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IDENTIFYING GAPS IN PERCIEVED ABILITY:
PROMOTING EXERCISE IN YOUNG ADULTS WITH DISABILITIES

BY

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Dedication

This manuscript is dedicated to the individuals with disabilities and their families whom I've had the pleasure of meeting and learning their stories during the summer of 2011 while completing this research.

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Abstract

Aim: The purpose of this study was to describe the perceived ability in making health decisions regarding exercise and its congruence between young adults with disabilities and their parents. **Methods:** The study design used a mixed methods approach. The convenience sample consisted of ($N = 10$) young adults with disabilities and ($N = 9$) parents of young adults with disabilities. Qualitative data were gathered using a preliminary structured interview guide for young adults with disabilities consisting of several short answer questions. Quantitative data were gathered from the parents of young adults with disabilities by using Pender's Health Promotion Questionnaire. **Results:** Data analysis began with simple descriptive statistics. The qualitative data, the structured interviews of the adolescents, were transcribed and evaluated for themes. The quantitative data, the parents' questionnaires, were analyzed by aggregating data for frequencies and descriptive statistics. The qualitative data were then compared with the quantitative data to identify similarities and differences in perceptions. **Conclusion:** Comparison of responses among dyads provides insight about disparities that exist between what parents perceive their children with disabilities can decide about exercise and the children's own perception about their abilities in making decisions regarding exercise.

Identifying Gaps in Perceived Ability: Promoting Exercise in Young Adults with Disabilities

Although there have been many improvements in the promotion of health in individuals with disabilities, there continues to be significant disparities. Disability is defined as "Any person who has a physical or mental impairment that substantially limits one or more major life activities" (United States Department of Labor, 2011, p. 1). Reinehr, Dobe, Winkel, Schaefer, & Hoffman (2010) in their study of obesity in disabled children found "the prevalence of overweight and obesity in children with disabilities was almost twice that in their non-disabled peers" (p. 268). Obesity is a chronic disease that has been associated with health problems such as hyperinsulinemia, insulin resistance, type 2 diabetes, hypertension, dyslipidemia, coronary heart disease, and certain cancers (Reineher et. al, 2010). Individuals with disabilities who are also obese may be less able to participate in physical activity, social and community events (Liou, Pi-Sunyer, & Laferrere, 2005). Nationally, in the United States there are 54 million people with a disability (CDC, 2011). Locally it is reported that in New Hampshire 22.3% of the population has a disability. (CDC, 2011) This magnitude of a vulnerable population with health disparities demands improvement in promotion of health-seeking behaviors such as exercise.

A guiding framework to explain motivating factors involved in making health behavior decisions is the Health Promotion Model (HPM) created and modified by Nola Pender (Srof & Velsor-Friedrich, 2006). The HPM describes individual characteristics and experiences, and behavior-specific cognitions and affect, both of which contribute to behavioral outcomes [see Appendix A]. The model has been used extensively in research studies to successfully explain health behavior. However few study the adolescent population, and even fewer study the disabled young adult population (Srof & Velsor-Friedrich).

During adolescence there is a transition from dependent to independent living, requiring adolescents for the first time to make health decisions on their own. A study determined that parent's roles in health promotion were: first demonstrating to their children the importance of physical activity, nutrition and hygiene; second fostering social interactions as well as purpose in life (Antle, Mills, Steele, Kalnins, & Roseen, 2008). However parents may play an even larger role in the ability of young adults with disabilities to engage in health promoting behavior. For young adults with disabilities, parents often make health decisions for, and not with their child. The result may be poor health decisions that lead to negative future health consequences.

Negative health behaviors can contribute to adverse health conditions, creating an increased need for care and increased cost. "In 2006, disability-associated health care expenditures accounted for 26.7% of all health care expenditures for adults residing in the United States and totaled \$397.8 billion" (CDC, 2006, p. 1). In New Hampshire, the estimated mean disability-associated health-care expenditures for the disabled population were \$10,824 (CDC, 2006). This means that a quarter of all healthcare expenses were for individuals with disabilities. This magnitude in cost and number of vulnerable individuals with health disparities demands improvement in promotion of health-seeking behaviors such as exercise. It is important for nurses to prevent these behaviors in order to improve quality of life. Health promotion for people with disabilities is aimed to create healthy lifestyles and environments to prevent secondary conditions (Lubkin & Larsen, 2009).

According to the few studies that have been done to date, successful change in health behavior in this population was enhanced by several factors. The first is by focusing on the perceived ability to carry out health promoting behaviors. (Stuifbergen & Becker, 1994) Others include a strong support system, a stable living condition, and financial security correlated with

positive health behaviors (Callaghan, 2006). The gap in the literature, as well as the focus of this current study, is evidence that demonstrates how parents perceive their disabled child's ability to carry out health promoting behaviors and if this is a shared perception.

