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Schlegelmilch, Amanda A. *The Health Literacy of Youth with Disabilities*

Abstract

UW-Stout's Vocational Rehabilitation Institution (SVRI) was interested in research pertaining to the health knowledge for youth with disabilities because of associated health problems and conditions that can develop later in life. The purpose of this research was to determine the health literacy and health status of youth with disabilities using a self-report survey instrument. The participants were 25 students from different school districts in Wisconsin with ages ranging from 11-17. The results from the survey revealed that in general youth with disabilities have a high to medium health literacy but a low to medium health status. The results also found that significant differences occurred between the health status scores with age and town of residency. Significant differences also occurred between the health literacy scores with school district and type of disability. Limitations to the study and reasons for the significant differences in health literacy and health status scores are discussed.

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Chapter I: Introduction

In the past few years there has been a greater emphasis on improving peoples' health literacy because it has an effect on health outcomes and behaviors (Manganello, 2006). Having a medium to high health literacy is important for everyone to maintain at all ages in order to lead a healthy lifestyle. It is especially important for youth to have a higher health literacy so that they have a good understanding of their health and how to make healthy life decisions that will transcend into their adult life. However, most research done on health literacy has been focused on adults and little attention has been given to the health literacy of youth ages 11-17. This research is particularly important for adolescents that have a higher risk of developing health conditions, like those with disabilities.

Statement of the Problem

Health attitudes and behaviors that develop in childhood and adolescence can predict adult health habits later in life (Borzekowski, 2009). Also, many health problems for adults, like smoking, unhealthy eating habits, and lack of exercise, have their start in adolescence (Zajicek-Farber, 1998). A growing number of adolescents with disabilities are now living longer lives because of new medical advances (White, 2002). The majority of youth with disabilities do not get the recommended amount of physical activity and often have unhealthy eating habits (Kalnins et al., 1999; Antle, Mills, Steele, Kalnins, & Rossen, 2007). As a result, youth living with disabilities have a much greater likelihood of developing secondary health conditions as they grow into adults, compared to youth without disabilities (Kalnins et al., 1999; Zajicek-Farber, 1998). Some of the secondary health conditions that can occur include: heart disease, stroke, respiratory problems, skin conditions, obesity, depression, muscle and joint pain, and

other chronic secondary health issues (Kalnins et al., 1999; Zajicek-Farber, 1998; Antle et al., 2007).

The main problem that youth with disabilities face is that their health literacy is lower than it should be which means they have a very difficult time making the appropriate health decisions, as well as, understanding basic health information (Steele et al., 1996). The problem with having a low health literacy is that it usually leads to poorer health outcomes, poorer use of health care services, higher health-related costs, and a lack of understanding health terms and written health information that are used to make health decisions (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). In contrast, improving the health literacy of youth can often lead to better health outcomes, overall improved health status, lower health-related costs, and an improved quality of life (Berkman et al., 2011; Sineonsson, Sturtz-McMillen, & Huntington, 2002).

The current study will try to answer three research questions about the health literacy and health status of youth with disabilities using a self-report survey. The three research questions are:

- What is the overall health status of youth with disabilities?
- What is the health literacy of youth with disabilities?
- Do differences exist between the demographic factors: age, type of disability, school district, and town of residency with health status/health literacy?

Purpose of the Study

The purpose of the study is to determine the health literacy and health status of youth with disabilities. The survey will also assess which stage of behavior change most youth are currently in, based on the health belief model theory. The study will examine if differences occur

in health literacy and health status based on type of disability, age, school district, and town of residency. The results from this study will be used to help improve the youth with disabilities' health literacy and health status and determine the stage of behavior change so that interventions can be tailored to the specific stage in the health belief model (HBM) in order to change unhealthy behaviors and habits.

Definition of Terms

Health Literacy. Healthy People 2010, a U.S. government program designed for health promotion, defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (as cited in Manganello, 2006, p. 840).

Types of Disabilities. Most of the studies in the literature review and the current study concentrated on one or two disabilities that included: spina bifida, cerebral palsy, developmental disabilities, and muscular dystrophy, learning disabilities, ADHD, and a few others (Kalnins et al., 1999; Zajicek-Farber, 1998; Antle et al., 2007).

Adolescents. This study and most of the studies in the literature review defined adolescents as youth aged 11-17 (Santoro & Speedling, 2011; Steele et al., 1996; Kalnins et al., 1999).

Secondary Conditions. One or more health conditions that are preventable and come as a result of an existing primary condition interacting with both environmental and individual factors (Sineonsson et al., 2002).

Health Belief Model (HBM). It is a behavior change health theory that contains different components to help explain, predict, and change health behaviors (Taylor et al., 2007).

Chapter II: Literature Review

Almost half of all Americans have limited or low health literacy (Berkman et al., 2011; Cashen, Dykes, & Gerber, 2004). Having a high health literacy can lead to better overall health outcomes, lower health-related costs, better quality of life, and greater ease with making health-related decisions (Berkman et al., 2011; Sineonsson et al., 2002). It has been reported that health care costs for individuals with a low health literacy are four times higher than for those individuals with an adequate health literacy. Those with limited health literacy also tend to spend about 500 more dollars on medical expenses (Rimmer & Rowland, 2008). It is especially important for youth to obtain a sufficient health literacy because health-related behaviors and attitudes often start in adolescence and transcend into adult life (Borzekowski, 2009).

Health Literacy

Literacy is the single best predictor of health status, even greater than age, income, employment status, education level, and race (Weiss, 2003). Therefore, literacy in general, and especially health literacy, is important for the overall health of youth as they grow into adults. The general health literacy for youth is relatively low, based on focus group results from adolescents in America (Santoro & Speedling, 2011). The focus groups found that adolescents have a low health literacy when it comes to reading health-related words, accurately describing symptoms, and identifying medical conditions (Santoro & Speedling, 2011).

There are several factors that contribute to someone's health literacy. The main aspects affecting health literacy include the abilities to obtain, process, and understand straightforward health information and services in order to make relevant decisions about their health. (Manganello, 2006). Obtaining health information refers to an individual's ability to search, find, ask, or access general and specific health information (Manganello, 2006). The information can

come from many different sources but it is important that the information come from an accurate and trusting source. Most young adolescents (age 11-15) used their mother as the primary resource for health information, as well as, primary healthcare providers, such as a doctor or school nurse (Ackard & Neumark-Sztainer, 2001). Compared to older adolescents (age 16-18) who used peers and media as their primary resource for health information and a small number who used their mother or health care provider (Ackard & Neumark-Sztainer, 2001). Processing and understanding health information refers to taking that information that was obtained and being able to apply it to different health situations in order to make accurate health decisions (Manganello, 2006). Most adolescents are concerned about their health and how to improve it, however several youth find the health information too challenging to comprehend (Manganello, 2006).

Adolescents with disabilities

More than 90% of youth with disabilities are now living into adulthood (White, 2002). Youth with physical, mental, and learning disabilities have been connected to low health literacy (Fetter, 2009). Youth without disabilities are associated with low health literacy as well, but the main difference between the two groups is that youth with disabilities are much more likely than youth without disabilities to develop secondary health conditions (Kalnins et al., 1999; Zajicek-Farber, 1998; Antle et al., 2007; Johnson, 2009; Santoro & Speedling, 2011). The secondary health conditions that can develop include: heart disease, stroke, respiratory problems, skin conditions, weight problems, depression, muscle and joint pain, and other chronic secondary health issues (Kalnins et al., 1999; Zajicek-Farber, 1998; Antle et al., 2007).

Youth with disabilities are more likely to have unhealthy eating behaviors, engage in more sedentary leisure activities, and get less regular physical exercise than youth without

disabilities (Kalnins et al., 1999; Antle et al., 2007; Hogan, McLellan, & Bauman, 2000; Johnson, 2009). Youth with disabilities have a 4.5 times higher rate of physical inactivity compared to those without disabilities (Johnson, 2009). This is leading to a greater number of health problems as they grow into adulthood (Rimmer & Rowland, 2008). They also have less social support from peers, experience more barriers to exercise, and have less independence from parents, than their youth counterparts without disabilities (Kemeny, Arnhold, & Herold, 2012; Hogan et al., 2000). In contrast, adolescents with disabilities are less likely to smoke cigarettes, drink alcohol, and use drugs when compared to youth without disabilities (Kalnins et al., 1999; Antle et al., 2007; Hogan et al., 2000; Steele et al., 1996).

