

DIFFERENCES IN SLEEP DISTURBANCES
AMONG SEVERELY AND PROFOUNDLY RETARDED ADULTS
WITH HIGH RISK BEHAVIORS

A Thesis

Submitted to the Graduate Faculty of the
Louisiana State University and
Agricultural and Mechanical College
in partial fulfillment of the
requirements for the degree of
Master of Arts

in

The Department of Psychology

By
Carrie Jo Malone
B.S., Millikin University, 2002
December 2004

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Abstract

Individuals with intellectual disabilities have been linked to higher incidences of a variety of mental illnesses when compared to the general population (Rutter, Tizard, Yule, Graham, & Whitmore, 1976; and Borthwick-Duffy, 1994). Because of the symptoms associated with mental retardation; such as limited social skills, delayed or minimal communication skills, and maladaptive behaviors, mental illness can be difficult to assess when combined with an intellectual disability (Sovner, 1986). Currently there is no available mechanism for diagnosing sleep disorders in adults with severe and profound mental retardation. The purpose of the first study is to provide validation of the Diagnostic Assessment for the Severely Handicapped-II (Matson, 1995) sleep subscale. The items of the subscale were compared to daily records of sleep behavior. Research about sleep disorders and mental retardation is sparse, and most of the available research focuses on the sleeping patterns of children with mental retardation (Stores, 1992). The second study attempts to provide exploratory data about sleep disorders and their relationship to high risk behavior problems in adults with severe and profound mental retardation, living in an institution. The overall presence of a sleep disturbance, as well as more specific topographies of sleep disturbances were examined.

Introduction

In ancient Greece and Rome, infanticide was a common practice. When children were suspected to be developmentally delayed, they were often thrown off cliffs (Biasini, Grupe, Huffman, & Bray, 1999). Around the time of the Enlightenment period (1656-1799) in Europe, there was a marked increase in knowledge, especially in science and art. At this time, the study of mental retardation (MR) began. MR was generally explored by physicians and medical theorists through the topics of epilepsy, brain injury, hydrocephalus and other medical conditions. Some conclusions they reached included claims that MR was a result of the moral conduct of the mother during pregnancy, or of the imbalanced levels of bodily humors (Scheerenberger, 1983). Most professionals at the time concluded that MR was not treatable and individuals were not introduced into educational settings. Many of their rights were withheld. These beliefs resulted in the mandatory confinement of most individuals, either at home or in various types of public and private institutions.

After recognition of the condition of MR during the Enlightenment, a trend of classifying the types and levels began. In the 1800's a variety of different conditions correlated with MR were discovered, including Tay-Sachs Disease, Laurence-Moon Syndrome, and many others (Scheerenberger, 1983). In the mid 1800's, Edouard Seguin divided idiocy (MR) into four specific categories: idiocy, imbecility, backwardness or feeble-mindedness, and simpleness (Abt, 1965). Seguin is more often credited for his recognition of the trainability of what he called idiots, breaking training into three categories: muscular/physical, sensory, and moral education (Trent, 1994). As a way of requesting action from the government to improve living conditions, Howe (1848) provided his definitions on the various levels of MR, as well as descriptions of different cases. He gives examples of what he calls idiots, fools, and simpletons, providing

reasons such as poor physical conditions of one or both parents, excessive alcohol ingestion by one or both parents, self-injurious behavior, inbreeding, and failed attempts to terminate the pregnancy.

Education efforts began in the nineteenth century and were led by Seguin and Itard (Scheerenberger, 1983). Seguin's efforts at education for individuals with MR marked the beginning of a comprehensive program of special education (Balthazar & Stevens, 1975). This program was based on Itard's successful education of Victor, the wild boy of Aveyron, a deaf and mute child. The movement for special education included Maria Montessori, who established Montessori schools throughout Europe, Africa, Asia, and parts of the Americas, and Johann Weise, who established auxiliary schools in Germany (Scheerenberger, 1983). In the United States large numbers of children with special needs began attending school around the late 1800's, following the increase in laws of compulsory attendance at public schools (Trent, 1994). Around this time, special schools were established to deal with the population outside of the public school, but many times as Trent (1994) notes, the schools tended to the delinquent and immigrant children, in addition to those individuals with MR.

In response to a similar situation in the French public schools, Alfred Binet was commissioned to set up testing that would differentiate between those that required special instruction and those that could remain in the standard curriculum (Scheerenberger, 1983). Thus, intelligence testing became linked intrinsically to the study and classification of MR. Binet also established new levels of MR, which were linked to education, as opposed to the levels indicated by the medical field. His classification system included three categories from least to most disabled and was based on the level the child reached during testing. The classifications were moron (no higher than Test 23 or 24), imbecile (no higher than Test 15), and idiot (no higher than

Test 6). While those in the moron classification were seen as similar to normally developing individuals, they were classified as such because of their lack of judgment and immoral behavior. Prior to this level of standardization, MR was diagnosed subjectively as an early-onset, intellectual impairment (Scheerenberger, 1983).

At the time of Binet's work on standardized mental testing, there was also an increase in the understanding of genetics and their role in MR. This trend led to the eugenics movement, which affected not only those with MR, but also people of various races and social classes in America. Whitney and Schick (1931) argued from the eugenical standpoint that sterilization was useful in all levels of MR, especially those who were borderline and more likely to be in the community. Sterilization laws were set up in many states around this time (Balthazar & Stevens, 1975), and the eugenics movement coincided with an immense increase in the numbers of institutions. For the most part institutions built in this time frame were constructed for custodial purposes, rather than educational or training (Balthazar & Stevens, 1975). Overall, this trend created a very negative image for the public, since the institutions were funded mostly through the state government. The population of individuals with MR was seen as a threat to and a drain on society.

As the services provided to individuals with MR were funded with a greater percentage of public money, there was an increased need for a more accurate and clear set of standards to define those who were eligible for public services. Due to the confusing terminology related to MR, which had taken on a variety of societal context, new levels were defined and linked to intelligence quotient (IQ) scores on the Stanford-Binet intelligence test (Scheerenberger, 1983). The levels of disability were identified as borderline, mild, moderate, severe, and profound and were related to the IQ ranges of 83-67, 66-50, 49-33, 32-16, and 16, respectively. Also included

in the definition provided by the American Association on Mental Deficiency (AAMD) in the late 1950's was that the origin of the MR had to occur during the developmental period and there must be an impairment of adaptive functioning present (Scheerenberger, 1983). This mention of adaptive functioning was the first attempt to add to IQ scores in classification, and led to a large number of adaptive functioning scales being developed in the 1960's and 1970's (Balthazar & Stevens, 1975).

After a slightly revised definition of MR, provided by the AAMD in 1973, the borderline classification was removed and new IQ ranges were assigned to the remaining four levels (Scheerenberger, 1987). Mild, moderate, severe, and profound retardation were associated with the IQ ranges of 67-52, 51-36, 35-20, and ≤ 19 , respectively. Also around this time standardized measures of adaptive functioning were becoming accepted, like the AAMD Adaptive Behavior Scale (ABS) (Nihira, Foster, Shellhaas, & Leland, 1969) and the Vineland Adaptive Behavior Scale (VABS) (Sparrow, Balla, & Cicchetti, 1984). This definition of MR has remained stable since that time, excluding a few modifications in the IQ ranges associated with the different levels.

The definition of MR has varied over time; early classifications were based on social competence, but more objective and intellectual criteria evolved following the development of standardized intelligence tests in the early 1900's (Mathias & Nettlebeck, 1992). Although the classification of substandard cognitive functioning is objective and measurable (commonly defined as two standard deviations below the mean on standardized intelligence tests), critics argue that the concept of adaptive behavior is much more difficult to define and measure (Zigler, Balla, & Hodapp, 1984). Despite this debate, the classification of MR currently includes the

concept of adaptive behavior, and this inclusion helps to provide valuable information that may prove useful in placement decision making and treatment planning.

Current Diagnosis of Mental Retardation

The current criteria used to diagnose MR are a product of the progression of Knowledge on the topic. This section focuses on how individuals with MR are diagnosed currently. As of 2000, the American Psychiatric Association (APA) defines MR in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) they used three criteria, which must be present for diagnosis. The first criterion is a significantly subaverage intellectual functioning, which is further described as an IQ of approximately 70 or below on an individually administered intelligence test. Individuals who are unable to complete an intelligence test, as well as infants, require clinical judgment when assessing their abilities intellectually. The second criterion is concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. Adaptive functioning is further defined as the person's effectiveness in meeting the standards expected for his or her age within the cultural group. The third criterion is that the age of onset is prior to 18.

For the most part, the different levels of MR are still associated with the ranges in IQ scores. The DSM-IV-TR describes four levels of MR and an unspecified type of MR (APA, 2000). Mild MR is generally associated with a range in IQ between 50-55 and approximately 70. Of all people with MR, those with a mild form make up about 85% and are not typically diagnosed until later in their development, because they appear to develop appropriately during their early years. Moderate MR falls into the IQ range between 35-40 and 50-55 and makes up

about 10% of the population. Severe MR is associated with the range in IQ between 20-25 and 35-40 and constitutes between 3% and 4% of the population. Profound MR falls into the IQ range below 20-25 and makes up between 1% and 2% of the entire population of MR. Those persons in the profound range generally are diagnosed early on because of a specific neurological impairment or obvious delays in early developmental milestones. MR, severity unspecified is described as a diagnosis to be used when a standardized test score is unavailable, which can include infants, and severely uncooperative or impaired individuals. This diagnosis may also be necessary if there is a medical condition that makes it difficult to assess the individual's level of functioning, like blindness.