Review of the Literature

Nursing is fundamental to health promotion. Nurses listen, teach, provide resources, encourage, support and advocate with patients in regards to health. "Health promotion is a multidimensional concept and focuses on maintaining or improving the health of individuals, families and communities" (Lubkin & Larsen, 2009, p. 347). In order to promote health behaviors in children and young adults it is important to consider how the children, parents and nurses cohesively impact decisions.

Perception of Autonomy

Blomquist (2006) studied health promotion and risky health behaviors in young adults with disabilities compared to typical young adults from Kentucky. The study was quantitative in design. The sample included 650 young adults who had been discharged from a children's hospital. The results were that 37% of young adults with disabilities said they exercised not much or never compared to 19% of typical Kentuckians (Blomquist, 2006). Also 24% of young adults with disabilities perceived their health to be fair or poor compared with 8% of Kentucky young adults (Blomquist, 2006). This statistic shows that young adults with disabilities have a negative outlook about their health. Nurses can encourage health promotion and improve these health perceptions through autonomy, by empowering others to make their own decisions. Autonomy can be achieved by nurses promoting the ability to make health decisions in individuals with disabilities. This study helps "nurses and others working with young people with disabilities develop health promotion and skill development programs to improve transition

to adult roles and responsibilities” (Blomquist, 2006, p. 177) Nurses can promote health promoting behaviors and improve the perception of health in young adults with disabilities.

Richardson examined the views, assumptions and experiences of people with disabilities (2000). The sample consisted of six participants living in a residential setting who were interviewed 30 times over 18 months. The design was qualitative and descriptive. A theme showed that residents were not always treated as partners in decisions for care. The balance of power resided with the staff and nurses (Richardson, 2000). Participants were not asked their input on new nurses, activities, preferences or incoming residents placed in their room (Richardson, 2000). The participants were mentally capable to express these concerns, and should not be excluded from decisions. Although this study was strong in description, the sample size of six limits generalizability of the results. However, the important implications for nursing includes the importance of sharing decisions with people with disabilities, establishing healthy relationships and supporting as well as assisting them with “confidence and skills that will enhance their participation” (Richardson, 2000, p. 1392). By doing so, nurses can enhance autonomy and health promoting behaviors in people with disabilities.

Parents of Children with Disabilities

The paradox of autonomy in parents with children who have a disability is that they are regarded as the expert on their child, but still need advice and support in decisions from health care experts. Avis and Reardon conducted a qualitative study that looks at parents’ views of nursing care for their child with special needs while in the hospital. Twelve parents were interviewed using open-ended questions. One identified theme, communicating support, spoke of parents valuing direct communication of nurses with their child. Some nurses assumed that the child was at a lower capacity to understand than they actually were, and failed to appropriately

communicate. In addition, parents explained that they desired to be informed about their child's care because they wanted to feel in control and have the power to make decisions. Another theme, nurse-parent relationships, detailed how nurses considered parents as the experts and therefore left them to provide medicine, food and personal care. Parents admitted that they liked to be respected as knowledgeable, yet they were never given autonomy or the right to choose if they would like assistance (Avis & Reardon, 2008). The limitation of this study was that all participants were recruited from the same children's center which could have contributed to bias. Also, the small sample of 12 does not allow for generalizability.

What this study does offer in terms of nursing implications regarding this study includes the importance of communicating appropriately with children who have disabilities during their care. Negotiating with the parent, or giving them autonomy to choose how much support they need to effectively care for their child improves outcomes of care and improves the nurse-patient relationship (Avis & Reardon, 2008). This study demonstrated the need for nurses to form partnerships with parents in decision making. Consistent with Pender's model, valuable interventions include a strong support system. This involves encouraging family support, effective communication, negotiating needs, and providing resources.

Exercise

Individuals with disabilities often face obstacles, struggles, and barriers when trying to exercise. Nola Pender's health promotion model was the conceptual framework of a study that found that there were significant relationships between the aspects of adolescents' health promoting behaviors such self-efficacy and an adequate support system (Callaghan, 2006). This points to the importance of the need for an adequate support system, for the best outcomes in adolescents' health decisions, regarding promoting exercise or health.

Another study examined factors that affect exercise in individuals with physical disabilities. The study found that the most important factors effecting exercise participation included access to exercise facilities, instructors with knowledge of adapted exercise, a sense of belonging, and support from family and friends (Junkar & Carlberg, 2011). A limitation of this study was that it only looked at adults with physical disabilities, and did not include individuals with developmental disabilities or adolescents. However the study is valuable in that the concept of family and friends' support in exercise in people with disabilities is a reoccurring theme in studies regarding exercise and individuals with disabilities. In addition it gives support to adapting exercises and knowledge to fit the needs of each unique individual.

A final study that was reviewed examined the effectiveness of a group exercise program in children with disabilities. The study looked at pre and post results of an exercise program in both a group based program and a home-based program (Fragala-Pinkham, Haley, Rabin & Kharasch, 2005). The study found that there were more improvements in energy expenditure index, leg strength, functional skills, fitness, self-perception and safety in children in the 5-9 year old in the group-program than in the home-based program (Fragala-Pinkham et al., 2005). the value of of these results indicate that a group-based exercise program may yield more positive results than individual home-based programs.