In addition to the development of secondary conditions, youth with disabilities that have a low health literacy also tend to have poorer health outcomes, poorer use of healthcare services, limited access to healthcare facilities, and lowered life expectancy (Berkman et al., 2011; Kemeny et al., 2012). It was also reported that youth with disabilities have a much greater risk of developing obesity that will likely result in greater health problems and healthcare costs in adulthood compared to those youth without disabilities (Rimmer & Rowland, 2008).

Influential Factors

There are several factors that can influence and affect the health literacy of adolescents with and without disabilities. Media and education have some influence on health literacy for both youth with and without disabilities, the most significant factors that affect health literacy for youth include: family, peers, media, and education (Scull, Kupersmidt, Parker, Elmore, & Benson, 2010; Campbell, 2003). Family is the biggest influence on the health literacy of youth with disabilities (Campbell, 2003). Peers have a lower impact on health literacy for youth with

disabilities but have a big influence on the health literacy of youth without disabilities (Scull et al., 2010).

Family. Children and adolescents living in a family with low literacy rates tend to have decreased access to preventative healthcare, more likely to have unmet health needs, and make more unnecessary visits to the emergency room compared to youth living in a family with higher literacy rates (Sanders, Shaw, Ghislaine, Baur, & Rudd, 2009). Family, especially parents, is one factor that can impact the low level of adolescents' health literacy, mainly for youth with disabilities (Manganello, 2006). Since adolescents with disabilities are less independent than those without disabilities, reliance on their parents for guidance and behaviors is more prevalent (Antle et al., 2007). Families with youth that have disabilities play an important role in the adolescents' healthy lifestyle choices and are an essential source of emotional and social support (Antle et al., 2007). Most parents are aware of their influence in their child's life and the significance of health promotion for their children with disabilities. However, they may not know how to incorporate healthy behaviors in their children's lives (Antle et al., 2007).

Peers. Likewise, peers can have an immense influence on youth's health behaviors, attitudes, and literacy. Adolescents who have friends that participate in risky health behavior strongly predict the adolescent's own health risk behaviors (Prinstein, Boergers, & Spirito, 2001). Risky health behavior is defined as actions that can harm or hinder an individual's health, for example, smoking cigarettes, doing street drugs, and drinking excessive amounts of alcohol (Prinstein et al., 2001). Peer influence on health behaviors can be either direct or indirect (Scull et al., 2010). The direct influence is seen through positive or negative peer pressure, most likely in the form of verbal persuasion. Whereas, the indirect influence is seen through observational learning, most likely in the form of observing dominant peers engaging in unhealthy or healthy

behaviors (Scull et al., 2010). In most cases the unhealthy and risky behaviors observed by peers are more likely to influence behavior than the healthy and non-risky behaviors.

Peer influence is also apparent for youth with disabilities. Bryan, Pearl, and Fallon (2001) completed a study looking at conformity between students in junior high with and without learning disabilities. The results revealed that students with learning disabilities were more willing to conform to peer pressure than did students without disabilities. Girls were also more likely to conform to peer pressure than boys for both groups of students with or without learning disabilities (Bryan et al., 2001).

Media. Media can also influence youth behavior. Adolescents are being exposed to more media than ever before (Santoro & Speedling, 2011). Therefore, it can be a great tool in increasing health knowledge and understanding. The majority of adolescents in America, 93%, use the internet to look for and gain knowledge on health-related information (Santoro & Speedling, 2011). Although it's a good source for health information, there is a somewhat lack of access for certain vulnerable populations who can't afford to have internet access, such as, families that have youth with disabilities (Cashen et al., 2004). A recent study found that about 50 percent of homes claiming to have disabilities use the internet, compared to 81 percent of homes who do not have a disability (Rothman, 2011). Rothman (2011) found that most individuals with disabilities have no problem using the internet but they lack the appropriate funds to be able to afford access at home.

Education. Interestingly, adolescents seem concerned about improving their health literacy. However, the educational material presented may be too challenging for them to comprehend. A survey discovered that most adolescents are interested in knowing more about health and how to improve their health, yet about a quarter find the information too difficult to

understand (Manganello, 2006). Another survey related to literacy and health found that almost half of adolescent respondents read below their own grade level and a majority of health information was written at a higher reading level than youth can understand (Davis et al., 2006). Despite youth being concerned about improving their health literacy, there is little evidence suggesting that schools or other education systems are addressing this issue of low health literacy at this time.

Youth with disabilities often lack knowledge about their disabilities and the causes (Kalnins et al., 1999). This may indicate that more information and knowledge are needed for youth with disabilities, so that they can be better informed about their specific disabilities. Educational material presented in health programs and interventions should also include information on their disabilities in addition to promoting healthy habits, so that they can participate more in their self-care (Kalnins et al., 1999; Blum, 1991).

Barriers

Youth with disabilities have more barriers to overcome with exercise, and they tend to rely more on their parents for daily activities and food choices (Kemeny et al., 2012). Other limitations to activities that should be considered are: fatigue, pain, weight, lack of knowledge, lack of time, lack of facilities, and low self-esteem (Kemeny et al., 2012; Kang, Ragan, Zhu, & Frogley, 2007). Also, students with disabilities are much more likely to avoid playing sports that require demanding energy and activities than students without disabilities. Therefore, they are more likely to spend additional time engaging in sedentary behaviors than their counterparts who are active in sports (Rimmer & Rowland, 2008). These factors might explain why adolescents with disabilities engage in less physical activities and eat unhealthier than adolescents without disabilities.

Need for health literacy programs

In the past, little attention was given on promoting health or improving health literacy for youth with disabilities, let alone the general adolescent population. There is also very little research on including families that have youth with disabilities in health literacy surveys and research. More emphasis has now been put into improving health literacy and examining the importance of living a healthy lifestyle for youth with disabilities (Kemeny et al., 2012). Rimmer and Rowland (2008) emphasized that interventions and programs should be tailored to accommodate these differences and the focus for such programs should be on increasing physical activities and improving eating behaviors. Table 1 illustrates the differences between youth with and without disabilities. These differences show that programs and interventions should be focused on different issues for the youth with disabilities compared to those without disabilities.

Table 1

Health Issues/Concerns	Youth with disabilities	Youth without disabilities	Both youth with and without disabilities
Low health literacy level	Yes	Yes	Yes
High risk of developing health conditions	Yes		
More likely to have a unhealthy diet	Yes		
More likely to not engage in physical activity	Yes		
More Peer influence		Yes	
More Parental influence	Yes		
Media influence	Yes	Yes	Yes

Similarities and Differences Between Youth with and without Disabilities

Table 1 shows the similarities and differences in health issues and behaviors of youth with and without disabilities. The table helps to demonstrate how the two populations differ and where they are the same. Youth with disabilities have more issues than those without disabilities. There are only two issues that do not pertain to youth with disabilities: more likely to smoke and drink alcohol and more peer influence. Remarkably, those two issues are the only two that are more susceptible for youth without disabilities. As the chart shows there are more differences than similarities concerning the health of youth. However, both groups of youth have two similarities between them. They are both susceptible to media influence and both have lot health literacy. Since there are more differences than similarities, programs and interventions for youth should be separate for those with disabilities and those without disabilities, so that the information can be tailored to the concerns that are most relevant to each group (Kemeny et al., 2012; Johnson, 2009). This chart also helps to see where more research and interventions are needed considering youth with and without disabilities.

The government has also noticed the health discrepancies that have occurred for youth with disabilities (Johnson, 2009). In response they have created objectives and guidelines for physical activity goals for those with disabilities (Kemeny et al., 2012; Johnson, 2008). Johnson (2009) further stated that regular physical activities have many benefits for youth with disabilities, including: a positive effect on vital capacity (body function), improved muscle symmetry, improved functional performance, and gross motor function. These many benefits demonstrate the need for wellness and fitness programs for youth with disabilities.

Health Theory Base

The health theory that is most relevant and applicable for improving the health of youth with disabilities is the Health Belief Model (HBM). The HBM is used in many health promotion programs and interventions for several different populations and health conditions (Yarbrough & Braden, 2001; Becker & Janz, 1985). There are various health theories available to use for promoting and encouraging healthy living. However, the HBM seems to fit the best for promoting good health for youth with disabilities and changing their behavior into more healthy living habits (Kang et al., 2007).

The HBM has several constructs that make up the components of the health model. They include: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action. The perceived susceptibility refers to the individual's believed risk of developing a certain disease or condition. The perceived severity refers to the individual's level of seriousness of developing the condition. The perceived benefits are the positive outcomes received from engaging in the healthy behavior. Perceived barriers are the obstacles that get in the way of the individual engaging in the healthy behavior. Self-efficacy is the individual's belief that they can accomplish that behavior or task. Finally, the cues to action are the events, information, or people that prompts the individual to participate in the behavior (Taylor et al., 2007). The model helps to explain the influence of social, economic, and environmental factors on health behavior and it can also work to motivate a person to change their current behavior (Taylor et al., 2007).