Prevalence and Etiology of Mental Retardation

While prevalence estimates of MR are usually similar across most studies, there are deviations, which can be accounted for by the different definitions used for classification, multiple methods of data collection, and group demographic characteristics (Jervis, 1959). The United States National Library of Medicine and National Institutes of Health (NLM & NIH; 2003) estimate the prevalence to range between 1% and 3% of the general population. Based on the 1994/1995 National Health Interview Survey Disability supplement, the prevalence of MR and/or developmental disabilities is about 14.9 people per every thousand (Larson et al., 2001). Larson et al. provide information on the individual categories of MR without developmental disabilities and MR with developmental disabilities, estimating their prevalence to be 3.6 and 4.2 people per thousand, respectively. Roeleveld, Zielhuis, and Gabreëls, (1997) reviewed literature on the prevalence of MR, finding severe MR (IQ < 50) estimates to vary slightly while mild MR (IQ < 70) estimates to vary by a large margin. Based on the literature, they estimate that MR affects about 3% of the population with 3.8 per 1000 being severe. Jervis (1959) estimates

prevalence of MR to be 1% of the general population. He goes on to break down the different levels of MR: 75% are in the mild range, 20% are in the moderate range, and 5% are in the severe range. The DSM-IV-TR (APA, 2000) estimates the gender ratio in the population of individuals with MR to be 1.5:1 with males having a higher incidence than females. This trend was reported by Roeleveld, Zielhuis, and Gabreëls, (1997) in their review of literature related to the prevalence of severe MR, indicating that males outnumber females by approximately 20%. This large difference found between males and females suggest that genetics play a powerful role in the etiology of MR.

In a large portion of cases of MR the etiology is not able to be determined (Jervis, 1959; Heiser, & Wolman, 1965). The APA (2000) estimates that no clear etiology is evident in 30%-40% of cases. Causes of MR are broken down into five categories by the APA (2000) and are also given prevalence estimates: hereditary factors account for approximately 5%, early alterations of embryonic development account for approximately 30%, pregnancy and perinatal problems account for approximately 10%, general medical conditions acquired in infancy and childhood account for approximately 5%, and environmental influences and other mental disorders account for approximately 15%-20%. Other sources use different ways of classifying the causes of MR (Scheerenberger, 1987; NLM & NIH, 2003), but all the known etiologies can be placed into one of the five categories: heredity, early alterations of embryonic development, pregnancy and perinatal problems, general medical conditions of infancy and childhood, and environmental influences/other mental disorders.

The first four categories are related to medical problems and examples of each are given. Hereditary factors include a variety of genetic abnormalities, like Tay-Sachs disease, phenylketonuria, Rett syndrome, fragile-X syndrome, and tuberous sclerosis. Early alteration of

embryonic development includes causes like trisomy 21 (Down's syndrome) and those related changes caused by changes in the prenatal environment, including exposure to alcohol, cocaine, or amphetamines and infections of the mother. Pregnancy and perinatal problems include fetal malnutrition, premature birth, infections of the mother (toxoplasmosis, sexually transmitted diseases, fever, etc.) and trauma (injury, lack of oxygen available to the brain, etc.). General medical conditions acquired in infancy and childhood include trauma, malnutrition, intoxication (e. g., lead poisoning), and infections like, meningitis or encephalitis.

The final category relates to environmental rather than medical etiology of MR and examples are provided. Environmental influences and other mental disorders include living in an impoverished environment with little or no stimulation of verbal and social skills, as well as the presence of severe mental disorders. Complications and overlapping conditions are now known to be common. One of the most debilitating of these disorders and most common is dual diagnosis. This topic will be reviewed in the following section

Dual Diagnosis

In 1690, John Locke first distinguished between MR and mental illness. “Herein seems to lie the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, but idiots make very few or no propositions and reason scarce at all” (Doll, 1962). Little was done to distinguish between psychopathology and MR until the latter half of 20th century. Once such a distinction was deemed essential in service provision, it was given the name dual diagnosis. A review article by Sturmey and Sevin (1993) provides an annotated bibliography of research related to the diagnosis, etiology, and treatment of mental illnesses, including developmental, organic, eating, substance, psychotic, mood, anxiety, somatoform, sexual, sleep, impulse, adjustment, and personality disorders, within the population of individuals with MR. Mental illnesses that are frequently associated with MR include Attention Deficit/Hyperactivity Disorder, Mood Disorders, Pervasive Developmental Disorders, Stereotypic Movement Disorder and Mental Disorders Due to a General Medical Condition (APA, 2000). Costello (1982) reviews unipolar affective disorder, bipolar affective disorder, schizophrenia, specific phobias, conversion hysteria, and obsessive-compulsive disorder in relation to assessment and diagnostic issues. The presence of psychopathology in MR is not an issue that is under speculation, but its prevalence, etiology, and assessment are frequently the subject of research.

Prevalence of psychopathology within the population of individuals with MR is generally accepted as being higher than for the general population (Rutter, Tizard, Yule, Graham, & Whitmore, 1976; and Borthwick-Duffy, 1994). The APA (2000) reports a rate three to four times greater than the general population. Differences in prevalence rates which Borthwick-Duffy (1994) reports range from 10% to over 80% and can be attributed to sampling, definition, and

identification issues (Costello, 1982; and Borthwick-Duffy, 1994). Sampling issues that may lead to a large range in the prevalence rate include using individuals who have been referred or those who are living in institutions. Costello (1982) points out that the rate of psychopathology is higher in samples of institutionalized individuals than in samples of those who live in the community. Definitional and identification issues discussed by Borthwick-Duffy (1994) include differences in assessment of MR, mental illnesses, and dual diagnosis. Prevalence rates, as well as assessment can be affected by the different approaches to psychopathology. Matson and Sevin (1994) present four models of the etiology of dual diagnosis: organic, behavioral, developmental, and sociocultural. Depending on which model is used by a study or clinician, individuals may be classified differently.

Assessment of mental illness for an individual with MR can be affected by a variety of factors. Previously discussed was the etiological approach to dual diagnosis, which could lead to misclassification. Another problem is the inability to use certain diagnostic criteria employed with the general population, like the DSM-IV-TR (APA, 2000), because of the lack of skills that an individual may possess. When diagnosing depression using the DSM-IV-TR criteria, those criteria related to self-report are very difficult with a person who is non-verbal, but more observable criteria, such as eating habits can be communicated by a caregiver. In addition to communication deficits, other problems that could affect diagnosis of a mental illness include social skills deficiencies, stress-induced inappropriate behaviors, and maladaptive behaviors (Sovner, 1986). Costello (1982) reports that some classification problems may arise because of the classification of MR being affected by the characteristics of mental illness, as well as the classification of mental illness being affected by the characteristics of MR. An example of this problem would be the diagnosis of MR and autism, which overlap on certain criteria, such as

deficits in social skills and communication skills. Dual diagnosis is made more difficult by any of the previous issues.

Borthwick-Duffy and Eyman (1990) look into the factors that influence dual diagnosis, by asking the question, “Who are the dually diagnosed?” Their sample consisted of anyone receiving services from the California Department of Developmental Services and totals 78,603 participants, who were living in a variety of settings. Diagnostic, as well as demographic, information was obtained through the system used to track those receiving services. Around 10% of the sample was dually diagnosed. Overall, the researchers state five possible conclusions: 1) referral and subsequent dual diagnosis is linked to high cognitive abilities which are unrelated to social skills, indicating that those clients who had the cognitive ability to cause a problem but lacked social skills would get a mental illness diagnosis; 2) behaviors that were more extrapunitive and caused problems were linked to dual diagnosis; 3) dual diagnosis being more frequent among those in institutions and community facilities rather than those living at home was indicative of availability of service, as opposed to actual diagnosis; 4) problem behaviors are still high among those without a dual diagnosis because they have not been referred; and 5) high levels of dual diagnosis in persons with mild MR are the result of more problematic cases being put into the system while those with fewer problems remain outside the system. The conclusions reached by Borthwick-Duffy and Eyman further explain the potential difficulties of dual diagnosis.

Assessment

In order to address the issues related to assessment of dual diagnosis, several measures have been developed for mental health problems with MR. The Aberrant Behavior Checklist (ABC), Diagnostic Assessment for the Severely Handicapped-II (DASH-II), and Assessment for

Dual Diagnosis (ADD) are three commonly used instruments for aiding in the assessment of psychopathology in this population. The ABC is an empirically derived rating scale designed to measure inappropriate and maladaptive behaviors in persons with moderate to profound MR (Aman & Singh, 1986). The ABC consists of five subscales, measuring irritability, lethargy, stereotypy, hyperactivity, and inappropriate speech. The DASH-II was designed to assess behavioral and psychiatric symptoms in individuals with severe and profound MR (Matson, 1995). The 84 items of the DASH-II represent the following 13 diagnostic categories: anxiety, depression, mania, pervasive developmental disorders (PDD)/autism, schizophrenia, stereotypies, self-injurious behavior, elimination disorders, eating disorders, sleep disorders, sexual disorders, organic syndromes, and impulse control. The ADD is similar to the DASH-II, but it focuses on providing diagnostic information on psychopathology in persons with mild or moderate MR (Matson & Bamburg, 1998). Items on the ADD were derived from the DSM-IV and research on psychopathology in MR. The diagnostic categories represented on the ADD include mania, depression, anxiety, post-traumatic stress disorder, substance abuse, somatoform disorders, dementia, conduct disorder, PDD, schizophrenia, personality disorders, eating disorders, and sexual disorders. These three assessment tools have provided clinicians and researchers with standardized methods for screening and studying psychopathology in the population, which is particularly important for those with more severe forms of MR who may exhibit less traditional symptomology.

Sleep Disturbances and Mental Retardation

Research on MR and sleep disturbances is limited. Of the available research, a small portion focuses on the sleep disorders from the DSM-IV-TR. Instead problems with sleep are referred to more as “behavior problems” rather than a diagnosis. The research that is available on sleep disturbances in the population of individuals with MR tends to focus on prevalence rates, description of the different sleep disturbances, related medical/neurological disorders, related mental illnesses, treatment, and related behavioral problems. For the most part, the research tends to deal predominately with children and adolescents, with very little research spanning all ages or examining adults with MR. This lack of research is difficult to understand based on the high rate of psychopathology in this population and the problems associated with sleep disturbances.