Health Promotion

During adolescence there is a transition from dependent to independent living, requiring adolescents for the first time to make health decisions on their own. A parent's role in health has been reported to be: demonstrating to their children the importance of physical activity, nutrition and hygiene; and fostering social interactions as well as purpose in life (Antle, Mills, Steele, Kalnins, & Roseen, 2008). However parents may play an even larger role in the ability of young

adults with disabilities to engage in health promoting behavior. For young adults with disabilities, parents often make health decisions for, and not with their child. The result may be poor health decisions that lead to negative future health consequences.

According to the few studies that have been done to date, successful change in health behavior in this population was enhanced by several factors. The first is by focusing on the perceived ability to carry out health promoting behaviors. (Stuifbergen & Becker, 1994) Others include a strong support system, a stable living condition, and financial security correlated with positive health behaviors (Callaghan, 2006).

Significance

Despite this there remain gaps in the literature that demonstrates how parents perceive their disabled child's ability to carry out health promoting behaviors and if this is a shared perception. This current research seeks to identify if disparities exist between the perceived abilities of young adults making health decisions with those of their parents specific to physical activity. If there is incongruence in perceptions by parents, the child may remain vulnerable. The results of this research have the potential to form the necessary elements of a partnership between the nurse, parent and the child in developing a health promotion plan to reduce this disparity if it exists.

On a larger scale, this study has the potential to make nurses more aware of how to effectively promote health and reduce negative outcomes in individuals with disabilities. In terms of the importance of autonomy in decision making, this research may provide parents with insight into how their children with disabilities make health decisions, in order to promote the necessary autonomy to make health decisions. Last, by having conversations with these young

adults, it may indirectly give them the self-awareness into the benefits, barriers and self-efficacy, which can help them make better health decisions.

Statement of Purpose

The purpose of this study was to explore how parents of young adults with disabilities perceive their child's ability to carry out health promoting behaviors, specifically exercise, and if this is a shared perception by the young adult.

Methodology

DESIGN

The study design used a mixed methods approach. The methodology includes weaving qualitative and quantitative designs, to provide a broader understanding of the shared perceived ability in making health decisions between young adults with disabilities and their parents. In order to accommodate a sample of young adults that may have an approximate sixth grade reading level, a face-to-face interaction was considered the best means of data collection. As a comparison, parents' were asked to complete Pender's Health Promotion Questionnaire (as cited in Strof & Velsor-Freidrich, 2006) providing similar data for comparison.

DESCRIPTION OF THE SAMPLE

The convenience sample consists of young adult campers with disabilities attending a summer program at a camp for children and adults with disabilities. Parents of the campers that met the inclusion criteria were invited to participate in the study. The sample consisted of 10 dyadic pairs of campers and their parents. Letters of consent and assent for this population was obtained prior to data collection.

Inclusion criteria for this study were determined by the campers' Individual Education Plans (IEP). Young adults with mild mental retardation (MMR) who may have deficits in

adaptive behavior such as serious emotional disturbances requiring classroom modification (CDC, 2005) were be eligible to participate. Campers with any sensory / physical disabilities were also included. Young adults with more extensive disabilities were excluded as it is less likely they would be able to make their own health promotion decisions, even with adequate supports.

INSTRUMENTS

A preliminary structured interview guide for young adults consisted of several short / answer questions [see Appendix C]. The reliability of this constructed tool was verified by three experts in the field of nursing. Parents completed the Pender's Health Promotion Questionnaire [see Appendix B]. The instrument was developed to measure why people exhibit health behaviors. Parents used the survey to identify how they measure their young adult's perception of making health decisions.

DATA HANDLING

The data was collected from a convenience sample of campers and their parents over an 8 week period. Each week the interviews were voice recorded and transcribed word for word. In addition, each week the data from the questionnaire was inputted into an excel spreadsheet on a non-networked computer. Combining analyses for themes in qualitative data, and calculations of percentages in qualitative data commenced following complete data collection. Analyzed data was synthesized, compared and conclusions were made. Data analysis began with simple descriptive statistics including prior health behavior and personal social behavior such as age, gender, diagnosis and weight. The quantitative data, the parents' questionnaires, was analyzed by aggregating data for frequencies and descriptive statistics. The qualitative data, the structured interviews of the adolescents, was transcribed and evaluated for themes. The qualitative data was

compared with the quantitative data to identify similarities and differences in perceptions. This mode of analysis accomplished the objectives because the rich data from the qualitative study provided insights into the young adults' perceived ability in making health decisions.

Comparison of responses among dyads provided insight about disparities that exist between what parent's perceive their children with disabilities can decide about health, and the children's own perception about their own abilities in making health decisions.