The constructs of the HBM can be applied to the current research that examines the health literacy of youth with disabilities. The perceived susceptibility is the youth's belief that he or she is at risk of developing a secondary condition, as result of unhealthy habits. It can also

refer to the parent's belief that their child is at risk of developing a secondary condition. The perceived severity is the youth or parent's belief of how risky or severe the development of the condition may be. The perceived benefits are the positive outcomes the youth can obtain from the healthy behavior, like prevention of a condition or a better quality of life (Johnson, 2009). The perceived barriers are the obstacles the youth encounter as a result of doing the behavior, for example fatigue, lack of access for exercise facilities, lack of time, and pain or discomfort (Kang et al., 2007; Kemeny et al., 2012). Self-efficacy is the youth's belief that he or she can actually do the behavior, like engage in exercise daily. Finally, cues to action refer to the youth's environmental factors that can encourage them to engage in the behavior, for example, parent's supporting an increase in physical activity.

There is some empirical evidence supporting the application of the HBM to youth with disabilities and their parents (Kang et al., 2007; King et al., 2006; Peterson et al., 2008). Most research done only looked at one or two constructs in the model to fit with improving health for youth with disabilities but not the entire model. Kang et al. (2007) investigated exercise for youth with disabilities using the perceived barrier construct of the HBM. The results revealed that the most significant barriers youth with disabilities faced when it came to exercise were lack of time, pain or discomfort, lack of a place to exercise, and weather. Programs and interventions for youth with disabilities address these barriers that might be hindering the youth from exercising regularly (Kang et al., 2007).

Cues to action and self-efficacy are the two other constructs of the HBM that have been studied and tested for individuals with disabilities in connection to health promotion (King et al., 2006; Peterson et al., 2008). King et al. (2006) used surveys and interviews with youth and families living with disabilities to find out which determinates were more influential on physical

activity levels. The results revealed that cues to action in the form of family support and participation, as well as, barriers in the form of functional ability were the most influential factors for physical activity levels for youth with disabilities (King et al., 2006).

Self-efficacy was also found to be a significant factor in influencing physical activity for individuals with disabilities (Peterson et al., 2008). The self-efficacy construct of the HBM, was tested for adults with disabilities. Even though it was only tested for adults the results can still be applied to youth with disabilities because it tested two groups, both young and old adults, where the young adults were aged 17-25, close to the ages of the youth in the current study. The results from the study exhibited that the greater the individual's self-efficacy the higher they reported participating in physical activities, especially with their peers (Peterson et al., 2008). The younger adults also reported higher physical activity levels when they had social support from their families, compared to older adults, who reported higher physical activity levels when they had peer support (Peterson et al., 2008).

Summary

The health literacy of youth with disabilities is low, even though their population is more at risk for developing secondary conditions compared to their peers without disabilities (Kalnins et al., 1999; Zajicek-Farber, 1998; Antle et al., 2007; Steele et al., 1996). They also get less exercise and physical activity than the recommended amount for adolescents (Kalnins et al., 1999). There are many factors affecting health literacy and the level of physical activity the youth receives, including but not limited to: barriers, family support and involvement, education, peers, media, and self-efficacy (Manganello, 2006; Antle et al., 2007; Kang et al., 2007; King et al., 2006; Peterson et al., 2008). Therefore, youth with disabilities are in need of programs and interventions aimed at improving their health literacy and habits in order to improve their overall

health status and health literacy in order to help prevent secondary health conditions from developing.

The Current Research

The current research will help in furthering a measure for assessing the health literacy and health status of youth, aged 11-17, with disabilities. A survey was developed to measure their health literacy, health status, and stage of behavior change according the HBM. The health literacy and overall health status will be analyzed to determine if differences occur with the demographic factors of age, type of disability, and location. The results from the survey will reveal the health literacy and health status of youth with disabilities. The study will also examine stages in the health belief model of behavior change for youth with disabilities. The results will serve as a base for further research to look at tailoring health promotions for behavior change and improving health literacy levels for youth with disabilities.

Chapter III: Methodology

Youth with disabilities have more difficulty making appropriate health decisions, as well as, understanding basic health information than youth without disabilities (Steele et al., 1996). These health related issues can often lead to poorer health outcomes, poorer use of health care services, higher health-related costs, and a lack of understanding health terms and written health information (Berkman et al., 2011). Adolescents who have these health literacy problems often carry their health behaviors and attitudes into their adult life (Borzekowski, 2009).

Therefore, this research was designed to investigate the health literacy and health status of youth with disabilities ages 11-17. A survey was modified and developed from two previous studies to assess the health status and health literacy of youth with disabilities. A pilot study was conducted in paper format to determine if any changes needed to be made before the actual survey was implemented. After making minor changes to the survey based on results from the pilot, the electronic study was put into an online survey tool. Once consent forms signed by the parents were received by the schools, the link was e-mailed to the superintendents of the school districts, then forwarded to the students with disabilities to complete.

Participants

The participants used in the study were students with varying disabilities and ages ranging between 11-17. There were seven students selected to be a part of the pilot study. They were recruited by the transition service coordinator of the UW-Stout Vocational Rehab Institute (SVRI). He had contacts with superintendents and school personnel of different school districts in the area. A paper format was used and mailed to those students for the pilot. The names and addresses of those students were only used to mail out the survey and no identifying information was used for data analysis. The same employee was also able to recruit school districts that had

youth with disabilities willing to take the electronic survey. Consent forms from the student's parents were signed and obtained prior to any student taking the online version of the survey. No names or identifying information was obtained from the students in the electronic survey.

Measures

The survey was developed using and modifying two validated studies about health literacy and the Health Belief Model (HBM). The very beginning of the survey has five demographic questions, which include: age, grade, primary and secondary disability, school district, and city or town of residency. After the demographic questions, there are two sections of the survey that both use 5-point Likert scales for answering the 35 questions. The first section includes questions 1-24 and deals with questions pertaining to the HBM. It was modified from a previous validated study titled *Development of a Health Belief Model Based Instrument to Assess Worker Beliefs Using Personal Protective Equipment* by Wall (2009). The study used the HBM to assess occupational illness and was found using a journal article search engine, EBSCOhost, using keywords: validated study using the HBM. The study was validated using the test-retest method, with a Cronbach's alpha of .727 (Wall, 2009). This study was selected to be used in this research because it was a validated measure of the health belief model. The survey instrument was then modified to measure the youth with disability's stage in the HBM. The question format stayed the same but instead of asking about using protective equipment, the modified survey asked about developing secondary health conditions. Also about seven questions were omitted from the original study because of repetition, the length of the survey, and sensitivity of the material for youth.

The second section includes questions 25-35 and measures the general health literacy knowledge and health related information. It was modified from a previous validated study titled

Early Adolescents Perceptions of Health and Health Literacy by Brown, Teufel, & Birch, 2007, that was used to assess the health literacy of youth in general. The article was found using a journal article search engine, EBSCOhost, using keywords: validated study assessing the health literacy of youth. The study was validated with a Cronbach's alpha of .826 (Brown et al., 2007). The study was then slightly adapted to fit youth with disabilities, with only a few minor changes and additions. The instrument was selected for this research because it was a validated study that already assessed the health literacy of youth. The questions themselves were not changed only the scales were slightly changed to align with the 5-point scale that was used for the first part of the survey. Also two questions were added to assess their exercise level and their opinion about if they need to improve their health. The whole study is available for view in Appendix A: Pilot Survey or Appendix D: Final Survey.

Procedure

Before the survey could be implemented to the intended population, the research had to be approved by UW-Stout's Institutional Review Board (IRB). There were four documents submitted to the IRB in order to give the board enough information to approve the study. They included:

- A detailed form, provided by UW-Stout, explaining the different elements of the research that included the purpose of the study, the participants involved, and the procedure.
- The consent form for the participants and their parents or guardians to sign (Appendix C: Consent Form).
- The survey to be completed by the participants (Appendix A: Pilot Survey).

- A certificate stating that the researchers went through Human Subjects Training, which is a training program required by UW-Stout for any student who does research involving human subjects (Appendix E: Human Subjects Training Certificate).

