enhance cultural sensitivity of care and optimize outcomes for the child and family within a rural community.

Problem

Research does not provide adequate demographic and descriptive data of children with ADHD in rural communities and until more is known about actual attributes of these

children, there will continue to be disparities in identification, access to treatment, and reports of the manifestations of ADHD and its co-existing conditions.

Purpose

The intent of this study will be to identify and describe the attributes in a clinical-sample of children with ADHD as they exist in a rural setting. The relationship among the identified attributes (variables) will also be explored.

Objectives

The study objectives include: (a) to describe the sociodemographic attributes (gender, current age, race, living situation, resource used for payment of health care services) of rural children diagnosed with ADHD; (b) to identify the distribution of ADHD subtypes and age at time of the ADHD diagnosis in the sample; (c) to identify the co-existing conditions exhibited with the diagnosis of ADHD; and (d) to examine the relationships among the sociodemographic attributes, diagnostic categorical attributes, and co-existing conditions.

Theoretical Framework

The theoretical framework for the study is based on Levine's Conservation Model. The Model includes a method for assessment; identification of the problems; development of a hypothesis about the problems; the identification, selection, and application of interventions; and an evaluation of the response to the interventions (Schaefer, 2001). The major prepositions formed by the conservation principles provide a

framework to organize the identification and assessment of attributes of children with ADHD within a rural community setting. See Figure 1.

Figure 1. Levine's Conservation Model-Nursing Process in the Community.

PROCESS	APPLICATION OF THE PROCESS
ASSESSMENT Collection of provocative facts through observation and interview.	The nurse uses observation, review of census data, statistics, data from community member interviews, etc. to collect facts about the community. Use of windshield assessments or other formally developed community assessments are helpful in the collection of data. (For the purpose of this study, data was obtained from a previous rural community assessment of children with ADHD. Assessment of the model's internal and external environment is proposed.)
TROPHICOGNOSIS Community diagnosis.	The nurse organizes that data in such a way as to provide meaning. A judgment or trophicognosis is made. (For the purpose of this study, secondary data analysis will be performed to address the objectives as outlined.)
HYPOTHESIS Directs the nurse to provide interventions that will promote adaptation and maintain wholeness of the community.	In discussion with the members of the community the nurse validates her judgments about the community's predicament and then proposes hypotheses about the problems and solutions. (This study proposes no hypotheses about ADHD in a rural community. An example of a possible hypothesis: Providing respite care to families of children with ADHD will reduce family stress.)
INTERVENTIONS Test the hypotheses.	Nurses use the hypotheses to direct the plan of care for the community and test the hypotheses to try to remedy the predicament. The nurses select the most appropriate solutions with the help of the community members. Interventions are based on the conservation principles of energy, structural integrity, personal integrity, and social integrity. (This study proposes no interventions.)
EVALUATION Observation of organismic response to interventions.	The outcome of hypotheses testing is evaluated by assessing for organismic response. (For example, an expected outcome of respite care for families of children with ADHD might be a reduction in reports of child abuse to Child Protection agencies).

Source: Alligood and Marriner-Tomey (1997).

Using secondary data analysis, facts will be collected on the internal and external environment of rural children with ADHD. The assessment of the internal environment directs the analysis of patterns of ADHD among children in a community. The internal environment assessment can include an examination of community programs available to assist children and their families.

The internal environment is continuously challenged by the external environment. Levine describes the external environment in three levels: the perceptual, the operational, and the conceptual. The assessment of the external environment for the study will examine the operational and conceptual level. The operational environment encourages a more detailed assessment of the factors in the environment that affect the health of the individual (child with ADHD and potential co-existing conditions). The environmental factors are not perceived by the people (rural community). The assessment of the conceptual environment focuses on the ethnic and cultural patterns of the community (sociodemographic patterns in the children diagnosed with ADHD). Further research will be needed to address the assessment of the perceptual environment and could include community perceptions of ADHD as a valid condition.

Assessment of the internal and external environment can increase community awareness of the social, political, and economic impact of ADHD. The community is then provided the opportunity to develop and design public programs that might improve the interventions in the context of ADHD. The goal becomes focused on the restoration of the integrity and well being of children suffering from ADHD in the rural setting. Awareness and recognition of the attributes exhibited by the children will assist in the building of systems that support family-centered, community based health care.

Concept Definitions

The demographic variables of age, gender, ethnicity, age at time of ADHD diagnosis, living situation, and payment source for healthcare are analyzed to provide a picture of the characteristics of the sample. The other variables to be studied include the ADHD categorical diagnosis or subtypes and the co-existing conditions found in the sample. The intent of the study is to observe or measure the research variables as they exist in the rural setting without the implementation of a treatment.

ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is defined by the American Psychiatric Association as a "persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than typically observed in individuals at a comparable level of development" (American Psychiatric Association, 1994, p. 28).

ADHD Subtypes. The ADHD subtypes identified for this study include: ADHD, Combined Type; ADHD, Predominantly Inattentive Type; and ADHD, Predominantly Hyperactive-Impulsive Type. Diagnostic criteria for each subtype is outlined in Appendix A-1 Definitions. For the purpose of this study a fourth subtype is defined. Children who exhibited prominent features of inattention or impulsivity/hyperactivity, but did not meet full criteria for *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) ADHD, were identified as having ADHD, Not Otherwise Specified (ADHD, NOS). An analysis performed by Faraone and Biderman (2005) suggests that the

diagnosis of ADHD, NOS may be particularly valid for individuals with onset of ADHD at 12 years of age or older.

Comorbidity

Comorbidity is defined as "two or more co-existing medical conditions or unrelated disease processes" (Mosby, 2002, p. 402). For children presenting with two or more diagnoses, one syndrome is considered primary and should account for many of the symptoms observed in the secondary syndrome.

For the purpose of this study, conditions evaluated as comorbid or co-existing include mood disorders, anxiety disorders, conduct disorder, learning disabilities, sleep disorders, elimination disorders, tic disorders, and seizure disorder.

Learning Disabilities. Learning disabilities are determined by federal law but can be interpreted differently by each state. To establish that an individual qualifies for accommodations under the protection of the Individuals with Disabilities Education Act (IDEA) or Section 504 of the Rehabilitation Act of 1973, documentation must indicate that the disability substantially limits one or more major life activity and supports the request for services, accommodations, academic adjustments, and/or auxiliary aids. See Appendix A.2 Definitions for a more comprehensive explanation of each disability.

Risk Factors. Research has found that ADHD is a result of the complex interactions of genetic, biological, and environmental risk factors (Conners, 2003). Biological risk factors were identified in the data source if pertinent to the child's diagnoses of ADHD and its co-existing conditions. Biological risk factors associated with a higher incidence

of ADHD include preterm labor, impaired placental functioning with resulting impairments in fetal nutrition and growth, impaired fetal oxygenation leading to distress, and low birth weight (Saigal, 2000). Assessment of these risk factors can be supported by the concept of perceptual environment as defined by Levine. Secondary analysis of data did not provide for the assessment of genetic or environmental risk factors in this study.

Rural

Rural refers to a geographical area or town with less than 2500 people, or a county with less than 50,000 people. Rural counties are defined as those with six to ten persons per square mile, or those with at least 25,000 people but not adjacent to a city of 50,000 or more residents (Bigbee, 1993; United State Bureau of the Census, 1996).

Child/Children

The concept of child is defined in terms of chronological age. Life is divided into chronological stages: the prenatal period from the moment of conception to birth; infancy from birth to 1 year; toddlerhood from 1 to 3 years; preschooler from 3 to 6 years; school-aged from 6 to 12 years; adolescence from 12 to 20 years; young adulthood from 20 to 45 years; middle age from 45 to 65 years; and late maturity which is 65 years and older (Murray & Zentner, 2001). For the purpose of this study, child is defined as a person 3 to 20 years of age.

Assumptions

The proposed assumptions for the study are based on the premise that some of the children in the sample received the diagnosis for ADHD and co-existing conditions

outside the clinical setting. Those children diagnosed with ADHD and comorbid disorders within the clinical setting were assessed by a pediatrician. Those children with a known diagnosis prior to presenting to the clinic were assessed by a psychiatrist or pediatrician. Learning disabilities were diagnosed by a licensed diagnostician provided by the local school district.

The assumptions made for this study include:

1. For each child, the diagnosis of ADHD is determined using the DSM-IV criteria;
2. The assessment process will rule out differential and/or concurrent comorbid conditions;
3. There is a systematic and comprehensive review of child physical, child psychosocial, family, and school/educational data prior to secondary analysis of this data;
4. The focus of health in a community is based on the assumption that community-based care is informed by the assessment of individuals receiving one-on-one care. Thus, supporting the sample selection of children seen in a rural clinic.

CHAPTER 2

REVIEW OF LITERATURE

Diagnosis

The process of diagnostic decision making has been enhanced, but not perfected, by the continual search for patterns in different data sets to confirm or disconfirm persistent patterns of ADHD symptomology. Currently, there is no "gold standard" or laboratory test to confirm the diagnosis. Diagnosis is based on the criteria from the DSM-IV. Even though disciplines agree diagnosis can be consistently identified using the DSM-IV as a reasonably reliable/valid way of assessing ADHD, common practice among disciplines in case identification continues to vary widely (Goldman et al., 1998; Greene et al., 2001; Hunt et al., 2001; Magyary & Brandt, 2002).

Validity of the ADHD Syndrome

For practice-based work with families, the clinical guidelines provided by the American Academy of Pediatrics (AAP) and American Academy of Child & Adolescent Psychiatristry (AACAP) offer a methodology to validate a systematic and comprehensive process of assessment using the DSM-IV and to direct management of children with ADHD. It is important that the diagnosis of this condition be founded on procedures supported by evidence from empirical investigations (Brown et al., 2001).

Rating scales have great utility in research and clinical practice (Primary Care Practice: A Peer-Reviewed Series, 2000). Behavioral rating scales completed by caregivers and teachers can identify children suspected of ADHD and summarize the

extent to which the child exhibits particular symptoms over a specified time. Rating scales should be employed to ascertain the DSM-IV criterion of cross-situational symptom display.

Review of literature classifies behavioral rating scales as either broad-based or ADHD-specific measures. Effect sizes were calculated for each of the rating subscales. An effect size refers to the difference in mean scores between two populations (referred children with ADHD vs. nonreferred children) which is divided by an estimate of the individual standard deviation. A larger effect size suggests less overlap between the two populations and is indicative of greater sensitivity and specificity of the measure. Thus, an effect size of 1.0 or less reflects substantial overlap between the distribution scores across the two populations and would be, under the same conditions, associated with a sensitivity and specificity of 0.71 and a false-positive and false negative rate of 29%, (Hasselblad & Hedges, 1995). An effect size of 3.0 suggests little overlap between scores reported for the two populations. “The average effect size across broad-band measures using total global scale scores was 1.5 (Brown et al.). These findings do not provide sufficient evidence to support using broad-scale rating scales to screen for or diagnose ADHD but they are useful for screening for co-occurring problems. The overall effect size of ADHD-specific rating scales ranged from 1.3 to 3.7 with slightly greater effect size for subscales assessing specific symptoms compared with indices of combined ADHD symptoms (Brown et al.). The American Academy of Pediatrics (AAP), the American Academy of Child and Adolescent Psychiatry (AACAP), and Decision Tree and Clinical Paths endorse the use of ADHD-specific behavior rating scales as reliable and valid for the assessment of the disorder. In addition to the behavior rating scales, a

thorough history of the symptoms and assessment of the functional consequences of the behaviors should supplement the evaluation.

In a final statement, professionals participating in the Public Health Consensus Conference concluded that there is substantial evidence for the validity of ADHD as a disorder. “When applying the classic validational criteria, the weight of evidence indicates that ADHD does indeed meet criteria as a valid behavioral syndrome that has reasonably discrete defining characteristics and can be reliably diagnosed” (Jensen et al., 2004).

Prevalence of ADHD

Because of the lack of a single, consistent, and standard research protocol for case identification of ADHD, variable and disparate findings on prevalence are noted in the literature. Studies confirm that ADHD is prevalent worldwide as children suffering from this disorder are found in all countries (Brown et al., 2001; Cantwell , 1996; Jensen et al., 2001) .

The DSM-IV (1994) cites a prevalence rate of 3% to 7% in school age children in the U.S. However, issues in methodology and the evolving dynamics of ADHD have led to a wide variation in the reported prevalence with estimates ranging form 1% to 20% (Department Of Health And Human Services, 2002). Across such studies, the setting, gender, and diagnostic classification affected the prevalence rates.

In community samples, studies using DSM-III criteria to diagnose ADHD in which inattention is not a criteria for impairment, reported prevalence rates ranged between 4% and 12% with a median of 5.8% (Newcorn, Halperin, & Schwartz, 1994). Wolraich and

colleagues (1998) investigated a community sample with 4323 children using the DSM-IV functional impairment criteria and found an overall prevalence rate of 6.8% when all ADHD subtypes were considered. Within the subtypes, most of the children met criteria for the Inattentive Type (3.2%) or the Combined Type (2.9%). If DSM-IV impairment criteria had not been considered, 16% of the sample qualified for a diagnosis (Wolraich et al., 1998). This underscores the importance of incorporating DSM-IV criterion for functional impairment when making the diagnosis of ADHD.

In a study by Glass and Wegar (2002), teacher perceptions of the incidence of ADHD suggest that teachers believe rates to be much higher. Only 28% of the teachers believed their classroom incidence of ADHD to be 5% or less. Thirty-six percent identified 6-15% as having ADHD; 23% identified 16-25% as having; and 13% identified an incidence of 26% or more (Glass & Wegar). Physicians estimate that one-half of the children diagnosed with ADHD were first referred by a teacher or other school employee. Parents suggested the diagnosis in about one-third of the referred children (Sax & Kautz, 2003).