PROTECTION OF HUMAN SUBJECTS

An IRB [institutional review board] application was completed, and full IRB approval was granted. Consent of parents for themselves was obtained [see Appendix E]. In addition, parental consent for their child to participate in the interview was obtained by a parental consent form [see Appendix F]. Last, child assent appropriate to the child's level of comprehension was obtained [See Appendix G]. Consent was also obtained from the director of the camp used as the site of this research project [see Appendix D].

Findings

Demographics

Young Adult Demographics

The gender breakdown for the young adult demographics was 6 males and 4 females. The majority of the participants were white (n=8), one was American Indian or Alaska native, and one did not reply. Four participants were 14-16 years old, four were 17-19 years old, one participant was 20-22 years old and one was 23-25 years old. Three participants weighed above 200 lbs, two participants weighed 161-170lbs, two participants weighed 151-160 lbs, one participant weighed 171-180 lbs, one participant weighed 131-140 lbs and one participant weighed 101-110 lbs. Four participants had graduated from high school, one participant was a

senior in high school, one participant was a junior in high school, two participants were sophomores in high schools, and two participants were freshmen in high school. The majority of the participants lived at home (n=7), one participant lived with foster parents, one participant lived with an adult mentor and one participant lived independently in an apartment. Parents were asked to identify their child's disability and three parents identified their child as having autism, two parents identified that their child had Down syndrome, and five participants were identified as having another specific disability.

Parent Demographics

Parent demographics include 6 mothers, one father, one mother/father pair and one foster parent (n=9). One parent did not return the survey. Two parents identified that their child had siblings but did not live with them, one parent identified that their child was an only child, four parents identified that their child had two other siblings, and two parents identified that their child had one other sibling. The salary range reported by these parents was \$150,000 or more (n=2); between \$100,000-\$149,999 (n=3), and one parent each reported making between \$70,000-79,999, between \$30,000-\$39,999, \$20,000-\$29,999 and less than \$10,000. Six parents are married, and three parents are divorced. The majority of parents were white (n=8), and one parent was American Indian.

Quantitative

Parent survey data was analyzed using scored responses from the scales on the health promotion survey. A 1-5 Likert scale was used by parents to rank each of the twenty seven questions from the options: not at all true (score=1), not very true, in-between, sort of true, and very true (score=5). There were three subscales designed by Pender to measure: perceived benefits, barriers, and self-efficacy. The mean summed score of parents perception of benefits

was 26.7 (range 23-31;). The mean summed score of parents perceptions of barriers was 23.1 (range 9-34) and finally mean summed score for perception of self efficacy was 26.9 (range 22-33). This means that patient perceived the strongest predictor of their child’s health promoting behavior was a belief in their self efficacy toward exercise and least predictive was their ability to discriminate barriers.

Next an aggregate of all parent’s scores for individual items were summed and ranked. Items with top scores represented the single item that made the strongest contribution to the parents’ perceptions. These items are presented in table 1. These individual items should be interpreted as themes identified by parents to match their children’s perception.

Table 1: Parent Perceptions		
Parent Response	Highest Scored Perceptions	Score
Perceived Benefits of Child	- A reason my child might exercise is because when he/she exercises he/she feels happier.	29
	- A reason my child might exercise is because when he/she exercises he/she has fun.	31
	- A reason my child might exercise is because when he/she exercises he/she likes himself/herself more.	28
Perceived Barriers of child	- My child might not exercise if he/she didn’t have enough time.	28
	- My child might not exercise if he/she didn’t know how to do a certain type of exercise.	31
	- My child might not exercise if he/she didn’t like to exercise.	34
Perceived Self-Efficacy of child	- My child could exercise even if he/she had other things he/she wanted to do.	30
	- My child could exercise even if he/she had a bad day at school.	32
	- My child could exercise even if he/she was not very good at it.	33

Qualitative

Analysis continued with thematic analysis of the data that emerged from the interviews. Themes were then categorized according to the same three subscales that measured the parents' responses: perceived benefits of action, perceived barriers of action, and perceived self-efficacy. Themes were then analyzed for frequency, and the most frequent themes were selected. Table 2 demonstrates a summary of the results:

Child Responses	Most Frequent Perceptions
Perceived Benefits	<ul style="list-style-type: none">- Individual sports- Fun/Happy/Excitement- Outside exercise- Socialization- Team sports- Alternative forms of exercise: Wii video games, role playing, pushing grocery carts, catching frogs
Perceived Barriers	<ul style="list-style-type: none">- Altered time perception- Bad weather- Feeling sick- Parental attitude
Perceived Self-Efficacy	<ul style="list-style-type: none">- Knowing limits: Decreasing or changing intensity or activity in order to overcome barrier- Overcoming barriers: Desire to exercise- Overcoming barriers: Would still play outside if it was poor weather.

Comparison

Finally a dyadic comparison was conducted that compared the most frequently expressed perception for each of the three behavior specific cognitive-affect variables identified in Pender's model. These are presented in Table 3.