The problems associated with sleep disturbances in the population, not only affect the person with the disturbance, but also those who care for them. Espie et al (1999) looked into factors that affected daytime arousal and attention levels in a sample of adults with epilepsy and severe or profound MR. Poor levels of daytime functioning in the sample were related to characteristics of the individual’s sleep, including poor quality sleep and long sleep periods. Another associated problem with sleep disturbances in this population is the high level of stress frequently found in parents and caregivers (Quine, 1991; Richdale, Francis, Gavidia-Payne, & Cotton, 2000; Stores, 1992). Quine (1991) compared parents of children with MR who exhibited a sleep disturbance to those who did not exhibit a sleep disturbance and found that those with a sleep disturbance were more likely to report more problems related to the child’s handicap, as well as higher levels of maternal irritability. Another finding in the group of children with sleep disturbances was that parents reported getting less sleep. Richdale et al. looked at parental

frequency and intensity of hassles with children diagnosed with varying levels of MR. Those parents with children who had sleep disturbances, specifically settling difficulties and night waking, reported more frequent and more intense hassles. Wiggs and Stores (2001) introduced a behavioral intervention for sleep problems and daytime behavior problems into families with an intellectually disabled child who presented sleep disturbances as well as daytime behavior problems. Those families receiving the intervention were more satisfied with their own sleep and more satisfied their child's sleep when compared to families in the control group. Specifically, mothers in the treatment group experienced increased levels of their ability to cope with their child's sleep problems and reduced levels of stress. Problems with sleep disturbances may be causing additional stress to parents and caregivers who already have high levels of stress caused by caring for an individual diagnosed with an intellectual disability.

This section will review the available literature on sleep disturbances in the population, including the types and prevalence rates of disturbances reported, related medical/neurological disorders, relationships to mental illness, and treatment. The final discussion in this section will focus on maladaptive behaviors that have been correlated with the presence of sleep disturbances in individuals with MR.

Types of Sleep Disturbances and Prevalence

Even with the little research that is available about sleep disturbances in the population of individuals with MR, it is evident that a range of sleep disturbances occur within the population. There are a variety of studies that look into the characteristics of sleep disturbances among children with MR. In a study by Grubar (1983) comparing a group of normally developing children to a group of children with MR, differences were found in the frequency and length of the rapid eye movement (REM) phase of sleep. The group of children with MR went into REM

sleep less often and the duration was shorter than for the normally developing children. Quine (1991) collected longitudinal sleep data in 200 children with severe mental handicap. Of the 200 participants 51% had difficulty settling at night and 67% had problems waking during the night. In addition to the high rate of sleep disturbances, Quine reported that between 36% and 71% of the participants exhibited the same sleep disturbance at the initial recording phase and three years later. In a review of the literature on sleep problems in children with MR, Stores (1992) reports that the most common problems evident in children with MR include night time settling difficulties, night waking, and short duration of night time sleep. He also reports that sleep disturbances tend to persist for a longer period of time than in the general population, and there is a higher incidence of sleep disturbances as the level of retardation becomes more severe. In a case study by Akaboshi, Inoue, Kubota, and Takeshita (2000) a young boy with MR was determined to have a rare sleep disorder, non-24 hour sleep-wake syndrome, stemming from a deficit in melatonin secretion. By using a parental report of sleep disturbances, Richdale et al. (2000) compared a group of normally developing children to a group of children with varying levels of MR. Children with MR were significantly more likely to have a current or a previous sleep problem, frequent night waking, and night yelling, and of those who identified as having a sleep problem, over 50% had duration of at least two years. Richdale et al. also made within-group comparisons for the MR group which indicated that children with more severe levels of MR were more likely to have daytime sleepiness and to have frequent sleep problems. Those individuals with milder levels of MR had a trend of improvement in their sleep problems over time. In an exploratory study of sleep problems and maladaptive behaviors (Didden, Korzilius, van Aperlo, van Overloop, & de Vries, 2002), parents of 286 children with varying levels of MR

reported a 16.1% prevalence rate for severe sleep problems. In accordance with previous studies, more sleep disorders were reported as the level of intellectual disability increased.

Descriptive research on the sleeping patterns of adults with MR is more limited than that on children, even though the rate is reported to be between 12%-15% (Espie & Tweedie, 1991; Chaney, Olmstead, & Givens, 1994), indicating a need for further research. Espie and Tweedie (1991) provide a comprehensive description of sleep problems within the population of adults with MR by comparing data on those in an institution setting and those in a community setting. They report that sleep problems are twice as likely in the severe/profound range of MR than the mild/moderate range. Those participants, who caregivers reported as having sleeping difficulties, slept significantly less, than those reported as “good sleepers”. The differences in the amount of sleep were typically caused by problems maintaining sleep, as opposed to problems initiating sleep. Differences between the hospital and community samples included the community sample having a longer period between bedtime and sleep onset and having more frequent but less lengthy awakenings at night, indicating more intrusive awakenings for the hospital sample. Sleep disturbances found in a sample of 40 adults with MR living in an institution included very few hours of sleep, delays in sleep onset, and multiple nighttime awakenings (Chaney, Olmstead, & Givens, 1994). Based on yearly staff interviews, 75% of the participants had evidence of insomnia, ranging in duration from two to five years. Poindexter and Bihm (1994) analyzed the sleep patterns of a sample of individuals with profound MR living in an institution and found that around 39% had short-sleep patterns, a weekly average of one night with less than five hours of sleep. The sleep patterns were analyzed through the use of nightly monitoring sheets which were broken down into half hour and hourly segments. Based on the cause of the short-sleep pattern, the group was divided into those with maintenance problems, those with initiation problems, and

those with both. The only difference between these groups was that those have problems with sleep initiation were significantly younger than those with maintenance problems and those who had problems with both maintenance and initiation. Brylewski and Wiggs (1998) used a sleep questionnaire to look at sleep and nighttime behavior of adults with MR living in health-authority or social services-managed community housing. Fourteen percent reported Parasomnias, including sleep talking, teeth grinding (bruxism), screaming in the night, head banging, nightmares, and sleepwalking. Other sleep related problems included settling problems, anxiety about sleep, night waking, sleep-related breathing problems, and excessive daytime tiredness. Around 56% of the participants with a sleep disturbance had two or more sleep problems with the most common combination being excessive daytime tiredness and settling or night waking problems. In an attempt to gather participants for research on the treatment sleep disorders, Gunning and Espie (2003) assessed the sleep of 155 adults with MR. Seventeen percent had significant difficulty initiating sleep and 11% had problems with sleep maintenance. The research pertaining to medical and neurological disorders and their relationship to sleep disturbances will be discussed in the following section.

Medical/Neurological Disorders

Much like the high probability of mental illness to be present in individuals with MR, a large number of medical and neurological disorders frequently occur with MR. A number of articles focus on the specific sleep disturbances associated with medical/neurological disorders that are linked to MR. Both of the major review articles in the area of sleep disorders linked to medical/neurological disorders in the population of individuals with MR focus on children (Hoban 2000; and Stores, 1992). This is probably the result of a lack of research in the subject area with adult participants. Stores (1992) reviews the available research related to genetic

syndromes and medical disorders. Sleep disturbances were associated with Down's syndrome, Prader-Willi syndrome, phenylketonuria, mucopolysaccharidoses, tuberous sclerosis, craniofacial syndromes, Lesch-Nyhan syndrome, hypothyroidism, and epilepsy. Hoban (2000) summarizes research on neurodevelopmental disorders and sleep problems in a very comprehensive review article and reports similar findings. Those specific genetic complications that were related to sleep problems include Down's, Rett, Angelman, Smith-Magenis, Cornelia de Lange, and Williams syndromes. Medical conditions linked to sleep problems included tuberous sclerosis complex and mucopolysaccharide disorders.

Down's syndrome is frequently linked to problems with obstructive sleep apnoea (Hoban, 2000; Stores, 1992; and Stores, Stores, & Buckley, 1996), which can lead to problems maintaining sleep. Some of the characteristics of sleep in individuals with Down's syndrome include frequent waking, frequent body movements, and longer total sleep time than normally developing individuals (Stores, 1992). In a study by Stores, Stores, and Buckley (1996) four groups of children (Down's syndrome, siblings, general population, and other intellectual disabilities) were compared on a sleep questionnaire. Both intellectually disabled groups had more sleep problems, especially related to initiating and maintaining sleep, than the two control groups, and the Down's syndrome group had a much larger number of problems related to sleep apnoea. As opposed to other findings, Brylewski and Wiggs (1998) report lower levels of excessive bedtime rituals, sleep maintenance, and nocturnal incontinence when compared to other individuals with developmental disabilities.

Prader-Willi syndrome has been associated with excessive sleepiness, initial insomnia, sleep maintenance problems, and long sleep duration. A group of adults with Prader-Willi syndrome were compared to a group of normally developing adults and differed on three

measures (Helbing-Zwanenburg, Kamphuisen, & Mourtazaev, 1993). The Prader-Willi group had a higher level of excessive daytime sleepiness, more rapid eye movement (REM) disorders, and a lower level of slow-wave sleep, indicating a lower sleep quality. Sarimski (1996) compared a group of children with Prader-Willi syndrome to a group of children with Williams-Beuren syndrome using a childhood sleep scale and parent interview. Overall the Prader-Willi syndrome group had fewer problems than the Williams-Beuren syndrome group, but both groups reported high levels of waking during the night.

Didden, Korzilius, Smits, and Curfs (2004) recently collected data on the sleep patterns of individuals diagnosed with Angelman syndrome. Forty percent of their sample met criteria for severe sleep problems, while parents and caregivers of the participants indicated that 54% had a severe sleep problem. Frequent night waking was endorsed for 37% of the sample, and of that group 31% required more than an hour to resettle after waking.

Stores (1992) warns against attempting to generalize findings about epilepsy and sleep disorders, because of the wide-range of differences in the presentation, severity, causes, and other characteristics of epilepsy. In a sample of adults with MR epilepsy was associated with higher levels of excessive bedtime rituals and nocturnal incontinence (Brylewski & Wiggs, 1998). All of those participants with a diagnosis of epilepsy were also taking antiepileptic medication, which may have affected the results. Linblom et al (2001) found that blindness, locomotor disability, and active epilepsy were independently associated with increased daytime sleep and increased number of sleep-wake transitions. In addition those who exhibited more than one of these medical problems tended to have more fragmented and abnormally distributed sleep. Poindexter and Bihm (1994) also report blindness as a predictive factor of sleep disturbance, specifically short-sleep patterns.

Some research has focused on sleep problems in people with other medical disorders. Telakivi, Partinen, and Salmi (1985) collected sleep data on participants with juvenile neuronal ceroid lipofuscinosis, a genetic disorder with autosomal recessive transmission, indicating respiratory sleep disturbances which increased over the duration of the disease. A study by Steinhausen, Willms, and Spohr (1993) reported a high level of psychiatric sleep disorders among children with fetal alcohol syndrome. Specific information about the types of disorders was not available, but data indicated the sleep disorders were persistent in many cases over a 14-year period. Hunt and Stores (1994) collected sleep disturbance data on a sample of individuals with tuberous sclerosis (85% with varied levels of MR), their normally functioning siblings, and a non-related, normally functioning sample. Those participants with tuberous sclerosis were more likely than the other two groups to have sleep disturbances. The following section will review research pertaining to mental illness and their relationship to sleep disturbances within individuals with MR.

