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A longitudinal descriptive study on the sleep of young adults with developmental disabilities

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Sleep is vital for optimal physical and mental health, as well as cognitive and social functioning. Young adults with developmental disabilities (DD) are at greater risk for physical and mental health disorders and experience limitations in cognitive and social functioning in ways that can prevent participation in meaningful activities associated with young adulthood. Sleep literature has reflected that persons with DD experience worse sleep than persons without DD. Suboptimal sleep could compromise functionality and thus participation in young adulthood activities. Not much is known however of the nature of sleep problems experienced by young adults with DD. This study is a short-term longitudinal descriptive study on the sleep of young adults with DD using actigraphy. Results identify potential sleep problems with getting enough sleep and maintaining sleep. With a better understanding of sleep issues, efforts can be made to improve the sleep, functionality, and outcomes for young adults with DD.

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CHAPTER I

INTRODUCTION

Introduction

Developmental disabilities (DD) are conditions that can impair a person's physical, behavioral, cognitive, and/or communicative abilities (Centers for Disease Control and Prevention [CDC], 2019). Disparities exist in reports of DD prevalence, but approximately 13 million Americans live with one or more DD (Anderson et al., 2019). Common developmental disability diagnoses include attention-deficit/hyperactivity disorder, autism spectrum disorder, cerebral palsy, Down syndrome, intellectual disability, and hearing or vision impairment. Many persons with DD present with homotypic comorbidities, co-occurrence of disorders within a diagnostic group (e.g. developmental disabilities) and heterotypic comorbidities, co-occurrence of disorders from different diagnostic groups (e.g. DD and an autoimmune disease; Dewey, 2018). Physical health problems such as mobility issues and epilepsy are more prevalent in this population (Stein et al., 2011), and they are at greater risk of developing psychiatric and behavioral disorders (Whitney et al., 2019). Moreover, persons with a DD may experience limitations in cognitive and social functioning that can interfere with performing day-to-day tasks and communicating with others (CDC, 2019). The severity of symptoms and limitations persons with DD experience can vary; for instance, a person with cerebral palsy may walk with a slight limp, may need special equipment to walk, or may never be able to walk (CDC, 2019).

Hence, while all individuals with DD experience some challenges and limitations to their functioning, some individuals experience more challenges and greater limitations than others. Young adults with DD face unique challenges to accomplishing some of the achievements associated with young adulthood: financial stability, employment, living independently (Austin et al., 2018). Many young adults with DD are not able to accomplish these tasks; some are able to maintain jobs and even live independently but those who do still require extra support and additional assistance from others.

Recent research has identified sleep to be crucial for physical and mental health (Dunham et al., 2018) as well as for optimal cognitive and social functioning (Walker, 2017). Insufficient sleep quantity and quality compromises physical and mental health and undermines cognitive and social functioning. Therefore, it may be even more important for young adults with DD to get sufficient sleep – so as to avoid further impediments to their health and functioning. Unfortunately, research has found that persons with DD have more sleep problems than the general population (Surtees et al., 2018), although the nature of those sleep problems remain poorly understood as well as understudied (McLay et al., 2019). The recognition and potential subsequent treatment of sleep disturbances in this study's vulnerable population may provide opportunity for improving the lives and independence outcomes of young adults with DD.

Statement of the Problem

As sleep is critical for optimal physical and mental health as well as cognitive and social functioning, getting sufficient sleep may help young adults with DD establish greater independence. Research has demonstrated that young adults with DD report significantly greater life satisfaction when they are able to be more independent and participate in post-high school education, employment, or other social activities with peers (Corby et al., 2018; Salkever, 2000).

Unfortunately, research has established that persons with DD experience poorer sleep than the general population, although gaps in the literature leave the nature of their sleep problems undefined (McLay et al., 2019). This is partially due to most studies having used subjective measures to evaluate sleep, such as surveys and interviews; there are concerns with the reliability and validity of using such measures to assess sleep with this population due to cognitive limitations that can contribute to difficulty with memory, tracking time, self-reflecting, and conceptual discerning (Richdale & Baker, 2014; Surtees et al., 2018). Additionally, most research on the sleep of persons with DD have been conducted with children. Due to these gaps in the literature, not much is known of the sleep of young adults with developmental diagnoses. This population's sleep must be better understood in order to inform professionals working with this population, and the individuals with DDs themselves on how to target and improve sleep in the attempt to optimize individuals' health, functioning, and pursuit of personal goals and independence. Results can be used to guide and inform intervention plans and the curriculum design for life skills and physical health self-care in programs that serve to assist and teach necessary skills to people with DD pursuing greater independence and other personal goals.

Background of the Problem

Young adults with one or more DD are less likely to move out of the home of origin, be financially independent, or be employed than other young adults (Austin et al., 2018). Those who are able to do so often require supplemental assistance and supervision such as an onsite job coach or mentor, or a semi-independent apartment facility where people check in on the young adult to assist with laundry or safety while cooking (Bianco et al., 2009; Park & Park, 2019). Fortunately, there are community and education programs that offer this assistance, facilitation, and guidance for young adults with DDs who are pursuing greater independence.

Non-degree seeking college programs for young adults with DD are increasing across America (Pacer Center Inc., 2019). Focal points of these non-degree seeking programs include academics, campus life, community involvement, employment opportunities, socialization, and self-awareness. The purpose of these college programs is to provide students with developmentally appropriate social experiences and to equip students with life skills and social tools to reach their potential and achieve their personal goals (Pacer Center Inc., 2019). Life skills are taught to help students be more independent by being able to keep a living space clean, make daily plans, manage time and money, and pay bills (Pacer Center Inc., 2019). Internships and instructions fostering communication skills help students secure and maintain employment and communicate with bosses and coworkers (Pacer Center Inc., 2019). Programs also focus on teaching personal health care. Students are taught ways to keep up with personal hygiene, exercise routinely, and get daily nutrition requirements (Pacer Center Inc., 2019). However, sleep, the often neglected pillar of health that is just as important as diet and exercise, has not been incorporated into personal health care curricula (Pacer Center Inc., 2019).

Sleep hygiene and the importance of sleep are not currently incorporated into the life-skills and hygiene curricula of the non-degree seeking college program from which this study's participants were sampled. Since people diagnosed with DD often have more difficulties with learning, consolidation, memory, and performance (Park & Park, 2019), it is perhaps even more crucial for this population to get the recommended quantity and quality of sleep. The literature has well-established that sleep is important for each of those tasks, as well as for health and well-being. The literature has not yet established the quantity and quality of sleep typical for a young adult with a DD, nor the nature of sleep problems experienced by this population. More research in this area could inform curricula.

Statement of Purpose

The purpose of this study is to evaluate the sleep of a sample of young adults enrolled in non-degree seeking college program for students with developmental disabilities. Actigraphy was used to objectively examine the sleep quantity measures of total sleep time and wake after sleep onset, as well as the sleep quality measures of sleep latency, activity mean during sleep, and sleep efficiency. Bedtimes and waketimes will also be noted. Intra-individual variability will also be evaluated, measuring the fluctuations of sleep quantity and quality from night to night. These findings can contribute to the gaps in sleep literature and research on young adults with DD.

Definitions

Developmental Disability	A group of diverse chronic conditions characterized by impairment in physical, learning, language, or behavior areas that may impact day-to-day functioning, and usually last throughout a person's lifetime (CDC, 2019).
Sleep	"A reversible behavioral state of perceptual disengagement from and unresponsiveness to the environment" that produces restorative benefits and protection against negative outcomes (Carskadon & Dement, 2011, p. 16).
Actigraphy	The use of an actigraph watch, a small device typically worn on the wrist, that records motion during sleep to assess sleep quantity and quality (Ambulatory Monitoring Inc., 2014).

Sleep Activity	A measure of sleep quality calculated by the percentage of 1-minute epochs the actigraph scored the body as in movement after sleep onset (Morgenthaler et al., 2007).
Sleep Efficacy	A measure of sleep quality calculated by the percentage of 1-minute epochs scored as sleep between sleep onset and waketime (Morgenthaler et al., 2007).
Sleep Latency	The number of minutes between bedtime and sleep onset (Ohayon et al., 2017).
Sleep Minutes	Total number of minutes spent asleep between bedtime and waketime (Morgenthaler et al., 2007).
Wake After Sleep Onset	The number of minutes spent awake between sleep onset and waketime (Morgenthaler et al., 2007).
Intra-individual Variability	The coefficient of variation; calculated to measure night-to-night fluctuation in sleep parameters for individuals (Fekedulegn et al., 2020).

Developmental Disabilities Pertinent to this Study

Fragile X Syndrome

Fragile X syndrome (FXS) occurs when the FMR1 gene on the short arm of the X chromosome is mutated (Mila et al., 2018). The FMR1 gene is responsible for producing the protein, FMRP, that participates in synaptic plasticity. The fragile FMR1 gene produces fewer FMRP which limits neurons' ability to bond with other neurons, resulting in cognitive impairment. Most persons with FXS have intellectual disability (ID); in fact, FXS is the most common cause of inherited ID (Mila et al., 2018). FXS can also manifest a broad spectrum of

clinical expressions: autism spectrum disorder, attention-deficit/hyperactivity disorder, generic social deficits, psychiatric disorders, enhanced stress, hearing loss, hypothyroidism, chronic pain syndromes, and sleep apnea (Mila et al., 2018). Sleep apnea is especially present in women with FXS. There is a wide phenotypic spectrum among adults with FXS. As males only have one X chromosome, more males have FXS than females, and males experience greater penetrance of the syndrome than females (Mila et al., 2018). One in 4000 males have FXS; one in 7000 females have FXS (Mila et al., 2018).

Down Syndrome

Down syndrome (DS) is a condition caused by a third chromosome 21 (Lott & Dierssen, 2010). One in every 650 to 1000 live births have this extra chromosome 21 which can result in cognitive abnormalities creating moderate to severe limitations in learning, memory, and language functioning (Bittles & Glasson, 2004; Lott & Dierssen, 2010). People with DS have higher rates of physical ailments including cardiac, gastrointestinal, immunological, respiratory, sensory, and orthopedic problems starting at birth (Bittles & Glasson, 2004). Teenagers and young adults with DS often experience the same changes teenagers and young adults without DS experience: mood swings, wanting independence, needing personal space, pushing boundaries, having crushes and first loves; these changes often come a little later in individuals with DS (Down's Syndrome Association, n.d.). Adulthood can bring additional complications including adult-onset epilepsy, thyroid disorders, sensory loss, and Alzheimer's disease in DS patients as young as 40 years old (Bittles & Glasson, 2004; Lott & Dierssen, 2010). Managing life with DS involves early assessment and intervention, prevention efforts, and monitoring comorbid health conditions with vigilance (Roizen & Patterson, 2003). If provided

with appropriate levels of guidance, treatment, and support, a proportion of people with DS lead creative, rewarding, and quite independent lives (Bittles & Glasson, 2004).

Mild Intellectual Disability

Intellectual disability (ID) is a term describing subaverage cognition functioning that is accompanied by deficits in adaptive skills (Stein et al., 2011). The cause of ID can sometimes be linked to genetic disorders such as FXS, DS, or fetal alcohol spectrum disorder but is often unknown, particularly with mild ID (Lott & Dierssen, 2010; Mila et al., 2018; Stein et al., 2011). Intellectual disability is diagnosed by IQ scores; an IQ level between 55-70 is classified as mild ID, 40-55 as moderate ID, and 25-40 as severe (Stein et al., 2011). Prevalence estimates of ID range from 1% to 1.5% in children and around 0.6% in adults (Stein et al., 2011). People with ID are at greater risk for various health problems (e.g. epilepsy, sensory impairments) and mental health and behavior disorders (Buckles et al., 2013; Stein et al., 2011). Physical, social, and vocational outcomes for individuals with ID varies. People with mild ID tend to be employed, live independently, get married, and have children more often than people with moderate to severe ID (Stein et al., 2011). With the appropriate treatment, care, and support people with ID have great potential to work, live independently, be healthy, and have meaningful relationships.