Table 3: Dyadic Comparison

Behavior Specific Cognitive Affective Variables	Parent [N=9]	Young Adult [N=10]
Perceived Benefits	<p>My child exercises because:</p> <ul style="list-style-type: none"> ▪ Feels happier ▪ Exercise is Fun ▪ Will like him/herself better 	<p>My story about exercise:</p> <ul style="list-style-type: none"> ▪ I prefer individual sports to teams ▪ I feel happy, it's fun, it's exciting ▪ I like to play outside ▪ I like to play with friends ▪ It's healthy! ▪ I like doing different activities for exercise
Perceived Barriers	<p>My child might not exercise if:</p> <ul style="list-style-type: none"> ▪ There's not enough time ▪ Doesn't know how ▪ Didn't like it 	<p>I might not exercise if:</p> <ul style="list-style-type: none"> ▪ I don't understand time ▪ The weather is bad ▪ If I'm feeling sick ▪ If my parents have a poor attitude about exercise.
Perceived Self-Efficacy	<p>My child could exercise even if he/she:</p> <ul style="list-style-type: none"> ▪ had other things he/she wanted to do. ▪ had a bad day at school. ▪ he/she was not very good at it 	<p>I could exercise even if:</p> <ul style="list-style-type: none"> ▪ Decreasing or changing intensity or activity in order to overcome barrier ▪ Overcoming barriers: Desire to exercise (including alternative forms) ▪ Overcoming barriers: Would still play outside if it was poor weather

The findings from these responses were that: There was congruence in perceived benefits and self-efficacy between the young adults with disabilities and their parents. The discrepancy however was regarding perceived barriers: Parents perceived that their child just did not have enough time to exercise. Young adults spoke of not being able to understand time.

Discussion

Nurses must face challenges and disparities of care for children and young adults who have disabilities. Practically, improving the health promotion of children will contribute to fewer health problems, less resource utilization and fewer hospital stays when they become adults. In addition, from a quality perspective the intention should be to promote the well being of this population and enhance autonomy in hopes to improve their quality of life. These problems cannot be improved unless they are faced, and research can help enhance the health and quality of life of the disabled population.

This current research has suggested interventions that could be implemented into nursing care. These include promoting healthy behaviors, creating a partnership in decision making, encouraging participation, and teaching self care skills. In addition, to be congruent, nurses need to iron out the wrinkle in time as a perceived barrier to exercise. Interventions for relationships with parents include discussing the expectation and needs of care, providing and encouraging a support system, effective and therapeutic communication and providing resources. These interventions enrich the care of future patients with disabilities by valuing autonomy which will lead to enhanced health promotion.

Further research is necessary to explore the perceived ability in making health decisions between young adults with disabilities and their parents. Autonomy is essential in this health

decision process. In the time of transition where young adults with disabilities move from depending on parents to make health decisions to a time of independent responsibility, autonomy in this process enhances the healthy behavior, thus positive health outcomes.

On a larger scale, further research will make nurses more aware on how to effectively promote health and reduce obesity in the disabled population. This research has the potential to provide parents with insight into how their children with disabilities make health decisions. Last yet most important, indirectly, this study indirectly may give young adults with disabilities the ability to live more independently, make better health decisions, and improve their overall quality of their life.

Limitations

A limitation of this pilot study was that it was a convenience sample, which is potentially non-representative because they were in a camp program. Additionally, not all parents were custodial parents. Despite the use of IEP's as a proxy for cognitive ability to answer the questions, there is no way to measure this as it was self report. Finally, using a mixed methodology limits the study, because it attempts to compare qualitative to quantitative results, which may hinder the comparison, however it was necessary in order to get the young adult responses through interviews.

Conclusions

This study added new knowledge to the field of disability nursing. Prior to this study, there were few studies regarding health promotion in individuals with disability related to exercise, and even fewer studying the young adult population. Again, there was congruence in perceived benefits and self-efficacy between the young adults with disabilities and their parents. The discrepancy however was regarding perceived barriers, specifically translating to a wrinkle

in time. Nurses need to iron out this wrinkle in order for health promoting behaviors, such as exercise, to occur in young adults with disabilities. Pender's Health Promotion model explains this deficiency in perceived barriers as impacting the behavioral outcome. For instance, since time perception is a barrier, this will negatively impact the commitment to a plan of action if there is no time reference for the plan, and furthermore decrease the behavioral outcome or health-promoting behavior such as exercise. Additionally, according to the model interpersonal influences, such as family support as well as situational influences also impact the health promoting behavior of exercise. Therefore, although the barrier of time can be resolved by way of technology to remind the individual to exercise, without parental support and a desirable situation, the outcome of the independent decision to exercise will not occur. Therefore, personal preferences regarding the ideal situation or environment should be promoted and sought. Finally, the interpersonal influences such as parents, family, peers, and the nurse significantly impact the outcome, which calls for an awareness of this support, and an encouragement in exercise for the young adult with a disability.