Mental Illness

Specific research on sleep disturbances in this population in relationship to other mental illnesses is extremely lacking. Again this could be an indication of the phenomenon of diagnostic overshadowing. Stores (1992) suggests that there may be additive affects of mental illness and MR on the sleep process, which could cause sleep disturbances. When reviewing the literature dealing with sleep problems in children with MR and autism, Johnson (1996) notes that the only problems assessed were those that were challenging to parents or caretakers, as opposed to those that would affect the individual. A study by Schreck and Mulick (2000) uses parental report to evaluate sleep problems in children. They report an increased level of Parasomnias and Dyssomnias among the autism/PDD group when compared to a MR alone, a special education

group, and a control group of normally developing children. This study does not indicate whether the autism/PDD group contained those with just autism/PDD or those with both autism/PDD and MR. In a review article Hoban (2000) reports high levels of severe disruption of sleep onset, sleep maintenance problems, irregular sleep patterns, and short duration of night time sleep among children with autistic spectrum disorders. The combination of sleep disturbances and mental illness in an individual with MR may effect the treatment options that are available. Specific research related to treatment of sleep disturbances in the population are reviewed in the following section.

Treatment

Treatment issues have received some attention in the literature, but the quality of the research indicates that there is not much of a contribution. Many of the treatments have been researched as case study designs with no return to baseline. This research design leaves room for error and the results may not generalize to other individuals. The studies available in this area can be divided into two categories: pharmacotherapy and non-pharmacological treatments.

In a review of available literature Hoban (2000) comes to the conclusion that there is very little available literature about the use of medications to treat sleep disorders in children. The use of melatonin as a treatment of fragmented sleep for children with MR is somewhat mixed and largely based on case studies (Camfield, Gordon, Dooley, & Camfield, 1996; Hoban, 2000; Jan, Espezel, Freeman, & Fast, 1998; Lancioni, O'Reilly, & Basili, 1999). A study by Akaboshi et al. (2000) successfully used melatonin in the treatment of non-24 hour sleep-wake syndrome in a young boy with MR. Most of the pharmacotherapy research reviewed by Hoban has questionable research quality or has not been formally tested in the population of individuals with MR.

Various treatments, such as chronotherapy (Piazza, Hagopian, Hughes, & Fisher, 1998), light therapy (Altabet, Nuemann, & Watson-Johnston, 2002), static-charge sensitive bed (Telakivi, Partinen, & Salvi, 1985), and optimal scheduling treatment (Espie & Wilson, 1993) have met with positive results in case study designs. Light therapy and optimal scheduling treatment also achieved improvements in daytime behaviors, in addition to improvements in sleep disturbances.

A multiple baseline design is used by Gunning and Espie (2003) to examine the effects of various psychological treatments on specific problems associated with sleep, including, sleep onset, daytime napping, getting out of bed at night, stripping the bed in the night, caregiver sleep, and nighttime rituals, which were exhibited by adults with MR. The treatments used included optimal scheduling, sleep hygiene, stimulus control, relaxation, light therapy, and cognitive behavior therapy. Based on visual inspection, most of the participants improved on one or both of their targeted behaviors.

Increased need for research relating to treatment of sleep disorders for people with MR is evident, especially research using rigorous methodology. This research will not only benefit those afflicted with sleep disturbances, but also parents and caregivers of these individuals. Wiggs and Stores (2001) report a decrease in maternal stress and an increase in perceived control following a behavioral treatment for sleep problems in their children with MR who exhibited both sleep and behavior problems. Both mothers and fathers reported an increased level of satisfaction with their own sleep.

Behavior Problems

A limited portion of the literature focuses on the presence of behavior problems in children with MR and sleep disturbances. Quine (1991) found that, when compared to children

with MR who did not exhibit a sleep disturbance, those with a sleep disturbance were more likely to have daytime behavior problems and were rated as more difficult to manage by their parents. Wiggs and Stores (1996) reported that children with sleep problems typically also had problems with irritability, lethargy, hyperactivity, and stereotypies. Not only were the behaviors present, but they were more likely to be severe in nature and co-exist with other problem behaviors. Behavior problems classified as disruptive or self-absorbed were also more likely to be associated with children with MR and a sleep disorder than those without a sleep disorder (Richdale, Gavidia-Payne, Francis, & Cotton, 2000). Additionally Didden et al. (2002) found that problem behaviors, like irritability, lethargy, hyperactivity, stereotypies, aggression, screaming, temper tantrums, noncompliance, and impulsivity were much more likely in a sample of children with MR and sleep disorders who lived with their parents. However there was no difference between the group with sleep disorders and the group without sleep disorders on levels of self-injurious behavior.

Some literature exists on the relationship between behavior problems and sleep disorders in adults with MR. High levels of aggression, self-injurious behavior, property destruction, hyperactivity, temper tantrums, poor social behavior, and stereotypic behavior was found in a sample of institutionalized adults with MR who had sleep disturbances when compared to those without sleep disturbances (Chaney, Olmstead, & Givens, 1994). Brylewski & Wiggs (1999) found similar results in a community-based sample of adults with MR and sleep disturbances who presented increased levels of irritability, stereotypies, and hyperactivity when compared to a group without sleep disturbances.

High Risk Behaviors

Maladaptive behavior problems, like mental illness, are extremely common in individuals with MR. Feldman and Griffiths (1997) provide a variety of reasons for the heightened probability of behavior problems in the population, including “limited appropriate cognitive, communicative, social, and problem-solving skills. Also life experiences involving stigmatization, rejection, abuse, restrictions on personal freedom, dependency on others, difficulty in learning, or lack of opportunities to learn appropriate behaviors through typical interactions with non-handicapped individuals (p.24).” These behavior problems can range from mild behaviors like task noncompliance to high risk behaviors that involve harm to the individual and/or others. These high risk behaviors are of great concern to those living with and caring for the individual. This issue is not only because of the potential harm that they and others face, but also because maladaptive behavior limits the individual. A person who exhibits a high risk behavior is not going to be a good candidate for moving into a community or obtaining a job where they must work with others. There are four specific behaviors that are monitored very closely in many institutions and in community settings: self-injurious behavior, aggressive behavior, pica, and rumination. Since pica and rumination are both problems with feeding, they will be put into the same category: feeding problems. Each of these behavior problems will be discussed in the remainder of this section; including descriptions, prevalence rates, and known relationships with sleep disturbances.

Functional assessment is a good way to understand and then treat these behaviors, since factors motivating behavior can be identified and incorporated into treatment technique (Horner, 1994). High risk behaviors can begin in a variety of ways, but the important task is to determine what maintains the behavior. An example might be that an individual with an ear ache does not

have communication skills, so in order to relieve the pain he bangs his head on a wall. With this scenario alone, once the pain has ceased, the individual would no longer bang his head on the wall. This is not the case, because most caregivers in any setting would be concerned about the newly acquired head-banging and soon the individual would be receiving quite a bit of extra attention. Now a behavior that was maintained by negative reinforcement (the removal of pain) is being maintained by positive reinforcement (the addition of attention). Applegate, Matson, and Cherry (1999) used a functional assessment rating scale to research the common functions of high risk behaviors. Self-injurious behavior, pica, and rumination all had nonsocial or self-stimulatory function as the highest, while aggressive behavior had escape as the highest function. By doing a functional assessment of the behavior and determining that attention is maintaining the behavior, a treatment plan could be developed that involves either ignoring the behavior or teaching the individual an appropriate way to ask for attention.

The assessments tools discussed previously in the dual diagnosis section contain subscales related to self-injurious behavior, aggressive behavior, and feeding problems. These scales can be used to screen for possible diagnoses and to get a better understanding of the topography of the behavior. The ADD and the DASH-II both have measures for frequency, duration, and severity of the behavior, so that a better understanding of how the behavior affects the individual and others around them can be obtained.

Self-Injurious Behavior

Self-injurious behavior is characterized by an individual inflicting harm upon their body, which is why it is considered a high risk behavior. Some types of self-injury include head slapping, eye gouging, skin picking, hand biting, ear banging, nail picking, and purposeful falling. A list of self-injurious behavior definitional parameters are provided by Fee and Matson

(1992) and include physical injury, direct or indirect injury, repetitiveness, ritualistic nature, frequency, duration, intensity, increases with agitation, response to treatment, concern to caregivers, body part involved, motor movement required, and intelligence level of the individual.

Prevalence rates self-injurious behavior can sometimes be difficult to compare, since researchers use different criteria for classification. Rojahn (1986) used a survey to assess the prevalence of self-injurious behavior of adults with MR living in the community. The overall prevalence rate was 1.7%, but the prevalence among the facilities that had self-injurious behavior was 2.6%. Rojahn acknowledges that this rate is lower than what is usually reported in institutions, which can range from 7.7% to 22.8%. Wacker, Northup, and Lambert (1997) state that the prevalence of self-injury is correlated with the level of MR and often occurs with other inappropriate behaviors. Rojahn's demographic data shows an increase in the percentage of individuals with self-injurious behavior as the level of MR gets lower. Certain disorders like Cornelia de Lange, Riley-Day, Rett, Fragile-X (Harris, 1992), Cri du Chat (Ross Collins, & Cornish, 2002), and Lesch-Nyhan (Harris, 1992; Wacker, Northup, & Lambert, 1997) syndrome are frequently associated with self-injurious behavior. In a sample of children with Cri du Chat syndrome around 92% had at least one type of self-injurious behavior, but in the group there was range of up to ten types. Iwata et al. (1994) summarizes a large number of self-injury case studies where functional analysis was used. Thirty-eight percent were had a function of task demand escape, 26% had a function of positive reinforcement (social or tangible), 26% were maintained through sensory reinforcement, 5% had multiple functions, and 5% had an indeterminate function.