In the DSM-IV field trials, symptoms of ADHD are apparent in most cases before the age of 7 years with median age of onset of the first symptoms at one year and median age of impairment at 3.5 years. The mean age for the onset of the hyperactive or impulsive subtype was 4.21 years; combined type 4.88 years; and inattentive type was 6.13 years (Applegate et al., 1997). These findings suggest that the diagnosis of ADHD, using standard clinical guidelines, can be reliably made in many preschool children, particularly the hyperactive/impulsive or combined type. Early hyperactivity is associated with continuing school difficulties, problems with attention, and poor reading in

adolescence (McGee, Prior, Williams, Smart, & Sanson, 2002). Early identification and treatment should ameliorate later impairment in social behaviors and poor school performance. Lesesne, Visser, and White (2003) found that age-specific rates of ADHD were higher in the older age groups with 5.4% in 4-11 year-olds and 7.5% in 12-17 year-olds. Although it was previously thought that ADHD remitted before or after adolescence, it is estimated that more than 70% of children with hyperactivity continue to meet criteria for ADHD as adolescents and up to 65% do as adults (Goldman et al., 1998).

Research provides evidence that there are more boys than girls diagnosed with ADHD. In the clinical setting, the ratio of boys to girls varies from 6:1 to 12:1. In larger population samples, the male-to-female prevalence ratio is estimated as 3:1, raising the concern that ADHD may be under-diagnosed in girls. ADHD with hyperactivity/impulsivity affects boys more often than girls, but girls are more likely to demonstrate the inattentive subtype (Gaub & Carlson, 1997). Girls are less likely to exhibit disruptive behavior and manifest more emotional distress with higher rates of depression and anxiety (Greene, Biederman, & Faraone, 2001). Hence, girls are not diagnosed until middle school or later when academic and social demands for autonomous functioning increase.

Comorbidity in ADHD

ADHD is associated with an extremely high rate of co-existing psychiatric disorders and is usually accompanied by a learning disability. Each comorbid condition modifies the clinical presentation of ADHD and challenges the response to treatment.

ADHD symptoms may not remit with treatment unless comorbid conditions are also adequately treated. ADHD with comorbid conditions are associated with greater cognitive, social, and psychological impairments that are prone to continuing into adulthood (Fredman & Korn, 2001; Jensen et al., 2004; Murphy et al., 2002; Sekelman & Snyder, 2000).

Most children with ADHD experience a 2 year delay in social development and at least a 2-3 year delay in cognitive development (Sekelman & Snyder, 2000). Parents may seek clinical evaluation when their children have cognitive difficulties that impede their progress academically. If there are academic difficulties, the referral for evaluation for learning disabilities is necessary (Hunt et al., 2001).

Ross-Kidder (1998) estimates that 30-50% of children with a formally diagnosed learning disability meet the diagnostic criteria for ADHD; 10-25% of children identified with ADHD have a diagnosed learning disability; and more than 50% of the children with ADHD under achieve in school. In a study by Woolraich and colleagues (1998) only 11% of the children diagnosed as ADHD using the DSM-IV criteria were reported to have learning disabilities. This low rate was thought to be due to restrictive methodology used to classify children as learning disabled.

Children with ADHD, predominantly the combined type, obtained lower Wechsler Intelligence Scale IQ scores than controls. They performed more poorly across a range of frontal lobe functions including verbal and non-verbal fluency, reasoning, problem solving, spatial working memory, and attention (Tripp, Ryan, & Peace, 2002).

Data from the National Health Interview Survey (Pastor & Reuben, 2002) reported the prevalence of mental retardation and other developmental delays in children with both

ADHD and learning disabilities as 34% and only 1% for children with neither. It has been inferred that there is a self-perpetuating cycle in which children with learning disabilities have a negative view of their academic skills and therefore exhibit a higher frequency of disruptive behaviors as a means to enhance their self image (Pisecco, Wristers, Swank, Silva, & Baker, 2001).

The co-existence of ADHD with psychiatric disorders was been widely studied. Comorbidity is present in as many as two-thirds of clinically referred children, with high rates for Oppositional Defiant Disorder (ODD), Conduct Disorder (CD), mood disorders, and anxiety disorders (Dunne et al., 1997). Data on summary prevalence of selected co-existing conditions shows the highest rate of comordity with ODD (35.2%) followed by CD (25.7%); then Anxiety Disorder (25.8%); and finally Depressive Disorder (18.2%) (Green et al., 1999). ODD includes persistent symptoms of "negativistic, defiant, disobedient, and hostile behaviors toward authority figures" (American Psychiatric Association, 1994). Growing evidence indicates that stimulant medication used to control ADHD symptoms may also reduce ODD symptoms (Jensen et al., 2001). Children and adolescents with persisting ODD can later develop a sufficient severity of symptoms to qualify for the diagnosis of CD. Features of CD include "a repetitive and persistent pattern of behavior in which the basic rights of others or major age-appropriate social norms or rules are violated" (American Psychiatric Association, 1994).

Depressed children demonstrate diminished concentration, and children with Bipolar Disorder often manifest psychomotor agitation and distractibility making it difficult to differentiate these symptoms from the principal symptoms of ADHD (Fredman & Korn, 2001). In a study by Biederman and colleagues (1995), 70% of

children referred for either severe or mild depression were found to have ADHD. Relatively, the younger the age at onset of depression, the higher the prevalence of comorbid ADHD (Biederman, Faraone, Mick, & Lelon, 1995). It is estimated that 50% of depressed prepubescent children manifest bipolar symptoms within 10 years of onset of depression (Geller et al., 2001). Children with ADHD and mania have higher rates of major depression, psychosis, multiple anxiety disorders, CD, ODD, and greater psychosocial functioning impairment (Wozniak et al., 1995).

In studies reviewed, researchers found that 50% of children with ADHD display alterations in sleep patterns. The sleep disturbances include decreased sleep efficiency with shorter REM sleep latency; shorter sleep onset; difficulties falling asleep; difficulties with awakening in the morning; and increased sleep activity and body movement. In ADHD children with depression, severity of the depressive symptomology was found to contribute substantially to the degree of sleep disturbance (Stein et al. 2002; O'Brien et al., 2003). A Greek study hypothesized that sleep disorders in ADHD children could contribute to lower verbal IQ's, when they discovered that verbal IQ's in children with ADHD and comorbid sleep disorder were 20 points lower than the controls (Andreon, Karapetsas, Agapitou, & Gourgoulianis, 2003).

Etiology of ADHD

Current evidence implicates multiple factors in the etiology of ADHD. Heredity is the best studied factor. Parents with ADHD have more than a 50% chance of having a child with ADHD, and about 25% of children diagnosed with ADHD have parents who meet diagnostic criteria for ADHD (Faraone & Doyle, 2001). Further research addressing

the differing aspects of genetic risk is needed as 20-40% of children show significant remission of symptoms in adolescence and adulthood.

Morphologic differences in the brain structures of children with ADHD have been more recently investigated. Magnetic resonance imaging (MRI) has been used to compare children with ADHD and a cohort group. Findings in the majority of the studies have revealed significant group differences with asymmetries, differences in shape or volume of the ventricles, and differences in brain size (Castellanos, Geidd, & Marsh, 1996; Filipek, Semrud-Clikeman, & Steingard, 1997). These differences were noted in the various regions of the brain that are involved in the regulation of attention and impulsivity (Voeller, 2004). Voeller also points out that treatment with stimulants were not responsible for the reduction in brain areas as findings were also noted in ADHD children who not been treated with medications. "These studies are provocative and will likely direct new research that has the potential to shed light on the pathogenesis of this disorder" (Brown et al., 2001). Future studies will need to include other child psychiatric control groups with conditions such as learning problems or other disruptive behavior disorders. Because imaging findings do not discriminate adequately between groups with and without ADHD, the use of imaging is not currently supported as a tool for diagnosis of ADHD.

Recent attention has also been focused on the investigation of measuring neurotransmitters such as serotonin, dopamine, and norepinephrine with findings suggestive of biological differences in ADHD children and controls (Cook, Stein, Ellison, Unis, & Leventhal, 1995; Lahoste, Swanson, & Wigal, 1996). Dopamine is the neurotransmitter that regulates the system in the brain responsible for learning,

motivation, goals, drives, and emotions. Norepinephrine is the neurotransmitter involved in recognition of stimuli that is important or novel and maintains the brain in a state of alertness and readiness in order to process these stimuli. Some children with ADHD have difficulty regulating their own level of alertness and awareness of important stimuli (Voeller, 2004). Psychostimulant medications are effective in the treatment in ADHD as they are shown to increase the amount of central dopamine and norepinephrine by reducing dopamine receptor availability (Ilgin et al., 2001).

In another study using mice as an animal model of ADHD, investigators found that serotonergic neurotransmission mediated the effect of stimulant medication on increased locomotor activity (Gainetdinov et al., 1999). Future studies will need to continue to explore how stimulant medications target the dopamine system and interact with the serotonin and norepinephrine system.

Other etiological risk factors have been studied and implicated as cause of the behaviors associated with ADHD. These risk factors arise from insults that disrupt normal brain growth. The dopamine system is extremely sensitive to hypoxia, especially in the fetus or infant. Thus, any event pre- or postnatally that disrupts the flow of oxygen to the brain might set the stage for later ADHD symptoms. Fetal alcohol syndrome is associated with a reduction in the volume of the prefrontal and temporal cortices of the brain involved in the regulation of attention and control of impulsivity (Riley, McGee, & Sowell, 2004). Results in studies further indicate that hyperactivity may result from prenatal nicotine exposure and that the risk of ADHD in children of smokers is fourfold higher even when controlling for maternal ADHD (Linnet et al., 2003). Later ADHD behaviors have been observed in premature infants with documented cerebral ischemia at

birth (Lou et al., 2004). Hyperbilirubinemia or even moderate levels of bilirubin in the newborn can evolve into ADHD-like behaviors later in childhood (Soorani-Lunsing, Woltil, & Hadders-Algra, 2001). Traumatic brain injury involving damage to the frontal lobes or shearing of white-matter tracts often results in ADHD-like behaviors (Gerring et al., 1998). As many as half of the children who suffered strokes involving subcortical areas in the prefrontal-subcortical circuits, develop ADHD (Max et al., 2003). Meningitis and encephalitis are also associated with ADHD behaviors (Voeller, 2004). Lyme disease has also been linked with a number of neuropsychiatric symptoms including ADHD (Fallon, 1998).

Research has consistently reported the association between elevated lead levels and delays in cognitive functioning, including attention problems (Needleman & Gatsonis, 1990). Associations between elevated lead levels and disruptive behavior problems were found in studies conducted by Thomson et. al (1989). But, because this study did not assess specific ADHD symptoms, the extent to which the findings can be applied to this disorder is unknown. Findings in research performed by Tuthill (1996) suggested a positive association between lead level and behavior problems. The routine use of lead screening as a diagnostic indicator of ADHD is not supported (Brown et al., 2001). However, the CDC recognizes that lead toxicity is associated with a 2-3 point decrease in IQ scores for every 10 μg/dL in blood level (Pirkle et al., 1998) and advocates the use of a screening questionnaire to identify lead exposure in all children.

Abnormal function of the thyroid can produce a range of behavior effects in children from impairment in concentration to severe neuropsychological deficits. In a study by Weiss et al. (1993), findings in the ADHD cohort suggested that 2% had

abnormal thyroid levels compared to less than 1% in the control group. Ultimately, the majority of research findings do not support the use of thyroid function test to screen for ADHD (Brown et al., 2001).

Intervention/Treatment

There is a great deal of data available on approaches to treatment for children with ADHD. Because ADHD can have lifelong consequences, interventions are designed to reduce the negative outcomes and increase functional capacities.

Only three treatments have been supported as effective short-term interventions for ADHD: behavioral modification; psychostimulants; and a combination of the two. Despite the evidence on efficacy, relatively little is known about the degree to which these interventions are used in clinical and educational practice, as well as in family settings. Little is known regarding the effectiveness with which these treatments are utilized in the non-research settings. Pharmacologic treatment is prevalent and short-term use has been proven effective in reducing ADHD symptoms. Overall, there is a lack of research data on the long-term efficacy of either behavioral or pharmacological treatments (Committee on Quality Improvement, 2001).

Stimulant prescribing for ADHD in the U.S. has increased dramatically. In 1996, epidemiological studies estimated that the 12 month prescription prevalence for school-age children ranged from 6% in urban settings (Safer, Zito, & Fine, 1996) and 7% in rural settings (Angold & Costello, 1997). There are "wide variations in the use of psychostimulants across communities and physicians" (National Institute Of Health Consensus Statement, 1998). As a result of research, multimodal treatment interventions

have become the gold standard for ADHD treatment. One of the most widely cited studies is the Multimodal Treatment Study of Children with ADHD (MTA) which was co-sponsored by the National Institute of Mental Health and the U.S. Department of Education. The purpose of this study was to investigate four different treatment conditions: medication only; medication and behavioral therapy; behavioral therapy only; and community care. At the end of a 14 month period, results indicated that medication management alone and combined medication and behavioral treatment provided greater treatment efficacy than did behavioral therapy alone and community care groups (The MTA Cooperative Group, 1999). At the end of the 24 months, 68% of the combined treatment group, 56% in the medication only group, 34% in the behavioral treatment group, and 25% in the community care group showed improvement (Swanson et al., 2001). In another study, family physicians estimated that 6.9% of children seen in their practice were using medications to treat ADHD. Pediatricians estimated 10.8% and child psychiatrists estimated 55.6% of children in their practice were taking medications (Sax & Kautz, 2003).

Medications used in treatment of ADHD act by inhibiting the dopamine transporter and/or increasing dopamine release into the synaptic cleft. Medications that increase norepinephrine have also been successful in treating ADHD symptoms. Studies document the improvement of the core symptoms of inattention, hyperactivity, and impulsivity. Effects on intelligence and achievement tests are more modest (American Academy of Pediatrics, Committee on Quality Improvement, 2001).