Recommendations

Some ideas for nurses to use to achieve this iron out the wrinkle in time perception, would be the use technology, iPADs, as one example, can used to do this. They can signal through an alarm when it is time to exercise, and can show in a bar graph, which is consistent with concrete learning as opposed to the abstract concept of time, how many minutes the individual should be exercising, and when they input their actual minutes it will show if there were any discrepancies, and where improvements need to be made. In addition, including an exercise plan in individuals with disabilities' IEP, so that once they graduate from the public school system, they will have a plan they are familiar with and can add to it as they advance in

their physical activity. Finally, communication is the key to creating an exercise plan, promoting independence and autonomy and providing support in order to promote health decisions in the young adult with a disability.

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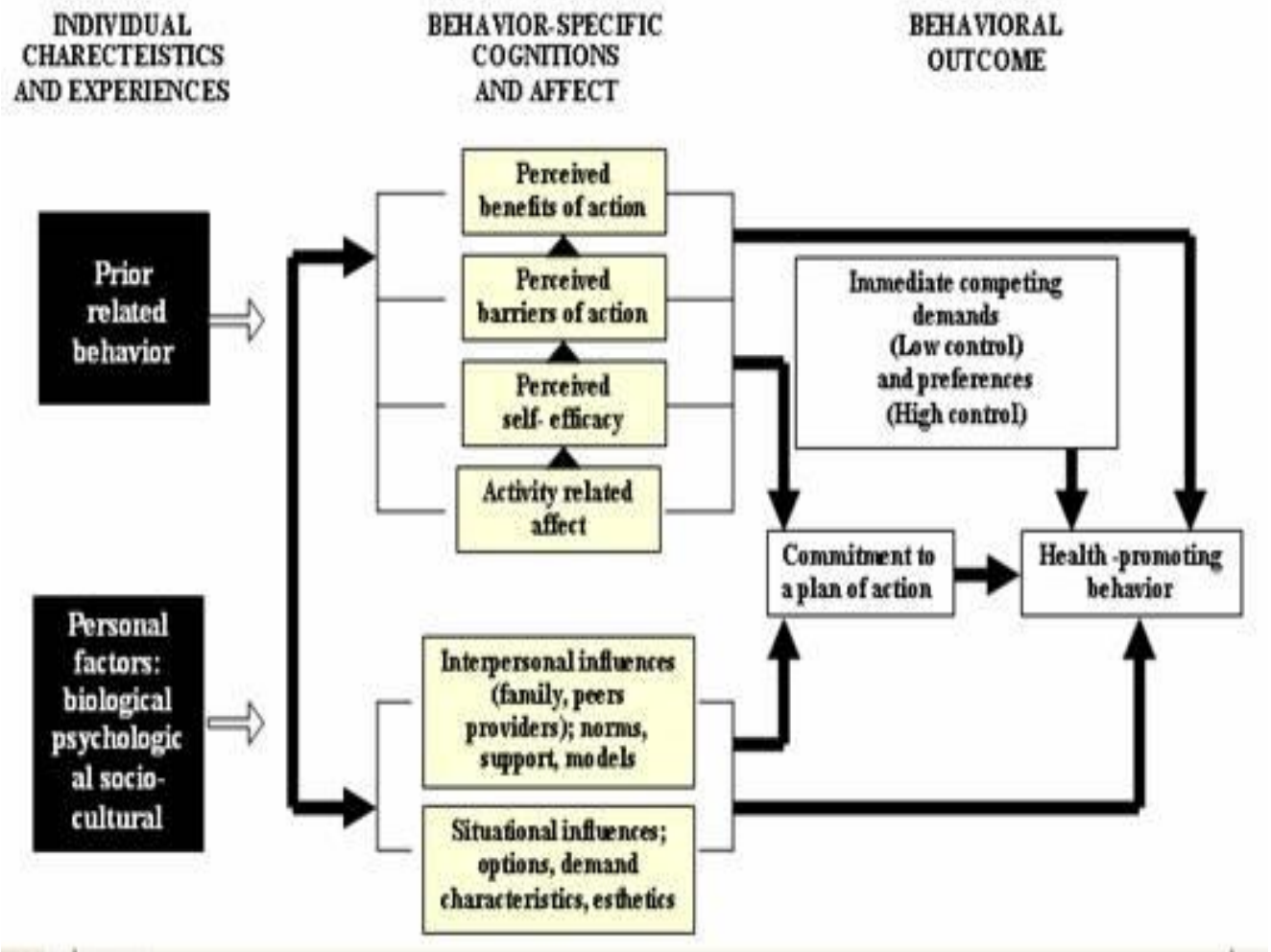
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Appendix A

Health Promotion Model (Nola Pender)



(Pender, Murdaugh, & Parsons, 2011)

Appendix B

Questionnaire Tool for Parents

Directions: Please answer the following questions about your child.

Descriptive Statistics	
1. What is your child's Diagnosis?	
2. What is your child's age?	
3. Is your child male or female?	
4. What is your child's weight?	