Assessment of self-injurious behavior using the ADD and the DASH-II was discussed previously, but further research has been done specifically on the self-injury subscale of the DASH-II. A study by Matson et al. (1997) using the DASH-II compared four groups of adults with severe and profound MR: people with stereotypies, people with self-injurious behavior, people with both, and a control group. Ninety-four percent of the self-injury group and 75% of the combined group were correctly classified according to the DASH-II cutoff scores when compared with the DSM-IV diagnosis. Persons in the self-injurious behavior group were more likely to be above the cutoff score for the sexual and sleep disorder subscales than the other three groups. Symons, Davis, and Thompson (2000) investigated the specific relationship between self-injurious behavior and sleep disturbances by comparing groups of adults with MR who did or did not exhibit self-injurious behavior based on their duration of sleep during the night. The self-injury group slept significantly less than the comparison group during the night, but no data was kept during the day to determine if there was a difference in their daytime sleeping habits.

Feeding Problems

Both pica and rumination are considered types of self-injurious behavior, but neither has been researched pertaining to their specific relationship with sleep disorders. Both behaviors are feeding problems that can result in serious harm to the individual. Based on their self-injurious classification, pica and rumination might have a correlation with sleep disturbances, but as separate types of self-injury the disorders may not be related at all. Based on available research neither behavior has been studied in relation to sleep disturbances.

Pica

Pica is defined as the ingestion or eating of items that are not food items, such as coins, cigarette butts, thread, dirt, or various available objects. This can result in gastro-intestinal

problems and even death. In a review article, Gravestock (2000) estimates the prevalence of pica to be between 4-26% of adults with MR. Those demographic characteristics that are associated with higher levels of pica are living in an institution, functioning in the lower levels of MR, being male, and increasing in age. Other behavioral problems and mental illnesses related to pica were autism and socialization problems, stereotypic movement, hyperactivity, self-injury, and other food related problems.

Rumination

Rumination is characterized by the regurgitation of food into the mouth, followed by the re-swallowing of the food. This behavior can lead to medical complications similar to gastro esophageal reflux disorder, like the breaking down of the esophagus after frequent regurgitations of partially digested foods. Also individuals can die from aspiration or swallowing down the trachea instead of the esophagus, which would put acid and partially digested food into the lungs. It is important that rumination be assessed accurately to rule out medical causes. It must have external reinforcement of the behavior and no know medical cause in order to be rumination. Gravestock (2000) estimates the prevalence of rumination to be between 5-10% of individuals with MR who are living in an institution. Conditions and demographic characteristics associated with higher levels of rumination include having more severe MR, being male, and having autism.

Aggressive Behavior

Aggressive behavior is a much broader subject than the other high risk behaviors. It can be characterized by verbal or physical aggression directed at people and/or objects. Property destruction, yelling, cursing, hitting, biting, spitting, punching, and fighting are some of the manifestations of aggressive behavior. This behavior can be part of many psychological

disorders, like conduct disorder, antisocial personality disorder, and impulse control disorders, which may determine how it is targeted during treatment.

Prevalence rates of aggression in the population of individuals with MR vary according to living situations. Eyman and Call (1977) estimated the prevalence of aggressive behavior to be 45%, 20%, and 20% for those individuals living in institutions, in community group homes, and with their parents, respectively. Genetic disorders, such as Cri du Chat syndrome have a high prevalence rate of aggressive behavior, around 88% (Ross Collins & Cornish, 2002).

In studies comparing adults with MR who had sleep disturbances to those that did not, aggressive behavior was more common in the groups with sleep disturbances (Brylewski, & Wiggs, 1999; Chaney, Olmstead, & Givens, 1994). Logically this does not translate into the statement that individuals with aggressive behavior will have sleep disturbances, but there is probability of finding a higher incidence of sleep disorders in a group of individuals with aggressive behavior.

Study One

Purpose

No scales have been specifically designed and validated for the assessment of sleep disorders in individuals with severe and profound MR. The best available test with norms for this population is the Diagnostic Assessment for the Severely Handicapped-II (DASH-II), a screening instrument for psychopathology that includes a sleep disorder subscale. However, validation of the sleep subscale of the DASH-II is needed.

Because the normative data of the scale was collected on the population of interest, this scale is a good starting point for assessing sleep problems in persons with severe and profound MR. The purpose of this study was to validate the sleep subscale items of the DASH-II, using daily logs of sleep behavior in half hour increments over 24-hour periods. Sleep logs were used since they are direct and overt validity criteria of sleep disturbance. The data obtained from the daily sleep logs was summed and correlated with the direct care staff responses to the DASH-II sleep subscale. Thus, the data from the daily sleep logs was used to provide validation of the DASH-II sleep subscale.

Method

Participants

Participants were 50 residents of Pinecrest Developmental Center (PDC). PDC is a state-run, residential facility located in central Louisiana. The center is home to approximately 600 individuals who represent a variety of ages, genders, and races. The majority of the population functions in the severe and profound levels of MR. Since the DASH-II is used with both individuals with severe and profound MR, half of the sample was randomly selected from the

severe group ($n = 25$) and half was randomly selected from the profound group ($n = 25$). Approval from the Institutional Review Board (IRB) at PDC and Louisiana State University was obtained.

Measures

The DASH-II, discussed previously, is an 84-item, informant-based screening tool designed to provide information on diagnosis of mental illness when evaluating individuals with severe and profound MR. The scale is made up of 13 subscales which represent different diagnostic categories: (1) anxiety, (2) depression, (3) mania, (4) autism and other pervasive developmental disorders, (5) schizophrenia, (6) stereotypies and tics, (7) self-injurious behavior (8) elimination disorders, (9) eating disorders, (10) sleep disorders, (11) sexual disorders, (12) organic syndromes, and (13) impulse control and other miscellaneous behaviors. All items are rated on frequency, duration, and severity on a 0-2 Likert scale. The sleep disorder subscale of the DASH-II includes five items: (1) has difficulty staying awake during the day, (2) wakes up frequently during the night, (3) has difficulty getting to sleep, (4) sleepwalks, and (5) wakes up crying or screaming. Inter-rater reliability ($r = .92-.96$) and test/retest reliability ($r = .88-.94$) of the items, reported in percent agreement are available for frequency, duration, and severity (Matson, 1995).

The sleep log used at PDC breaks the day into 48-half hour segments. The direct care staff observes the participant and places a “Y” in the corresponding box when they are observed to be asleep. In the instance that the participant is not sleeping, there are 10 codes that can be placed in the box: 1) in bed awake; 2) pacing or running around the home; 3) trying to interact with staff or clients; 4) watching TV or listening to radio; 5) using the bathroom; 6) sitting in the day hall or living room; 7) standing or sitting in room out of bed; 8) screaming or crying; 9) getting something to eat or drink; or 10) other. In the event that one of the other nine options

does not correspond to the participant's behavior, the staff can put a "10" in the box and use an additional data sheet to write down a description of the behavior. These 10 options are considered "disruptions" when they occur during the specified sleep time (between 20:00 and 8:00) after the initial period of sleep. The day interval (between 8:00 and 20:00) is used to monitor occurrences of daytime sleeping. These intervals are the same intervals used by Lindblom et al. (2001) to monitor sleep-wake behavior in a sample of institutionalized participants with MR.

Inter-rater reliability data of the daily sleep log was collected for 20% of the total sample. The inter-rater reliability data was collected by a member of the psychology staff, independent of the first observer. The second rater made checks throughout the data collection period at different times during the day using the same sleep log that the direct care staff were filling out. In total, a full day of sleep data was collected and compared to the corresponding data from the daily sleep logs filled out by the direct care staff.

The variables that can be obtained from the sleep logs that correspond to the items of the DASH-II include: (1) number of intervals asleep per day interval (12-hour period); (2) number of disruptions per night interval (12-hour period); (3) number of intervals between going to bed and falling asleep; (4) number of times crying or screaming occurs following an interval of sleep and (5) number of times sleepwalking is noted. Sleepwalking can be noted in the "other" section on the data collection forms. These items were pulled from the sleep logs, since they correspond most closely to DASH-II sleep items and thus, provide the best validity check of the items.

Procedures

Data was gathered for each of the selected participants by administering the DASH-II. The measure was administered according to the DASH-II manual specifications to a primary

direct care staff member who had worked with the client for at least six months. The daily sleep logs were obtained from the participants' charts and were filled out by the direct care staff, based on observation of the client at half hour intervals. In total, two weeks of sleep logs were collected, including the 14 days before the administration of the DASH-II. This schedule follows the time frame of the DASH-II, which inquires about behavior in the two weeks prior to administration.

Results and Discussion

Inter-Rater Reliability

Inter-rater reliability of the sleep log data was calculated using Cohen's kappa correlation coefficient. This method was selected due to the dichotomous nature of the variable (asleep vs. not asleep) and in order to measure agreement between two raters (direct care staff and psychology staff member), while removing chance agreement (Hinkle, Wiersma, & Jurs, 1998). Based on this analysis, the sleep logs collected by the staff were significantly correlated to the reliability sleep data collected by the second rater, $\kappa = .71, p < .001$.

Validation

The correlation between the sleep log data and DASH-II sleep subscale items was calculated using a one-tail Pearson product-moment correlation coefficient, which provides an index of the linear relationship between continuous variables. Each item of the DASH-II was compared to the corresponding data from the sleep logs, resulting in five correlation coefficients. All of the sleep subscale items of the DASH-II were significant, $r = 0.65 - 0.90, p < .001$ (see Table 1). The DASH-II item related to sleepwalking could not be analyzed with the Pearson product-moment correlation coefficient because the behavior did not occur during the data collection period. Some of the participants were nonambulatory; therefore this item is only

appropriate for a subset of the participants. Further implications of this research will be addressed in the general discussion.

Table 1

Pearson Product Correlation Coefficients for DASH-II Items and Sleep Log Data

<u>DASH-II Item</u>	<u>Sleep Log Data</u>	r	p-value
Has difficulty staying awake during the day	#of intervals asleep per day interval	0.70	<.001
Wakes up frequently during the night	# of disruptions per night interval	0.65	<.001
Has difficulty getting to sleep	# of intervals between going to bed and falling asleep	0.72	<.001
Wakes up crying or screaming	# of times crying or screaming occurs following an interval of sleep	0.90	<.001
Sleepwalking	# of times sleepwalking is noted	*	*

* Unable to calculate due to lack of variance

Study Two

Purpose

The purpose of this study was to provide exploratory data on sleep disorder patterns in persons with severe and profound levels of MR who live in an institutional setting. Several primary variables were studied as a means to build a database of knowledge about the presentation of sleep disturbances in the population. This study looked at the relationship between a measure of sleep disturbances and the presence of a high-risk maladaptive behavior targeted on the participant's treatment plan. Four groups, including a no maladaptive behavior group, a self-injurious behavior group, an aggressive behavior group, and a feeding problem group, were compared using the overall sleep disturbance subscale score, as well as the specific items of the subscale. The feeding problem group consisted of individuals who were identified with pica or rumination, since these behaviors occur less often than aggression and self-injury and are both related to feeding.