Mild Intellectual Disability & Generalized Anxiety Disorder

Anxiety is an adaptive response to stress or threat; however, when anxiety levels exceed or outlast the presence of a threat the response becomes pathological (Reid et al., 2011). Higher rates of anxiety and depression issues have been found amongst young adults with ID and generalized anxiety disorder (GAD) is the most common anxiety disorder diagnosed in young adults with ID (Austen et al., 2018; Reid et al., 2011). Prevalence reports of GAD in this population range from 2% to 17.4% (Reid et al., 2011). Severity of ID has been found to be

significantly associated with anxiety disorders; persons with mild ID experienced anxiety disorders more than persons with moderate or severe ID (Reid et al., 2011). Anxiety disorders were also found more commonly in those with ID who had no daytime occupation, experienced significant life events within the past 12 months and had experienced long-term residency in a hospital (Reid et al., 2011). Psychosocial interventions and cognitive-behavioral interventions have been proven useful in treating people with ID (Dagnan, 2007; Dagnan & Jahoda, 2006). Research on the impact of an anxiety disorder on overall functioning and life outcomes for individuals with ID is lacking and needed to best treat and improve the livelihood and functioning of individuals with ID and anxiety disorders.

7p Deletion Syndrome

7p deletion syndrome is a rare chromosome abnormality caused by the absence of a copy of genetic material from the short arm (p) of chromosome 7 (Genetic and Rare Diseases Information Center [GRDIC], 2015); only 30 cases have been reported in medical literature (Kulkarni, 2009). Chromosome 7 represents more than 5 percent of the total DNA in cells and provides instructions for producing numerous proteins that perform a variety of functions (National Center for Biotechnology Information, 2020). Chromosome 7 has an unusually high amount of sequence segment duplicates, particularly on the short arm, making chromosome 7p particularly susceptible to segment deletion (NIH, 2006); missing segments most often occur at random (Kulkarni et al., 2009). Symptoms and severity of impact on functioning are variable and depend on the size and location of the chromosomal deletion (Kulkarni et al., 2009). Craniosynostosis is consistently associated with 7p deletion (Chotai et al., 1994). Other physical features of 7p deletion syndrome include growth deficiency, musculoskeletal abnormalities, and congenital heart defects (Kulkarni et al., 2009). Developmental delay, intellectual disability, and

behavioral problems are other common features of this disorder (Grebe et al., 1992; GRDIC Center, 2015). Neurological complications are also found with 7p deletion syndrome, including hydrocephalus, seizures, and deteriorating mental functioning (Kulkarni et al., 2009). Treatment and care vary with the symptoms present in each case of 7p deletion syndrome (GRDIC, 2015). Treatment efforts often require a team of professionals: pediatricians, surgeons, early interventionists, physical therapists, occupational therapists, and speech pathologists (Kulkarni et al., 2009).

Bilateral Perisylvian Polymicrogyria

Bilateral perisylvian polymicrogyria (BPP) is a rare neurological disorder that affects the cerebral cortex along both sides of the Sylvian fissure (Genetic and Rare Disease Information Center [GRDIC], 2018). BPP can be caused by spontaneous genetic mutation and/or prenatal complications (GRDIC, 2018). With BPP, the folds and grooves along the Sylvian fissure which are typically deep are instead small and shallow (GRDIC, 2018). The Sylvian fissure divides the frontal and parietal lobe from the temporal lobe and it spans areas in both the left and right brain hemispheres (Mallela et al., 2020). It is a cortical region heavily involved in language functioning; therefore, it is unsurprising that speech, language, and oral functioning impairments are characteristic of BPP (Braden et al., 2019; Mallela et al., 2020). Deficits in both expressive and receptive communication are common in persons with BPP, with expressive deficits being more prevalent and more severe than receptive deficits (Braden et al, 2019). BPP can also cause mild to severe intellectual disabilities, developmental delay, learning impairments, seizures, and partial paralysis of the face, tongue, jaw, and throat. Quality of life, life expectancy, and treatment plans vary between individuals according to severity and presence of symptoms

(GRDIC, 2018). Speech therapy can be particularly imperative for the functioning and livelihood of this population (Braden et al., 2019; GRDIC, 2018).

Research Objectives

The following research objectives will guide this research study:

1. To describe the quantity and quality of sleep among a group of young adults with developmental disabilities over the course of 16 nights.
2. To describe the quantity and quality of sleep among young adults with unique developmental disabilities over the course of 16 nights
    a. An individual diagnosed with fragile X syndrome
    b. An individual diagnosed with Down syndrome
    c. An individual diagnosed with mild intellectual disability
    d. An individual diagnosed with intellectual disability and generalized anxiety disorder
    e. An individual diagnosed with 7p deletion syndrome
    f. An individual diagnosed with bilateral perisylvian polymicrogyria
3. To compare aggregate level sleep data of a group of young adults with developmental disabilities to National Sleep Foundation recommendations and guidelines.
4. To compare individual level sleep data of young adults with developmental disabilities to National Sleep Foundation recommendations and guidelines.

Significance of Study

Results of this study will contribute significantly to the literature. Research studies on the sleep of individuals with DD are primarily conducted with children (Angriman et al., 2015; Jan

et al., 2008; McLay et al., 2019; Richdale & Baker, 2014; Surtees et al., 2018). Of studies involving adults in the sample most also include children and adolescents (Richdale & Baker, 2014). Sleep is developmental in that sleep needs and sleep patterns change with age (Hirshkowitz et al., 2015; Ohayon et al., 2017). This creates a need for sleep studies on distinctive age groups in order to truly understand sleep quantity and sleep quality for each population (e.g. young adults).

Furthermore, most studies have employed subjective sleep measures such as self-report sleep questionnaires which are not designed for populations with DD (Richdale & Baker, 2014; Surtees et al., 2018). Due to symptoms of their disability, many individuals in this population can have difficulty tracking time to report when they went to bed and fell asleep or how many times they woke up in the night (Richdale & Baker, 2014). Additionally, most subjective sleep tools focus on frequency of problems and do not evaluate severity of problems (Spruyt & Gozal, 2011). Actigraphy, however, is a recommended objective sleep instrument for appraising sleep quantity and quality, when the use of the ideal sleep instrument, polysomnography, is infeasible (Kudisha et al., 2001; Morgenthaler et al., 2007). Polysomnography uses brain waves, oxygen levels, heart rate, and breathing to measure sleep and is the gold standard for sleep assessment; however it is costly, invasive, most often used in laboratory settings, and therefore can be disruptive to normal sleep routines (Fekedulegn et al., 2020). Actigraphy is a more feasible option than polysomnography because it is less costly, less invasive, more convenient, and allows for collecting sleep data from participants sleeping within their natural living environment rather than a laboratory (Fekedulegn et al., 2020; Meltzer et al., 2012; Sadeh, 2011). With this population it is particularly valuable that participants were able to sleep in their home environment, as research on children with DD demonstrates that children with DD sleep better in

their familiar environment: behavior, inhibition, and sleep may deteriorate in strange environments where the bed, textures, visuals, voices, sounds, and smells are unfamiliar (Jan et al., 2008).

Finally, there are calls in the literature for more sleep research to be conducted on individuals with DD to determine what distinctive sleep quantity and quality is more common for different disorders (McLay et al., 2019; Richdale & Baker, 2014). While most investigations have involved heterogenous samples, the available research on distinct disorders suggests that some sleep issues are more common in some disorders than in others (Richdale & Baker, 2014). To address these gaps in the literature this study has objectively measured sleep quantity and sleep quality of a unique sample of young adults with DD, using a non-invasive, validated actigraph watch. The sample is even more unique in being non-degree seeking college students with DD, learning to live independently on a college campus.

Results of this study further the literature by providing insight into potential sleep problems experienced by the population represented in this sample; recommendations for further research and suggestions for education and intervention techniques are also made. Results can inform and guide the curriculum design for life skills and physical health self-care in programs that serve to assist and teach necessary skills to people with DD pursuing greater independence and other personal goals.

CHAPTER II

REVIEW OF THE LITERATURE

Theoretical Framework

There are four theories that provide the theoretical framework for this study: a theory of development and three theories of sleep. Dynamic systems theory (DST) is a theoretical framework that originated in mathematics and physics to understand the self-organization process, changes, and progression observed in complex systems (Connell et al., 2017). It has since been adopted by a multitude of researchers and applied to various disciplines, including human development. According to the *complexity* principle of DST, systems are composed of many individual interacting elements which work together to organize into a coherent pattern in accordance with task, social, and environmental constraints (Thelen, 2005). Applying this principle to human development can be used to understand how development occurs – through the organization of dynamic interacting elements of a person's internal factors (physical and cognitive abilities) and external factors (physical and social environment). This self-organization of many dynamic parts produces preferred patterns that can change overtime as internal and external factors change (Smith & Thelen, 2003).

An individual with a DD will have unique individual and environmental constraints that may lead to the production of patterns viewed as "alternative" to "typical" patterns of development. In the past decade, DST enthusiasts have called for a shift in approach within intervention and therapy professions, to view these "atypical" patterns as just as valid as typical

ones and as something to celebrate and encourage rather than attempt to "correct" (Skelton & Rosenbaum, 2010). Professionals should work with the individual's strengths and constraints in a creative manner, to find ways for the individual to participate in life activities.

However, according to the *dynamic stability* principle of DST, it is possible for maladaptive patterns to emerge as the result of excessive stability in internal and external factors (Thelen, 2005). Similarly, individuals may continue to use rigid patterns that served well in the past but are not appropriate for new situations (Thelen, 2005); a young adult with a DD may be in this position as they struggle to transition from childhood into as much independence as they can safely manage. Professionals who work with young adults with DD may need to disrupt patterns of behavior that do not serve their patients in the pursuit of participating in "typical" young adult activities (e.g., employment, independent living, social and romantic partnerships). In order for professionals to know what to disrupt, individual and environmental factors must be isolated and empirically examined to identify what can be changed or altered to improve the individual's internal and external functioning (Thelen, 2005). In this study, researchers will isolate and examine the internal factor of sleep.

Sleep is a plausible factor to examine as it serves an important role in a person's cognitive, biophysiological, and social/emotional functioning. Since there is yet a single sleep theory to wholly explain the purpose and role of sleep (Brinkman et al., 2020), a combination of sleep theories will be utilized in this study: brain plasticity theory, restoration sleep theory, and Dahl's sleep theory.

Brain Plasticity Theory

Brain plasticity theory posits that sleep serves an important role for the brain. According to this theory, sleep fosters the brain's ability to change and adapt as a result of waking hours

experiences (i.e., brain plasticity; Maquet et al., 2003; Ribeiro, 2012). Sleep is an active mind state during which neural connections are filtered and important neural connections are strengthened, an essential process for learning and memory consolidation (Ribeiro, 2012). Neural connections made during waking hours about less important information, such as information irrelevant to survival, are abandoned (Ribeiro, 2012). Thus, sleep is an internal factor that has potential in influencing a person's patterns of cognitive operation.