Behavioral problems leave a legacy of low self-esteem for the child and high levels of stress for the parent (Sekelman & Snyder, 2000). The risk of social skills deficit is

greater in the children with learning or attention problems (Kavale & Forness, 1996). Behavioral modification therapy includes interventions used to modify the physical and social environment to alter or change the child's behavior. Strategies involving social skills training and/or cognitive behavioral therapy often help the child with ADHD gain control over irritating facets of their behavior and teach them to master every day routines through organizational strategies (Stein, 2002).

Parent training in behavioral modification and classroom behavioral interventions has successfully changed the disruptive behaviors of children with ADHD. Research provides evidence of the positive treatment effects of parent training including increases in child compliance, use of appropriate parental commands, knowledge of appropriate parenting techniques, and positive parental statements (McGoey, Eckert, & Dupaul, 2002). Preliminary research evidence suggest that once effective parenting patterns are established and maintained, positive effects in the behavior of preschool-age children with ADHD may be observed in settings outside of the home and over a long time (McGoey et al.). Increasing parent knowledge about ADHD may also increase parental satisfaction and sense of competency. Research has shown that parental knowledge does affect choices regarding their child's treatment and long-term compliance with a treatment plan (Flannagan, Pillow, & Wise, 2002). Because ADHD has a genetic component, one or both parents can have ADHD making it difficult for parents to regulate their own behaviors and provide the systematic support that the child requires (Voeller, 2004).

Productive behavioral approaches in the classroom include "additional time to make transitions between activities or topics; simplifying multistep tasks; supporting the

development of metacognitive strategies; teaching organizational techniques; relaxing overall time constraints; and moderating the amount and speed of output required" (Weiler, Bernstein, Bellinger, & Waber, 2002).

Outcomes/Burden of ADHD

Given the nature of ADHD, it is believed to have a noticeable impact on social, economic, educational, and health care delivery systems. The associated burden of ADHD may take place at the levels of the individual with ADHD symptomology; family members and caregivers; social and peer groups; school systems; employers; systems of care including medical and mental health professionals; insurers; and the juvenile justice system (Hinshaw, 2004). The burden may be associated with extremes in behavior and the ramifications and/or deficits in skill obtainment and the resulting implications for eventual productivity. Documentation of the magnitude of the social and economic burden in these areas has been limited. In addition, there is a lack of definitive data on which interventions can or do improve the outcome of children with ADHD.

Effects on the Individual

Several studies have explored the functional impairments associated with ADHD in childhood, especially if it goes untreated. Children with ADHD may have compromised academic achievement and school performance. Up to 80% demonstrate academic performance problems with a substantially higher history of grade retention, special education placement, suspension and school-drop out when compared to their peers (Rabiner, 2003). Rabiner's study also indicated that the percentage of students with

inattentive subtype of ADHD rating below grade level ranged from 76% in reading to 92% in written language. Up to 50% of children with ADHD are suspended from school as a result of impulsive acts. The graduation rates for combined and inattentive ADHD students were 82% and 78%, respectively (Murphy et al., 2002). In another study, a comparison of IQ and achievement test results examined whether the associated subtypes of ADHD related to different neuropsychological profiles. Results showed IQ scores for children with ADHD, Inattentive Type as 98; Combined Type as 99; Hyperactive/Impulsive Type as 113, and control group as 115. Children with the Inattentive and combined subtypes of ADHD have significantly lower IQ scores than the control group and Hyperactive/Impulsive subtype. Children with all three subtypes had significantly lower reading achievement scores than comparison children. Attention problems predicted poorer performance on measures of neuropsychological functioning (Chabildas et al., 2001). The prevalence of children in special education with ADHD and a specific learning disability is 65% compared to 46% of children with just a specific learning disability. Among children with the diagnosis of learning disability, 54% were in special education. This was nearly five times greater than the percent observed for children with ADHD only (Department Of Health And Human Services, 2002).

Review of literature also reveals that in childhood and adolescence, ADHD is clearly associated with lowered self-esteem and marked difficulties with social relationships. Because a child's self-image is dependant on the success experienced in school and in relationships with parents and peers, it is not difficult to imagine how self-esteem in children with ADHD may suffer.

Researchers investigated self-esteem in children with ADHD and co-occurring internalizing and externalizing problems. In this study, findings suggested that ADHD alone does not appear to be associated with lowered self-esteem. It is the presence of co-occurring internalizing problems (mood or anxiety disorders) that are predictive of lower self-esteem (Bussing et al., 2000). Topplski and colleagues (2004) surveyed adolescent males with ADHD to assess their quality of life, based on their social relationships, sense of self, and environment. Adolescents with ADHD reported lower quality of life ratings than comparison groups without ADHD or adolescents with mobility impairment. Results also indicated that adolescents who identified themselves as having fewer ADHD symptoms also experienced higher quality of life.

Females are dramatically underrepresented in most studies and the need for additional research on ADHD among girls is great. Hinshaw (2002) investigated preadolescent girls with the intention of filling this prominent gap in the literature. The focus of data analysis was to examine differences between girls with ADHD, Combined Type; girls with ADHD, Inattentive Type; and comparison girls without ADHD. Relative to comparison girls, girls with both ADHD subtypes had significantly higher rates of special education placement (28% for both ADHD subtypes vs. 3.5% for the comparison group. Girls with ADHD were more likely to have experienced speech/language problems (Combined type 25.6%; Inattentive type 29.8%; Comparison 7%). Rates of co-occurring disruptive behaviors such as ODD and CD were equivalent to rates reported in samples of boys with ADHD. Rates of ODD with the Combined subtype were 71%; with Inattentive subtype 47%; and comparison group 7%. Rates of CD with Combined subtype were 27%; Inattentive Type 11%; and comparison 0%. The percentage of girls

with anxiety disorder and Combined subtype was 31%; Inattentive Type 19%; and comparison group 3%. Those identified with depression and Combined subtype were 10%; Inattentive Type 4%; and comparison 0%. Girls with the Combined Type of ADHD were least liked by their peers, while girls with the Inattentive Type were more likely to be seen as socially isolated. These findings corroborate the importance of community systems becoming better informed about the manifestations of ADHD in girls, so that the greater tendency for girls to go undiagnosed and untreated is brought to an end.

Findings in research suggest that difficulties with peer relationships predict a number of subsequent problems. Rejected children fare worse in adolescence and adulthood than children who can establish harmonious peer relations. One explanation for this is that rejected adolescents often gravitate towards one another reinforcing and escalating each other's antisocial behavior (Rabiner, 2001). The findings in the review of literature suggest that ADHD during childhood predicts later impairment in adolescents' peer relationships, including parents' reports of their child's close friendships and acceptance by peers (Bagwell et al., 2001).

Social difficulties can be explained as manifestation of social knowledge deficit (not having the knowledge of ways to interact appropriately) or social performance deficits (knowing what to do but not putting it into action). With this premise, Maedgen & Carlson (2000) examined whether children with different subtypes of ADHD differ in the primary reason for social difficulties. Children with ADHD, Combined Type, were less popular with peers according to parents and teachers and were seen as less liked than children with Inattentive type. Children diagnosed with ADHD, Combined Type, were rated as more likely to enact aggressive behavior, thus exhibiting social performance

deficits. Children with ADHD, Inattentive Type also exhibited social performance deficits and were more likely to respond in passive ways (i.e. just letting things go without taking steps to deal with the situation). Children with the Inattentive Type of ADHD were slightly less knowledgeable about the most socially appropriate ways to respond (deficit in social knowledge). Children with the Combined subtype are more prone to intense displays of negative emotion and have difficulty regulating their negative emotions. Problems with emotion regulation could contribute to being disliked by peers. One limitation of research on improving peer relationships for children with ADHD is that findings focus on improving children's overall standing in peer groups, rather than helping them develop a single close friendship.

The review of literature demonstrates an increased risk for accidental injuries in children and adolescents with ADHD. Teens with ADHD who are not treated have a much higher rate of traffic violations than their peers (Barkley, Murphy, Dupaul, & Bush, 2002). Those with significant ADHD symptoms were nearly three times as likely to be involved in an accident than those with less significant symptoms; were about 2.3 times more likely to report having driven while seriously intoxicated; were about 2.5 times more likely to have been involved in street racing; and were more likely to have been cited for a traffic violation (Woodward, Fergusson, & Horwood, 2000). A small study provided evidence that the controlled release stimulant medications yielded substantial improvement in the driving performance of individuals with ADHD (Cox et al., 2004).

Other health risk behaviors identified as more likely to occur in adolescents with ADHD include smoking, alcohol use, marijuana use, and use of other illicit drugs. Investigators found that adolescents with a high level of ADHD symptomology were ten

times more likely to have smoked, eight times more likely to report an urge to smoke, and almost four times more likely to have consumed alcohol (Whalen, Jamner, Henker, Delfino, & Lozano, 2002).

Researchers have also examined predictors of substance use among adolescents with childhood ADHD. Children with inattentive symptoms more strongly predicted adolescent substance use than hyperactive/impulsive symptoms. In explanation as to why inattentive ADHD symptoms might be an important predictor of adolescent use, the researchers note that attention problems are more strongly associated with academic failure than hyperactive/impulsive symptoms. Ongoing academic struggles may lead a child away from conventional peers oriented toward academic success and toward nonconformist peer groups where substance abuse may be more tolerated, modeled, and encouraged. Adolescents with persistence of ADHD were more than twice as likely to be smokers. Rates of other substance use problems were comparable to adolescent without ADHD. Adolescents with persistent ADHD and who had developed Conduct disorder had the highest rate of substance use problems (Molina & Pelham, 2003).

Although parents may be concerned that starting a child on psychostimulant medication for the treatment of ADHD will increase the risk of drug abuse later in life, available data suggests the opposite. A meta-analytic review of literature performed by Faraone & Wilens (2003), pooled data from six different studies with results indicating that children treated with stimulant medication were about half as likely as other children to develop a substance abuse disorder later in life. And, in studies where medication treated and non-medication treated children showed equivalent severity in symptoms

prior to treatment, those who did not receive medication were over three times more likely to develop a substance abuse disorder.

Review of literature on functional impairment due to ADHD symptoms provides evidence for continuity of ADHD related impairment across the lifespan and suggests that ADHD related challenges faced by adolescents correlate with difficulties in adulthood. In the past decade, adults with ADHD have changed jobs more often than individuals without ADHD. They are less likely to report good current relationships with parents and peers, and 28% have been divorced compared to 15% of controls (Faraone & Biederman, 2005). In another study, rates of arrest (ADHD, Combined Type 40%; Inattentive type 19%; and 13% in the control) and self-reported drug and alcohol use (80% in Combined type; 81% in Inattentive type, 52% in the control) were consistently higher among adults with ADHD (Murphy et al., 2002).

Effects on the Family

ADHD can also affect the health of family members. These families are more prone to conflict and increased levels of familial stress. The child with ADHD may impact parental productivity and competitiveness in the workplace. Some of the disorders associated with ADHD are due to the fact that ADHD is a marker of genetic risk for psychopathology among family members. It is apparent after review of literature that there is a considerable need for research to clarify the impact that ADHD has on the family unit. Knowledge of stress and coping in parents of children with ADHD is limited in several ways. Rabiner (2002) speculates that the co-occurring behavior problems and not the core symptoms of ADHD are the reasons for increased stress in parents. He points

out that little is known about the strategies that families use to cope with their unique challenges and whether particular strategies are associated with reduced stress levels.

Parents of children with both the inattentive and combined subtypes of ADHD report more stress and less satisfaction as parents. However, this resulted from the greater level of oppositional/defiant behaviors reported, rather than from the direct impact of the core symptoms of inattention and hyperactive/impulsive displayed (Pololski & Nigg, 2001). Confusion for parents lies in how hard it can be to distinguish between a child who can't do something and a child who won't do something. If a child seems to be having behavioral problems, they may be confronting difficulties in accomplishing a task. If a task is too demanding, the child may withdraw or act out (Smith, 2002). Pololski & Nigg found that mothers and fathers that used positive reframing as a coping strategy reported more satisfaction as parents and less stress associated with parenting. Positive reframing is a coping strategy in which parents redefine stressful experiences making them more manageable. By learning to redefine stressful events as challenges to overcome rather than unsolvable problems, parents may be taking appropriate steps leading to fewer behavioral problems in their children.

Researchers have also examined how parents' think about their child, themselves, and their parenting may influence their child's treatment outcome. Rabiner (2004) hypothesized that parents who lack confidence in their parenting ability or who had low self-esteem may find it difficult to enforce consequences or administer medication to the resistant child. In other families, parents who believe that the behavior problems of their child with ADHD are deliberate and willful may be unwilling to consider that ADHD symptoms are a contributing factor and react with anger and punitive discipline.

Investigators found that children with ADHD whose mother had higher self esteem and who used fewer dysfunctional disciplinary strategies showed fewer ADHD symptoms and less oppositional behavior. Among fathers, those with higher feelings of parental efficacy and who were less prone to blame their children's non-compliance on poor effort had more positive involvement with their child and fewer dysfunctional disciplinary practices (Hoza et al., 2000).

Because ADHD is so common in parents of children with ADHD, and may contribute to difficulties in parenting, research is necessary for the development of more effective parenting programs for parents with ADHD themselves. Rabiner (2004) points out that in many cases, ADHD in parents has never been diagnosed or some do not become aware that they have ADHD until it is diagnosed in their child. Harvey et al., (2004) examined the relation between parents' self-reported ADHD symptoms and their parenting behavior. For mothers with ADHD, they found higher levels of inattentive symptoms were associated with a more permissive parenting style which tends to be related with higher levels of child behavior problems. Fathers with ADHD who reported high impulsivity and inattentiveness were more lax in their parenting and tended to be more emotionally reactive with their child. This suggests a parenting style in which they may frequently lose their temper, but fail to follow through on enforcing consequences. Parent training programs did not significantly modify their parenting practices. Further research will need to consider how parent training programs can be tailored so they are more effective for parents with ADHD.