After everything was received, IRB approval was granted for the research to be conducted (Appendix F: IRB Approval). The pilot study was then sent out to seven students with the intent to: determine the average time needed to complete the survey and to make sure the questions were easily understood and readable. The pilot study used a packet that was mailed out to seven students, who had previously agreed to participate in the study. The pilot study packet included an introductory letter that introduced this study and gave the participants instructions on how to complete the survey (Appendix B: Introductory Letter), a consent form for both the student and the student's parent(s) or guardian(s) to sign (Appendix C: Consent Form), the survey (Appendix A: Pilot Survey), and an addressed return envelope. Once the pilot surveys were returned, the results were used to revise the survey questions, as needed, the revised survey is available for view in (Appendix D: Final Survey).

Seven different youth were sent the pilot study packet to complete and return to the researchers. Their names and addresses were given by the different school districts and only used to send out the packets, no identifying information was used for data analysis. The students were given two weeks to complete the survey and send it back. Two surveys were mailed back to the researchers within the two week time frame. The participants were between ages 15 and 16, attending 9th and 11th grades in high school. Their primary and secondary disabilities were hydrocephalus, cerebral palsy, and Ehlers-Danlos. They were from the Eau Claire and Altoona school districts. Based on the results from the pilot study the survey on average took about 17.5

minutes to complete. One survey returned took 5 minutes, while the other survey returned took 30 minutes, both having different disabilities. This suggests that differing disabilities may alter how much time it takes to complete the survey. The only other comment that was on the pilot survey was stating that the participant already had developed a secondary health condition. Therefore, the only revision made on the electronic survey was rewording a few questions to accommodate participants that already had developed secondary health conditions (Appendix D: Final Survey).

The survey items were then transposed into Qualtrics, an online survey tool, with access provided by UW-Stout. The consent forms were mailed to the participant's parents or guardians by the school districts for the electronic survey. The parents mailed the consent forms back to the school's superintendent. Once the forms were received, the link to the online survey was then e-mailed to the school superintendents or school personnel of the different school districts. Only those participants who had signed consent from their parents would receive the link to the online survey from the school's superintendent of the different school districts. Those students who could take the survey then completed the electronic survey using the online survey tool.

Hypotheses

There are three research questions to be answered by the survey that was created and five hypotheses about the intended results. The three research questions are listed below:

- R1: What is the overall health status of youth with disabilities?
- R2: What is the level of health literacy for youth with disabilities?
- R3: Do differences exist between age, type of disability, school district, and town of residency with both health literacy and health status?

The five hypotheses for the results from the study were based on the research questions and are listed below:

- H1: The overall health status of youth with disabilities is low or unhealthy.
- H2: The level of health literacy for youth with disabilities is generally low.
- H3: Differences exist between age and health status/health literacy.
- H4: Differences exist between type of disability and health status/health literacy.
- H5: Differences exist between location/district and health status/health literacy.

Data Analysis

There will be a few different analysis techniques that will be used to assess the results from the survey. The first two hypotheses will be tested by using a score based on the responses of each question that pertains to the health status and health literacy. The scoring method will be used to test the health status and health literacy because of the use of the 5-point scale for the questions, it will be the best option for determining health literacy and health status. The higher score on the scale means a higher health literacy and a more healthy status, while a lower score on the scale means a lower health literacy and a more unhealthy status. Then, the means and standard deviations will be calculated to determine the average health literacy and average health status for the youth. The other three hypotheses will be tested by using t-tests and chi-squared to determine if there are significant differences between the dependent variables: health literacy and health status and the independent variables: age, type of disability, town of residency, and school district. The chi-square and t-test are being used in the analysis because they are the best test to use in order to measure if significant differences occur between the independent and dependent

variables. Since the dependent variables are dichotomous and the independent variables are nominal the t-test along with the chi-squared are the best available options for data analysis.

Chapter IV: Results

This study aimed to discover the health literacy and health status of youth with disabilities and to determine if any differences occur between health status and health literacy based on age, disability, school district, and town of residence. The data was collected between March and April of 2013. There were a total of 30 participants who took the survey. However, only 25 surveys were useable for data analysis. Four of the survey responses had to be deleted because either no responses were recorded or only the demographic questions were answered. One more response had to be omitted because the age of the participant was 18, which is one year older than the age range the study intended.

Descriptives and Frequencies

There were six different demographic questions the participants answered at the beginning of the survey which included: age, grade or year in school, type of disability, secondary disability, school district, and town or city of residence. The participants' ages ranged from 11-17 with an average or mean age ($M = 15.08$) and standard deviation ($SD = 1.82$). Their year in school ranged from 5th to 12th grades with an average grade of 9th or freshman in high school ($M = 9.40$, $SD = 1.98$).

There were six types of disabilities reported that included: ADHD, autism, cognitive disability, emotional and behavioral disorder, hearing impaired, learning disability, and one that was not specified. The most frequent disability listed was learning disability with 48% of the participants (Table 2). There were also seven different secondary disabilities that included: ADHD, asthma, diabetes, learning disability, short term memory, mood disorder/anxiety, and not applicable. The most frequent secondary disability listed was not applicable (64%) and ADHD (16%), all others were only reported once (Table 3).

Table 2

Frequencies of the Primary Disabilities

Disability	Frequencies	Percentages
ADHD	4	16%
Autism	2	8%
Cognitive disability	3	12%
Emotional and behavioral disorder	1	4%
Hearing impaired	2	8%
Learning disability	12	48%
Not specified	1	4%

Table 3

Frequencies of Secondary Disabilities

Secondary Disability	Frequencies	Percentages
ADHD	4	16%
Asthma	1	4%
Diabetes	1	4%
Mood disorder, anxiety, and ODD	1	4%
Short term memory	1	4%
Learning disability	1	4%
Not applicable	16	64%

The last two demographic questions pertained to their school district and town of residence. There were a total of 7 different school districts reported that included: Altoona, Eau Claire Area, New Auburn, Hortonville, Marshfield, Oconomowoc, and Chippewa Area Catholic Schools. The school district with the highest number of responses was Altoona (68%). Eight different towns included: Altoona, Chippewa Falls, Eau Claire, Fall Creek, Greenville, Marshfield, New Auburn, and Oconomowoc. The highest responses came from the town of Altoona (36%) followed by Eau Claire (20%). Table 4 illustrates frequencies of responses to school districts and town of residence.

Table 4

School Districts and Town of Residence for Youth with Disabilities

School District	Frequencies	Percentages	Town	Frequencies	Percentages
Altoona	17	68%	Altoona	9	36%
Eau Claire	2	8%	Eau Claire	5	20%
Hortonville	1	4%	Greenville	1	4%
Chippewa Area Catholic School	1	4%	Chippewa Falls	2	8%
Marshfield	1	4%	Marshfield	1	4%
New Auburn	2	8%	New Auburn	2	8%
Oconomowoc	1	4%	Oconomowoc	1	4%
			Fall Creek	4	16%

Hypothesis Testing

There were three different research questions to be answered and five different hypotheses to be tested using the data collected. Below are the results from the survey and various data analyses used to answer the research questions and hypotheses.

Health literacy. The health literacy level of youth with disabilities was calculated by adding the values from six questions measuring health literacy. Each of the six questions used a 5-point Likert scale to measure health literacy (Appendix D):

- Most of what I hear about health is,
- I try to follow what I'm taught about health,
- How much can an adolescent do to grow up to be a healthy adult?
- What is your knowledge on health related issues?
- What is your understanding of general health information?
- How interested are you in improving your knowledge and understanding about health?

The answers from the questions were added together to give a health literacy score for each participant. The last question was reverse coded, meaning their answers to the questions were scored opposite, for example if someone put a 2 for their answer it would be scored as a 4 and someone who put a 5 would be scored as a 1; that was done because youth with higher health literacy will not need to improve their knowledge or understanding of health related issues. Scores ranging from 6-15 were considered low health literacy, scores ranging from 16-19 were considered medium health literacy, and scores ranging from 20-28 were considered high health literacy. The average score of the participants was ($M = 19.16$) and ($SD = 4.43$).

According to the results most youth with disabilities have a medium to high health literacy. This finding is inconsistent with the hypothesis that youth with disabilities have low health literacy.

The bar graph (Figure 1) displays the frequencies of the health literacy scores.