Restoration Sleep Theory

Kristine Adams (1980) proposed and advanced the restoration sleep theory to describe how sleep regulates bodily functioning; sleep is the process by which the body tends to its own biological performance. During sleep, cells are repaired, rejuvenated, and replenished; tissues, muscles, and organs are thus repaired, rejuvenated, and replenished (Adams, 1980). Additionally, hormones are released throughout the sleep cycle that are needed for proper heart functioning, metabolism, and immune system response (Adams, 1980). Restoration theory is used, in research, not only as a proposed function of sleep, but also as a sufficient description of the feedback mechanisms that produce homeostatic regulation within the body (Benington & Heller, 1995). Explicitly, sleep is an important mechanism for maintaining homeostasis. Relating back to DST, sleep is an internal factor that influences physical health, along with the operation of other internal factors.

Dahl's Sleep Theory

Finally, sleep affects social-emotional functioning. Dahl (1996) offered a model with his theory for how sleep plays a major role in mood and emotion regulation. The prefrontal cortex (PFC) plays an involved modulatory role in many important systems including mood, attention,

motivation, and emotion regulation. Studies have shown the PFC is extremely sensitive to sleep deprivation; sleep deprivation appears to weaken PFC functioning resulting in fewer cognitively motivated, goal-directed behaviors and less regulation of drives, impulses, and emotions (Dahl, 1996). According to Dahl's sleep theory, sleep creates opportunities for recalibrations between the PFC and the many multi-oscillator systems it influences, including mood and emotion regulation (Dahl, 1996). Other studies have substantiated this theory's claim by finding good sleep to be a protective factor against depression in children, adolescents, and adults (Forbes & Dahl, 2005; Talbot et al., 2010). In conclusion, as sleep appears to be crucial for optimal mental, physical, and emotional operation, and as people with DD tend to have more challenges with such functioning, it is important to understand their typical sleep – especially in this particular understudied age group as young adulthood is a time of transitioning and establishing independence.

Collectively, these theories provide a framework that guides our understanding of the biophysiological implications of sleep for persons with developmental disabilities. Dynamic systems theory (DST) posits that internal and external factors influence the self-organization process that drives development within an organism (Thelen & Smith, 1994). According to Thelen (2005) the job of researchers and therapists is to isolate the factors influencing the self-organization process, in order to identify what factors may be causing less-desirable patterns and can be manipulated to produce a more efficient pattern that better serves the individual. Brain plasticity theory, restoration sleep theory, and Dahl's sleep theory provide a foundation for the possibility that sleep is an internal factor that can significantly contribute to self-organization. Together these three sleep theories and the dynamic systems theory for human development serve as the theoretical framework guiding this study.

Young Adults with Developmental Disabilities

Developmental disabilities are a group of conditions characterized by impairment in physical, cognitive, communicative, and/or behavioral functioning (Centers for Disease Control and Prevention [CDC], 2019). Common developmental disorder diagnoses include attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy (CP), intellectual disability, learning disability, and hearing or vision impairment (CDC, 2019). Recent research in the United States has led to the estimation that about 17%, or 1 in 6, children aged 3 through 17 are diagnosed with one or more DD. While most of these disabilities are diagnosed in childhood they last throughout the lifespan (CDC, 2019).

People diagnosed with DD are at greater risk for physical and mental health problems. Elevated physical health risks for this population include obesity, digestive problems, epilepsy, mobility problems, unidentified sensory impairments, osteoporosis, and sexually transmitted infections (Stein et al., 2011). In one study, researchers discovered that participants diagnosed with an intellectual disability had been hospitalized twice as often, with stays lasting 4 times as long as people with an average IQ (Taanila et al., 2005). From childhood throughout adulthood, people with DD diagnoses are at greater risk of developing psychiatric and behavioral disorders (Stein et al., 2011; Whitney et al., 2019). Physical multi-morbidity and mental health problems are so profoundly present in this population that Dunham and colleagues (2018) recommend for mental health interventions and preventative measures to be included in general care for the entire population of people with intellectual disabilities.

Children diagnosed with a DD often reach developmental milestones later than "typically"-developing children while some do not accomplish significant developmental tasks at all (Austin et al., 2018; Bianco & Lehmann, 2009; CDC, 2019). Developmental disabilities may

impede cognition and the ability to execute day-to-day tasks (Su et al., 2008) and as a result can impede a person's ability to live independently. Austin and colleagues (2018) found that young adults diagnosed with an intellectual disability (ID) are less likely to accomplish tasks associated with the emerging adulthood years: employment, financial independence, living independently, etc. (Arnett, 2000). This barrier can impact their mental health and overall life-satisfaction, as reflected by Austin and colleagues' (2018) finding that young adults with ID experience increased anxiety and depression symptoms when they are not able to achieve these emerging adulthood tasks. Inversely, young adults with DD have significantly greater life satisfaction when they are employed, involved in schooling and/or volunteer work, than their peers who are idle and uninvolved in independent and social activities (Salkever, 2000).

Unfortunately, unemployment is more common than employment within this population (Austen et al., 2018; Salkever, 2000, Su et al., 2008). In fact, a review of several studies on DDs across the lifespan revealed that only 25% of participants were employed (Stein et al., 2011). Common reasons reported for unemployment or dismissal from employment include lack of emotional control, limited attention span and memory, and deficits in social skills and expressive language skills (Stein et al., 2011; Su et al., 2008; Tomaszewski et al., 2018). Participants were more likely to be employed when they had higher cognitive and social functioning related to interpersonal skills, communication skills, social problem solving, and time, place, and person orientation (Park & Park, 2019, Su et al., 2008; Tomaszewski et al., 2018). Participants were also more likely to be employed when they were able to understand appropriate work behaviors and able to adapt to different situations and settings well (Su et al., 2008; Tomaszewski et al., 2018). Unfortunately, difficulty with such cognitive functioning, adaptive functioning, and social skills are characterizing symptoms of intellectual and DD (Bridges et al., 2020).

In accordance with the principles of DST, young adults with DDs can accomplish emerging adulthood tasks but it may look differently from how their contrasting peers accomplish such tasks; extra support and assistance is necessary, as young adults with DD often struggle in their roles of employment and independent living. Bianco et al.'s (2009) inquiry into parent's perceptions of postschool years for their young adult children revealed that most young adults with DD still live at home with parents, and those who do move out most often live in a group home or semi-independent apartment facility. Moreover, parents of young adults who live "independently" report their ongoing parental involvement remains time intensive and emotionally demanding; their adult children still require constant, vigilant monitoring, instruction, and assistance to complete day-to-day tasks such as locking the door at night and turning off the oven after use. Parents also reported difficulty in finding facilities or programs that serve and assist adults with DD (most facilities and programs target children and their families). The need has led to the creation of non-degree seeking university programs. The demand and shortage of such programs for young adults with DD leave many individuals on a waiting list for services and participation. Considering this need for supplemental assistance, and a lack of adult services for people with DD, more attention should be allocated towards developing best practices for adult services that do exist for this population.

The Impact of Sleep on Well-Being

Years of sleep research with the general population has identified sleep to be crucial for physical and mental health (Czeisler, 2015; Walker, 2017) as well as for cognitive and social functioning (Walker, 2009; 2017). During sleep the body performs important functions to optimize physical health. Sleep and mental health are deeply connected and correlate strongly with each other (Reynolds, 2011). Neural connections are evaluated, filtered and strengthened

during sleep, solidifying learning and promoting cognitive functioning. Sleep is furthermore impactful on many aspects of social functioning including emotion regulation, conflict resolution, empathy, and reading the emotions of others. While sleep is needed by everyone for optimal brain and body functioning, those with DD already deal with inhibited brain and body functioning, and therefore may be even more sensitive to getting appropriate quantity of sleep and high quality sleep.

Physical Health

Sleep is an indispensable pillar of physical health. During sleep the body attends to certain physical functions it does not attend to during waking hours, such as releasing hormones that regulate body systems (Walker, 2017). In fact, disturbances in sleep threaten the functioning and health of every major body system: cardiovascular, metabolic, immune, reproductive, etc. A review of more than 20 large-scale epidemiological longitudinal studies led to the linkage of heart disease, obesity, dementia, Type 2 diabetes, and cancer to poor sleep (Walker, 2017). Short sleep duration and insomnia increases blood pressure and the risk of hypertension, even after controlling for other risk factors such as smoking, alcohol use, unmanaged diabetes, and obesity (Palagini et al., 2013). Even for young and healthy adults, sleep reduction as minor as an hour or two one night can speed up heart rate and significantly increase systolic blood pressure (Tochikubo et al., 1996).

Furthermore, sleep regulates hormones. When getting four or five hours of sleep a night instead of the recommended eight, the body will decrease production of the appetite suppressing hormone leptin and increase production of the appetite inducing hormone ghrelin, leading to overeating, obesity and obesity-related illnesses (Reutrakul & Van Cauter, 2018; Spiegal et al., 2004). Additionally, sleep plays an important role in immune responses and the production of

antibodies. Participants whose sleep was restricted produced as low as half the immune response to influenza (Spiegal et al., 2002), the common cold (Prather et al., 2015), and other infectious diseases (Prather et al., 2012). A shortage of sleep also weakens the immune system's ability to fight off cancer by depleting up to 70% of the immune cells that are capable of destroying cancer cells (Irwin et al., 1996). Therefore, getting efficient sufficient sleep every night is crucial for optimal physical functioning and health.

Mental Health

Sleep and mental health appear to have a strong, interesting, and rather enigmatic correlation. The very regions of the brain that are involved in sleep regulation and are the first regions to be impacted by sleep loss, are the same regions of the brain commonly impacted by psychiatric mood disorders (Walker, 2017). Disturbed sleep is both a symptom of and a risk factor for mental illnesses including depression, anxiety, mood, and substance use disorders (Reynolds, 2011). In fact, not one major psychiatric condition is accompanied by normal sleep (Walker, 2017). Common sleep symptoms of psychiatric conditions include having difficulty initiating and maintaining sleep (i.e. insomnia), excessive daytime sleepiness, oversleeping, poor sleep efficiency, nightmares, and panic attacks arising from sleep onset (Mellman, 2006). Anxiety disorders and sleep disturbance are so interrelated that interventions used to treat the former are also used to treat the later: overlapping pharmaceutical medications and cognitive behavioral strategies to target worry, tension, and maladaptive cognitions (Mellman, 2006).

While it remains unclear whether one causes the other, research points to the relation between sleep and mental health as being bidirectional and mutually exacerbating (Cox & Olatunji, 2016). In fact, Matthew Walker (2017), a leading sleep researcher, described the

relationship between sleep and mental health as a "a two-way street of interaction, with the flow of traffic being stronger in one direction or the other, depending on the disorder" (p. 150).

Extreme sleeplessness mimics psychosis. That is, even mentally healthy subjects experience symptoms of psychiatric mood disorders such as schizophrenia when deprived of sleep for twenty-four hours (Petrovsky et al., 2014). Getting recommended sleep on the other hand, has been found to be therapeutic in studies of patients suffering from depression, anxiety, bipolar disorder, and suicidal thoughts (Asarnow & Manber, 2019; Harvey et al., 2015). In conclusion, while the relation between sleep and mental health is not fully understood, it is well understood that sleep is important for mental health and stability.

Cognitive Functioning

During sleep the brain executes important operations to maximize cognitive functioning during waking hours. Sleep is an active mind state during which the brain reviews and strengthens neural connections (Walker, 2017). In fact, it is during sleep that the brain consolidates newly learned information into long-term memory, and it is during sleep that the brain prepares itself to learn more information (Saletin & Walker, 2012). Moreover, functional magnetic resonance imaging (fMRI) conducted by Walker (2009) has shown that sleep deprived brains do not operate in the same manner as well-rested brains. Significantly, regions of the brain that are important for learning and memory consolidation are less active when the brain is sleep deprived.