- Below are sentences about exercise. Exercise is being active enough to breathe fast, get sweaty, or have your heart beat fast.
- Directions: Please circle the box to show how true each sentence is about **your child**.

Perceived Benefits of Action					
11. A reason my child might exercise is because when he/she exercises he/she looks better.	Not at all true	Not very true	In-between	Sort of true	Very true
12. A reason my child might exercise is because when he/she exercises he/she has more energy.	Not at all true	Not very true	In-between	Sort of true	Very true
13. A reason my child might exercise is because when he/she exercises he/she feels happier.	Not at all true	Not very true	In-between	Sort of true	Very true
14. A reason my child might exercise is because when he/she exercises he/she has fun.	Not at all true	Not very true	In-between	Sort of true	Very true
15. A reason my child might exercise is because when he/she exercises he/she makes more friends.	Not at all true	Not very true	In-between	Sort of true	Very true
16. A reason my child might exercise is because when he/she exercises he/she gets stronger.	Not at all true	Not very true	In-between	Sort of true	Very true
17. A reason my child might exercise is because when he/she exercises he/she likes himself/herself more.	Not at all true	Not very true	In-between	Sort of true	Very true
18. A reason my child might exercise is because when he/she exercises he/she gets in better shape.	Not at all true	Not very true	In-between	Sort of true	Very true
19. A reason my child might exercise is because when he/she exercises he/she feels healthier.	Not at all true	Not very true	In-between	Sort of true	Very true

Perceived Barriers of Action					
H1. My child might not exercise if he/she didn't have enough time.	Not at all true	Not very true	In-between	Sort of true	Very true
H2. My child might not exercise if he/she has too many chores to do.	Not at all true	Not very true	In-between	Sort of true	Very true
H3. My child might not exercise if he/she didn't have a good place to exercise.	Not at all true	Not very true	In-between	Sort of true	Very true
H4. My child might not exercise if the weather was too bad to exercise	Not at all true	Not very true	In-between	Sort of true	Very true
H5. My child might not exercise if he/she didn't have the right clothes/shoes to exercise.	Not at all true	Not very true	In-between	Sort of true	Very true
H6. My child might not exercise if he/she didn't know how to do a certain type of exercise.	Not at all true	Not very true	In-between	Sort of true	Very true
H7. My child might not exercise if he/she didn't have the right equipment to exercise.	Not at all true	Not very true	In-between	Sort of true	Very true
H8. My child might not exercise if he/she had too much homework.	Not at all true	Not very true	In-between	Sort of true	Very true
H9. My child might not exercise if he/she didn't have anyone to exercise with him/her.	Not at all true	Not very true	In-between	Sort of true	Very true
H10. My child might not exercise if he/she didn't like to exercise.	Not at all true	Not very true	In-between	Sort of true	Very true

Perceived Self-Efficacy					
G1. My child could exercise even if he/she was tired.	Not at all true	Not very true	In-between	Sort of true	Very true
G2. My child could exercise even if he/she had other things he/she wanted to do.	Not at all true	Not very true	In-between	Sort of true	Very true
G3. My child could exercise even if he/she had to exercise alone.	Not at all true	Not very true	In-between	Sort of true	Very true
G4. My child could exercise even if he/she had a bad day at school.	Not at all true	Not very true	In-between	Sort of true	Very true
G5. My child could exercise even if he/she was feeling lazy.	Not at all true	Not very true	In-between	Sort of true	Very true
G6. My child could exercise even if he/she was not very good at it.	Not at all true	Not very true	In-between	Sort of true	Very true
G7. My child could exercise even if he/she was sore from exercising the day before.	Not at all true	Not very true	In-between	Sort of true	Very true
G8. My child could exercise even if he/she was not in the mood.	Not at all true	Not very true	In-between	Sort of true	Very true

Appendix C

Young Adult Structured Interview Questions

Directions: Please answer the following questions about yourself. I will ask them and you will tell me as best as you can what the true answers are.

Dependent Variable
1. How many minutes do you exercise a day?
2. How many days during the week do you exercise?
3. Do you play any sports?
4. What is your favorite exercise?
Health Promotion Model Structure Questions- Independent Variable
1. What are some reasons that you might exercise?
2. What would be some reasons you might not exercise?
3. How would you still try to exercise even if you had reasons not to?

Appendix D

Permission to Conduct Research



Camp Allen
56 Camp Allen Rd.
Bedford, NH 03110

Permission to Conduct Research

February 24, 2011

Please note that Briana Terrill, an undergraduate nursing student at the University of New Hampshire, has the permission of the Camp Allen Director, Mary Constance to conduct research at our facility for her study, "Identifying Gaps in Perceived Ability: Promoting the Health of Young Individuals with Disabilities".

Briana will be conducting structured interviews of young adults with disabilities and administering questionnaires to parents of young adults with disabilities.