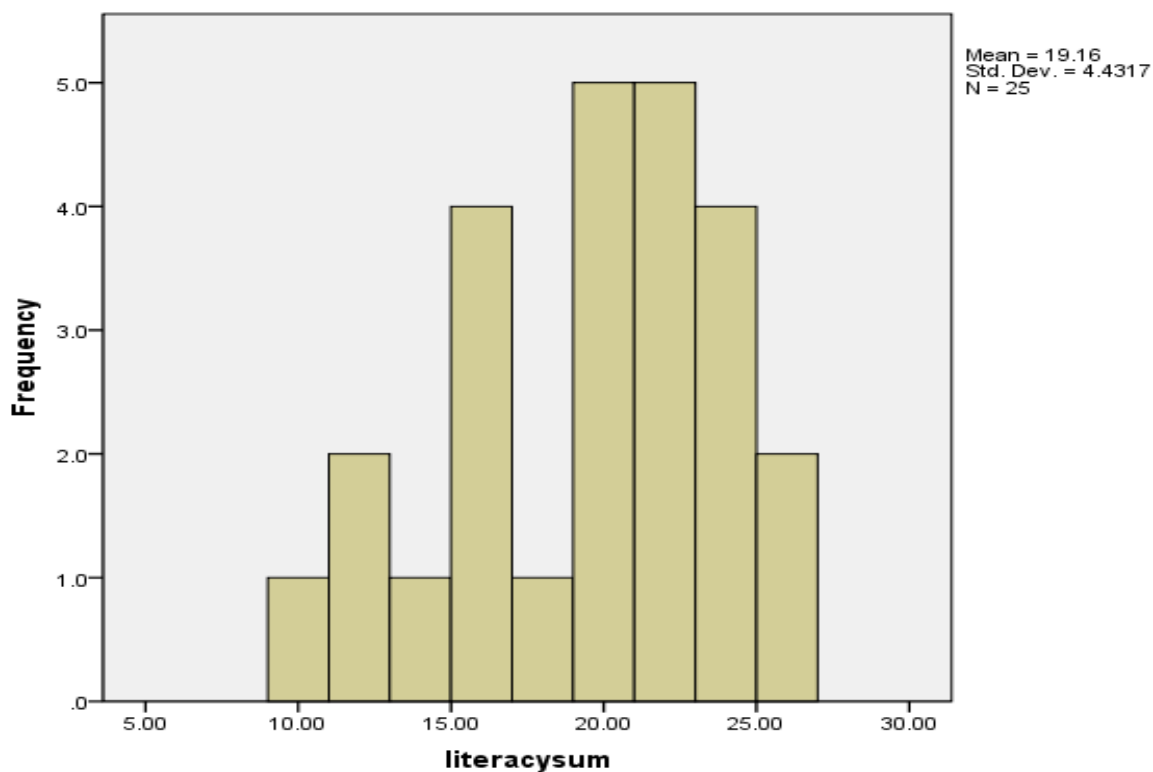


Figure 1: Bar Graph of Frequencies for the Health Literacy Scores

Health status. The health status of youth with disabilities was calculated by adding the values of three questions measuring health status. Each of the three questions used a 5-point Likert scale to measure health status (Appendix D):

- I consider my health to be,
- How many days a week do you participate in physical activities?
- Do you think you need to improve your health?

The answers from the questions were added together to give a health status score for each participant. The last question was reverse coded which means their answers to the questions were scored opposite, for example if someone put a 2 for their answer it would be scored as a 4 and someone who put a 5 would be scored as a 1; because those who are healthy will not need to improve their health. Scores ranging from 3-9 were considered unhealthy, scores ranging from 10-12 were considered neutral, and scores ranging from 13-15 were considered to be healthy. The average score of the participants was ($M = 9.8$) and ($SD = 2.8$). Therefore, the results indicate that most youth with disabilities have an unhealthy to neutral health status. This finding is consistent with the hypothesis that youth with disabilities have an unhealthy or low health status. The bar graph (Figure 2) illustrates the frequencies of the health status scores:

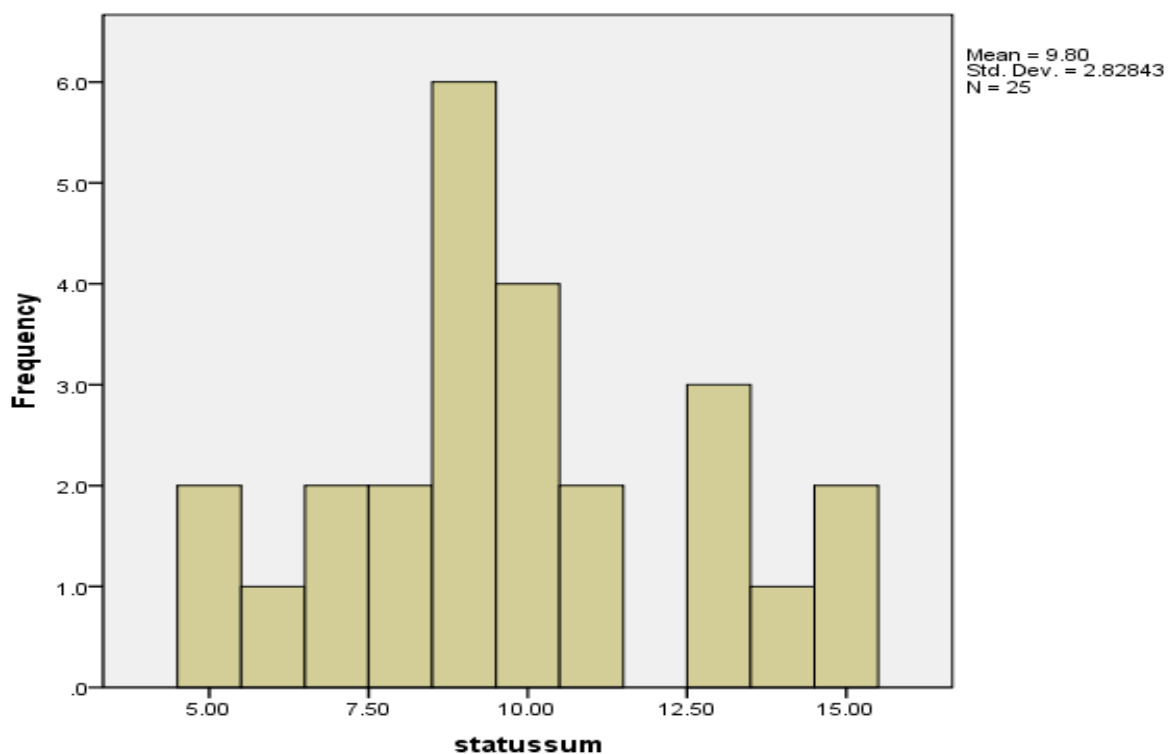


Figure 2: Bar Graph of Frequencies for the Health Status Score

Significance testing

Since the dependent variables of health literacy and health status in this study were continuous and the independent variables of age, disability, school district and town of residency were nominal, both Chi-square and t-tests were performed to test if significant differences occurred between the groups. Significance was found with health status and two of the independent variables: age and town of residency. Significance was also found with health literacy with two of the independent variables: type of disability and school district. These results were somewhat consistent with the hypotheses that were proposed in the current research.

Chi-square Tests. The chi-square test was performed on the dependent variables of health status and health literacy with the independent variables of age, type of disability, school district, and town of residency. Significance was discovered with health status scores and two of the independent variables: age and town of residency. Significance was also discovered with health literacy and two of the independent variables: type of disability and school district. There was a significant difference between health status and age, $X^2 (54, N = 25) = 73.4, p = .041$, and health status and town of residency, $X^2 (63, N = 25) = 83.3, p = .045$. In addition, significance was found between health literacy and type of disability, $X^2 (72, N = 25) = 100.5, p = .015$, and between health literacy and school district, $X^2 (60, N = 25) = 88.7, p = .009$. Finally, marginal significance was found between health status and school district, $X^2 (45, N = 25) = 58.4, p = .087$. Based on the results from the survey, four of the five hypotheses were confirmed.

- H1: The overall health status of youth with disabilities is low or unhealthy.
- H3: Differences exist between age and health status.
- H4: Differences exist between type of disability and health literacy.

- H5: Differences exist between school district and health literacy; differences exist between town of residency and health status.

T-tests. Four different demographic questions were analyzed with both the health literacy and health status scores to see if significant differences occurred within the different groups. Each of the four questions had 7 to 8 different answers. In order to perform t-tests, the nominal variables of age, disability, school district, and town of residency, had to be divided into two groups. Since all of the variables had one dominant response, the groups were divided into one dominant group and the other group with all other responses. Age was divided into two groups with ages 11-14 being one group and ages 15-17 being the other group; this was done so that both groups had about even participants. Disability was divided into one group with just learning disabilities because it was the dominant answer and the other group with all other responses. School district and town were both divided the same way with Altoona being in one group because it was the dominant response and other all responses into the other group.