During waking hours, the brain initially stores novel information from the environment in the hippocampus, a small temporary information storage unit within the brain (Saletin & Walker, 2012). However, the hippocampus has limited storage space and can become full. During sleep electronic bursts called sleep spindles transfer and consolidate information originally stored in

the hippocampus into long-term memory located in the neocortex. This process occurs during non-rapid eye movement (NREM) sleep, and in numerous studies participants who did not get NREM sleep did not remember information learned during the study, prior to sleeping (Walker, 2017).

While sleeping enhances cognitive functioning, the lack of adequate sleep compromises cognitive functioning. The brain's ability to concentrate is one of the first to suffer from sleep deprivation and even minor sleep deprivation can have detrimental effects on concentration (Dinges & Kribbs, 1991). On a test of concentration, subjects who got four hours of sleep for six nights performed as badly as participants who were sleep deprived for twenty-four hours straight; subjects who got six hours of sleep for ten days performed just as poorly as those who were kept awake for twenty-four hours (Dinges & Kribbs, 1991). Therefore, sleep that is even one hour shorter than usual has an impact on response time; one night of poor sleep can alter cognitive processing.

Social Functioning

Sleep affects how the brain operates, what portions of the brain are most activated, and how information is spread through the brain. The effect suboptimal sleep has on the brain leads to impairments in social functioning in the form of less inhibited reactions, greater difficulty regulating emotions, more extreme emotions, and greater difficulty in reading social situations and others' emotions (Christian & Ellis, 2011; Gordon & Chen, 2014; Maccari et al., 2014; Palmer & Alfano, 2017). Sleep problems have been linked to poorer social well-being, undermining the motivation and reward for participating in social activities (Palmer & Alfano, 2017).

When deprived of sleep the brain becomes more reactionary towards stimuli, particularly negative stimuli. Research has established a link between inadequate sleep and an increase in occurrence of negative emotions, and a decrease in experiencing positive emotions (Palmer & Alfano, 2017). Furthermore, when sleep deprived, the brain is hyper-vigilant to negative or threat related information (Anderson & Platten, 2011). In fact, the amygdala, the brain structure most responsible for responding to external stimuli and linked to fight-or-flight reactions, such as anger and rage, is as much as 60% more activated in brains that are sleep deprived than the amygdala in brains that are well rested (Yoo et al., 2007). This increased activation can result in more intense emotions and more intense behavioral reactions to stimuli. It appears as though sleep deprivation primes the brain to appraise, interpret, and experience events as negative events, and primes the body for more intense reactions, which may interfere with social interactions and compromise social functioning and well-being.

In addition to experiencing more extreme and negative emotions when deprived of sleep, people experience greater difficulty inhibiting their reactions to emotions. Along with the amygdala being more activated, the connection between the amygdala and the prefrontal cortex is weakened after one night of poor sleep (Yoo et al., 2007). The functioning of this amygdala-prefrontal cortex connection is crucial for rational decision-making and appropriate social behaviors and judgements (Walker, 2017). A lack of sleep impairs a person's ability to self-monitor, control impulses and make decisions (Palmer & Alfano, 2017). In one experimental study involving young adults, participants who were sleep deprived (defined as getting 6 or fewer hours of sleep in a 24-hour period) had poorer impulse control, less self-control, difficulty delaying gratification, and a lack of concern for negative consequences (Christian & Ellis, 2011).

These symptoms can greatly interfere with social functioning in casual contexts as well as (and perhaps especially) in educational and occupational contexts.

Sleep disruptions can further disturb social functioning by altering the way in which individuals understand, interpret, and respond to the emotions of others. Studies have reflected that brains deprived of sleep direct increased attention to threatening faces while paying decreased attention to positive and neutral faces (Maccari et al., 2014). This attention allocation can lead to difficulty in accurately perceiving and recognizing the emotions of others, as well as diminish the experience of social interactions. Furthermore, poor sleep has been linked to decreased empathetic accuracy; couples had more difficulty perceiving their partner's emotions, engaging in empathy, and understanding their partner while engaging in conflict after a night of poor sleep (Gordon & Chen, 2014). Couples were also more likely to engage in blaming behavior and were less willing to alleviate conflict, which can negatively impact the quality of the relationship. In these ways, poor sleep undermines social functioning.

In conclusion, sleep is critical for physical and mental health, as well as cognitive and social functioning. Getting the recommended amount and quality of sleep each night maximizes personal functioning. For young adults with DD diagnoses, sleep may be the key to reaching full potential and the fulfillment of important developmental tasks such as engaging with peers, working a paying job, and living outside the home of origin.

Sleep of Young Adults with Developmental Disabilities

As young adults diagnosed with DD are at higher risk for physical and mental health problems and have more difficulty with cognitive and social functioning (Cooper et al., 2015; Dunham et al., 2018), it may be even more important that this population receives the full protective benefits of adequate sleep, as inadequate sleep may exacerbate their symptomologies.

In addition to preventing worse outcomes, sleep could be the key to achieving optimal health and functioning for this population.

Unfortunately, research has found that persons with DD have more sleep problems than the general population (Surtees et al., 2018). In a meta-analysis of studies comparing the sleep of people with intellectual disabilities (ID) to people without intellectual disability, Surtees and colleagues (2018) found that, on average, children under 18 with ID get 18 minutes less sleep every night than children without ID. They also found that in 93% of the comparison groups, the sleep of the group with ID was of poorer quality than the control group. The literature reports the most common sleep issues found in children and adults with DD to be problems settling down at night and waking up in the night with difficulty falling back asleep (Angriman et al., 2015; van de Wouw et al., 2012). Other common sleep issues are irregular sleep schedule and daytime sleepiness (an indicator of poor sleep; Angriman et al., 2015). Richdale and Baker (2014) found the severity of cognitive impairment to be associated with increased sleep disturbance.

There are a few notions of why sleep problems tend to be prevalent in this population. First, many individuals with DD take medications to treat symptoms of the DD and comorbid physical and psychological problems. Out of the most common medications prescribed to individuals with DD, most of the medications treat gastrointestinal issues, psychological disorders, stabilize mood, and combat allergies (DDS SafetyNet, 2010). The most common side effect of these medications are gastrointestinal issues and altered sleep, including sleepiness, sleeplessness, and drowsiness (DDS SafetyNet, 2010). It has also been suggested that differences in biophysiology due to DD underpin sleep problems. Differences in melatonin secretion, circadian rhythm, and sleep architecture have been discovered in people with DD (McLay et al., 2019). Until the sleep of young adults with DD is further studied and better understood, the

underlying reasons for sleep problems will remain unknown and effective treatments to improve their sleep (and subsequently their health and functioning) will remain obscure.

Still, the nature of the sleep problems young adults with DD experience remain poorly understood due to limitations in the literature (McLay et al., 2019). Much of the previous research on persons with DD has been conducted with children (Surtees et al., 2018), limiting our understanding of the sleep of young adults with DD. Of the sleep studies that do include adults with DD in the sample, most of them include a wide age range of children and adolescents too (Richdale & Backer, 2014). Sleep is a developmental phenomenon with changes in need and pattern across the lifespan (Hirshkowitz et al., 2015; Ohayon et al., 2017). For example, infants need more sleep than adults; children and older adults often require more daytime napping; circadian rhythm changes in adolescence cause adolescents to get sleepy later and wake up later than people of other ages (Walker, 2017). So, studies that include a wide range in age of participants and do not analyze the data separately, potentially mask age-specific findings. Sleep studies that involve samples from specific developmental stages (such as young adulthood) are needed in order to characterize sleep and sleep problems for specific age ranges. Much of the existing literature have used subjective measures such as surveys or questionnaires that have not been adjusted for population with DD (Richdale & Baker, 2014; Surtees et al., 2018). There is a risk with using such measures of gathering data that overrepresents or underrepresents sleep problems as this population can have troubles accurately tracking and recalling time and sleep (Spruyt & Gozal, 2011). Furthermore, since most sleep studies on people with DD involve heterogenous samples, researchers have not been able to discern sleep problems associated with specific diagnoses. The literature that does report sleep of specific diagnoses does suggest that some sleep issues are more common in some disorders than others. McLay et al. (2019) called

for more detailed sleep analyses of specific diagnoses. For that reason, and in order to give insight into sleep of young adults with DD and sleep of individuals with specific DDs, our participants' sleep data will be analyzed aggregately and individually.

Sleep and Fragile X Syndrome

Few research studies evaluating the sleep of individuals with FXS exist; most of the studies that do exist were conducted with small sample sizes of children and used parent reports to evaluate sleep. A literature review of research on the sleep of children with neurodevelopmental disabilities reported a 32 to 50% prevalence of significant sleep problems in children with FXS (Angriman et al., 2015). The most common sleep problems reported have been reduced sleep time, decreased REM sleep, high activity during sleep, settling problems, night awakenings, and obstructive sleep apnea (Angriman et al., 2015; Kronk et al., 2009; Kronk et al., 2010; Richdale, 2003).

Sleep and Down Syndrome

Several studies have suggested that people with DS experience sleep disturbances (Angriman et al., 2015; Picchioni et al., 2014; Stores, 2019). The most commonly found and studied sleep disturbance for this population is obstructive sleep apnea syndrome (OSAS); the distinctive physical features of DS likely contribute to OSAS (e.g. craniofacial and upper airway abnormalities, macroglossia, and tonsil hypertrophy; Angriman et al., 2015; Ridore et al., 2017). An estimated 50 to 80% of individuals with DS experience OSAS (Angriman et al., 2015; Cornacchia et al., 2019). Other common sleep problems for this population include decreased total sleep time, decreased sleep efficiency, difficulty with sleep maintenance, fragmented sleep,

early waking, and daytime sleepiness (Angriman et al., 2015; Picchioni et al., 2014; Stores, 2019).

Sleep and Mild Intellectual Disability

Estimations for prevalence rates of sleep problems in adults with ID range from 8.5% to 34.1%, with a 9.2% prevalence rate of significant sleep problems (i.e. meets diagnostic criteria for clinical sleep problems; Boyle et al., 2010; van de Wouw et al., 2012). The most commonly reported sleep problems for this population are settling problems, night awakening problems, early waking problems, and daytime sleepiness. In a meta-analysis of sleep studies comparing the sleep of people with and without ID, 93% of the group with ID had poorer sleep than the group without ID (Surtees et al., 2018). Interventions targeting behavior and environment (e.g. relaxation methods and dimming lights) leading up to bedtime have been able to improve the sleep of adults with ID (van de Wouw et al., 2012).

Sleep, Mild Intellectual Disability, and Generalized Anxiety Disorder

Clinically significant sleep problems are found more commonly in adults with ID who also have mental health diagnoses (Boyle et al., 2010). Psychiatric comorbidities and psychiatric medications may contribute to experiencing more severe sleep problems (Richdale & Baker, 2014; van de Wouw et al., 2012).

Sleep and 7p Deletion Syndrome

Information about sleep and 7p deletion syndrome could not be found upon searching the literature.

Sleep and Bilateral Perisylvian Polymicrogyria

Information and studies involving the sleep of individuals with BPP could not be found upon reviewing the literature.

CHAPTER III

METHODS

This exploratory study will describe the sleep of a sample of young adults enrolled in an inclusive, 4-year, non-degree seeking college program for students with DD. The purpose of this study is to describe the objective sleep of young adults with severe DDs learning to become more independent adults while living on a college campus. The guiding research objectives will lead to findings that further the literature and our understanding of the sleep of young adults with DD diagnoses.