Research on the relationships and psychological adjustments of children with an ADHD sibling is limited. Only one study addressing siblings was found in the review of

literature. This study examined adjustment outside the family for children having an older sibling with ADHD (Smith et al., 2002). The findings indicated that mothers who reported more conflict in their relationship with their ADHD child also reported greater levels of conflict in their relationship with the siblings. This may be explained by the concern that parents may be stressed from the challenges of raising a child with ADHD and that this could "spill over" into their relationships with their other children. The researchers predicted that high levels of conflict within the family would be associated with poorer adjustment and peer competence among the siblings. However, findings indicated just the opposite. The greater the amount of conflict reported by mothers with their ADHD child, the more competent and well adjusted the siblings were identified to be by their teachers. The researchers offer several speculations as to why this may have been. They suggest that the siblings of children with ADHD may learn good social coping skills as a result of their interactions with and responsibilities for the ADHD sibling, thus, refining their ability to get along with others. These siblings have observed their parents' conflicted interactions with the child with ADHD and may "overcompensate" or try extra hard to succeed in school so they do not create additional stress for their parents.

Costs to Individuals, Families, and Society

It has been proposed that ADHD has a substantial impact on the social, economic, educational, and health care delivery systems. It is difficult to measure the developmental toll of ADHD. It not only affects the individual with ADHD, but also the family, peer, and co-workers. The magnitude of the social and economic burden has not fully been

examined by research. More research is needed to determine the potential reduction of cost burden associated with early identification and intervention. Community-based interventions and education can be promoted with evidence based research addressing systems development in the identification and treatment of children with ADHD.

In research presented by Birnbuam et al. (2005), the estimated annual cost of ADHD was $31.6 billion with approximately half attributable to persons with ADHD and half to family members. Adults accounted for 77% of the total ADHD cost while children represented 23%. Costs incurred by the individual with ADHD totaled $16.3 billion with $3.3 billion attributable to children with ADHD and $13.0 billion to adults with ADHD. The greater costs for adults with ADHD are due to work loss costs. In another study, adults with ADHD earned $9,000 less on average than their non-ADHD peers. Professionals with ADHD reported earning an average of $40,000 less when compared to non-ADHD peers. Findings from this research translate into a $67 billion national income loss due to ADHD (Turgay et al., 2005).

Individuals with ADHD may have higher health care costs than those without ADHD. Patients with ADHD had 2.6 more medical claims during 2003. Of significance is that this difference could not be attributed to ADHD treatment specifically, which accounted for only 24% of the total claims, (Swensen et al., 2003). According to Birnbaum et al., (2005), 10% of $16.3 billion of total costs was related directly to ADHD treatment and nearly 75% was attributable to the excess costs of treating other comorbid medical conditions. Over 40% of patients had no prescription for ADHD medication filled during the year, implying that many individuals are not receiving care that is consistent with the published treatment guidelines from the American Academy of

Pediatrics. Swensen and colleagues estimated the annual medical expenditure for patients with ADHD as $1,574 vs. $541 in the non-ADHD control. Using Medicaid managed care figures which include medication costs; the average reimbursement for total treatment costs of a child with ADHD was $1,795 (Hinshaw, Peele, & Danielson, 1999).

In Birnbaum's study (2005), family members incurred a total excess cost burden of $15.3 billion. Family members experienced substantial healthcare and work loss costs. Swensen and colleagues (2003) indicated that medical care costs per family member of ADHD individuals was twice as high with $2,060 vs. $1,026 in families without an ADHD individual. Other studies have documented the adverse effects on caregiver work status and work productivity. In Noe and Hankin (2001), changes in work status as a result of a child with ADHD were reported. Of these changes, 15% changed type of job, 46% reduced hours worked per week, and 11% stopped working completely. Caregivers also reported having lost an average of 0.8 days from work and being 25% less productive, for an average of 2.4 days attributed to their child's ADHD.

Students with ADHD impose a burden on the school systems. The estimated educational cost of ADHD is between $3.5 and $4 billion annually and accounts only for the ADHD children receiving special education services (Hinshaw et al., 1999). ADHD is also associated with a higher likelihood of delinquent behavior, adding to the costs of law enforcement and social services systems. In one study, 2.3% of the youth admitted to juvenile detention centers were found to have ADHD (Wasserman, Ko, and McReynolds, 2004). This percentage was lower than found in previous studies. Abram et al., (2003) found that 56.5% of female youth met the criteria for two or more comorbid psychiatric disorders, including ADHD compared to 45.9% of male youth. Review of current

literature suggests that these indirect financial costs have not been adequately investigated or described by research findings.

Timely diagnosis and effective treatment of children with ADHD may not only help mitigate the severity of the condition but potentially makes treating children before they become adults, an effective strategy in reducing the economic burden associated with ADHD. Findings built on earlier research, emphasize the critical need to develop community systems that address the problems associated with ADHD while the child is young.

CHAPTER 3

METHODS

Design

A Descriptive Correlational study design is used to gain more information about a clinical-sample of rural children with ADHD. The primary purpose is to describe the attributes of children with ADHD and examine the possible relationships among the variables that exist in a single sample of children, ages 3-18, in one site, a rural Pediatric Outreach Clinic.

ADHD will be defined using the current *DSM-IV* criteria described earlier in Chapter 1 and outlined in Appendix A.1. ADHD is diagnosed with a behavioral criterion checklist that is based on observational information. The ANSER Form is an age specific tool completed by the family, the child if over 9 years of age, and educational personnel. This assessment tool is used by the Pediatrician in the Outreach Clinic to diagnosis ADHD. It is the opinion of the Pediatrician that the ANSER Forms provide a clearer picture of the child's current level of functioning, taking into account the high incidence of comorbidity. This tool is more comprehensive than the Conner tools or other parent teacher rating scales used to assess ADHD. Due to copyright law, the ANSER forms are not available for review in this study. Copies of the forms can be obtained from Educators Publishing Services, Inc., 31 Smith Place, Cambridge, MA 02138-1000.

The purpose of the ANSER form is to provide information regarding the health, development, educational history, and current behavior of children, who are experiencing

school adjustment and learning difficulties. Information is obtained and recorded on separate questionnaires from the parents, school personnel, and if over the age of 9 years, the child. The inclusion of a self administered student form is a definite strength in the diagnostic process as individuals have generally been ignored as data sources in educational and psychological assessment. The questionnaires are provided for different age groups (3 to 5 years, 6 to 11 years, and 12+ years) so that responses can be based on age-appropriate observations of the child's behavior. By comparing responses to a variety of Likert-type questionnaire items and open-ended questions, a diagnosis is established. Observational measurements assist with the diagnosis of ADHD.

Diagnosis of ADHD and the subtype classification are documented on the child's case report form. To identify any co-occurring/comorbid conditions or risk factors, the case report form is searched for outpatient International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes.

For Specific Learning Disability (SLD), the primary criteria used in the definition will be based on Federal mandates: "(1) average to above average intellectual potential, (2) an information processing dysfunction, (3) a significant discrepancy between overall potential and current achievement, and (4) that discrepancies do not exist because of emotional or cultural reasons" (Department of Education, 1999). SLD will be measured by psychometric testing performed by the local School District's Office of Special Education. Diagnosticians from the local Office of Special Education consistently use the Wechsler Intelligence Scale for Children-Third Edition (WISC-III) to determine IQ and the Woodcock Johnson Psychoeducational Battery-Revised (WJ III-R) as a means of determining achievement. In order to receive Special Education services in Wyoming

under the Specific Learning Disability category, there must be a 22 point discrepancy between the IQ score and scores on achievement tests. The IDEA provides definition of 13 other disability categories that determine who is eligible for free and appropriate Special Education services. These definitions can be found in Appendix A-2.

Population/Sample

The data used for this study are obtained from an earlier study that focused on the prevalence of ADHD and comorbid learning disabilities in a population of rural children. In the original study, clinic staff reviewed the medical records of 128 children routinely seen at a Pediatric Outreach Clinic and identified 98 children with a diagnosis of ADHD. Parents were then contacted and permission obtained to collect data from the children's medical record. Because there were no demands on the subject's time and they did not have to be present for data collection, families readily consented to study participation. The original data is intended for broader use and supports secondary data analysis for this study with the purpose of identifying and exploring the attributes of rural children diagnosed with ADHD. All original data is free of identifiers that could permit association with the individual research participant.

The sample consists of children seen at a Pediatric Outreach Clinic located in southern Wyoming. According to the U.S. Census Bureau (2000), the county has a population of 12,286 and covers 2,225 square miles. There is an estimated 5.6 persons per square mile. Thus, the population of the county meets the researcher's definition of rural. Specialty clinics are brought into several communities in the State to facilitate the concept of family-centered, community-based care for children with special health care

needs. The outreach clinic facilitates access to specialty care within the community, rather than having to travel long distances to regional medical centers.

The sample subjects were chosen using the non-probability sample method of quota sampling. Quota sampling is used for several reasons. The subjects have similar known characteristics of a larger target population identified in previous studies. Quota sampling also guarantees the inclusion of subjects (especially minorities and females) that could be underrepresented if random sampling was used. As random sampling is not used, a broader description of the attributes presented by rural children with ADHD can be explored. Heterogeneity of the subjects reduces the risk of bias and increases generalizability.

The inclusive criterion for participants is a diagnosis of ADHD using the diagnostic criteria outlined in the DSM III-R or DSM-IV Criteria. The accessible population consists of 98 children with a known diagnosis of ADHD in a clinical setting.

Of the 98 data sets reviewed for the diagnosis of ADHD, 10 were excluded because it had been more than two years since the child was last seen at the clinic and pertinent data was missing. The final sample consists of 88 children with a known diagnosis of ADHD based on DSM criteria.

IRB Exemption

The research project is exempt from the requirement of review by the Institutional Review Board in accordance with the Code of Federal Regulations, Part 46, section 101, paragraph (b)(4). See Appendix B, IRB Exemption. Data is presented in such a way that there can be no deductive disclosure of the identity of individuals and/or their family. As

the child cannot be identified, there are no anticipated effects on the subjects. There is a low risk of invasion of privacy. Case report forms and statistical analysis data will be stored in a personal file in the investigator's home for five years.

Procedure for Data Collection

The staff of the Pediatric Outreach Clinic provided the investigator with a dataset that is anonymous and free of identifiers that would permit linkage to individual participants. The data on each individual child was reordered by random number assignment and sequentially reviewed for inclusion and exclusion criteria. Data was then transferred from the original database to a case report form over a timeframe of two months. Mutually exclusive and exhaustive coding categories were developed. Data on the case report form was coded numerically and entered into a data file created in SPSS 12.0 over a one month timeframe. There were no direct costs incurred. Indirect costs included the investigator's time in developing a case report form, reviewing the original database, and entering information into a statistical analysis program on the computer. No problems were encountered during data collection.

Instrumentation

The case report form includes demographic and diagnostic information. It is noted that there are standardized tools available to collect similar data with stronger reliability and validity. But in order to organize the data in such a way as to provide meaning for a community, a case report form is developed with input from various human services providers. A copy of the tool is found in Appendix B, Tools.

Sociodemographic attributes to be identified in the sample population include the variables of gender, ethnicity, current age, age at time of ADHD diagnosis, living situation, and payment source for health care. Variables describing the diagnostic categories for ADHD include ADHD, Inattentive Type; ADHD, Hyperactive/Impulsive Type; ADHD, Combined Type; and ADHD, Not Otherwise Specified. Variables describing co-existing mood, anxiety, and conduct disorders include Anxiety; Bipolar Disorder; Depression, Obsessive-Compulsive Disorder; Oppositional Defiant Disorder; Pervasive Developmental Disorder; and Post-traumatic Stress Disorder. Variables describing co-existing medical conditions include Brain Trauma, Cerebral Palsy, Encopresis; Enuresis; Prematurity, Seizure Disorders, Sleep Disorders; and Tic Disorders. Other medical diagnoses may be identified with review of medical records and the case report forms.

SLD will be measured by psychometric testing performed by the local School District's Office of Special Education. Specific Learning Disabilities are diagnosed using the WISC-III and the WJ-R).

The purpose of the WISC-III is to measure the intellectual ability of a child. The measurement of IQ can be considered an indirect, interval-scale measurement. The abstract attributes of intelligence measure the potential of the child. However, it can be argued that IQ measures not what a child is capable of doing in the future, but what the child has learned at this point in time. It is common to rank IQ categories. People with IQ's over 130 are labeled "gifted"; scores of 70 - 84 have been categorized as "borderline retarded"; 55 - 69 as "mildly retarded"; 40 - 54 as "moderately retarded"; and 25 - 39 as "severely retarded". However, when placing labels, one must remember that

intelligence tests only test a narrow range of abilities. The WISC-III is a norm-referenced test with a mean of 100 and standard deviation of 15. In reliability testing, subtest reliability is identified as .61 - .92; consistency of IQs and Indexes is .80 - .97; subtest stability coefficients are .56 - .89; IQ and Index stability is .74 - .95; and interrater reliabilities on the Verbal Scale subtests are greater than .92. According to the Mental Measurement Yearbook, research strongly supports the WISC-III validity. The convergent/divergent validity between the WISC-III and comparable composite metrics is .59 to .92. The most important outcome identified was academic achievement and supports the ability of the instrument to predict relevant outcomes. "Published studies corroborate theory-expected patterns of performance in children in the following clinical categories: gifted, at risk, LD, dyslexic, generic special education, ADD, L/S children, and the hearing impaired" (Braden, 1975).