T-tests for all of the demographic groups with health literacy and health status revealed significance with only one variable, school district. The average health literacy scores for participants in the Altoona school district was ($M = 20.6, SD = 3.5$) and the average health literacy scores for participants in all other school districts was ($M = 16.0, SD = 4.8$). A significant difference was found between the mean health literacy scores for the two school districts groups $t(25) = 2.76, p = .01$. This result suggests that participants in the Altoona school district have, on average, higher health literacy compared to the other school districts.

Reliability

The reliability of the survey measures was tested by using Cronbach's alpha for the health literacy measure, the health status measure, and the HBM measure. Cronbach's alpha for

the health literacy measure was .78, the health status measure was .66, and the HBM measure was .88. Therefore, the HBM was highly reliable, the health literacy measure's reliability was acceptable, and the health status measure was marginally reliable. The low reliability of the health status measure was probably because it had only three questions.

Health Information Sources

There were two questions in the survey that pertained to the sources where youth with disabilities received most of their information about health. The questions were:

- From which of these sources do you learn the most about health?
- If you had an important question about health, where would you go first for information?

The results show that most of the youth get their health information from school (40%) followed by a doctor or nurse (28%). The results of the other question show that most of the youth go to their parents for questions about health (36%) followed by doctor or nurse (24%) and the internet (24%). Table 5 illustrates the frequencies of the participants' answers to both questions.

Table 5

Frequencies of Answers for the Health Information Source Questions

Important Question About Health	Frequency	Percentage	Learn most About Health	Frequency	Percentage
Internet	6	24%	Internet	1	4%
School	3	12%	School	10	40%
Parents/Guardian	9	36%	Parents/Guardian	6	24%
A Doctor or Nurse	6	24%	A Doctor or Nurse	7	28%
Some Other Source	1	4%	Some other Source	1	4%

Health Belief Model Data

The results from the health belief model (HBM) portion of the survey revealed that most youth with disabilities are in the “perceived barriers stage”. The results were calculated by adding together the scores from each question pertaining to each of the six stages in the HBM. Then the means and standard deviations were calculated for each of the six stages. The average score of the barriers stage was ($M = 20$) and ($SD = 7.4$), this was the highest rated stage by far compared to the rest of the stages in the HBM. This means that most youth know they are at risk for developing secondary health conditions, however certain barriers such as: pain or discomfort, adequate exercise facilities, fatigue, time, education, confidence, and exercise companionship may be hindering the youth from making appropriate health decisions.

Chapter V: Discussion

This research was conducted with the intent to measure the health literacy and health status of youth with disabilities between the ages of 11-17 and to determine if differences occur between the demographic factors such as: age, type of disability, school district, and town of residency with reported health status and health literacy. The results from the self-report survey revealed that the health literacy of youth with disabilities is medium to high and the health status of youth with disabilities is low to medium. Significant differences were found between the health status and two of the demographic factors: age, and town of residency. There were also significant differences found between health literacy and two of the demographic factors: type of disability, and school district. Marginal significance was found between health status and school district. These findings were consistent with the research presented in the literature review.

Limitations

There were a few limitations to the study that may have affected the results. The sample size was small ($N = 25$) - the school district that had the most prospective students decided at the last minute not to participate because of unforeseen circumstances. Also, the Altoona school district had the most frequent responses by the participants. This might have skewed the data and shown significant differences which may not have occurred if a more diverse population was used for this study. Also, since most of the participants were from towns in north central Wisconsin, these results should not be generalized to other populations.

Another limitation to the study was that the participants were minors or under the age of 18. Therefore, consent needed to be obtained by their parents or guardians. Since only those individuals that had signed consent forms were permitted to attempt the survey, and since the process to obtain parental consent was difficult and time consuming, it further limited the

number of participants in this study. The lengthy time lapse for the school superintendents to respond to the invitation e-mails for both the pilot study and the electronic study also further delayed the implementation of the survey.

Some of the previous research looked at certain youth with disabilities that were more at risk for developing secondary health conditions such as, spina bifida, cerebral palsy, and muscular dystrophy (Kalnins et al., 1999; Zajicek-Farber, 1998; Antle et al., 2007). However, the current study had the majority of youth with disabilities listing their disability as either a learning disability or ADHD. Therefore, the results may have been different if the disabilities would have been more diverse and among those with a higher risk of developing a secondary health condition.

The survey was a self-report survey, so the results may not reflect the whole truth because the participants could be altering their answers and not giving the true responses (Van Selm & Janskowski, 2006). Another limitation to consider is that the survey was done electronically using an online survey tool, as a result, there is no certainty that the participant who took the survey was the person who was supposed to take the survey (Van Selm & Janskowski, 2006).

Also, since it was done electronically there is a possibility that there could have been technical problems with the pages loading correctly or the software working properly. Similarly, there could have been difficulty understanding the directions and how to answer the questions accurately. Another issue of having the survey online is accessibility to online access and knowledge of using computer software. Some youth may have limited access to a computer or the internet, with the only access available while they are at school (Rothman, 2011). Another

issue to consider is that some youth may have a disability that could hinder them from using a regular computer or certain computer software. Some of the youth may also have limited knowledge about how to use a computer (Langone, Clees, Rieber, & Matzko, 2003).

Conclusions

The results from this study are mixed. The current study found that the majority of youth with disabilities have a low to medium health status, implying that most youth with disabilities are somewhat unhealthy. This finding is consistent with the prior research which discovered that youth with disabilities tend to have significantly lower levels of physical activity and less healthy diets than those without disabilities (Rimmer & Rowland, 2008; Steele et al., 1996). However, another finding from the current study showed that youth with disabilities have a medium to high health literacy, while research indicated that physical, mental, and learning disabilities can be factors in contributing to low health literacy (Fetter, 2009). Finally, the findings from the current study demonstrate that significant differences occur in health status when it comes to age and town of residency; and also in health literacy when it comes to type of disability and school district. However, there was limited research looking at those demographic factors and their relationship to health literacy and health status.

Significant differences were discovered based on results from the survey between health status and age, as well as, town of residency. These differences may have occurred for multiple reasons. One possible reason why a difference in health status was found with this age group (11-17) is that they may still have more of a parental influence on their lives and therefore follow healthier behaviors. It is important to note that the results simply implicated that there was a significant difference in health status between the different ages and should not be implied that

certain ages had a better or worse health status. Therefore, more research needs to be conducted to investigate the relationship and reasons for the differences.

An explanation for the differences found with health status and town of residency might be the perception of better health facilities in certain towns. The results did not indicate which towns had youth with better health statuses, just that a significant difference in health status occurred between the different towns. Consequently, more research should be conducted to evaluate the causal factors influencing the health statuses for youth with disabilities in these towns.

Significant differences were discovered based on results from the survey between health literacy and type of disability, as well as, school district. One possible explanation why health literacy was better in Altoona school districts compared to others might be because their general health education is better than other school districts in the area. Another reason for the discrepancy might be that parents are more involved with their student's health knowledge and understanding than other districts. A reason for the difference in health literacy and type of disability might be that specific disability groups may be offered different classes or programs about knowledge on health related issues that are not available for everyone that has a disability. The results did not show which disability had a better or worse health literacy, just that differences in health literacy occurred between the types of disability. As a result, more research needs to be conducted to find out why these differences occur.

The results from the HBM portion of the survey discovered that most youth with disabilities are in the "perceived barriers stage". This is consistent with the findings from previous research which indicated that barriers were a big issue with hindering physical activity

among youth with disabilities (Kemeny et al., 2012; Kang et al., 2007). Therefore, it is important to engage in further research to figure out these specific barriers that are hindering the youth from engaging in healthy habits and target these barriers in programs and interventions in order to encourage the youth to change their unhealthy behaviors.

Recommendations

There are a few recommendations for future research on the topic of health literacy and health status of youth with disabilities. One recommendation for further research is conducting a similar study that specifically targets certain disabilities that are more at risk for secondary conditions rather than any disability. A suggestion for future research should be focused at looking into the school districts' health curriculum as this seems a likely influential factor on youth's health literacy.

Another recommendation for research is using a larger survey with more questions and having example questions that are not self-report. For example, have participants identify health conditions based on symptoms to further measure their health literacy, instead of just having self-report data. Gender should also be included in future research to determine if gender has an effect on health status or health literacy.

The results also revealed that most youth with disabilities are in the "perceived barriers stage" in the HBM, therefore programs should be focused on fixing the specific barriers that could be hindering the youth from exercising regularly or eating more healthy. Also, more research on which specific barriers are the most problematic for youth with disabilities would be useful in preventing and helping fixing those barriers. Finally, programs and interventions for

youth with disabilities should be focused on improving overall health and health habits instead of health literacy education, at least for the school districts in this study.