Research Objectives

The following research objectives will guide this research study:

1. To describe the quantity and quality of sleep among a group of young adults with developmental disabilities over the course of 16 nights.
2. To describe the quantity and quality of sleep among young adults with unique developmental disabilities over the course of 16 nights
    a. An individual diagnosed with fragile X syndrome
    b. An individual diagnosed with Down syndrome
    c. An individual diagnosed with mild intellectual disability
    d. An individual diagnosed with intellectual disability and generalized anxiety disorder
    e. An individual diagnosed with 7p deletion syndrome

f. An individual diagnosed with bilateral perisylvian polymicrogyria

3. To compare aggregate level sleep data of a group of young adults with developmental disabilities to National Sleep Foundation recommendations and guidelines.
4. To compare individual level sleep data of young adults with developmental disabilities to National Sleep Foundation recommendations and guidelines.

Research Design

This study has been a secondary analysis of existing data that were originally collected for an experimental study examining the impact of exergaming (i.e. exercising with video games) on the sleep and cognitive functioning of college students with DD participating in a non-degree seeking university program. The experimental study found no effects of exergaming on sleep. This short-term longitudinal study collected observational data of the same phenomenon (sleep) over an extended period of time: four nights (Monday, Tuesday, Wednesday, and Thursday) a week for four weeks (Babbie, 2007). This is a long period of data collection particularly in the context of sleep research wherein most studies analyze sleep for a much shorter time period (Fekedulegn et al., 2020).

Utilizing a quantitative research approach, a predetermined instrument was used to gather observational data that could be statistically analyzed (Creswell, 2003). The predetermined instrument used in the original data collection was Octagonal Basic motionloggers from Ambulatory Monitoring; the data collected was observational. A statistical analysis of the following sleep parameters have been performed for the present study: sleep latency, sleep minutes, sleep efficiency, activity mean, and wake after sleep onset (WASO). Intraindividual variability in sleep parameters were also analyzed to discover how much a participant's sleep quantity and quality varied from night to night.

Participants

Participants were recruited from an inclusive four-year, non-degree seeking program for students with intellectual and/or DD located in a southern U.S. state. The program welcomed the initial researchers' study (IRB # 16-211). Enrollment in the program was required for inclusion in the study. Assent was collected from the students and consent was required from their legal guardian or representative. The following participant characteristics were collected at the beginning of the study: age, gender, diagnosis, and severity of mental disability according to intelligence quotient (IQ) ranges established by the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (American Psychiatric Association, 2013). An IQ score of 50 to 70 is indicative of mild intellectual disability, 35-50 is indicative of moderate intellectual disability, and an IQ score between 20-35 is indicative of severe intellectual disability. As part of the program, each participant was living on campus at the time of data collection.

Eight participants were initially recruited for data collection, however, data from two participants was not usable. One participant routinely forgot to put the watch back on after showering at night, rendering few nights of valid data. For the other participant the actigraph malfunctioned, resulting in significant data loss. Gender of participants is withheld (with the exclusion of one participant whose diagnosis makes gender of particular relevance) in order to limit identifiable information and protect privacy of participants. 2018). Exact age of participants is also withheld to limit identifiable information, but the college program from which participants were recruited accepts young adults ages 18 through 26. This coincides well with the research of Jeffery Arnett, lead researcher in young adulthood and emerging adulthood who includes ages 18 through 25 in his research (Arnett, 2000).

Participant A is a female with fragile X syndrome, who displays the phenotype and experiences the symptoms typical of FXS; this is uncommon among females because of their genetic makeup (i.e. two X crhomosomes). Most females with FXS are carriers of the disorder, but do not display phenotypes typical to the disorder (Mila et al., 2018). Participant A has an IQ of 89 which does not meet diagnostic criteria for ID, which is also uncommon with FXS, but could be due to her having another X chromosome to produce more FMRP to foster greater neural synapsis plasticity.

Participant B is dagnosed Down syndrome with a moderate ID due to an IQ of 54.

Participant C is diagnosed with mild intellectual disability (i.e. IQ falls within 70-55).

Participant D is diagnosed with intellectual disability and generalized anxiety disorder (i.e. IQ falls within 70-55).

Participant E is diagnosed with 7p deletion syndrome and an IQ of 69 (mild intellectual disability).

Participant F is diagnosed with bilateral perisylvian polymicrogyria. Participant F's IQ is 96, quite high for diagnosis; however, the participant had such severe deficits in expressive and receptive language skills that they fell behind peers (without BPP) socially and academically.

Due to the comorbidity often found in this population, many participants took multiple medications to treat disability symptoms, physical ailments, and psychiatric conditions. Medications could not be controlled for; however, since medications were taken daily, any effects on sleep would be consistent. Therefore, the data is still a representation of typical sleep for the participants.

Instruments

Actigraph (Ambulatory Monitoring Motionlogger) watches were used to collect sleep data for four nights a week for four weeks. The Motionlogger Octagonal Basic actigraph watch measures motion in 1-minute epochs using Zero Crossing Mode setting (Ambulatory Monitoring Inc., 2014). Zero Crossing Mode was chosen because of its ability to estimate sleep with a high degree of accuracy; this model counts the number of times per minute that electrical signal from the skin exceeds a preset reference threshold (Fekedulegn et al., 2020). The Cole-Kripke scoring algorithm was used to score each epoch as either wake or sleep (Cole et al., 1992). The Cole-Kripke algorithm correctly distinguishes sleep from wakefulness at a high degree of accuracy (91%) and a high degree of sensitivity (99%) and is accepted as an appropriate algorithm to use with adult populations (Cole et al., 1992; Fekedulegn et al., 2020). Action W2 software from Ambulatory Monitoring and SPSS from IBM were used to compute data results.

Actigraphy devices measure activity through the skin which is then used to estimate sleep and wake data (Fekedulegn et al., 2020). It is considered a reliable and validated method for objective sleep assessments (Fekedulegn et al., 2020). There are concerns however about actigraphy generally overestimating sleep. Underestimations of sleep onset latency and wake after sleep onset are of particular concern when using actigraphy, because time spent lying awake in bed waiting for sleep can be read by actigraph watches as sleep (Fekedulegn et al., 2020; Morgenthaler et al., 2007).

To combat this issue, it is recommended that actigraphy be used in conjunction with other objective or subjective methods when possible; in this study sleep diary logs were used for participants to fill out and report what time they went to bed and what time they woke. Participants in this study completed a sleep diary with the help of program volunteers in one-on-

one interviews every morning to collect bedtimes and waketimes. Information from the sleep diary was then used to corroborate actigraphy data.

Objective analyses of sleep parameters are needed to better understand and characterize the sleep experienced by young adults with DD. In this study actigraphy and sleep diaries were used in the gathering and analyzing of data to describe the sleep of a sample of young adults with DD and describe the sleep of participants with distinctive diagnoses.

Procedures

Only procedures pertinent to the current study are detailed in this thesis. First, the university's Internal Review Board (IRB) approval was obtained (IRB # 16-211). Next participants were recruited; letters for informed consent were sent to student guardians for their consent, and assent was required and obtained from the students. Demographic information including gender, diagnosis, and severity of mental disability were gathered at onset of participation.

Data were collected over the course of four weeks; sleep data were collected for four nights each week, resulting in 16 nights of sleep data. Some studies recommend collected five days of data to increase reliability and other studies have recommended seven days to accurately measure variability of sleep parameters (Fekedulegn et al., 2020). This study far exceeds these recommendations.

On Monday mornings the students were given actigraph watches to wear throughout the day and night, except for during swimming, showering, or bathing to protect the watch from water damage. The watches were set in Zero Crossing Mode. Under this setting the electrical voltage signals from the skin are crossed with a reference voltage (set close to zero; Fekedulegn

et al., 2020). Participants were asked to return the watch to research assistants on campus on Friday evenings before the weekend began.

Every weekday morning of the study participants individually met with one of the program volunteers to discuss bedtime (i.e. what time participant got in bed to go to sleep) and waketime (i.e. what time the participant woke up in the morning) for that previous night and morning; the volunteers recorded the answers which were used in junction with the actigraphy data to analyze their sleep. Of note, the intellectual disabilities of some of the participants did not always lead to reliable reporting of sleep schedules (e.g. difficulty with memory; conceptual problems with tracking time), and in cases where the diary information was significantly different from the actigraphy data an expert in actigraphy data analyses (i.e., a consultant with ten years of experience in actigraphy coding) made a determination of the start and end times of sleep.

Data Analysis

Data analysis involved the use of Action W2 software from Ambulatory Monitoring. The Cole-Kripke algorithm within the software was used to derive the sleep measures previously mentioned: sleep minutes, sleep latency, activity during sleep, sleep efficiency, and wake after sleep onset. The Cole-Kripke mathematical algorithm uses the electrical signal activity read by the watch device to determine whether a 1-minute epoch was spent asleep or awake (Cole et al., 1992; Fekedulegn et al., 2020).

Entering data into the Action W2 software began with downloading actigraph observations, and then establishing bedtime, sleep onset time and waketime in a process called data preprocessing (Fekedulegn et al., 2020). Sleep diaries were used in conjunction with the actigraphy watch to establish these three times. Then, the Cole-Kripke algorithm was used to

derive data scores for the following measures: sleep minutes (i.e., number of minutes spent asleep between sleep onset and waketime), sleep latency (i.e., amount of minutes spent awake between bedtime and sleep onset), activity mean (i.e., percentage of sleep epochs that also ready physical activity), sleep efficiency (i.e., percentage of epochs scored as sleep between sleep onset and waketime), and wake after sleep onset (i.e., number of minutes spent awake between sleep onset and waketime; Ambulatory Monitoring Inc, 2002; Fekedulegn et al., 2020; Morgenthaler et al., 2007). α statistics were as follows: sleep minutes = .91; sleep latency = .72; activity mean = .90; sleep efficiency = 1.05; wake after sleep onset = .85; bedtime = .99; waketime = .95. These reliability statistics exceed Acebo and colleague's (1990) conclusion that stability levels above 0.70 indicate adequate reliability of measures. Raw data scores were derived for each participant for each night sleep was recorded. All participants had several nights of data however data are missing for some nights due to watch malfunctions or watch removal. One participant had data for 100% of nights; one had data for 87% of nights; one had data for 81% of nights; two had data for 75% of nights, and one had data for 56% of nights. These rates of valid actigraph data are considered usable (Acebo et al., 1999). The raw data scores were then exported from Action W2 software into an Excel spreadsheet. Finally, SPSS was used to run descriptive statistics to report the sleep of the sample as a collective and for each participant individually. SPSS was also used to calculate coefficient of variation for each parameter to measure intraindividual variability.

To present the aggregated sleep data overall means are reported. Averaging sleep parameter data can provide a stabilized measurement of participants' sleep (Fekedulegn et al., 2020). For reporting the sleep of individual participants, sleep data for each parameter were averaged overall and weekly. Additionally, intraindividual variability is reported; measuring variability in sleep from night-to-night can reveal important information about an individual's

sleep that a mean alone cannot demonstrate. It is a revealing yet underused variable in sleep research (Fekedulegn et al., 2020).

Table 1 provides technical definitions of sleep parameters and established recommendations for sleep parameters. Data results are compared to these standards. Special interest will be given to sleep latency and wake after sleep onset (WASO) as they are the most commonly reported sleep problems in the limited literature on the sleep of individuals with DD. Bedtime and waketime routine is also examined to evaluate sleep hygiene (e.g., sticking to a bedtime and waketime routine). Bedtime in this study refers to what time the participant got in bed to go to sleep and waketime refers to what time the participant woke in the morning to start the day. Previous literature has recommended going to bed and waking up within the same hours every night and morning respectively (Jan et al., 2008). Measuring and analyzing these sleep measures will advance the literature by providing a better understanding of the sleep of young adults with DD.