The purpose of the WJ-R is "to provide a co-normed set of tests for measuring general intellectual ability, specific cognitive abilities, scholastic aptitude, oral language, and academic achievement" (Cizek, 1975). The scores obtained are derived from raw scores, grade and age equivalent percentile ranks, discrepancy scores, and scores from various scales within the WJ -R. The instrument provides a good example of an indirect, interval-scale, normed-referenced test. As intelligence and achievement are abstract concepts, intervals are ranked, and the norm group is representative of the North American population. The split half reliability method is used to determine standards for the mean and standard deviation with median reliabilities ranging from the .70s to .90s. After a one year interval, test-retest reliabilities were between the .80s - .90s. Interrater reliabilities for individual tests were in the .80s - .90s and .90s for cluster tests. Although

specific data was not outlined, review indicates the WJ-R has high construct validity, positive confirmatory factor analyses especially from participants age 6 to adult, and scores ranging to .80 when correlating with other achievement tests. Predictive validity is in the .70s indicating predicted achievement does correlate with achievement clusters.

The ANSER forms are the tools used for outlining behavioral criterion of combined historical observations to help support the diagnosis of ADHD and its subtypes. The ANSER forms are administered and objectively weighted by the clinic's Pediatrician.

According to the Mental Measurements Yearbook (Harrington & Howell) the core of the problems with the ANSER system is that it provides no data addressing reliability or validity; the questionnaires have not been standardized; there are no norms or criterion data presented; assignment of developmental ages has not been supported by norm-reference or criterion-reference research data; and observational measurement is objective so less credible.

Analysis

Descriptive statistics will be used to organize the data as described in the objectives of the study. The computer program, SPSS Graduate Pack 12.0 will be used to perform data analysis.

Specific objectives and analysis is as follows:

Objective (a): To describe the sociodemographic attributes of rural children diagnosed with ADHD. The variables include gender, current age, race, age at time of ADHD diagnosis, living situation, resources used for payment of health care services. Data will be organized using ungrouped frequency distribution. Percentage distributions

will be analyzed to compare presenting data with findings from other studies. Interval data such as current age and age at time of ADHD diagnosis will be explored using measures of central tendency (mode, median, mean) or measures of dispersion (range, sum of squares, variance, and standard deviation). Descriptive statistics will be analyzed to explore deviations in the data.

Objective (b): To identify the distribution of ADHD subtypes in the sample. The variables include the diagnostic categories of ADHD, Inattentive Type; ADHD, Hyperactive/Impulsive Type; ADHD, Combined Type; and ADHD, Not Otherwise Specified. These variables represent nominal data measurements and will be explored using descriptive statistics.

Objective (c): To identify the co-existing conditions exhibited with the diagnosis of ADHD. These variables are nominal measurements and represent psychological, medical, and educational conditions identified during data collection. Descriptive statistics will be explored.

Objective (d): To examine the relationships among the sociodemographic attributes, diagnostic attributes, and co-existing conditions. Differences in the nominal level in one group designs can be analyzed using one-sample χ^2 tests. Differences in interval level measurements in a one group design can be analyzed using Single Sample *t* tests. Associations between variables with nominal level measurement can be analyzed using Chi-Square Analysis; ordinal level with Spearman's Rank Correlation or Kendall's Tau; and interval level with Pearson's Correlation or Simple Linear Regression Analysis.

CHAPTER 4

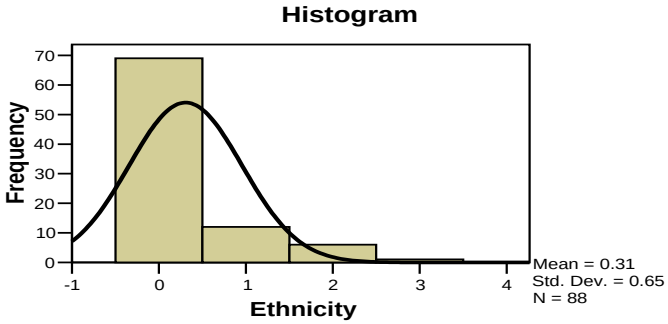
RESULTS

Description of Sociodemographic Attributes

The sociodemographic attributes of the sample are outlined in Table 1. Analysis indicates that for the sample of 88 rural children, 69.3% (n= 61) are male and 30.7% (n=27) are female. The ratio of boys to girls is approximately 2.3:1.

The majority of the children are Caucasian (78.4%) creating an asymmetrical distribution due to the large number of Caucasian children compared to the small number of minority children seen (skewness, 2.173; kurtosis 4.175). See Figure 2.

Figure 2. Asymmetry of Distribution for Ethnicity in Rural Children with ADHD



The mean age of the sample is 10.97 years with the range from three to eighteen years. In this community, children three to five years are provided preschool services. Children in elementary school are five to ten years of age. However, physically, children five to seven years of age are located in one building and children eight to ten are housed in another building. Analysis of the sample shows that the majority (35 children/39.7%) of the children seen in this rural clinic are of grade school age (5-10 years of age or

grades K through 5th) with greater frequencies in 2nd graders (9/10.2%) and 4th graders (11/12.5%). However, children 11-12 years (middle school or grades 6th and 7th) had the highest frequencies with nine (10.2%) 6th graders and thirteen (14.8%) 7th graders.

The majority of the children (58%) live with two parents. Although not statistically significant, the number of children living in a single parent home (31.8%) or in foster care (9.1%) may be clinically significant in a rural community due to the challenge biological families may have raising a child with behavioral problems and lack of support within their community.

Medicaid is the source of payment for health care services in 58 (65.9%) of the 88 children; 24 (27.3%) have private insurance; and 5 children are covered by private insurance and Medicaid. Only one family covers the health care expense on self-payment. Children living with a single parent are more likely to be on Medicaid (67.8%) than have private insurance.

Table 1. Sociodemographic Attributes of Rural Children with ADHD

	(n=)	(%)
GENDER		
Male	61	69.3
Female	27	30.7
ETHNICITY		
Caucasian	69	78.4
Hispanic	12	13.6
American Indian	6	6.8
African American	1	1.1
FAMILY LIVING SITUATION		
Two Parent Family	51	58.0
Single Parent Family	28	31.8
Foster Parents/Guardians	8	9.1
Adopted	1	1.1

Table 1. Sociodemograhic Attributes of Rural Children with ADHD (Continued)

PAYMENT SOURCE FOR HEALTH CARE	(n=)	(%)
Medicaid/CHIPS	58	65.9
Private Insurance	24	27.3
Medicaid/Insurance	5	5.7
Self-Payment	1	1.1

Distribution of ADHD Subtypes and Age at Time of Diagnosis

Overall, ADHD, Combined Type was diagnosed in 37.5% (n=33) of the sample and was identified more frequently in males than females with a ratio of 3:1. Those children with ADHD, Not Otherwise Specified made up 29.5% (n=26) of the sample. ADHD, Inattentive Type was detected in 21.6% (n=19) and ADHD, Hyperactive/Impulsive Type was diagnosed in 11.4% (n=10). Males and females were equally distributed in the Inattentive Type (1.4:1) and the Hyperactive/Impulsive Type (1.5:1). See Table 2 for further description of gender and diagnostic subtypes.

Table 2. Gender and ADHD Diagnostic Subtypes in Rural Children

ADHD SUBTYPE	FEMALE	MALE	TOTAL
ADHD, Combined Type	8	25	33
ADHD, Not Otherwise Specified	7	19	26
ADHD, Inattentive Type	8	11	19
ADHD, Hyperactive/Impulsive Type	4	6	10
TOTAL	27	61	88

The age at time of ADHD diagnosis was identified in 83 children of the sample. Review of the medical records of 5 of the children did not show documentation of the child's age at time of the diagnosis as they were diagnosed by another professional outside of this rural clinic. The mean age at time of diagnosis was 6.96 years with a range of 3-16 years of age. There were 15 (17.1%) children diagnosed during preschool, ages 3-

4 years. Thirty-five children (39.8%) were diagnosed during the age group of 5-7 years of age (K through 2nd grade) with the majority (n=27) during kindergarten and first grade. Twenty-five children (28.4%) were diagnosed from age 8-10 years of age (3rd through 5th grade) with thirteen diagnosed at age eight (3rd grade). Interestingly, 1st and 3rd grade were identified as transition times as children transferred to new buildings and routines within the district. Four children were diagnosed in middle school (ages 11-13 years) and four diagnosed during high school (ages 14-16 years).

Comorbidity in Rural Children with ADHD

Comorbid or co-existing conditions were identified as psychological conditions, medical conditions, or learning disabilities. The child's file or case report form documented diagnostic codes (ICD-9) for psychological and medical conditions and special education categories for learning disabilities.

Comorbid Psychological Conditions

Analysis indicates that 24 children (27.3%) were diagnosed with comorbid psychological disorders. Of these 24 children, four had dual psychological diagnoses with one diagnosed with depression and PTSD; one with anxiety and depression; one with ODD and PTSD; and another with Bipolar Disorder and ODD. Depression (n=8) and Oppositional Defiant Disorder (n=8) were most the frequently diagnosed psychological disorders within the sample. Females were more likely to exhibit depression (n=5) while males (n=6) more frequently displayed symptoms of Oppositional Defiant Disorder.

Table 3 summarizes the frequency of comorbid psychological conditions identified in this rural sample of children with ADHD.

Table 3. Frequency of Comorbid Psychological Conditions in Rural Children with ADHD

PSYCHOLOGICAL CONDITIONS	FEMALE (n=)	MALE (n=)	TOTAL (n=)	%
Anxiety	0	2	2	2.6
Bipolar Disorder	2	3	5	5.7
Depression	5	2	7	8.0
Obsessive Compulsive Disorder (OCD)	0	1	0	1.1
Oppositional Defiant Disorder (ODD)	1	6	7	8.0
Pervasive Developmental Disorder (PDD)	0	2	2	2.6
Post-Traumatic Stress Disorder (PTSD)	2	2	4	4.5

Comorbid Medical Conditions

Review of medical records indicates that 33 children (37.5%) were identified with co-existing medical conditions. Nine of the children had a dual diagnoses and one child with multiple diagnoses. Analysis showed that these 33 children were diagnosed with 48 medical conditions. See Table 4 for a breakdown of the frequency of medical conditions coexisting in rural children with ADHD.

Sleep disturbances were diagnosed in 13.6% (n=12) of the children seen in the clinic. Encopresis was diagnosed in 8.0% (n=7) of the children. Boys experienced both Encopresis and Sleep disturbances more often than girls. Brain trauma was documented in 5.7% (n=5) of the children seen. Specific diagnoses for brain trauma included Hydrocephalus; Encephlomalacia; Shaken Baby Syndrome; Hypoxia; and Vein of Galen Malformation. Other medical diagnoses displayed by the children in this sample included such conditions as Neurofibramotosis; Turners Syndrome; Constitutional Growth Delay;

Otitis Media; Hemiparesis, and Adrenoleukodystrophy. Three children in the Other Medical Conditions were diagnosed with Migraines.

Table 4. Frequency of Medical Conditions Co-existing with ADHD in Rural Children

MEDICAL CONDITIONS	FEMALE (n=)	MALE (n=)	TOTAL (n=)	%
Brain Trauma	2	3	5	5.7
Cerebral Palsy	0	3	3	3.4
Encopresis	2	5	7	8.0
Enuresis	0	3	3	3.4
Prematurity	0	3	3	3.4
Seizure Disorder	2	1	3	3.4
Sleep Disturbances	4	8	12	13.6
Tic Disorders	1	2	3	3.4
Other Medical Diagnoses*	2	7	9	10.2

*Other Medical Diagnoses identified in text above.

Comorbid Learning Disabilities

Analysis indicates that a total of 49 children (55.7%) receive special education services under the federal law known as Individuals with Disabilities Education Act (IDEA). Under IDEA, children aged 3-9 years of age may receive services under the term "developmental delay". The IDEA lists another 13 different categories under which children, aged 3-21 years, may be eligible for services.

Two preschool-aged children were identified as having developmental delays. IDEA allows the term "developmental delay" to be used for children 3 through 9 years of age. This allows local educational agencies, if they choose, not to say that a child has a specific disability. In this community, the term developmental delay can be used for children ages 3 through 5 years of age. Then, the child must be tested for a Specific

Learning Disability or another disability that could be affecting the child‘s educational performance.

The age at the time of identification of a learning disability is known for 83 of the children in the sample. The age was not documented for five of the children as they were evaluated outside the local school district. The age of initial identification was either not transferred during the districts reevaluation or the original evaluation was requested from the child’s previous school and not received before review of the child’s information for this study.

The mean age at the time of identification of a learning disability was 6.76 years with a range between 1-16 years. Nine children (10.2%) were identified and shown eligible for early intervention services as preschoolers (ages 1-4 years). The majority were found eligible for special education services during the span of kindergarten through second grade (n=20/22.8%) and 3rd through 5th grade (n=12/13.7%). These have been identified as transitional times and may be a time when there may be new academic challenges for the children. Fewer adolescents were found eligible for special education with two identified in middle school and two in high school.

Full Scale IQ scores were documented for 39 children; Performance IQ scores for 32; and Verbal IQ scores for 33 children. IQ scores are required to determine if a child is eligible for services under the category of Specific Learning Disabilities (SLD’s). As only seventeen children are identified as having SLD’s, the other children with documented scores reflect the number of children evaluated and found not eligible for this category. However, they did receive services under one or more of the other thirteen

disability categories. Intellectual evaluation is not required if a child clearly meets the requirements as defined in the other disability categories.

The mean for the Full Scale IQ score was 82.08 with a range of 42-113. For Performance IQ, the mean was 84.53 with a range of 46-112. The mean for Verbal IQ scores was 81.24 with a range of 48-112.

No children were identified as Gifted with an IQ ≥ 130. None were identified as severely retarded with IQ's of 25-39. A child is described as moderately retarded with IQ scores of 40-54; mildly retarded with scores of 55-69; and borderline retarded with scores of 70-84. Children with scores ≥ to 85 are depicted as of average intellect. Table 5 recaps the frequency of IQ scores for the children.