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Appendix A: Pilot Study

Modified survey for youth with disabilities (Wall, 2009; Brown, Teufel, & Birch, 2007)

Definition of secondary health condition- One or more health conditions that are preventable and come as a result of an existing primary condition interacting with both environmental and individual factors (Sineonsson, Sturtz-McMillen, & Huntington, 2002).

Directions- For questions 1-24, Indicate for each question which best describes you using a 5-point scale, ranging from 1 being strongly disagree and 5 being strongly agree. For questions 25-35, use the scale that is associated with each question.

What is your age? _____

What grade are you in? _____

What is your Gender? _____

What type of primary disability do you have? _____

If you have a secondary disability, what is it? _____

Which school district do you attend? _____

What town do you live in? _____

- 1. I believe my chances of developing a secondary health condition sometime in my adult life, are great.**

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1

2

3

4

5

2. I worry about developing a secondary health condition.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

3. Measures to increase my health will help prevent me from developing secondary health conditions.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

4. If I developed a secondary health condition, my life would change.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

5. I am concerned that I may develop a secondary health condition in my lifetime.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

6. Engaging in more physical activity will help prevent the development of secondary health conditions.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

7. I can prevent secondary health conditions from developing.

<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither Agree or Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1	2	3	4	5

8. I benefit by exercising on a regular basis.

<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither Agree or Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1	2	3	4	5

9. I experience pain or discomfort when I exercise.

<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither Agree or Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1	2	3	4	5

10. I don't have access to acceptable exercise facilities.

<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither Agree or Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1	2	3	4	5

11. I experience fatigue when I exercise.

<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither Agree or Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1	2	3	4	5

12. I don't have enough time in my day to exercise.

<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Neither Agree or Disagree</i>	<i>Agree</i>	<i>Strongly Agree</i>
1	2	3	4	5

13. I would exercise more if I was more educated about exercise activities.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

14. I would exercise more if I were more confident in my abilities to exercise.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

15. I would play more sports if they were less physically demanding.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

16. I have no one to exercise with.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

17. I would exercise more if my family would join me.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

18. I would exercise more if my friends would join me.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

19. I would exercise more if there were after school programs to join for physical fitness.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

20. My family supports and encourages me to exercise regularly.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

21. My friends support and encourage me to exercise regularly.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

22. I believe that I have the ability to exercise more.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

**23. I am confident that if I exercise more it can help to prevent a secondary health
condition from developing.**

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

24. I am confident that if I exercise more it will improve my overall health.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

For this section please answer each question using the appropriate scale, located after each question.

25. Most of what I hear about health is,

Very hard to understand Sort of hard to understand Neither hard or easy to understand

1 2 3

Sort of easy to understand Very easy to understand

4 5

26. From which of these do you learn the most about health?

The Internet School Parents/Guardian A doctor or nurse Friends/peers Another way

1 2 3 4 5 6

27. If you had an important question about health, where would you go first for information?

The Internet School Parents/Guardian A doctor or nurse Friends/peers Another way

1 2 3 4 5 6

28. I try to follow what I'm taught about health

Never Hardly ever Sometimes Most of the time All of the time

1 2 3 4 5

29. How much can an adolescent do to grow up to be a health adult?

I don't know Almost nothing A little Some A lot

1 2 3 4 5

30. What is your knowledge on health related issues?

Very unknowledgeable Sort of unknowledgeable Neither knowledgeable or unknowledgeable

1 2 3

Sort of knowledgeable Very knowledgeable

4 5

31. What is your understanding of general health information?

Very low Low Neither low or high High Very high

1 2 3 4 5

32. How interested are you in improving your knowledge and understanding about health?

Very uninterested Sort of uninterested Neither uninterested or interested

1 2 3

Sort of interested Very interested

4 5

33. I consider myself to be,

Very unhealthy	Sort of unhealthy	Neither health or unhealthy
1	2	3
Sort of healthy	Very healthy	
4	5	

34. How many days a week do you participate in physical activities?

0	1-2	3-4	5-6	7
1	2	3	4	5

35. Do you think you need to improve your health?

Not at all	A little	Somewhat	Mostly	Very much
1	2	3	4	5

About how long did it take you to complete the survey? _____

Thank you very much for your time and attention with completing the survey!

Use the space below for any additional comments about the survey.

Appendix B: Introductory Letter

Dear Participant,

I am inviting you to please participate in the survey on the next pages to help in finding more about perceptions and knowledge on health related issues for youth ages 11-17. This survey is a pilot study, using only about 10 people. The purpose of the pilot study is to find any areas or sections of the survey that need improvement or modification before the survey gets distributed into a larger population In Wisconsin. When completing the survey, please pay attention to the few questions below:

- **Are the survey questions easy to understand? If no, which questions did you not understand?**
- **Were the questions easy to answer? If no, what questions were not easy to answer?**
- **Were the scales for answering the questions easy to read and answer? If no, what might help to make them easier?**
- **Are there any questions that need to be reworded? If yes, which questions?**
- **Is there anything about the survey questions that you would change? What are those changes?**

Directions: First please read over the consent form and make sure to sign and have your parent or guardian sign it before completing the survey. Then, complete the survey by answering the questions using the scales located below each question. I also would like feedback about the survey questions, using the questions above as a guideline. Please write in all of your comments and concerns right on the survey by each of the questions. At the end of the survey there is a

space to write in about how much time it took you to complete this survey and there is space available to write in any other comments or concerns you have regarding the survey questions.

Participation in this survey is completely voluntary and confidential. Names or any other identifying information will only be available to the investigator and advisor and will not be used for any data analysis. If you do not wish to complete this pilot survey, please dispose of the contents. Since some of the questions might change as a result of the pilot you can also take the real version, which will be available online and a link will be e-mailed to you at a later date, if you wish to participate in both. Enclosed is a return envelope with our address and paid postage, when done completing the survey please include both the signed consent form and the filled out survey, as soon as you can, preferably within two weeks of receiving this packet.

Thank you very much for your time and comments on this survey.

If you have any questions or concerns, please feel free to contact me or my research advisor

Investigator: Amanda Schlegelmilch, B.A.

715.579.0594

schlegelmilcha@my.uwstout.edu

1618 Laurel Ave

Eau Claire, WI 54701

Research Advisor: John Lui, PhD., MBA, CRC

715.235.2470

luij@uwstout.edu

SVRI 221 10th Ave., Voc. Rehab Dept. Rm. 101A

Menomonie, WI 54751

Appendix C: Consent Form

Consent form to participate in UW-Stout Approved Research Project

Title: The Health Literacy of Youth with Disabilities

Investigator: Amanda Schlegelmilch, B.A.

715.579.0594

schlegelmilcha@my.uwstout.edu

1618 Laurel Ave

Eau Claire, WI 54701

Research Advisor: John Lui, PhD., MBA,

CRC

715.235.2470

luij@uwstout.edu

SVRI 221 10th Ave., Voc. Rehab Dept. Rm.

101A

Menomonie, WI 547

Description: Adolescents living with disabilities are much more likely to develop secondary health conditions as they grow into adulthood, which can lead to lowered life expectancy, decreased quality of life, increased healthcare costs, and poorer health related outcomes. They are also twice as likely to live a sedentary lifestyle and not get the recommended activity levels compared to youth without disabilities. Improving the health literacy for youth with disabilities can help to prevent the development of secondary health conditions as they become adults. The survey is designed to assess the youth's current health status, health literacy, and stage in the health belief model. The adolescent will be e-mailed a link once the consent form is signed and received. The link will bring them directly to the survey. There are three demographic questions to be answered followed by about 35 questions. The directions for the survey are indicated at the top of each page. The participants will choose which best describes them using a 5-point scale,

ranging from 1 being strongly disagree and 5 being strongly agree for most of the questions and other similar scales for the rest of the questions as indicated.

Risks and Benefits: Participating in this study has minimal to no risks to the participants involved. However, there are many possible benefits to participating in this study, they include:

- Identifying current health status
- Increasing their health literacy awareness
- Overcome barriers
- Realize the benefits of increasing physical activity levels
- Increase physical activity
- Improving the health literacy for youth with disabilities
- Decrease health care costs
- Improve the quality of life
- Help prevention of secondary health conditions
- Aid in future research
- Designing of programs to improve health literacy and overall health

Special Populations: The survey is intended for a special population of adolescents (ages 11-17) with disabilities.

Time Commitment: The estimated amount of time required to finish this survey is about 15-20 minutes.