Table 1 Technical Definitions and Established Recommendations for Sleep Parameters

Sleep Parameter	Technical Definition	Recommendation
Sleep Minutes	The number of minutes spent asleep during interval from sleep onset to sleep offset (Fekedulegn et al., 2020, p. 357).	7-9 hours a night for young adults ages 18-25 (National Sleep Foundation [NSL]; Hirshkowitz, 2015).
Sleep Onset Latency (SOL)	"The number of minutes it took a subject to fall asleep" (Fekedulegn et al., 2020, p. 357).	10-15 minutes ideally; less than 20 minutes. SOL less than 5 minutes could indicate sleep debt (Allen et al., 2018).

Table 1 (continued)

Sleep Parameter	Technical Definition	Recommendation
Sleep Efficiency	"The percentage of time spent asleep…between onset of persistent sleep and sleep offset" (Fekedulegn et al., 2020, p. 357).	Sleep efficiency percentages that fall below 64% indicate poor sleep quality for young adults (NSL; Ohayon et al., 2017).
Sleep Activity	"Average activity score or frequency of wrist movement" (Fekedulegn et al., 2020, p. 356).	No set recommendation found in literature; incorporated into sleep efficiency calculation (Morgenthaler er al., 2007).
Wake After Sleep Onset (WASO)	"Number of minutes a participant was awake between sleep onset and sleep offset" (Fekedulegn et al., 2020, p. 358).	Spending greater than 21 minutes awake through the night after sleep onset is a marker of poor sleep quality (Ohayon et al., 2017); spending greater than 29 minutes awake after sleep onset more than twice a week is indicative of insomnia (Buysse et al., 2006; Lichstein et al., 2003).
Intraindividual Variability	"a measure of the night-to-night variability of a sleep parameter that can be computed by calculating the standard deviation of the sleep parameter across the sampling days" (Fekedulegn et al., 2020, p. 359).	Combining means and variability participants can be classified into one of four groups: short and consistent sleepers, long and consistent sleepers, short and variable sleepers, and long and variable sleepers (Fekedulegn et al., 2020).

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CHAPTER IV

RESULTS

Study results address the research objectives for this study. Sleep quantity and quality will be reported at the aggregate level to observe the sleep experienced by a group of young adults with developmental disabilities across 16 nights. The aggregate level results are compared to recommendations for sleep quantity and quality established by the National Sleep Foundation. Additionally, individual sleep results are reported to observe and compare the sleep quantity and quality experienced by persons diagnosed with fragile X syndrome, Down syndrome, mild intellectual disability, mild intellectual disability and generalized anxiety disorder, 7p deletion syndrome, and bilateral perisylvian polymicrogyria. These individuals' sleep results were also compared to National Sleep Foundation recommendations.

Sleep Quality and Quantity of Young Adults with Developmental Disabilities

Aggregate Results and Comparison to National Sleep Foundation Recommendations

Four hundred and seventy sleep data scores were analyzed to produce aggregate results on the sleep of six young adults with developmental disabilities. The data, presented in Table 2, report that on average these individuals have short sleep latency that falls in between the ideal sleep onset latency of 10-15 minutes, but is still greater than the 5 minute sleep onset latency that indicates sleep debt, low activity during sleep, and high sleep efficiency. The sample mean suggests they get just enough sleep per night to meet NSL recommendations but experience a clinically high amount of wake after sleep onset. For all individuals, sleep parameters varied

little night-to-night in bedtime, waketime, sleep minutes, and efficiency, varied a bit more in latency and activity, but varied most in WASO.

Table 2 Aggregate Sleep Parameter Means and Standard Deviations

Overall	Bedtime	Waketime	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
Mean (SD)	11:55 pm	7:42 am	7h 2.7 mins (69 min)	6.9 min (3.99)	16.76 (7.6)	92 (5.7)	**37.22 mins (28.38 min)**

Note. Data that quality as poor or inadequate sleep according to established sleep standards are emboldened. H = hours; min = minutes

Individual Results and Comparison to National Sleep Foundation Recommendations

Participant A – Fragile X Syndrome

Participant A had 16 nights of data to be analyzed. Table 3 displays the weekly means for each sleep parameter; Table 4 displays the means and standard deviations of all 16 data points for each parameter. Participant A had a rather consistent bedtime and waketime, going to bed and waking up within the same hours respectively. For 75% of the nights the participant got less than the recommended amount of sleep. Sleep onset latency was always between 10 minutes, the recommended, and 5 minutes, the sleep debt indicator. Activity and sleep efficiency means indicate good sleep quality. Wake after sleep onset however was very high and within bounds of insomnia diagnostic criteria except for one week. Overall means indicate this participant does not get enough sleep and spends a great deal of time awake in the night. For intraindividual variability, bedtime, waketime, sleep minutes, and efficiency varied very little, varied some for latency and activity, but most for wake after sleep onset.

Table 3 Participant A's Weekly Sleep Parameter Averages

Week	Bedtime	Waketime	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
1	11:34pm	6:12 am	**6 h 10.5 min**	6.75 min	13.77	92.77	**28.5 min**
2	11:28pm	6:40 am	**6 h 40.5 min**	7 min	15.2	92.41	**32.75 min**
3	11:23 pm	6:39 am	**6 h 33.5 min**	9 min	16.85	90.16	**43.25 min**
4	11:03 pm	7:43 am	7 h 18.5 min	8.25 min	20.6	85.2	**77 min**

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. h = hours; min = minutes.

Table 4 Participant A's Overall Sleep Parameter Means, Standard Deviations, and Intraindividual Variation

Overall	Bedtime	Wake-time	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
Mean (SD)	11:22 pm	6:48 am	**6h 41 min** (32.32 min)	7.75 min (3.37)	16.61 (4.32)	90.14 (5.27)	**45.38 min** (29.42 min)
IIV	.01	.09	.08	.44	.26	.06	.65

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. IIV = intraindividual variation; h = hours; min = minutes.

Participant B – Down Syndrome

There were 13 nights of data to analyze for Participant B. Table 5 displays sleep parameter means by week and Table 6 displays sleep parameter means and standard deviations

for all 13 nights. Participant B consistently went to bed in early morning hours and awoke in the mid-morning hours. This participant had adequate sleep efficiency and low activity during sleep. Sleep minutes was consistently below the recommendation of 7-9 hours of sleep a night. Sleep latency was short, at times short enough to indicate sleep debt. WASO was long, above the threshold indicating poor sleep (21 minutes), 75% of the time. Intraindividual variation was low for waketime, efficiency, and sleep minutes, slightly greater for bedtime and activity, but highest for wake after sleep onset and sleep latency with a coefficient of variation of 1.22.

Table 5 Participant B's Weekly Sleep Parameter Means

Week	Bedtime	Waketime	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
1	2:36 am	9:06 am	**6 h 5.5 min**	6.25 min	17.77	93.66	**25 min**
2	1:38 am	9:06 am	**6h 44.5 min**	9.25 min	21.92	89.82	**44.25 min**
3	1:52 am	9:24 am	**6h 45 min**	**1.5 min**	21.64	90.73	**40 min**
4	2:29 am	8:53 am	**6h 7 min**	**3 min**	16.87	95.06	19 min

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. IIV = intraindividual variation; h = hours; min = minutes.

Table 6 Participant B's Overall Sleep Parameter Means, Standard Deviations, & Individual Variation

Overall	Bedtime	Wake-time	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
Mean (SD)	2:01 am	9:07 am	**6h 24min (62.26 min)**	5.77 min (7.01)	19.43 (6.55)	92.35 (4.5)	**33.33 min (19.52)**
IIV	.22	.02	.16	1.22	.34	.05	.61

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. IIV = intraindividual variation; h = hours; min = minutes.

Participant C – Mild Intellectual Disability

Nine nights of data were collected and used from Participant C. Table 7 and Table 8 display weekly and overall sleep parameter means respectively. Participant C got the recommended amount of sleep each week with averages above 8 hours a majority of the time. Sleep efficiency and activity mean percentages do not indicate poor sleep. Sleep latency was near indications of sleep debt, with one week's average below 5 minutes and an overall average of 5.78 minutes. Every week but one WASO fell below the threshold indicative of sleep problems; overall WASO did indicate sleep problems however this is likely due to cases of extreme outliers when WASO average for a week was 67 minutes. The participant's bedtime, waketime, sleep minutes, and efficiency did not vary much from night to night; latency and activity varied more and wake after sleep onset varied most with a coefficient of variability of 0.98.

Table 7 Participant C's Weekly Sleep Parameter Averages

Week	Bedtime	Waketime	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
1	12:47 am	8:16 am	7h 12min	6 min	8.53	96.93	13 min
2	11:59 pm	8:21 am	8h 9 min	**4.75 min**	6.7	97.67	12.5 min
3	11:21 pm	8:50 am	8h 23 min	7 min	16.11	88.25	**67 min**
4	11:12 pm	8:30 am	8h 36 min	6.5 min	13.82	96.82	17 min

Note Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. h = hours; min = minutes.

Table 8 Participant C's Overall Sleep Parameter Mean, Standard Deviation, & Intraindividual Variation

Overall	Bedtime	Wake-time	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
Mean (SD)	11:50pm	8:29 am	8h 23 min (68.31min)	5.78 min (2.49)	10.91 (7.32)	96.25 (3.53)	**20.56 (20.19 min)**
IIV	.03	.02	.14	.43	.67	.04	**.98**

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. IIV = intraindividual variation; h = hours; min = minutes.

Participant D – Intellectual Disability and Generalized Anxiety Disorder

Participant D had 14 nights of data gathered to be analyzed. Table 9 presents the sleep data averaged across weeks and Table 10 presents the averages and standard deviations for data

overall. Participant D did not get the recommended amount of sleep for three out of four weeks, with an overall average of 6 hours and 46 minutes. While the participant slept, sleep efficiency was satisfactory and activity percentage was relatively low. Sleep latency feel in between the ideal, 10 minutes, and the indicator of sleep debt, 5 minutes. The most striking aspect of Participant D's sleep is the very high WASO averages, with an overall average of almost 52 minutes. Participant D's bedtime, waketime, sleep m, and efficiency varied little from night to night; latency, activity, and wake after sleep onset varied more.

Table 9 Participant D's Weekly Sleep Parameter Means

Week	Bedtime	Waketime	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
1	11:35 pm	6:27 am	**6h 19 min**	6.75 min	13.88	92.43	**31.75 min**
2	10:48 pm	6:51 am	**6h 30 min**	8 min	29.20	85.79	**61.50 min**
3	10:57 pm	8:12 am	8h 13 min	7 min	18.07	90.22	**52.33 min**
4	10:49 pm	6:08 am	**6h 16 min**	6.33 min	19.97	85.51	**64 min**

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. h = hours; min = minutes.

Table 10 Participant D's Overall Sleep Parameter Means, Standard Deviations, & Interindividual Variation

Overall	Bedtime	Wake-time	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
Mean (SD)	11:02 pm	6:54 am	**6h 46 min** (63.78 min)	7.07 min (2.2)	20.46 (9.24)	88.57 (5.77)	**51.57 (25.66 min)**
IIV	.02	.13	.16	.31	.45	.07	.50

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. IIV = intraindividual variability; h = hours; min = minutes.