The first step was to examine the relationship of the total sleep subscale score and the maladaptive behavior groups. As indicated by previous researchers, aggression may frequently be associated with high levels of sleep disturbances in both intellectually disabled children (Didden et al., 2002) and adults (Brylewski & Wiggs, 1999; Chaney et al., 1994). Additionally high levels of self-injurious behavior were related to sleep disturbances in adults with MR (Brylewski & Wiggs, 1999; Chaney et al., 1994; Symons, Davis, & Thompson 2000), but not in children with MR (Didden et al., 2002). No available sleep disturbance research on adults with MR and high risk feeding behaviors has been conducted to date. Based on the available research (Brylewski & Wiggs, 1999; Chaney et al., 1994; Didden et al., 2002; & Symons, Davis, & Thompson 2000), individuals in the aggressive behavior and self-injurious behavior groups were

expected to have higher levels of sleep disturbances than the group without any behavior problems.

Following the comparison across the four groups of the overall sleep subscale score, the groups were then compared on the five, individual items of the DASH-II sleep subscale. This method provided further information beyond the presence of a sleep disturbance, by indicating if specific items of the DASH-II sleep subscale were correlated with certain maladaptive behavior groups. An example would be if the majority of the individuals in the aggressive behavior group were given high scores on the item related to waking frequently during the night. This high correlation might indicate that individuals with aggressive behavior may have problems with insomnia. This relationship between the type of sleep disturbance and the specific maladaptive behavior has not been researched in the literature.

Method

Participants

Participants were 144 residents of Pinecrest Developmental Center (PDC). PDC was described previously in Study One.

An a priori power analysis was conducted to determine the sample size of the groups required for the present study. The recommended level of power is .80, when alpha, the predetermined level of significance, is set at .05 (Cohen, 1965). Based on the exploratory nature of this study, the effect size was set at 0.25. This number was defined by Cohen (1965) as a small effect size. Using GPOWER (Faul, & Erdfelder, 1992), a statistical program for determining power levels, it was determined that a total sample of 180 participants would be required for an ANOVA with four groups. Through random sampling 45 individuals from each category (no behavior problems, self-injurious behavior, aggressive behavior, and feeding problems) were to

be selected. Because there were only 36 participants available that fit into the feeding problems group, and one of the requirements of homogeneity of variance is that the groups have equal numbers, the other groups were also decreased to 36 participants, resulting in a total of 144 participants.

Those individuals included in the study only had one of the high-risk behaviors targeted on their behavior treatment plan. This method eliminated the possibility of a person being selected for two different groups and decreased the possibility of error. The four groups were compared using chi-square tests for categorical variables and one-way ANOVAs for continuous variables to determine if there are any demographic differences between the groups. Variables examined include level of MR, season of annual evaluation, number of psychotropic medications, age, gender, and race.

Measure

The DASH-II was described previously in Study One.

Procedure

Data was gathered for each of the 144 selected participants by obtaining the yearly DASH-II questionnaires from their psychological records. The DASH-II questionnaires were administered by a master's level college graduate during annual evaluation of the clients, periodically throughout the year. This method of sampling was used to control for any seasonal effects at the time of the interview. The year was broken down into three-month segments. Spring included evaluations completed in March, April, and May; summer included June, July, and August; fall included September, October, and November; and winter included December, January, and February. As stated previously, the season during which the evaluation was administered was compared using a chi-square statistical test to determine if there were any

significant differences between the four groups. Interviews were conducted according to the DASH-II manual specifications, using a primary direct care staff member who had worked with the client for at least six months.

Results and Discussion

Demographic Comparisons

In order to assure that the four groups did not differ significantly on demographic characteristics, the groups were compared on age, race, gender, level of MR, season of annual evaluation, and number of psychotropic medications. Categorical variables, like race, gender, level of MR, and season of annual evaluation were compared using chi-square analysis. Continuous variables, like age and number of psychotropic medications were compared using one-way ANOVAs. Race, gender, season of annual evaluation, and age did not differ significantly between the groups (see Table 2). Based on these analyses, there was a significant difference between the groups for level of MR, $\chi^2(3) = 14.80, p < .01$, which is attributable to the large number of participants with severe MR in the aggressive behavior group. In addition, the groups differed significantly on the number of psychotropic medications, $F(3, 140) = 5.68, p < .001$. Post hoc analysis with Tukey's HSD indicated that the aggressive behavior group has significantly more psychotropic medications than no behavior problems group. There were no other significant interactions.

Group Comparison

DASH-II item scores were summed for the sleep disorder subscale for frequency, duration, and severity. The DASH-II sleep subscale total was then compared using a one-way ANOVA across the four groups: no behavior problems group, self-injurious behavior group,

Table 2

Demographic Characteristics of the Participants by Groups: No Behavior Problems, Self-Injurious Behavior, Aggressive Behavior, and Feeding Problems

	<u>Groups</u>				F	p-value
	<u>NBP</u>	<u>SIB</u>	<u>AB</u>	<u>FP</u>		
<u>Age</u>						
Mean	48.44	47.69	49.47	48.06	0.15	n.s.*
σ	12.37	11.60	10.35	13.13		
<u>Meds</u>					F	p-value
Mean	0	0.28	0.56	0.22	5.68	<.001
σ	0	0.51	0.88	0.54		
<u>Gender</u>					χ^2	p-value
Males	17	22	22	23	2.51	n.s.*
Females	19	14	14	13		
<u>MR Level</u>					χ^2	p-value
Severe	6	2	13	3	14.80	<.01
Profound	30	34	23	33		
<u>Race</u>					χ^2	p-value
Caucasian	27	33	29	26	8.29	n.s.*
African-American	9	3	6	10		
Other	0	0	1	0		
<u>Season</u>					χ^2	p-value
Spring	14	12	14	16	5.60	n.s.*
Summer	12	12	7	7		
Fall	5	4	7	4		
Winter	5	8	8	9		

* n.s. is not significant

aggressive behavior group, and feeding problems group. Based on this analysis, the groups did not differ significantly on their DASH-II sleep subscale totals, $F(3, 140) = 2.33$, n.s.

Item Endorsement

The four groups were then compared across the individual items of the DASH-II sleep subscale, using a 4X5 MANOVA. The MANOVA was utilized since the groups were compared on more than one dependent variable at the same time (Weisstein, 1999). Based on this analysis, the groups did not significantly differ on any of the individual items of the DASH-II, $F(9,336) = 1.28$, n.s. Since the MANOVA was not significant, post hoc testing was not necessary.

General Discussion

The purpose of study one was to examine the validity of the DASH-II sleep subscale in comparison to daily sleep log data. Overall, DASH-II sleep subscale items corresponded significantly to the information obtained from the sleep log data. The correlations for the items range from 0.65 to 0.90. The item related to waking up crying or screaming had the highest correlation to the sleep log data ($r = 0.90$). This finding is probably explained by the fact that the behavior can cause a disturbance for staff and other clients and warrants a large amount of attention. Therefore, staff are more likely to report this behavior, relative to other DASH-II sleep items. In contrast, the item related to waking up frequently during the night, which had the lowest correlation to the sleep log data ($r = 0.65$), does not necessitate that the participant caused a disturbance. With no disturbance, the staff may be less likely to remember the behavior when it is questioned. Also, this lower correlation could be attributable to the fact that some of the participants were on a nightly schedule, which required the staff to wake them periodically throughout the night, so they can use the bathroom. This procedure would have resulted in the client being coded as awake on the daily sleep logs, but the participant is not waking frequently on their own.

Another important item that should be considered is the sleepwalking item. This item could not be analyzed using Pearson product correlation coefficient. The lack of endorsements could be attributable to the portion of the sample that was nonambulatory, which decreases the possibility that a person who sleepwalks would be chosen for the sample. The lack of information about sleepwalking is consistent with the findings in the literature review, where sleepwalking was only referenced in one article (Brylewski & Wiggs, 1998). Overall the

sleepwalking item was not endorsed, but no sleepwalking was noted on the daily sleep logs, indicating a perfect agreement.

Because there were no available measures that had been normed or validated with this population, it was important that the comparison measure for the DASH-II items was based on observable data and was checked for interrater reliability. The information obtained from the participants' daily sleep logs was based on direct care staff observation at half hour intervals throughout the day. The comparison data obtained from the participants' sleep logs was significantly correlated with the sleep log filled out by the second rater, $\kappa = .71$, $p < .001$. Cicchetti (1994) classified this kappa level to have good clinical significance. Differences between the two raters could be based on observing the participant at different times during the half hour.

Overall the items of the DASH-II sleep subscale were shown to have significant levels of convergent validity when compared to observational data. As a screening tool, the DASH-II may therefore be an important screening tool for sleep disturbance in individuals with severe and profound MR. Also, use of such a screening tool can substituted for lengthy procedures, such as the daily sleep logs, which are tedious and time-consuming for staff who must attend to multiple clients at one time in addition to daily paperwork. The data obtained from the DASH-II sleep subscale only pertains to the two weeks prior to administration, but could be used over intervals to determine the course of a sleep disturbance. Future research on the validity of the DASH-II sleep subscale could explore whether the subscale is able to distinguish individuals with a sleep disorder diagnosis from individuals without a diagnosis.

Based on the results of study one, the DASH-II is a reliable and valid way to assess sleep disturbances and was used accordingly in study two. The purpose of study two was to examine

sleep disturbances among individuals with severe and profound MR who exhibit high risk behavior problems or no behavior problems. Overall, the data indicates that there is no significant relationship between the specific high risk behaviors and the presence of a sleep disturbance, as measured by the DASH-II sleep subscale. This finding does not mean that there is no relationship between behavior problems and sleep disturbances. Rather, it appears that the relationship is not sufficiently robust to produce a significant correlation between the frequency of sleep disturbances and the maladaptive behavior groups. The groups did not differ on presence of a sleep disorder or on the specific disorders represented by the DASH-II sleep subscale. As discussed by the following section, there may be many reasons the relationship between behavior problems and sleep disturbances was not supported. In addition, future research directions related to this area are also suggested in this section.