Confidentiality: Your name will not be collected or included on any documents. We do not believe that you can be identified by any of the information collected from the survey. This informed consent will not be kept with any of the other documents completed for this project. To

ensure the confidentiality and the anonymity of the source of the data, this investigator and the research advisor are the only persons with access to the list of e-mail addresses, which will be loaded into a distribution list. All survey items will be loaded into Qualtrics. Through the use of alphanumeric identifiers, the data cannot be traced back to the original source from identifiers used in the questionnaires. Further, all questionnaires will be stored in a designated locked file cabinet, which can only be accessed by the researchers. All materials with real names will be destroyed and all research instruments and notes will be kept only for three years after the completion of the study to maximize confidentiality.

Right to Withdraw: Your participation in this study is completely voluntary. You may choose not to participate without any adverse consequences to you. You have the right to discontinue at any time. Should you choose to participate and later wish to withdraw from the study, you may discontinue your participation at any time without incurring adverse consequences.

IRB approval: This study has been reviewed and approved by The University of Wisconsin-Stout's Institutional Review Board (IRB). The IRB has determined that this study meets the ethical obligations required by federal law and University policies. If you have questions or concerns regarding this study please contact the Investigator or Advisor. If you have any questions, concerns, or reports regarding your rights as a research subject, please contact the IRB Administrator.

Investigator:

Amanda Schlegelmilch, B.A.
715.579.0594
schlegelmilcha@my.uwstout.edu

Advisor:

John Lui, PhD., MBA, CRC
715.235.2470

luij@uwstout.edu

IRB Administrator:

Sue Foxwell, Director, Research Services

UW-Stout, 152 Vocational Rehabilitation Bldg.

Menomonie, WI 54751

715.232.2477

foxwells@uwstout.edu

Statement of Consent: By signing this consent form you agree to participate in the project entitled, the Health Literacy of Youth with Disabilities

Signature of participant	Date
--------------------------	------

Signature of parent or guardian	Date
---------------------------------	------

Appendix D: Final Survey

This was transposed into an electronic survey, it is in this format so it can be more easily read.

Please answer the following questions as best as you can and follow directions as indicated at the top of each section.

Your name will not be collected or included on any documents. You cannot be identified by any of the information collected from the survey. This informed consent will not be kept with any of the other documents completed for this project. Through the use of alphanumeric identifiers, the data cannot be traced back to the original source from identifiers used in the questionnaires.

Your participation in this study is completely voluntary. You may choose not to participate without any adverse consequences to you. You have the right to discontinue at any time. Should you choose to participate and later wish to withdraw from the study, you may discontinue your participation at any time without incurring adverse consequences.

By clicking on the button with two arrows below, you are giving your consent to participate in this study.

Modified survey for youth with disabilities (Wall, 2009; Brown, Teufel, & Birch, 2007)

Definition of secondary health condition- One or more health conditions that are preventable and come as a result of an existing primary condition interacting with both environmental and individual factors (Sineonsson, Sturtz-McMillen, & Huntington, 2002).

Directions- For questions 1-24, Indicate for each question which best describes you using a 5-point scale, ranging from 1 being strongly disagree and 5 being strongly agree. For questions 25-35, use the scale that is associated with each question.

What is your age? _____

What grade are you in? _____

What type of primary disability do you have? _____

If you have a secondary disability, what is it? _____

Which school district do you attend? _____

What town do you live in? _____

- 1. I believe my chances of developing one or another secondary health condition sometime in my adult life, are great**

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1

2

3

4

5

- 2. I worry about developing one or another secondary health condition.**

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1

2

3

4

5

- 3. Measures to increase my health will help prevent me from developing one or another health condition.**

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

4. If I developed one or another secondary health condition, my life would change.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

5. I am concerned that I may develop a secondary health condition in my lifetime.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

6. Engaging in more physical activity will help prevent the development of one or another secondary health condition.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

7. I can prevent secondary health conditions from developing.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

8. I benefit by exercising on a regular basis.

Strongly Disagree *Disagree* *Neither Agree or Disagree* *Agree* *Strongly Agree*

1 2 3 4 5

1 2 3 4 5

15. I would play more sports if they were less physically demanding.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

1 2 3 4 5

16. I have no one to exercise with.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

1 2 3 4 5

17. I would exercise more if my family would join me.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

1 2 3 4 5

18. I would exercise more if my friends would join me.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

1 2 3 4 5

19. I would exercise more if there were after school programs to join for physical fitness.

Strongly Disagree Disagree Neither Agree or Disagree Agree Strongly Agree

1 2 3 4 5

20. My family supports and encourages me to exercise regularly.

For this section please answer each question using the appropriate scale, located after each question.

25. Most of what I hear about health is,

Very hard to understand	Sort of hard to understand	Neither hard or easy to understand
1	2	3
Sort of easy to understand	Very easy to understand	
4	5	

26. From which of these do you learn the most about health?

The Internet	School	Parents/Guardian	A doctor or nurse	Friends/peers	Another way
1	2	3	4	5	6

27. If you had an important question about health, where would you go first for information?

The Internet	School	Parents/Guardian	A doctor or nurse	Friends/peers	Another way
1	2	3	4	5	6

28. I try to follow what I'm taught about health

Never	Hardly ever	Sometimes	Most of the time	All of the time
1	2	3	4	5

29. How much can an adolescent do to grow up to be a health adult?

I don't know	Almost nothing	A little	Some	A lot
--------------	----------------	----------	------	-------

34. How many days a week do you participate in physical activities?

0	1-2	3-4	5-6	7
---	-----	-----	-----	---

1	2	3	4	5
---	---	---	---	---

35. Do you think you need to improve your health?

Not at all	A little	Somewhat	Mostly	Very much
------------	----------	----------	--------	-----------

1	2	3	4	5
---	---	---	---	---

Thank you very much for participating in the survey!

Modified survey from previous studies (Wall, 2009; Brown, Teufel, & Birch, 2007)

If you have any questions or concerns about the survey or research content please contact the investigator or research adviser

Investigator: Amanda Schlegelmilch, B.A.

715.579.0594

schlegelmilcha@my.uwstout.edu

1618 Laurel Ave

Eau Claire, WI 54701

Research Advisor: John Lui, PhD., MBA, CRC

715.235.2470

luij@uwstout.edu

SVRI 221 10th Ave., Voc. Rehab Dept. Rm. 101A

Menomonie, WI 54751

Appendix E: Human Subjects Training Certificate**UW-Stout Human Subjects Training Certification****Name:** Amanda Schlegelmilch**Stout ID:** 431139**College or Unit:** College of Human
Development**Training Date:** 3/25/2008
11:44:42 AM**Department:** Psychology**Phone:** 715-579-0594**Comments:**

Appendix F: IRB Approval

October 8, 2012

Amanda Schlegelmilch

Psychology

UW-Stout

RE: The Health Literacy of Youth with Disabilities

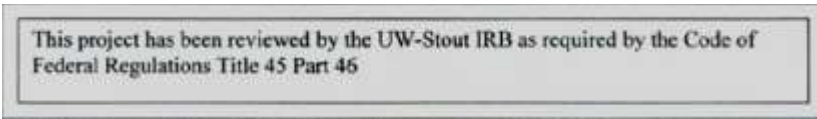
Dear Amanda,

The IRB has determined your project, "*The Health Literacy of Youth with Disabilities*" is

Exempt from review by the Institutional Review Board for the Protection of Human Subjects.

The project is exempt under **Category # 2** of the Federal Exempt Guidelines and holds for 5 years. Your project is approved from **10/8/2012**, through **10/8/2017**. Should you need to make modifications to your protocol or informed consent forms that do not fall within the exemption categories, you will need to reapply to the IRB for review of your modified study.

If your project involved administration of a survey, please copy and paste the following message to the top of your survey form before dissemination:



This project has been reviewed by the UW-Stout IRB as required by the Code of Federal Regulations Title 45 Part 46

If you are conducting an **online** survey/interview, please copy and paste the following message to the top of the form:

“This research has been reviewed by the UW-Stout IRB as required by the Code of Federal Regulations Title 45 Part 46.”

Informed Consent: All UW-Stout faculty, staff, and students conducting human subjects research under an approved “exempt” category are still ethically bound to follow the basic

ethical principles of the Belmont Report: 1) respect for persons; 2) beneficence; and 3) justice. These three principles are best reflected in the practice of obtaining informed consent from participants.

If you have questions, please contact Research Services at 715-232-1126, or foxwells@uwstout.edu, and your question will be directed to the appropriate person. I wish you well in completing your study.

Sincerely,

A handwritten signature in cursive script that reads "Susan Foxwell".

Susan Foxwell

Research Administrator and Human Protections Administrator,

UW-Stout Institutional Review Board for the Protection of Human Subjects in Research (IRB)