The ratio of boys to girls with IQ's ≤ to 84 is fairly equal when Full Scale scores (boys n=11 and girls n=9) and Performance scores (boys n=9 and girls n=8) are compared. Boys were two times more likely to have Verbal IQ scores ≤ to 84 (boys n=12 and girls n=6).

Table 5. Frequency of the Range of IQ Scores Identified in Rural Children with ADHD

IQ	MODERATELY RETARDED (n=)	MILDLY RETARDED (n=)	BORDERLINE RETARDED (n=)	AVERAGE (n=)
Full Scale	4	5	11	19
Performance	3	4	10	15
Verbal	3	7	8	15

It is noted that approximately 20 children meet the requirements in the category of Cognitive Disability/Mental Retardation. However, only nine children were found to receive special education services under this category.

Specific Learning Disabilities. Seventeen children (19.3%) are receiving Special Education services for Specific Learning Disabilities. Specific Learning Disabilities, defined in Chapter 1, are identified after a child's intellect (IQ) is determined and then compared with performance testing. A 22 point discrepancy between the two must be shown for the child to receive special education services. Table 6 exhibits the frequency of Specific Learning Disabilities in the sample of rural children.

Seven of the children had Reading/Written Language disabilities and five had Reading/Written Language/Math disabilities. Of interest, none of the children had disabilities in Math alone. Boys (n=14) were 4.7 times more likely to be diagnosed with a Specific Learning Disability than girls (n=3).

Table 6. Frequency of Specific Learning Disabilities Associated with ADHD in Rural Children

SPECIFIC LEARNING DISABILITY	FEMALE (n=)	MALE (n=)	TOTAL (n=)	%
Math	0	0	0	0
Reading	0	3	3	3.4
Written Language	0	1	1	1.1
Reading/Written Language	1	6	7	8.0
Reading/Math	0	1	1	1.1
Reading/Math/Written Language	2	3	5	5.7
TOTAL	3	14	17	19.3

Other Special Education Categories. Thirty children (34.1%) met the definitions required to be provided special education services under another disability category. Table 7 provides information on the frequency of other disabilities associated with ADHD.

Eight of the 30 children received services under a primary and secondary category. Not of surprise, three of the eight children received services under the primary category of Cognitive Delay (Mental Retardation) and secondary category of Speech/Language Impairment Of interest, three children received services under the primary category of Speech/Language Impairment and their secondary category as Other Health Impairment (OHI). The community's local educational agency has in the past not recognized the OHI category as a primary category to serve children with ADHD, who struggled academically but did not meet the definition of a Specific Learning Disability. Parents and staff providing early intervention services requested testing for speech/language impairment so that these children would not be lost to services as they transitioned from preschool to elementary school.

Table 7. Frequency of Other Special Education Disabilities Associated with ADHD in Rural Children

SPECIAL EDUCATION DISABILITY	FEMALE (n=)	MALE (n=)	TOTAL (n=)	%
Developmental Delay	1	1	2	2.3
Cognitive Impairment/Mental Retardation	4	5	9	10.2
Emotional Disturbance	0	2	2	2.3
Orthopedic Impairment	0	1	1	1.1
Other Health Impairment	3	7	10	11.4
Speech/Language Impairment	9	9	18	20.5
Visual Impairment	0	2	2	2.3

Relationships among Attributes, ADHD Subtypes, and Comorbid Conditions

Relationships between variables with nominal level measurement were explored using Chi-Square and Pearson's Correlation Bivariate analysis. Chi-Square measurements with a low significant value indicate that there maybe some relationship

between the two variables but does not indicate the strength or direction of the relationship. Pearson's Correlation Coefficient is a measure of linear association between two variables and values range from -1 to 1. Larger absolute values indicate a stronger relationship and the negative (-) or positive (+) signs indicate the direction of the relationship. The significance level (p-value) is the probability of obtaining results as extreme as the one observed. If p value is less than .05 then the correlation is significant and the two variables are linearly related. Table 8 displays the Pearson Correlation Coefficients for variables with a significance level of greater than .05.

Gender showed a weak but positive linear association with depression (p=.015) and Speech Language Impairment (p=.047). Girls were more likely than boys to be diagnosed with depression. Both sexes were equally identified with Speech Language Impairments for special education services.

Rural children diagnosed with ADHD, Hyperactive/Impulsive Type received services more frequently under the special education category of Other Health Impaired (p=.002) than any other category. Those with ADHD, Combined Type were more likely identified with a Reading disability than any other Specific Learning Disability. The diagnosis of anxiety had a higher probability in children diagnosed with ADHD, Not Otherwise Specified.

Anxiety in rural children with ADHD was displayed with more depression and Reading/Written Language disabilities. There were strong positive relationships between anxiety and prematurity (p=.000) as well as anxiety and sleep disturbances (p=.000).

The five children diagnosed with Bipolar Disorder were more likely to experience enuresis than other medical diagnoses. Bipolar Disorder was more likely associated with

the special education categories of Other Health Impairment and Speech/Language Impairment.

The diagnosis of depression has a weak association with the diagnosis of encopresis and strong relationship to the diagnosis of prematurity. Of the seven children diagnosed with depression, one was born prematurely and experienced encopresis and the other two children had either diagnoses.

Rural children with the diagnosis of Obsessive Compulsive Disorder were most likely to receive special education services under the category of Emotional Disturbance and/or Other Health Impairment. Those with the diagnosis of Oppositional Defiant Disorder had more probability of receiving services under the Emotional Disturbance category.

There was a strong association with the diagnoses of Pervasive Developmental Disorder (PDD) and seizures. Two of the three children diagnosed with seizures were also diagnosed with PDD.

The risk factor of brain trauma was associated with the diagnoses of Cerebral Palsy and seizures. Children with known brain trauma were more likely to receive special education services under the categories of Cognitive Disability/Mental Retardation or Other Health Impairment, rather than the category of Brain Trauma. Children with seizures were most likely to receive special education services under the category of Speech/Language Impairment.

There is a strong correlation between rural children diagnosed with Cerebral Palsy (CP) and receiving special education services under the category of Orthopedic

Impairment. Children with CP meet the definition of Orthopedic Impairment because of their difficulties in motor activities.

The diagnosis of encopresis is strongly correlated to the diagnosis of enuresis. Children experiencing difficulty with bowel control are more likely to experience difficulty with bladder control as well.

The diagnosis of enuresis was also strongly associated with the risk factor of prematurity in this population. The risk factor of prematurity was also strongly associated with the diagnosis of sleep disturbances and tic disorders (especially motor tics).

Table 8. Relationships AmongVariables

VARIABLES	PEARSON CORRELATION	SIG. (2-TAILED)	N
Gender			
-Depression	.260*	.015	88
-Speech/Language Impairment	.212*	.047	88
ADHD, Hyperactive/Impulsive Type			
-Other Health Impairment	.323**	.002	88
ADHD, Combined Type			
-Reading Disability	.243*	.023	88
ADHD, Not Otherwise Specified			
-Anxiety	.235*	.027	88
Anxiety			
-Depression	.237*	.026	88
-Reading/Written Language Disability	.237*	.026	88
-Prematurity	.392**	.000	88
-Sleep Disturbances	.384**	.000	88
Bipolar Disorder			
-Enuresis	.224*	.032	88
-Other Health Impairment	.221*	.038	88
-Speech/Language Impairment	.241*	.024	88
Depression			
-Encopresis	.224*	.036	88
-Prematurity	.408**	.000	88

Table 8. Relationships Among Variables (Continued)

VARIABLES	PEARSON CORRELATION	SIG. (2-TAILED)	N
Obsessive Compulsive Disorder			
-Emotional Disturbance	.703**	.000	88
-Other Health Impairment	.299**	.000	88
Oppositional Defiant Disorder			
-Emotional Disturbance	.237*	.026	88
Pervasive Developmental Disorder			
-Seizures	.391**	.000	88
Brain Trauma			
-Cerebral Palsy	.224*	.036	88
-Seizures	.224*	.036	88
-Cognitive Disability/Mental Retardation	.241*	.024	88
-Other Health Impairment	.221*	.038	88
Seizures			
-Speech Language Impairment	.215*	.044	88
Cerebral Palsy			
-Orthopedic Impairment	.517**	.000	88
Encopresis			
-Enuresis	.408**	.000	88
Prematurity			
-Enuresis	.310**	.003	88
-Sleep Disturbances	.290**	.006	88
-Tic Disorders	.286**	.007	88

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

CHAPTER 5

DISCUSSION

The data collected provided sorely needed data on ADHD in a rural community. Although the findings may not be considered statistically significant due to a small sample size, the information is critical to understanding the magnitude of the disorder and the expression of ADHD in a diverse population group, rural children. Findings are considered clinically significant as they provide meaning to the diagnosis of ADHD in rural child and outline potential medical, psychological, and educational comorbidities.

Exploration of the information provided an assessment of the internal environment as described in Levine's Model of Conservation and described the patterns of ADHD among children in a community. Assessment of the external environment outlined the sociodemographic attributes (conceptual environment) and risk factors that are associated with co-existing conditions (operational environment). The study findings have been organized in such a way as to provide meaning and can assist the community in proposing hypotheses about the problems associated with ADHD. Enhancing the understanding of ADHD in rural children will increase the ability to make informed decisions and recommendations concerning potential public health prevention and intervention strategies.

Summary of Results

In the sample of 88 rural children, the ratio of boys to girls diagnosed with ADHD is 2.3:1. Research provides evidence that in larger population samples, the male-to-female ratio is 3:1 (Gaub & Carlson, 1997). Findings in this sample are surprisingly similar, raising the concern that ADHD may also be under-diagnosed in girls in a rural community.

The majority of the children are Caucasian with a small number of minority children seen. The findings reflect the ethnicity of the county at large with Caucasians representing 93.8% of the population; 8.8% are Hispanic, 0.9% are American Indian; and 0.2% are African American (United States Census Bureau, 2005).

More than one-half of the children live in a two-parent home. Medicaid is the primary source of payment for health care services in the sample. However, children living with a single parent have a higher probability of being on Medicaid. To be eligible for Medicaid, a family must be at the 133% poverty level. Living in poverty has been identified as an environmental risk factor associated with ADHD (Conners, 2003).

Within the subtypes, most children were diagnosed with ADHD, Combined Type (37.5%) and fewer with ADHD, Hyperactive/Impulsive Type (11.4%). In research performed by Wolraich et al (1998), most children met criteria for the Inattentive Type. Findings from a Colombian were similar with a distribution for Combined Type as 6.4%; Inattentive Type as 4.8%; and Hyperactive/Impulsive Type as 0.3%. In this study, males were more frequently diagnosed with Combined Type and Not Otherwise Specified Type. The sexes were equally distributed in the Inattentive Type and Hyperactive/Impulsive Type. Other studies have shown girls to have a higher prevalence

of Inattentive Type than any other subtype (Sax and Kautz, 2003). ADHD with hyperactivity/impulsivity affects boys more often than girls ((Gaub & Carlson, 1997).

The mean age of diagnosis was 6.96 years with the majority seeking evaluation during school transition times during 1st and 3rd grade. As children are required to comprehend large amounts of information, to perform tasks rapidly, to flexibly shift between activities, or to link a sequence of cognitive operations, their performance may deteriorate, causing them to appear inattentive or disorganized (Weiler, Bernstein, Bellinger, and Waber, 2002). Applegate et al. (1997) documented similar findings with symptoms of ADHD apparent in most cases before the age of seven years.

Almost one-third of the children in the sample were diagnosed with comorbid psychological disorders. In other studies, comorbidity is present in as many as two-thirds of clinically referred children (Dunne et al., 1997). Depression and Oppositional Defiant Disorder were the most frequently diagnosed disorders, whereas in other studies ODD was diagnosed with the highest rate and depressive disorders with the lowest frequency rate (Dunne et al.; Green et al., 1999). Females were more likely to exhibit depression and males more likely to display symptoms of Oppositional Defiant Disorder thus, supporting findings from Dunne and Green.

Over one-third of the children were diagnosed with co-existing medical conditions. Sleep disturbances and encopresis were diagnosed most often with males experiencing these conditions more frequently than girls. In studies reviewed, other researchers found that at least 50% of children with ADHD displayed alterations in sleep patterns (O'Brien et al. 2003; Stein et al. 2002). Review of literature indicates that there is an association between attentional dysfunction and encopresis (Johnston & Wright, 1993). Another

study found a small but significant association between nocturnal enuresis and hyperactivity (Rey, Bird, & Hensley, 1995).

Over one-half of the children were identified as having learning disabilities and received special education services. Rates in other studies range from 10-50% (Ross-Kidder, 1998; Wolraich, Hannah, Baumgaertal, & Feurer, 1998). The mean age at time of identification of a learning disability was 6.76 years.

The mean for Full Scale IQ scores in the children tested for special education services was 82. Performance IQ scores were 85 and Verbal IQ scores were 81. The IQ scores ranged from 42-113. The IQ scores in Weiler's (2002) study ranged from 98-113. According to IDEA definitions, 20 children (22.7%) met the requirements necessary to receive services under the category of Cognitive Disability/Mental Retardation (IQ of 40-84). However, only nine children received special education services under this category. This may be based on focusing on areas of the child's weakness and de-emphasizing "labeling" or categorizing. Assigning a category of Mental Retardation can exaggerate the child's feeling of being different (Kaplan et al., 2001).

Boys were 4.7 times more likely to be identified with a Specific Learning Disability and were two times more likely to have lower Verbal IQ scores. Thirty children met the requirements defined under one or two of the other thirteen categories of disability described by IDEA. Speech/Language Impairment was identified more frequently than any other special education category (20.5%). In another study, 45% of children diagnosed with ADHD manifested some type of language impairment (Kaplan et al., 2001).