In previous research that has found a significant relationship between sleep disturbances and maladaptive behaviors among children and adults with MR, a specific method of sampling was utilized (Brylewski & Wiggs, 1999; Chaney et al, 1994; Didden, 2002; Quine, 1991; Richdale et al, 2000; Symons et al, 2000; Wiggs & Stores, 1996). This method consisted of using a population identified as having a sleep disturbance and then examining their rates of maladaptive behaviors or comparing their rates of maladaptive behaviors to those without a sleep disturbance. In comparison, this study identified individuals who were exhibiting behavior problems and then examined their level of sleep disturbances. This technique may have resulted in a floor effect. That is, there may have been such low levels of sleep disturbances overall that the groups did not differ significantly when compared, which is reflected in the difference in prevalence rates between the two phenomena. Prevalence of sleep disturbances in adults with MR is estimated to be between 12% and 15% (Chaney, Olmstead, & Givens, 1994; Espie &

Tweedie, 1991). The estimated prevalence of aggression alone among adults with MR is between 20% and 45% (Eyman & Call, 1977), suggesting that the total prevalence rate of the high risk behaviors is even higher.

In addition, the groups were chosen based on current behaviors that were targeted in the participants' behavior treatment plans, but their DASH-II was obtained from the annual evaluations which were completed throughout the year. While this data collection technique was chosen to eliminate any seasonal effects of when the data was collected, it is a possibility that the DASH-II scores were not obtained at the time the individual was exhibiting the maladaptive behavior. While previous research indicates that sleep disturbances are persistent over time in individuals with MR (Chaney, Olmstead, & Givens, 1994; Quine, 1991; Richdale et al., 2000; Stores, 1992), this stability does not guarantee that the behaviors were co-occurring.

Another potential problem is the decrease in the sample size, based on the lack of individuals who fit the criteria for the feeding problem group. By reducing the recommended sample size so that the groups were equal, the power was compromised (Hinkle, Wiersma, & Jurs, 1998). The groups were obtained through random sampling and differed on two demographic characteristics: the number of psychotropic medication and the level of MR. These variables could have been controlled through different sampling techniques, eliminating possible error caused by the differences between the groups. While controlling for presence of psychotropic medication may have controlled for the group differences, it could have also truncated the sample of individuals with feeding problems.

Despite the possible causes of error in this study, there is a possibility that the results are representative of the relationship between sleep disturbances and maladaptive behaviors. Based on the current research, there was no relationship between maladaptive behaviors and sleep

disturbances. While maladaptive behaviors, like self-injurious behavior and aggression, can occur with sleep disturbances at significant levels, as indicated by prior research (Brylewski & Wiggs, 1999; Chaney et al., 1994; Didden et al., 2002; & Symons, Davis, & Thompson 2000), a possibility is that the relationship is not a straightforward correlation. A third factor could be mediating the correlation, such as a general medical condition or an environmental factor.

Future research appears warranted given the present results in combination with previous literature. Researchers in this area may want to explore the specific mechanisms that relate sleep disturbances and maladaptive behaviors. Possibilities may include looking at the variability of both over time (e.g. a day with high behavior problems is correlated to sleep disturbances that night). Correlation between the variables may indicate a causal relationship or there could be an extraneous variable accounting for the fluctuation of both. In addition, the causal relationship could go one of two ways. For example, not getting enough sleep or quality sleep may result in irritability and behavior problems the next day. Another possibility is that a day filled with maladaptive behaviors could result in little or low quality sleep that night.

In addition, the hypothesis of this study could be further tested using different methods, since the results of this study may have been compromised by error. A possible method is to follow the sampling techniques of previous research in the area (Brylewski & Wiggs, 1999; Chaney et al, 1994; Didden, 2002; Quine, 1991; Richdale et al, 2000; Symons et al, 2000; Wiggs & Stores, 1996) by starting with a sample of individuals with sleep disturbances, assuring high rates of sleep disturbances. Based on the results of study one, the DASH-II would be an excellent method for determining the presence of a sleep disturbance in an individual with severe or profound MR. The DASH-II could determine the initial sample, which would decrease the need for lengthy procedures, like sleep logs. The sample could then be broken down into groups based

on the presence and type of maladaptive behaviors. The different groups could be compared based on the topography of their sleep disturbances, providing insight about the relationship of sleep disturbances and behavior problems.

Essentially, it is important to emphasize that sleep disturbances in adults with severe and profound MR need to be addressed with further research. While the overall findings of study two were not significant, this research does add to the knowledge of sleep disturbances in adults with severe and profound MR, even though it is not consistent with previous findings (Brylewski & Wiggs, 1999; Chaney et al., 1994; Didden et al., 2002; Symons, Davis, & Thompson 2000). Future research should continue to address in sleep disturbances in adults with severe and profound MR, and the DASH-II sleep subscale should be utilized, based on its high rates of reliability (Matson, 1995) and validity, as well as its concise nature.

References

- Abt, I. (1965). History of pediatrics. Philadelphia: W.B. Saunders.
- Akaboshi, S., Inoue, Y.-I., Kubota, N., Takeshita, K. (2000). Case of a mentally retarded child with non-24 hour sleep-wake syndrome caused by deficiency of melatonin secretion. Psychiatry and Clinical Neurosciences, 54, 379-380.
- Altabet, S., Neumann, J. K., & Watson-Johnson, S. (2002). Light therapy as a treatment of sleep cycle problems and depression. Mental Health Aspects of Developmental Disabilities, 5(1), 1-6.
- Aman, M.G., & Singh, N.N. (1986). Manual for the Aberrant Behavior Checklist. East Aurora, NY: Slosson Educational Publications, Inc.
- American Psychiatric Association (2000). Diagnostic and statistical manual of mental disorders (4th ed., text revision). Washington, D.C.: Author.
- Applegate, H., Matson, J. L., & Cherry, K. E. (1999). An evaluation of functional variables affecting severe problem behaviors in adults with mental retardation by using the Questions About Behavioral Function scale (QABF). Research in Developmental Disabilities, 20(3), 229-237.
- Balthazar, E. E., & Stevens, H. A. (1975). The emotionally disturbed, mentally retarded: A historical and contemporary perspective. Englewood Cliff, NJ: Prentice-Hall.
- Biasini, F. J., Grupe, L., Huffman, L., & Bray, N. W. (1999). Mental retardation: A symptom and a syndrome. In S. D. Netherton & D. Holmes (Eds.) Child and adolescent psychological disorders: A comprehensive textbook (pp. 6-23). New York: Oxford University.
- Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. Journal of Consulting and Clinical Psychology, 62(1), 17-27.
- Borthwick-Duffy, S. A., & Eyman, R. K. (1990). Who are the dually diagnosed? American Journal on Mental Retardation, 94(6), 586-595.
- Brylewski, J. E., & Wiggs, L. (1998). A questionnaire survey of sleep and night-time behaviour in a community-based sample of adults with intellectual disability. Journal of Intellectual Disability Research, 42(2), 154-162.
- Brylewski, J. E., & Wiggs, L. (1999). Sleep problems and daytime challenging behaviour in a community-based sample of adults with intellectual disability. Journal of Intellectual Disability Research, 43(6), 504-512.

- Camfield, P., Gordon, K., Dooley, J., & Camfield, C. (1996). Melatonin appears to be ineffective in children with intellectual deficits and fragmented sleep: Six "N of 1" trials. Journal of Child Neurology, 11(4), 341-343.
- Chaney, R. H., Olmstead, C. E., & Givens, C. A. (1994). Activity and behavioral rhythm disturbances in adults with mental retardation. Developmental Brain Dysfunction, 7, 17-25.
- Cicchetti, D.V. (1994). Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. Psychological Assessment, 6, 284-290.
- Cohen, J. (1965). Some statistical issues in psychological research. In B. B. Wolman (Ed.), Handbook of Clinical Psychology (pp.95-121). New York: McGraw-Hill.
- Costello, A. (1982) Assessment and diagnosis of psychopathology. In J. L. Matson, & R. P. Barrett (Eds.) Psychopathology in the mentally retarded (pp. 37-52). New York: Grune & Stratton.
- Didden, R., Korzilius, H., Smits, M. G., Curfs, L. M. G. (2004). Sleep problems in individuals with Angelman syndrome. American Journal on Mental Retardation, 3, 275-284.
- Didden, R., Korzilius, H., van Aperlo, B., van Overloop, C., & de Vries, M. (2002). Sleep problems and daytime behaviours in children with intellectual disability. Journal of Intellectual Disability Research, 46(7), 537-547.
- Doll, E.A. (1962). Trends and problems in the education of the mentally retarded, 1800-1940. American Journal of Mental Deficiency, 72, 175-183.
- Espie, C. A., & Tweedie, F. M. (1991). Sleep patterns and sleep problems amongst people with mental handicap. Journal of Mental Deficiency Research, 35, 25-36.
- Espie, C. A., & Wilson, A. (1993). Improving sleep-wake schedules amongst people with mental handicaps: Some preliminary case material. Behavioural Psychotherapy, 21, 51-55.
- Espie, C. A., Paul, A., McColl, J. H., McFie, J., Amos, P., Gray, J., et al. (1999). Cognitive functioning in people with epilepsy plus severe learning disabilities: A systematic analysis of predictors of daytime arousal and attention. Seizure, 8(2), 73-80.
- Faul, F., & Erdfelder, E. (1992). GPOWER: A priori, post-hoc, and compromise power analyses for MS-DOS [Computer software] Bonn, FRG: Bonn University, Department of Psychology.
- Fee, V. E., & Matson, J. L. (1992). Definition, classification, and taxonomy. In J. K. Luiselli, J. L. Matson, & N. N. Singh (Eds.) Self-injurious behavior: Analysis, assessment, and treatment, (pp. 3-20). New York: Springer-Verlag.