Participant E – 7p Deletion Syndrome

Participant E had 12 nights of sleep data to be analyzed. Details of Participant E's sleep averages by week can be found in Table 11and details of Participant E's sleep averages overall can be found in Table 12. Participant E had a rather consistent bedtime and waketime routine. This participant consistently got the recommended 7 – 9 hour sleep recommendation, had low activity percentages and high sleep efficiency percentages. This participant's sleep latency fell between 5 and 10 minutes, falling between the markers indicating sleep debt and health sleep. However, Participant E had very high WASO averages weekly and overall, ranging from 27 minutes to 75 minutes. This participant's sleep varied little from night to night in terms of bedtime, waketime, sleep minutes, and efficiency; sleep varied a bit more in latency and activity and varied most in wake after sleep onset.

Table 11 Participant E's Weekly Sleep Parameter Means

Week	Bedtime	Waketime	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
1	12:18 am	8:14 am	7h 25.5 min	6.5 minutes	15.43	93.65	**29 min**
2	12:06 am	8:05 am	7h 33 min	6.33 minutes	12.97	94.07	**27 min**
3	11:21 pm	8:02 am	7h 26.5 min	6.67 minutes	22.79	85.17	**75.33 min**
4	12:03 am	7:58 am	7h 20 min	6.5 minutes	14.59	92.84	**34.25 min**

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. h = hours; min = minutes.

Table 12 Participant E's Overall Sleep Parameter Means, Standard Deviations, & Intraindividual Variation

Overall	Bedtime	Wake-time	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
Mean (SD)	11:57pm	8:08am	7h 26min (76.82 min)	6.5 min (2.35)	16.37 (5)	91.36 (5.17)	**41.83 (25.35 min)**
IIV	.02	.01	.17	.36	.31	.06	.61

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. IIV = intraindividual variation; h = hours; min = minutes.

Participant F – Bilateral Perisylvian Polymicrogyria

Twelve nights of sleep data from Participant F were analyzed. Means for each week are presented in Table 13; means and standard deviations for all 12 nights are presented in Table 14.

The participant had a relatively routine bed and wake schedule. Means for two weeks met sleep minute recommendations and fell just below recommendations the other two weeks; the overall sleep minutes averaged within the 7-9 hour recommendation. Sleep latency mean was below 5 minutes, indicating sleep debt, for one week, but was above5 minutes for the rest of the week with an overall mean of 7.5 minutes. Low activity percentages and high sleep efficiency percentages suggest good sleep quality. Means for WASO ranged from 0 to 52.67 minutes; for two weeks WASO was very low but was high enough for insomnia diagnosis the other two weeks. WASO across all 12 nights was 23.33 minutes, greater than the threshold of 20 minutes that indicates poor sleep. Participant F experienced little variation night-to-night in bedtime, waketime, sleep minutes, and efficiency, experienced a bit more variation in latency, but quite a bit in activity. Participant F experienced a great deal of variation in wake after sleep onset reflected by a coefficient of variation of 1.56.

Table 13 Participant F's Weekly Sleep Parameter Averages

Week	Bedtime	Waketime	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
1	11:41 pm	6:38 am	**6h 58 min**	**4 min**	6.97	100	0 min
2	10:37 pm	7:00 am	7h 33 min	8 min	21.09	93.28	**32 min**
3	11:16 pm	6:57 am	**6h 31 min**	8.67 min	21.74	90.41	**52.67 min**
4	11:02 pm	6:37 am	7h 28 min	8 min	7.96	98.37	7.25 min

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. h = hours; min = minutes.

Table 14 Participant F's Overall Sleep Parameter Means, Standard Deviations & Intraindividual Variation

Overall	Bedtime	Wake-time	Sleep Minutes	Sleep Latency	Activity Mean Percentage	Sleep Efficiency Percentage	Wake After Sleep Onset
Mean (SD)	11:09pm	6:48am	7h 10 min (62.79 min)	7.5 (2.32)	14.52 (9.82)	95.38 (6.22)	**23.33 (36.42 min)**
IIV	.02	.03	.15	.31	.68	.07	1.56

Note. Data that qualify as poor or inadequate sleep according to established sleep standards are emboldened. IIV = intraindividual variation; h = hours; min = minutes.

CHAPTER V

DISCUSSION

Discussion

This study is an important step towards characterizing the sleep of young adults with developmental disabilities. It has been established in the literature that this population does not get optimal quantity or quality of sleep, but characteristics of typical sleep for this population remains largely unknown. Results of this longitudinal study are described and discussed in this chapter to offer insight into the sleep experienced by young adults with developmental disabilities.

Potential Sleep Problems and Variation within Sleep Parameters for Young Adults with Developmental Disabilities.

Pooled together, the results surprisingly suggest that this sample got the recommended amount of sleep for young adults (7-9 hours), with a sleep minutes average of 7 hours and 2.7 minutes. While the sample as a whole meets the recommendation, it is important to note that the criteria is only met by 2.7 minutes. Considering literature reports of decreased sleep time among individuals with DD (Angriman et al., 2015; Richdale & Baker, 2014; Surtees et al., 2018; van de Wouw et al., 2012) and that the majority of participants in this study did not meet that recommendation most nights, the is surprising that this sample met the NSF recommendation. Taken together, it is likely that these participants are still not getting the ideal amount of sleep every night.

This sample experienced a short sleep latency average of 6.9 minutes. This finding differs from previous findings of individuals (children) with DD having problems settling at night; however, this sleep latency average does indicate sleep debt (Angriman et al., 2015). A sleep latency of 10 to 15 minutes is considered normal and ideal (Allen et al., 2018). Falling asleep in less than 5 minutes is considered an indication of sleep debt, the cumulation of extended inadequate sleep (Allen et al., 2018). With a sleep latency falling between 5 and 10 minutes, it is suggestive that these participants may be experiencing suboptimal sleep in quantity or quality. While this short sleep latency suggests sleep debt, it does not reflect what has been found in the literature of problems settling at night. Problems with settling at night has predominately been found in studies with children who have DD, and can be both common and persistent in children without DD (Angriman et al., 2015; Ramchandani et al., 2000), suggesting a potential difference in sleep patterns by developmental stage.

One sleep problem that certainly can be contributing to potential sleep debt amongst this sample is difficulty with sleep maintenance and frequent night awakenings. Wake after sleep onset aggregate average is 37.22 minutes, high enough to indicate insomnia (Lichstein et al., 2003). Other studies have observed these problems in children, adults, and older adults with DD (Angriman et al., 2015; Richdale & Baker, 2014; Surtees et al., 2018; van de Wouw et al., 2012).

Intraindividual variability was calculated for each parameter for each participant. For every participant the sleep parameters of activity, sleep latency, and wake after sleep onset varied the most. Intraindividual variability for activity ranged from 0.26 to 0.68. Intraindividual variability for sleep latency ranged from to 0.31 to 1.22. Intraindividual variability for wake after sleep onset ranged from 0.50 to 1.56. These findings identify activity, sleep latency, and wake after sleep onset as areas of potential variability, and problems with getting enough sleep and

maintaining sleep as areas of potential problems for young adults with developmental disabilities.

The Sleep of a Young Adult with Fragile X Syndrome

Results from Participant A reinforce previous findings of participants with FXS having reduced sleep minutes, getting around 6 and a half hours a night (Angriman et al., 2015; Kronk et al., 2010; Richdale 2003). Participant A's sleep results also reinforce past findings of frequent night awakenings for individuals with FXS, with a wake of sleep onset average of 45 minutes and ranging from 28.5 minutes to 77 minutes; these night awakenings are long enough and frequent enough to indicate insomnia (Buysse et al., 2006; Lichstein et al., 2003). Based on past findings with participants with FXS, it was expected that Participant A would have difficulty falling asleep, but with a sleep latency of less than 10 minutes. Instead, her short sleep latency suggests the problem of sleep debt, which could be the result of not getting the recommended amount of sleep and experienced extended wakings in the night (i.e. poor sleep health; Allen et al., 2018). Sleep activity and efficiency however does not seem to be suboptimal. So, it appears that this female with fragile X syndrome experiences sleep problems with getting enough sleep and maintaining sleep, which could be contributing to her shortened sleep latency.

The Sleep of a Young Adult with Down Syndrome

The most common sleep problem for people with DS is obstructive sleep apnea syndrome, which cannot be measured with actigraphy (Cornacchia et al., 2019). Participant B's sleep results do however duplicate previous findings of reduced sleep minutes, fragmented sleep, and difficulty with maintaining sleep (Stores, 2019). Participant B did not get the recommended amount of sleep most nights and had many extended awake periods after sleep onset. Early

waking, which is present in the literature for individuals with DS, was not found with this participant, however this could be due to participant going to bed around 2:00 am most nights. Due to going to sleep at such an hour, the participant likely needed to sleep in later into mid-morning hours to get more sleep; still, participant did not get the recommended amount of sleep. The consistent bedtimes in the early morning hours and consistent waketimes in the mid-morning hours reflects a circadian rhythm typically observed in adolescents (Hagenauer et al., 2009). Adolescents tend to get sleepy later in the evening and need to sleep later into the morning (Hagenauer et al., 2009). Evolutionary theorists have posited that this natural shift in circadian rhythm serves to provide opportunities for individuation from sleeping family members and socialization with peers, an important aspect of adolescence (Walker 2017). It could be that this young adult with DS is developmentally delayed in sleep needs and circadian rhythm; it would not necessarily be surprising for this participant to be "developmentally sleep delayed," as Down syndrome can cause developmental delay in other areas of life (e.g. behavioral, physical, cognitive, social delay; CDC, 2019).

The Sleep of a Young Adult with Mild Intellectual Disability

Participant C had the best sleep quantity and quality of all the participants in the study by far. Participant C got well above the minimum recommendation for sleep minutes at night, with an average of 8 and a half hours. Participant C's activity percentages and sleep efficiency percentages reflect good sleep quality. However, sleep latency averages that fall below 10 minutes most nights, and below 5 minutes a few nights, indicate sleep debt. This debt could be the result of time spent awake in the night; wake after sleep onset average is 20.56 minutes, right above the recommended maximum of 20 minutes. So, this participant possibly has difficulty with sleep maintenance and fragmented sleep but that appears to be the extent of data suggesting

suboptimal sleep for this participant. Richdale and Baker (2014) found that severity of sleep problems often positively correlates with severity of intellectual disability; Participant C's results seem to reflect that correlation as signs of sleep problems are small and diagnosis of intellectual disability is mild.

The Sleep of a Young Adult with Mild Intellectual Disability and Generalized Anxiety Disorder

Participant D, diagnosed with mild intellectual disability and generalized anxiety disorder (GAD), appears to experience significant sleep disruptions. There appears to be considerable differences between Participant D and Participant C, highlighting both comorbidity issues and individual variation in DD. With a GAD diagnosis, it is not surprising to find increased sleep disruptions given the adverse effects anxiety can have on sleep (Walker, 2017). Individuals with anxiety disorders often experience difficulty with initiating and maintaining sleep, and poor sleep efficiency (Mellman, 2006). These findings are reflected in the sleep patterns noted for Participant D, particularly difficulty with falling asleep, with very long wake after sleep onset, ranging from 31.75 to 64 minutes. Whether Participant D's sleep disruptions are caused by GAD or contribute to GAD, it is clear that Participant D experiences suboptimal sleep and has potential problems with getting enough sleep and with staying asleep.

The Sleep of a Young Adult with 7p Deletion Syndrome

This study is a first step towards understanding the sleep of young adults with 7p deletion syndrome in that, to this researcher's knowledge, it is the first study investigating the sleep of a young adult with 7p deletion syndrome. Participant E got the recommended amount of sleep and while there was some activity during sleep, overall had a high sleep efficiency rate. Sleep latency is suggestive of sleep debt and the participant experienced difficulty with sleep maintenance,

averaging 42 minutes awake after sleep onset. The extended wake after sleep onset could be contributing to the sleep debt demonstrated in the short sleep latency.