Relationships between all the variables of the study were explored and those with a correlation significance of less than 0.05 or 0.01 were identified. Children with ADHD, Hyperactive/Impulsive Type received services more frequently under the special education category of Other Health Impaired than any other disability category. This is not of surprise considering research indicates that the average IQ of children with Hyperactive/Impulsive Type was 113 (Chabildas et al., 2001), making it difficult for these children to meet the requirements under any of the special education categories. Those with ADHD, Combined Type had a greater probability of being identified with a Reading Disability than any other educational disability. The diagnosis of anxiety was associated with ADHD, Not Otherwise Specified. Sleep disturbances had a high probability of being identified with the diagnosis of anxiety. Review of literature indicates that Depression was found to contribute substantially to sleep alterations (Andreon, Karapetsas, Agapitou, & Gourgoulianis, 2003). Anxiety and Depression were closely associated.

Other spurious associations were found between Depression and Encopresis. Prematurity was found to also contribute considerably to Depression. Enuresis, sleep disturbances, and Tic Disorders have significant correlation with prematurity.

Implications for Clinical Practice

Advance Nurse Practitioners can play the role of advocate and educator when working with rural children at risk for ADHD. Bussing, Schoenberg, and Perwein (1998) found that less than one-third of parents of children who were at high risk for ADHD had been provided with information about the disorder by their physicians. Increasing

parent's knowledge about ADHD may also increase parental satisfaction and sense of competency and affects parents' choices regarding their child's treatment (Corkum, Rimer, & Schacher, 1999).

According to the American Academy Clinical Guidelines (Committee On Quality Improvement, 2001), any child who presents with inattention, hyperactivity, impulsivity, academic underachievement, or behavior problems, the primary care clinician should initiate an evaluation for ADHD. Awareness and utilization of DSM-IV diagnostic criteria can minimize over-identification and under-identification. All clinical visits should include general questions that screen for school performance.

Family Nurse Practitioners can provide a provisional diagnosis of ADHD and refer to specialist services for confirmation of the diagnosis and initiation of management. The earlier the recognition of the problem, the sooner the appropriate interventions, treatment, and counseling can begin to counter negative effects of family stress, lowered self-esteem, and ensuing learning and social difficulties (Fewell & Beutscher, 2002). Assessment of ADHD requires evidence directly obtained from parents or caregivers, classroom teachers or other school professionals, and the child if age appropriate regarding the core symptoms of ADHD, the age of onset, duration of symptoms, and degree of functional impairment. Information can be obtained using open-ended questions, focused questions about specific behaviors, semi-structured interviews, and questionnaires and rating scales. Consideration and examination for co-existing conditions should be an integral part of the evaluation.

Family Nurse Practitioners can assist with monitoring progress once a management plan is in place. They can play a key role in data collection, treatment planning, and

working with the children and their families in community and school systems. Practitioners are in a pivotal position to provide a host of interventions that facilitate optional function and quality of life (Zimmerman, 2003). In one study it was found that in 6 months after an ADHD diagnosis, the median number of follow-up visits was one. "This is too few visits to permit adjustment of medication or support adherence to treatment" (Gardner et al., 2004). Family Nurse Practitioner can and do provide competent family-centered, community based health care on a more frequent and routine basis.

Rural communities experience numerous obstacles in obtaining specialty services including mental health services. Obstacles include a lack of accessible services, a general scarcity of resources; and absence of human services infrastructure (Levin & Hanson, 2001). A key competency of the Family Nurse Practitioner is to implement critical thinking and build "collaborative, interdisciplinary relationships to provide optimal care to the patient" (Department of Health and Human Services, 2002, p. 23). When core agencies are working together, with a common set of objectives, a common understanding of what these children need, and a collaborative approach, there is efficient use of the special skills and the resources from each system (Brazelon Center for Mental Health Law, 2003).

Recommendations for Future Research

Until more is known about actual attributes and mechanisms of family functioning in rural children with ADHD, it is not possible to specify type of interventions that would be most effective in decreasing symptoms. Coming to understand the health experiences

from the perspective of the children living with ADHD, will sensitize and informs the health community and community at large of what it like to live with ADHD. Further research is needed to uncover common attributes in rural children; common courses of ADHD; and how families manage the disorder.

Further research is necessary to provide epidemiological data on ADHD. Information is critical to understanding the magnitude of the disorder, the expression of ADHD in rural communities, the receipt and quality of community care, and factors associated with differential outcomes in children with the disorder.

Limitations

Theoretical Limitations

Theoretical limitations reflected in the study framework and definitions are based on the use of the American Psychiatric Association Diagnostic and Statistical Manuel of Mental Disorders, 4th edition (DSM-IV) criteria for diagnosis and lack of data on the genetic and environmental risk factors associated with ADHD and its co-existing conditions. Genetic and environmental risk factors are not identified in the data provided for each child in this study.

DSM-IV criterion is not a perfect tool for establishing the diagnosis of ADHD for several reasons: (a) the categories function as guidelines of behavior; (b) it does not make compensations for age or gender where differences in presentation are known to occur; (c) it does not quantify how impulsive or inattentive the child should be; and (d) subjective interpretation of symptoms can lead to discrepancies in diagnosis (Primary Care Practice: A Peer-Reviewed Series, 2000).

Review of literature outlines factors of genetic risk. Statistically about 25% of children with ADHD have a first degree relative with ADHD (Hunt, Paquin, & Payton, 2001). Other markers include parental mood and conduct disorders, learning disabilities, and antisocial behavior. Parental substance abuse and smoking are implicated as many adults attempt to improve their sense of well-being with drugs, alcohol, and nicotine (Biederman et al., 1997). Further study of the rural population would help define characteristics of the conceptual environment as outlined in Levine's Conservation Model.

Further exploration and assessment of the operational environment is needed. Environmental risks for ADHD include exposure to heavy metal toxins, such as lead and mercury, as well as exposure to carbon monoxide fumes (Conners, 2003). Other factors that increase the risk include poor childhood diet, family stress, and living in poverty (Jacobvitz & Sroufe, 1987).

Methodologicial Limitations

Methodological limitations are identified and addressed before determination of research design and statistical analysis. Convenience sampling of a clinical vs. community-based population provided a small sample size of 88 children diagnosed with ADHD seen in a rural pediatric outreach clinic. It can be argued that children seeking care in this setting may be different from those who seek care for the same condition in other settings. Children with ADHD living in a rural community may not have the same access to health care services as children in an urban setting. Children seeking specialty care are possibly more likely to have comorbid conditions that are affecting their daily

functioning and so are less likely to seek care from a local family provider. However, it should be pointed out that exploratory studies are not intended for generalization to large populations, but designed to increase knowledge of the field of study (attributes of children with ADHD). Use of a normative clinical-based sample can help determine whether findings of previous research are generalizable to children in a rural setting.

Limitation of Instruments

Limitations of the tools/instruments with criterion behavioral checklists must also be discussed. These behavioral checklists help establish presence of DSM criteria for the diagnosis of ADHD and its subtypes.

The Aggregate Neurobehavioral Student Health and Educational Review (ANSER) tool is used by the clinic's pediatrician. According to the Mental Measurement Yearbook test review (Harrington & Howell); there are many problems with utilization of the ANSER form as it is considered a broad-based tool providing indirect measure of ADHD symptomology. In critiquing the ANSER system, there is frequent reference to cognitive, affective perceptual traits such as impulsivity, emotional liability, and visual-spatial processing. These terms are hypothesized constructs and although popular, are not well defined. Review of the literature indicates there are presently no instruments available to accurately measure the concepts. Because there is no numerical score obtained from the ANSER system, measurement error will also be hypothesized. There are factors that could result in random error from transient personal factors such as the teacher or parent's mood, mental set, and motivation when recording their observations. Situational factors could also affect responses (i.e. the fear of being "labeled"). The variation in the

administration procedure is not directly influenced as each individual completes the form. Processing the data can be the biggest concern with random error. There is no standardization of this tool so there is a heightened possibility of inconsistent objectivity during the summation of the subscales. In considering systematic error, it has been criticized that the concepts may be repetitive in the subscales making it difficult to score a specific area. However, if more questions throughout the instrument are used to clarify the observations of the person completing it, it could be hypothesized that two or more questions measuring the concept may demonstrate the true relationship of the behaviors. There are no levels of measurement found in this tool. The categories of the subscales are not mutually exclusive, exhaustive, or ordered. Research indicates that there are no definitive diagnostic tests or scales available to diagnosis the presence of ADHD; therefore it becomes a clinical diagnosis. In support of the ANSER system, as more information is obtained, construct validity and eventually predictive validity of this instrument is possible. Continued familiarity with the ANSER tool can increase interrater reliability within a community especially among local educators. Projective technique used by medical providers can help interpret the inferences made about the decidedly complicated relationships of the medical disorders and current behavior addressed by the ANSER. The idea of a multimodal treatment approach is enforced by the possibility of the correlation of disorders with behavior. This supports the inclusion of Physicians and Advanced Practice Nurses in the evaluation of behavioral and educational difficulties to assure possible identification of underlying medical conditions.

The data collection tool developed by the researcher is not standardized and has not been used in previous studies. Validity and reliability has not been tested. However, it

does identify the sociodemographic variables, the diagnostic categorical variables, and the co-existing conditions present in this clinical sample. See Appendix B for a copy of the data collection tool.

Conclusion

As identified in this study, ADHD can be characterized by heterogeneity and ambiguity, and confounded by comorbidity. Implicit in the strategies provided by a Family Nurse Practitioner is collaborative and integrative assessment, case planning, advocacy, management, and therapeutic services embedded in a montage of systems including clinicians, mental health professionals, education, social services, and the community.

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APPENDICES

APPENDIX A

ATTENTION DEFICIT/HYPERACTIVITY DISORDER*SYMPTOMS OF ADHD

Attention Deficit/Hyperactivity Disorder*Symptoms of ADHD

The year 2000 Diagnostic & Statistical Manual for Mental Disorders (DSM-IV-TR) provides criteria for diagnosing ADHD. The criteria are presented here in modified form to make them more accessible to the general public. They are listed for information purposes and should be used only by trained health-care providers to diagnose or treat ADHD.

DSM-IV Criteria for ADHD

I. Either A or B:

A) Six or more of the following symptoms of inattention have been present for at least 6 months to a point that is disruptive and inappropriate for developmental level:

Inattention

1) Often does not give close attention to details or makes careless mistakes in schoolwork, work, or other activities.

2) Often has trouble keeping attention on tasks or play activities.

3) Often does not seem to listen when spoken to directly.

4) Often does not follow instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions).

5) Often has trouble organizing activities.

6) Often avoids, dislikes, or doesn't want to do things that take a lot of mental effort for a long period of time (e.g., schoolwork and homework).

7) Often loses things needed for tasks and activities (e.g., toys, school assignments, pencils, books, and tools).

8) Is often easily distracted. 9) Is often forgetful in daily activities.

B) Six or more of the following symptoms of hyperactivity-impulsivity have been present for at least 6 months to an extent that is disruptive and inappropriate for developmental level:

Hyperactivity

1) Often fidgets with hands or feet or squirms in seat.

2) Often gets up from seat when remaining in seat is expected.

3) Often runs about or climbs when and where it is not appropriate (adolescents or adults may feel very restless).

4) Often has trouble playing or enjoying leisure activities quietly.

5) Is often "on the go" or often acts as if "driven by a motor".

6) Often talks excessively.

Impulsivity

7) Often blurts out answers before questions have been finished.

8) Often has trouble waiting one's turn.

9) Often interrupts or intrudes on others (e.g., butts into conversations or games).

II. Some symptoms that cause impairment were present before age 7 years.

III. Some impairment from the symptoms is present in two or more settings (e.g., at school/work and home).

IV. There must be clear evidence of significant impairment in social, school, or work functioning.

V. The symptoms do not happen only during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder. The symptoms are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Based on these criteria, three types of ADHD are identified:

1) ADHD, Combined Type: if both criteria 1A and 1B are met for the past 6 months

2) ADHD, *Predominantly Inattentive Type*: if criterion 1A is met but criterion 1B is not met for the past six months

3) ADHD, *Predominantly Hyperactive-Impulsive Type*: if Criterion 1B is met but Criterion 1A is not met for the past six months.

American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision. Washington, DC, American Psychiatric Association, 2000.

Promoting the health of babies, children and adults, and enhancing the potential for full, productive living. 1-888-212-5920, www.cdc.gov/ncbddd Department of Health and Human Services 11290

APPENDIX B

PUBLICATION OF THE NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES

Publication of the National Dissemination Center for Children with Disabilities

General Information about Disabilities:

Disabilities That Qualify Infants, Toddlers, Children, and Youth for Services under the IDEA

General Resources 3 (GR3) 2002

Introduction

Every year, under the federal law known as the Individuals with Disabilities Education Act (IDEA), millions of children with disabilities receive special services designed to meet their unique needs. For infants and toddlers with disabilities birth through two and their families, special services are provided through an *early intervention* system. For school-aged children and youth (aged 3 through 21), *special education and related services* are provided through the school system. These services can be very important in helping children and youth with disabilities develop, learn, and succeed in school and other settings.

Table of Contents

Who is Eligible for Services?

Under the IDEA, states are responsible for meeting the special needs of eligible children with disabilities. To find out if a child is eligible for services, he or she must first receive a full and individual initial evaluation. This evaluation is free. Two purposes of the evaluation are:

- to see if the child has a disability, as defined by IDEA, and
- to learn in more detail what his or her special needs are.

Infants and Toddlers, Birth Through Two. Under the IDEA, "infants and toddlers with disabilities" are defined as children from birth through age two who need early intervention services because they. . .

...are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas:

- cognitive development.
- physical development, including vision and hearing.
- communication development.
- social or emotional development.
- adaptive development; or

...have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

The term may also include, if a state chooses, children from birth through age two who are at risk of having substantial developmental delays if early intervention services are not provided." (34 *Code of Federal Regulations* §303.16)

Children Aged 3 Through 9. It is important to know that, under IDEA, States and local educational agencies (LEAs) are allowed to use the term "developmental delay" with children aged 3 through 9, rather than one of the disability categories listed at the top of page 2. This means that, if they choose, States and LEAs do not have to say that a child has a specific disability. For children aged 3 through 9, a state and LEA may choose to include as an eligible "child with a disability" a child who is experiencing developmental delays in one or more of the following areas:

- physical development,
- cognitive development,
- communication development,
- social or emotional development, or
- adaptive development...