- Feldman, M. A., & Griffiths, D. (1997). Comprehensive assessment of severe behavior problems. In N. N. Singh (Ed.) Prevention and treatment of severe behavior problems: Models and methods in developmental disabilities, (pp. 23-48). New York: Brooks/Cole.
- Gravestock, S. Eating disorders in adults with intellectual disability. Journal of Intellectual Disability Research, 44(6), 625-637.
- Grubar, J.-C. (1983). Sleep and mental deficiency. Review of Electroencephalography and Neurophysiology, 13, 107-114.
- Gunning, M. J., & Espie, C. A. (2003). Psychological treatment of reported sleep disorder in adults with intellectual disability using a multiple baseline design. Journal of Intellectual Disability Research, 47(3), 191-202.
- Harris, J. C. (1992). Neurobiological factors in self-injurious behavior. In J. K. Luiselli, J. L. Matson, & N. N. Singh (Eds.) Self-injurious behavior: Analysis, assessment, and treatment, (pp. 59-92). New York: Springer-Verlag.
- Heiser, K. F., & Wolman, B. B. (1965). Mental deficiencies. In B. B. Wolman (Ed.) Handbook of clinical psychology, (pp. 838-854). New York: McGraw-Hill.
- Helbing-Zwanenburg, B., Kamphuisen, H. A. C., & Mourtazaev, M. S. (1993). The origin of excessive daytime sleepiness in the Prader-Willi syndrome. Journal of Intellectual Disability Research, 37, 533-541.
- Hinkle, D.E., Wiersma, W., & Jurs, S.G. (1998). Applied statistics for the behavioral sciences. New York: Houghton Mifflin Company.
- Hoban, T. F. (2000). Sleeplessness in children with neurodevelopmental disorders: Epidemiology and management. CNS Drugs, 14(1), 11-22.
- Horner, R. H. (1994). Functional assessment: Contributions and future directions. Journal of Applied Behavior Analysis, 27(2), 401-404.
- Howe, S. G. (1848). Report of commission to inquire into the conditions of idiots of the Commonwealth of Massachusetts. Boston: Senate Document No.51, pp. 1-37. (Reprinted from The history of mental retardation: Collected papers: Vol.1, pp. 31-60, by M. Rosen, G. R. Clark, & M. S. Kivitz, Eds., 1976, Baltimore: University Park.)
- Hunt, A., & Stores, G. (1994). Sleep disorder and epilepsy in children with tuberous sclerosis: A questionnaire-based study. Developmental Medicine and Child Neurology, 36, 108-115.
- Jan, J. E., Espezel, H., Freeman, R. D., & Fast, D. K. (1998). Melatonin treatment of chronic sleep disorders. Journal of Child Neurology, 13(2), 98.

- Jervis, G. A. (1959). The mental deficiencies. In S. Arieti (Ed.) American Handbook of Psychiatry, Vol. 2 (pp. 1289-1314). New York: Basic Books.
- Johnson, C. R. (1996) Sleep problems in children with mental retardation and autism. Child and Adolescent Psychiatric Clinics of North America, 5(3), 673-683.
- Lancioni, G. E., O'Reilly, M. F., & Basili, G. (1999). Review of strategies for treating sleep problems in persons with severe or profound mental retardation or multiple handicaps. American Journal on Mental Retardation, 104(2), 170-186).
- Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American Journal on Mental Retardation, 106(3), 231-252.
- Lindblom, N., Heiskala, H., Kaski, M., Leininen, L., Nevavlinna, A., Iivanainen, M., et al. (2001). Neurological impairments and sleep-wake behaviour among the mentally retarded. Journal of Sleep Research, 10, 309-318.
- Mathias, J. L., & Nettlebeck, T. (1992). Validity of Greenspan's models of adaptive and social intelligence. Research in Developmental Disabilities, 13, 113-129.
- Matson, J.L. (1995). Diagnostic Assessment for the Severely Handicapped-II. Baton Rouge, LA: Scientific Publishers.
- Matson, J.L., & Bamburg, J.W. (1998). Reliability of the Assessment of Dual Diagnosis (ADD). Research in Developmental Disabilities, 19, 89-95.
- Matson, J. L., & Sevin, J. A. (1994). Theories of dual diagnosis in mental retardation. Journal of Consulting and Clinical Psychology, 62(1), 6-16.
- Matson, J. L., Hamilton, M., Duncan, D., Bamburg, J., Smiroldo, B., Anderson, S. et al. (1997). Characteristics of stereotypic movement disorder and self-injurious behavior assessed with the Diagnostic Assessment for the Severely Handicapped (DASH-II). Research in Developmental Disabilities, 18(6), 457-469.
- Nihira, K., Foster, R., Shellhaas, M., & Leland, H. (1969). AAMD Adaptive Behavior Scale. Washington, D.C.: American Association on Mental Deficiency.
- Piazza, C. C., Hagopian, L. P., Hughes, C. R., & Fisher, W. W. (1998). Using chronotherapy to treat severe sleep problems: A case study. American Journal of Mental Retardation, 102(4), 358-366.
- Poindexter, A. R., & Bihm, E. M. (1994). Incidence of short-sleep patterns in institutionalized individuals with profound mental retardation. American Journal on Mental Retardation, 98(6), 776-780.

- Quine, L. (1991). Sleep problems in children with mental handicap. Journal of Mental Deficiency Research, 35, 269-290.
- Richdale, A., Francis, A., Gavida-Payne, S., & Cotton, S. (2000). Stress, behaviour, and sleep problems in children with and intellectual disability. Journal of Intellectual Disability Research, 25(2), 147-161.
- Roeleveld, N., Zielhuis, G. A., & Gabreëls, F. (1997). The prevalence of mental retardation: A critical review of literature. Developmental Medicine & Child Neurology, 39, 125-132.
- Rojahn, J. (1986). Self-injurious and stereotypic behavior of noninstitutionalized mentally retarded people: Prevalence and classification. American Journal of Mental Deficiency, 91(3), 268-276.
- Ross Collins, M. S., & Cornish, K. (2002). A survey of the prevalence of stereotypy, self-injury, and aggression in children and young adults with Cri du Chat syndrome. Journal of Intellectual Disability Research, 46(2), 133-140.
- Sarimski, K. (1996). Specific eating and sleeping problems in Prader-Willi and Williams-Beuren syndrome. Child: Care, Health and Development, 22(3), 143-150.
- Scheerenberger, R. C. (1983). A history of mental retardation. Baltimore: Brookes.
- Scheerenberger, R. C. (1987). A history of mental retardation: A quarter century of promise. Baltimore: Brookes.
- Schreck, K. A., & Mulick, J. A. (2000). Parental report of sleep problems in children with autism. Journal of Autism and Developmental Disorders, 30(2), 127-135.
- Sovner, R. (1986). Limiting factors in the use of DSM-III criteria with mentally ill/mentally retarded persons. Psychopharmacology Bulletin, 22, 1055-1059.
- Sparrow, S., Balla, D., & Cicchetti, D. (1984). Vineland Adaptive Behavior Scales. Circle Pines, MN: American Guidance Service.
- Steinhausen, H.-C., Willms, J., & Spohr, H.-L. (1993). Long-term psychopathological cognitive outcome of children with Fetal Alcohol Syndrome. Journal of the American Academy of Child and Adolescent Psychiatry, 32(5), 990-994.
- Stores, G. (1992). Annotation: Sleep studies in children with a mental handicap. Journal of Child Psychology and Psychiatry, 33(8), 1303-1317.
- Stores, R., Stores, G., & Buckley, S. (1996). The pattern of sleep problems in children with Down's syndrome and other intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 9(2), 145-158.

- Sturmev, P., & Sevin, J. (1993). Dual diagnosis: An annotated bibliography of recent research. Journal of Intellectual Disability Research, 37, 437-448.
- Symons, F. J., Davis, M. L., & Thompson, T. (2000). Self-injurious behavior and sleep disturbance in adults with developmental disabilities. Research in Developmental Disabilities, 21, 115-123.
- Telakivi, T., Partinen, M., & Salmi, T. (1985). Sleep disturbance in patients with Juvenile Neuronal Ceroid Lipofuscinosis: A new application of the SCSB-method. Journal of Mental Deficiency Research, 29, 29-35.
- Trent, J. W., Jr. (1994). Inventing the feeble mind: A history of mental retardation in the United States. Los Angeles: University of California.
- United States National Library of Medicine & National Institutes of Health. (n.d.). Medical encyclopedia: Mental retardation. Retrieved November 3, 2003 from <http://www.nlm.nih.gov/medlineplus/ency/article/001523.htm>
- Wacker, D., Northup, J., & Lambert, L. K. (1997). Self-injury. In N. N. Singh (Ed.) Prevention and treatment of severe behavior problems: Models and methods in developmental disabilities, (pp. 179-198). New York: Brooks/Cole.
- Weisstein, E. W. (1999). MANOVA. From MathWorld – A Wolfram Web Resource. Retrieved May 12, 2004 from <http://mathworld.wolfram.com/MANOVA.html>.
- Whitney, E. A., & Schick, M. M. (1931). Some results of selective sterilization. Journal of Psycho-Asthenics, 36, 330-338. (Reprinted from The history of mental retardation: Collected papers: Vol.2., pp. 201-210, by M. Rosen, G. R. Clark, & M. S. Kivitz, Eds., 1976, Baltimore: University Park.)
- Wiggs, L., & Stores, G. (1996). Severe sleep disturbances and daytime challenging behavior in children with severe learning disabilities. Journal of Intellectual Disability Research, 40(6), 518-528.
- Wiggs, L., & Stores, G. (2001). Behavioural treatment for sleep problems in children with severe intellectual disabilities and daytime challenging behaviour: Effect on mothers and fathers. British Journal of Health Psychology, 6, 257-269.
- Zigler, E., Balla, D., & Hodapp, R. (1984). On the definition and classification of mental retardation. American Journal of Mental Deficiency, 89, 215-230.

Vita

Carrie Jo Malone is a third year graduate student in clinical psychology at Louisiana State University in Baton Rouge, Louisiana. Carrie was born in Olney, Illinois, and was raised in Centralia, Illinois, since the age of 8. She graduated from Centralia High School with honors in May of 1998. She attended Millikin University in Decatur, Illinois, from August of 1998 to May of 2002 when she graduated magna cum laude. Her undergraduate degree is a bachelor of science with a double major in psychology and philosophy. Carrie is currently under the guidance of Dr. Johnny L. Matson and is specializing in working with individuals with mental retardation and mental health needs.