The Sleep of a Young Adult with Bilateral Perisylvian Polymicrogyria

This study is also a first step towards understanding the sleep typical for young adults with BPP as it is, to this researcher's knowledge, the first study to investigate the sleep of a young adult with BPP. The most striking characteristic of Participant F's sleep is the variability of sleep parameters. Participant F got the recommended amount of sleep about half the time and less than 7 hours the of the time. One week after sleep onset average was 0 minutes, another 7.25, and another 52.67 minutes. Participant did consistently have high sleep efficiency percentages and low activity percentages. For most nights sleep latency fell between 5 and 10 minutes, suggesting possible poor sleep health. It appears that for this participant, the most pressing sleep problem is inconsistency in sleep quantity and sleep quality.

Implications

This study aimed to empirically investigate the sleep of young adults with developmental disabilities in order to identify potential sleep problems to be addressed in efforts to maximize individuals' functionality. According to dynamic systems theory, internal factors such as sleep influences a person's self-organization, development, and thus health and functioning (Smith & Thelen, 2003). This study's findings implicate that young adults with DD experience suboptimal sleep. Participants had greatest difficulty with getting the recommended amount of sleep each night and maintaining sleep.

Getting sufficient sleep is crucial for optimal physical health. According to restorative sleep theory and the findings of numerous studies, during sleep the body tends to the

rejuvenation and renewal of cells, tissues, and organs; the body releases important hormones that regulate physical functioning (Adams, 1980; Walker, 2017). By not getting the recommended amount of sleep every night, these processes may be compromised or limited, adversely effecting participants' physical health. Compromised sleep, such as found in this sample, can increase risk for physical health problems, including health problems to which this population is already predisposed (e.g. obesity, osteoporosis, digestive problems, and autoimmune disorders; Prather et al., 2012; Reutrakul & Van Cauter, 2018; Spiegal et al, 2004; Stein et al., 2011). Study findings also suggest participants may experience mental health symptoms due to inadequate sleep. Not getting adequate sleep quantity and quality can cause depression and anxiety symptoms; young adults with developmental disabilities are already at greater risk of experiencing depression and anxiety symptoms, especially when unable to participate in activities associated with young adulthood (Austin et al., 2018; Dunham et al., 2018; Salkever, 2000; Stein et al., 2011; Walker, 2017; Whitney et al., 2019). In order to optimize mental health, functionality must be maximized so young adults with DD can pursue and achieve young adulthood goals.

Limitations in cognitive and social functioning are characteristics of developmental disabilities (CDC, 2019). According to brain plasticity theory sleep is an important mechanism for learning and cognitive functioning (Maquet et al., 2003; Riberio, 2012). Therefore, the potential sleep problems identified in this study implicate that participants may not be experiencing maximized cognitive functioning. According to Dahl's sleep theory, sleep provides the prefrontal cortex with important opportunities to recalibrate communications with systems influencing mood and emotion regulation (Dahl, 1996.) Consequently, the potential sleep disturbances observed in these participants can also be compromising social functioning.

Individuals with DD are more likely to be employed when they have higher cognitive and social functioning (Park & Park, 2019; Su et al., 2008; Tomaszewski et al., 2018). Interpersonal skills, communication skills, social problem solving, and time, place, and person orientation are important skills for employment. In fact, the most common reasons for individuals with DD to not be employed or dismissed from employment are lack of emotional control, limited attention span and memory, and deficits in social skills and expressive language skills (Stein et al., 2011; Su et al., 2008; Tomaszewski et al., 2018). As impaired sleep can compromise cognitive and social functioning, addressing potential sleep problems in this population is necessary to maximize cognitive and social functioning and consequently improve individuals' ability to pursue and achieve goals related to young adulthood. Research has demonstrated the importance of sleep for functionality and health; the young adults in this study do not appear to get optimal sleep to experience functionality and health necessary for participation in developmentally appropriate activities.

This study's findings of suboptimal sleep, and the implications that has for participants' functioning, suggests that programs and professionals working with young adults with DD should make efforts to improve the quantity and quality of young adults' sleep. By investigating and establishing what is typical in the sleep of this population, programs and professionals can be better informed in how to optimize the sleep of this population through treatment and/or education. By improving the sleep of this population, individuals' physical and mental health can improve, cognitive and social functioning can improve and overall quality of life, participation in activities, and independence can increase.

Recommendations for Future Research

Future research should include pilot studies to test the efficacy of approaches to improving sleep within this population. Meta-analyses of the effectiveness of behavioral interventions for improving sleep in children with rare genetic neurodevelopmental disorders revealed promising effects of improving sleep by modifying sleep hygiene practices and sleep-wake schedules (Jan et al., 2008; McLay et al., 2019). These interventions educated participants about the importance of sleep and sleep hygiene practices. Participants were taught to create sleep-conducive environments: darkening the room, lowering the temperature, and eliminating auditory and visual stimulants as bedtime approaches (McLay et al., 2019). Calming activities that individuals can incorporate into routines include taking quiet baths, listening to quiet sounds, stories or lullabies, and rhythmic, repetitive, low-frequency movements such as stretching or self-massage (Jan et al., 2008). Best practices for programs and professionals who work with this population need to be established through future research efforts to promote individuals' highest level of functionality.

Further research should also continue the investigation of the sleep of young adults with DD. We must continue developing an understanding of the sleep that is typical for young adults with developmental disabilities. Based on the findings of the current study, more sleep studies should be conducted with young adults with DD using objective sleep measures to further investigate areas of potential sleep problems identified in this study: getting enough sleep and maintaining sleep. Future research studies should also explore the intraindividual variation findings of this study; for every participant night-to-night variation was greatest within wake after sleep onset, sleep latency, and activity.

Future studies should collect outcome data, potential correlates, and contributors to sleep to know how sleep or insufficient sleep contributes to the lives, health, and livelihood of young adults with DD as well as to know how to best target and improve sleep for this population. As this study was a secondary analysis of existing data and such variables were not collected and could not be used in guiding the interpretation and implications of this study's results.

Studies should also be conducted using different sample sizes. Studies can be conducted with larger sample size to increase generalizability of findings. Such studies can offer insight into the sleep commonly experienced by young adults with DDs. Studies can also be conducted with single or a small sample size with the same diagnoses but gather more personal details about the participant: diagnosis symptoms, functioning, medications, personal goals, and outcome variables (McLay et al., 2019). Such studies can identify sleep characteristics associated with specific developmental disabilities.

Limitations

The small sample size of this study leads to less generalizability of findings; according to the law of large numbers, the smaller the sample size the less likely sample results will be accurately representative of the population (Gravetter & Wallnau, 2013). However, generalizability of any study's findings will be limited; the variability of symptoms and severity of symptoms within and across developmental disabilities demands caution when generalizing participant findings to the population. However, this study has been an important step towards investigating the sleep of young adults with DD and is the first study to this researcher's knowledge to characterize sleep of individuals with 7p deletion syndrome and bilateral perisylvian polymicrogyria.

The participants of this study were on medications that could potentially affect sleep but could not be controlled. However, medications were taken daily and consistently therefore effects of medication on sleep were consistent each night. Future studies should collect information about participants' medications and consider potential impact on sleep findings.

Finally, actigraphy is suspected to significantly underestimate sleep onset latency and wake after sleep onset; since people are typically inactive while lying in bed waiting to fall asleep (or fall back asleep), the actigraph device may read awake time as sleep time. Sleep diaries as used (and were used in this study) in attempt to differentiate sleep and inactivity in bed before sleep onset, but still actigraphy has been found to significantly underestimate sleep latency and wake after sleep onset when compared to the more refined polysomnography (Frekedulegn et al., 2020). This is a noteworthy limitation especially considering that some of the most common sleep problems found in this population are extended sleep latency and wake after sleep onset, as well as problems settling at night, falling asleep, frequent night awakenings, difficulty maintaining sleep, and difficulty falling back asleep. This study did find long wake after sleep onset times but short sleep latency times. Further research should also investigate the sleep of young adults with DD using polysomnography to more accurately measure sleep latency and wake after sleep onset.

Conclusion

This study and its design addressed several gaps in the literature. First, this was a study of the sleep of young adults with DD, whereas most sleep research has studied the sleep of children with DD (McLay et al., 2019; Surtees et al., 2018). By including participants of one developmental stage (young adulthood) this study can provide information relevant to the developmental nature of sleep as sleep needs, quantity and quality changes across the lifespan

(Hirshowitz et al., 2015; Ohayon et al., 2017). Second, this study used objective sleep measures instead of subjective sleep measures. Subjective sleep measures provide a less detailed insight into sleep quality and have not been adjusted for participants with DD risking the underreporting or overreporting of sleep issues (Richdale & Baker, 2014; Spruyt & Gozal, 2011). This study also uniquely reports intraindividual variability of sleep parameters for participants. Most actigraphy studies have focused on reporting the mean values of sleep parameters with little attention to day-to-day fluctuations in sleep quantity and quality (Fekedulegn et al., 2020). Means for sleep parameters can provide a stable measure for understanding the character of a participant's sleep; including variability of sleep parameters provides a more holistic picture of what sleep is like for a participant (Fekedulegn et al., 2020). Another distinct strength of this study was that sleep data were gathered for 9-16 nights per participant. Actigraphy data is considered valid with four nights of data; five nights of data is considered extended monitoring (Sadeh, 2011). Gathering data across several nights for several weeks provides a longitudinal evaluation of the sleep typically experienced by these participants. Lastly, this study furthers our understanding of sleep of young adults with DD by presenting sleep parameters of a sample of non-degree seeking college students with DD. By reporting sleep parameters for individuals with specific diagnoses, this study answers McLay and collogues' (2019) call for more detailed analysis of sleep characteristics for distinctive diagnoses. Notably, this study includes participants with unique diagnoses including a female with fragile X syndrome, a participant with 7p deletion syndrome, and a participant with bilateral perisylvian polymicrogyria. Upon reviewing the sleep literature no studies could be found by this researcher on the sleep of individuals with 7p deletion syndrome or BPP. In all, this study contributes to the literature by

providing a detailed, objective look into the sleep of individuals and a group of young adults with developmental disabilities.

Sleep is important for physical health, mental health, cognitive functioning, and social functioning and persons with developmental disabilities have greater problems across these four domains. Literature has established that individuals with DD have suboptimal sleep, but objective research on the sleep of young adults with DD is lacking. This study addressed this gap and found indications suggesting that young adults with DD do experience insufficient sleep. Aggregate results indicate participants barely got the minimum recommendation of sleep a night (7-9 hours), but when individually analyzed, half the participants were getting less than 7 hours of sleep a night on average. Participants were found to have extensive wake after sleep onset times (greater than 20 minutes a night). Programs and professionals working with this population can use these findings in guiding the development of treatment and curricula. These findings suggest that education on the importance of getting sleep and behavior plans for bedtime and waketime routines can improve and increase the sleep of young adults with DD. Further research is needed to empirically evaluate the efficacy of such endeavors in improving the sleep of young adults with DD. Further research should also be conducted to evaluate the impact suboptimal sleep has on young adults with DD in their health, functioning, and pursuit of age-appropriate and diagnosis-appropriate independence. Doing so can improve the physical and mental health, as well as the cognitive and social functioning of young adults with DD. It can improve the degree to which young adults with DD are able to meet goals and participate in young adult activities such as employment, peer involvement, and independent living.

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