...and who, because of the developmental delays, needs special education and related services.

"Developmental delays" are defined by the state and must be measured by appropriate diagnostic instruments and procedures.

Children and Youth Aged 3 Through 21. The IDEA lists 13 different disability categories under which 3 through 21-year-olds may be eligible for services. For a child to be eligible for services, the disability must affect the child's educational performance. The disability categories listed in IDEA are:

- autism,
- deaf-blindness,
- emotional disturbance,
- hearing impairment (including deafness),
- mental retardation,
- multiple disabilities,
- orthopedic impairment,
- other health impairment,
- specific learning disability,
- speech or language impairment,
- traumatic brain injury, or
- visual impairment (including blindness).

Under IDEA, a child may not be identified as a "child with a disability" just because he or she speaks a language other than English and does not speak or understand English well. A child may not be identified as having a disability just because he or she has not had enough instruction in math or reading.

How Does IDEA Define the 13 Disability Categories?

The IDEA provides definitions of the 13 disability categories listed above. These federal definitions guide how states define who is eligible for a free appropriate public education under IDEA. The definitions of disability terms are as follows:

1. Autism...

...means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects educational performance. Characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to changes in daily routines or the environment, and unusual responses to sensory experiences. The term autism does not apply if the child's educational performance is adversely affected primarily because the child has emotional disturbance, as defined in #5 below.
A child who shows the characteristics of autism after age 3 could be diagnosed as having autism if the criteria above are satisfied.

2. Deaf-Blindness...

...means concomitant [simultaneous] hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.

3. Deafness...

...means a hearing impairment so severe that a child is impaired in processing linguistic information through hearing, with or without amplification, that adversely affects a child's educational performance.

4. Emotional Disturbance...

...means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:
(a) An inability to learn that cannot be explained by intellectual, sensory, or health factors.
(b) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
(c) Inappropriate types of behavior or feelings under normal circumstances.
(d) A general pervasive mood of unhappiness or depression.
(e) A tendency to develop physical symptoms or fears associated with personal or school problems.
The term includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.

5. Hearing Impairment...

...means an impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance but is not included under the definition of "deafness."

6. Mental Retardation...

...means significantly subaverage general intellectual functioning, existing concurrently [at the same time] with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.

7. Multiple Disabilities...

...means concomitant [simultaneous] impairments (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.), the combination of which causes such severe educational needs

that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include deaf-blindness.

8. Orthopedic Impairment...

...means a severe orthopedic impairment that adversely affects a child's educational performance. The term includes impairments caused by a congenital anomaly (e.g. clubfoot, absence of some member, etc.), impairments caused by disease (e.g. poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).

9. Other Health Impairment...

...means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—
(a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and
(b) adversely affects a child's educational performance.

10. Specific Learning Disability...

...means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include learning problems that are primarily the result of visual, hearing, or motor disabilities; of mental retardation; of emotional disturbance; or of environmental, cultural, or economic disadvantage.

11. Speech or Language Impairment...

...means a communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects a child's educational performance.

12. Traumatic Brain Injury...

...means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not include brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

13. Visual Impairment Including Blindness...

...means an impairment in vision that, even with correction, adversely affects a child's educational performance. The term includes both partial sight and blindness.

Finding Out More About Disabilities

IDEA's definitions of disability terms help states, schools, service providers, and parents decide if a child is eligible for early intervention or special education and related services. Beyond these definitions, there is a great deal of information available about specific disabilities, including disabilities not listed in IDEA. NICHCY would be pleased to help you find that information, beginning with:

- our disability fact sheets and other publications on the disabilities listed in IDEA;
- contact information for many organizations that focus their work on a particular disability. These groups have a lot of information to share.

More About Services

Special services are available to eligible children with disabilities and can do much to help children develop and learn. For infants and toddlers aged birth through two, services are provided through an *early intervention* system. This system may be run by the Health Department in the state, or another department such as Education. If you are a parent and you would like to find out more about early intervention in your state, including how to have your child evaluated at no cost to you, try any of these suggestions:

- ask your child's pediatrician to put you in touch with the early intervention system in your community or region;
- contact the Pediatrics branch in a local hospital and ask where you should call to find out about early intervention services in your area;
- call NICHCY and ask for the contact information for early intervention in your state. The state office will refer you to the contact person or agency in your area.

For children and youth ages 3 through 21, *special education and related services* are provided through the public school system. Probably the best way to find out about these services is to call your local public school. The school should be able to tell you about special education policies in your area or refer you to a district or county office for this information. If you are a parent who thinks your child may need special education and related services, be sure to ask how to have your child evaluated under IDEA for eligibility. Often there are materials available to tell parents and others more about local and state policies for special education and related services.

There is a lot to know about early intervention, about special education and related services, and about the rights of children with disabilities under the IDEA, our nation's special education law. NICHCY offers many publications, all of which are available on our Web site or by contacting us directly. We can also tell you about materials available from other groups.

Other Sources of Information for Parents

There are many sources of information about services for children with disabilities. Within your community, you may wish to contact:

- the Child Find Coordinator for your district or county (IDEA requires that states conduct Child Find activities to identify, locate, and evaluate infants, toddlers, children, and youth with disabilities aged birth through 21);
- the principal of your child's school; or
- the Special Education Director of your child's school district or local school.

Any of these individuals should be able to answer specific questions about how to obtain special education and related services, or early intervention services, for your child.
In addition, every state has a Parent Training and Information (PTI) center, which is an excellent source of information. The PTI can:

- help you learn about early intervention and special education services;
- tell you about what the IDEA requires;
- connect you with disability groups and parent groups in the community or state; and
- much, much more!

To find out how to contact your state's PTI, look at the NICHCY *State Resource Sheet* for your state (available on our Web site or by contacting us directly). You'll find the PTI listed there, as well as many other information resources, such as community parent resource centers, disability-specific organizations, and state agencies serving children with disabilities.

Publication of this document is made possible through a Cooperative Agreement between the Academy for Educational Development and the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

NICHCY
P.O. Box 1492
Washington, DC 20013
(800) 695-0285 · v/tty
(202) 884-8441 · fax
nichcy@aed.org
www.nichcy.org

APPENDIX C

CASE REPORT FORM-DEMOGRAPHIC & DIAGNOSTIC INFORMATION FOR RURAL CHILDREN WITH ADHD

Case Report Form-Demographic & Diagnostic Information for Rural Children with ADHD

ID#_____

GENDER: **0: FEMALE 1: MALE** CURRENT AGE: _____ **99: NOT KNOWN**

ETHNICITY: **0: CAUCASIAN**
1: HISPANIC
2: AMERICAN INDIAN
3: AFRICAN-AMERICAN
4: OTHER

FAMILY SITUATION: **0: SINGLE PARENT**
1: TWO PARENT
2: FOSTER PARENT(S)/ GUARDIAN(S)

PAYMENT SOURCE FOR HEALTH CARE: **0: SELF PAY**
1: INSURANCE
2: MEDICAID/KIDCARE
3: DUAL: INSURANCE & MEDICAID
4: NOT KNOWN

ADHD DIAGNOSTIC CATEGORY:
0: ADHD, INATTENTIVE TYPE
1: ADHD, HYPERACTIVE/IMPULSIVE TYPE
2: ADHD, COMBINED TYPE
3: ADHD, NOT OTHERWISE SPECIFIED

AGE AT TIME OF ADHD DX:_____
99: NOT KNOWN

COMORBIDITY:

MENTAL HEALTH
0: ANXIETY
1: BIPOLOR DISORDER
2: DEPRESSION
3: OCD
4: ODD
5: PDD
6: PTSD
7: OTHER
99: NONE

MEDICAL CONDITIONS
0: BRAIN TRAUMA
1: CEREBRAL PALSEY
2: ENCOPORESIS
3: ENURESIS
4: PREMATURITY
5: SEIZURE DISORDER
6: SLEEP DISORDER
7: TICS/TOURETTES
8: OTHER
99:NONE

SPECIFIC LEARNING DISABILITY
0: MATH
1: READING
2: WRITTEN LANGUAGE
3: READING/WRITING
4: READING/MATH
5: READING/MATH/WRITING
99: NONE

OTHER SPECIAL ED CATEGORIES
0: 504 PLAN
1: DEVELOPMENTAL DELAY
2: EMOTIONAL DISABILITY
3: MENTAL/COGNITIVE DISABILITY
4: ORTHOPEDIC DISABILITY
5: OTHER HEALTH IMPAIRMENT
6: VISUAL IMPAIRMENT
7: REFERRED FOR EVALUATION
8: SPEECH LANGUAGE IMPAIRMENT
99: NONE

AGE AT TIME OF LD IDENTIFICATION: _____
99: NOT KNOWN

IQ SCORES: **FULL SCALE_____**
PEFORMANCE_____
VERBAL_____

APPENDIX D

REQUEST FOR DESIGNATION OF RESEARCH AS EXEMPT FROM THE REQUIREMENT OF IRB REVIEW

Request for Designation of Research as Exempt from the Requirement of IRB Review

Montana State University Human Subjects Committee Application Form
MONTANA STATE UNIVERSITY
Request for Designation of Research as Exempt from the Requirement of Institutional Review Board Review

(3/22/05)

Include copies of PI's and Co-PI's "Completion Certificate(s)" as proof that all have received the education and instructions for researchers using human subjects. The preferred instruction and education is that from the National Cancer Institute: http:/Cancer.gov - Human Participant Protections Education for Research Teams/cme.cancer.gov/clinicaltrials/learning/ humanparticipant-protections.asp

****

THIS AREA IS FOR INSTITUTIONAL REVIEW BOARD USE ONLY. DO NOT WRITE IN THIS AREA.

Confirmation Date: 6/17/2005

Application Number:

****

PLEASE TYPE. Submit one (1) copy of this application, along with one (1) copy of the subject consent form, one copy of grant contract proposal (if applicable) and all other relevant materials, to: Institutional Review Board Chair, Mark Quinn, Veterinary Molecular Biology, MSU, 960 Technology Blvd., Room 127, Bozeman, MT 59717. For information and assistance, call 994-6783.

DATE: 6/14/05

I. INVESTIGATOR:

Name: Debra J. Miller

Department/Address: College of Nursing, P.O. Box 799; Ennis, MT 59729

Telephone: (406)682-7429

E-Mail Address: deloji@yahoo.com

DATE TRAINING COMPLETED: 11/18/03

Name of Faculty Sponsor: Karen Zulkowski, DNS, RN, CWS

(if above is a student)

II. TITLE OF RESEARCH PROJECT: ADHD in a Rural Community

III. BRIEF DESCRIPTION OF RESEARCH METHODS: Secondary analysis of de-identified data.

IV. RISKS AND INCONVENIENCES TO SUBJECTS: None

V. SUBJECT:

A. Expected numbers of subjects: __88_____

B. Will research involve minors (age <18 years)? Yes No

(If 'Yes', please specify and justify.)

Secondary data analysis of data set obtained from a small community study addressing Prevalence of ADHD in that community.

C. Will research involve prisoners? Yes No

D. Will research involve any specific ethnic, racial, religious, etc. groups of people?

(If 'Yes', please specify and justify.) Yes No

VI. FOR RESEARCH INVOLVING SURVEYS OR QUESTIONNAIRES:

A. Is information being collected about:

Sexual behavior?	Yes	No
Criminal behavior?	Yes	No
Alcohol or substance abuse?	Yes	No
Matters affecting employment?	Yes	No
Matters relating to civil litigation?	Yes	No

B. Will the information obtained be completely anonymous, with no identifying information linked to the responding subjects? Yes No

C. If identifying information will be linked to the responding subjects, how will the subjects be identified? (Please circle or bold your answers)

By name	Yes	No
By code	Yes	No
By other identifying information	Yes	No

D. Does this survey utilize a standardized and/or validated survey tool/questionnaire? Yes No Not applicable. Data set provided from small community study.

VII. FOR RESEARCH INVOLVING PATIENT INFORMATION, MATERIALS, BLOOD OR TISSUE SPECIMENS RECEIVED FROM OTHER INSTITUTIONS:

A. Are these materials linked in any way to the patient (code, identifier, or other link to patient identity)? Yes No

B. Are you involved in the design of the study for which the materials are being collected?

Yes No

Data set will be used in a descriptive study of attributes of children with ADHD.

C. Will your name appear on publications resulting from this research?

Yes No

D. Where are the subjects from whom this material is being collected?

A small rural community in southwestern Wyoming.

E. Has an IRB at the institution releasing this material reviewed the proposed project?

(If 'Yes", please provide documentation.) Yes No

Data set obtained from a previous community study and previously available for public use.

F. Regarding the above materials or data, will you be:

Collecting them	Yes	No
Receiving them	Yes	No
Sending them	Yes	No

G. Do the materials already exist? Yes No

H. Are the materials being collected for the purpose of this study? Yes No

I. Do the materials come from subjects who are:

Minors	Yes	No
Prisoners	Yes	No
Pregnant women	Yes	No

J. Does this material originate from a patient population that, for religious or other reasons, would prohibit its use in biomedical research?

Yes No Unknown source

VIII. FOR RESEARCH INVOLVING MEDICAL AND/OR INSURANCE RECORDS

A. Does this research involve the use of:
Medical, psychiatric and/or psychological records Yes No
Health insurance records Yes No
Any other records containing information regarding personal health and illness
Yes NO

If you answered "Yes" to any of the items in this section, you must complete the HIPAA Worksheet.

APPENDIX E

INSTITUTIONAL REVIEW BOARD

Institutional Review Board