Briana's permission to conduct research is contingent upon her submission of copy to our office of the University of New Hampshire IRB-approved consent before she begins the study. In addition she agrees to provide a copy of the results.

If there are any questions, please contact my office.

Signed,

Mary C. Constance
Executive Director
Camp Allen Inc.
56 Camp Allen Road
Bedford, NH 03110
603.622.8471
fax: 603.626.4295
mary@campallennh.org

Appendix E

Parental Consent Letter for Themselves



UNIVERSITY of NEW HAMPSHIRE

INFORMED CONSENT LETTER FOR ADULT PARTICIPANTS

Dear Participant,

I am conducting a research project to find out perceived ability in making health decisions between young adults with disabilities compared to their parents. I am writing to invite you to participate in this project. I plan to work with approximately 8-10 parents in this study.

If you agree to participate in this study, you will be asked to complete a questionnaire. You will not receive any compensation to participate in this project.

The potential risks of participating in this study are minimal. Although you are not anticipated to receive any direct benefits from participating in this study the benefits of the knowledge gained are expected to be a better understanding of how parents and children with developmental disabilities work together to promote health.

Participation is strictly voluntary; refusal to participate will involve no prejudice, penalty, or loss of benefits to which you would otherwise be entitled. If you agree to participate and then change your mind, you may withdraw at any time during the study without penalty.

I seek to maintain the confidentiality of all data and records associated with your participation in this research. You should understand, however, there are rare instances when I am required to share personally-identifiable information (e.g., according to policy, contract, regulation). For example, in response to a complaint about the research, officials at the University of New Hampshire, designees of the sponsor(s), and/or regulatory and oversight government agencies may access research data. You also should understand that I am required by law to report certain information to government and/or law enforcement officials (e.g., child abuse, threatened violence against self or others, communicable diseases). Data will be kept in a locked file cabinet in my office; only I will have access to the data.

Appendix E (Continued)

The work will be conducted by me and Dr. Pamela DiNapoli RN PhD, a professor in the nursing department at the University of New Hampshire. I am a junior undergraduate nursing student at the University of New Hampshire.

If you have any questions about this research project or would like more information before, during, or after the study, you may contact Briana Terrill, (603)689-6312 blk34@unh.edu. If you have questions about your rights as a research subject, you may contact Dr. Julie Simpson in UNH Research Integrity Services at 603-862-2003 or Julie.simpson@unh.edu to discuss them.

I have enclosed two copies of this letter. Please sign one indicating your choice and return in the enclosed envelope. The other copy is for your records. Thank you for your consideration.

Sincerely,

Briana Terrill

Student Researcher

Yes, I, _____ consent/agree to participate in this research project.

No, I, _____ do not consent/agree to participate in this research project.

Signature

Date

Appendix F

Parental Consent for Child



UNIVERSITY of NEW HAMPSHIRE

Dear Parent,

I am conducting a research project to find out perceived ability in making health decisions between young adults with disabilities compared to their parents. I am writing to invite your child to participate in this project. I plan to work with approximately 8-10) children in this study.

If you allow your child to participate in this study, your child will be asked to participate in a 20 minute structure interview, which will be tape recorded and later transcribed. Neither you nor your child will receive any compensation to participate in this project.

The potential risks of your child participating in this study are minimal. Although your child is not expected to receive any direct benefits from participating in this study, the benefits of the knowledge gained are expected to be a better understanding of health promotion in adolescents with disabilities.

Participation is strictly voluntary; refusal to participate will involve no prejudice, penalty, or loss of benefits to which you or your child would otherwise be entitled. If you agree that your child may participate in this project and your child wants to, and then either you change your mind or your child changes his/her mind, you may withdraw your child, or your child may withdraw, at any time during the study without penalty.

I seek to maintain the confidentiality of all data and records associated with your child's participation in this research. You should understand, however, there are rare instances when I am required to share personally-identifiable information (e.g., according to policy, contract, regulation). For example, in response to a complaint about the research, officials at the University of New Hampshire, designees of the sponsor(s), and/or regulatory and oversight government agencies may access research data. You also should understand that I am required by law to report certain information to government and/or law enforcement officials (e.g., child abuse, threatened violence against self or others, communicable diseases). Data will be kept in a locked file cabinet in my office; only I and Dr. DiNapoli, my faculty advisor will have access to the data. The tape recording will be kept in a locked drawer when not in use, and after they are transcribed they will be deleted.

Appendix F (Continued)

The work will be conducted by me and Dr. Pamela DiNapoli RN PhD, a professor in the nursing department at the University of New Hampshire. I am a junior undergraduate nursing student at the University of New Hampshire.

If you have any questions about this research project or would like more information before, during, or after the study, you may contact Briana Terrill, (603)689-6312, blk34@unh.edu. If you have questions about your child's rights as a research subject, you may contact Dr. Julie Simpson in UNH Research Integrity Services at 603-862-2003 or Julie.simpson@unh.edu to discuss them.

I have enclosed two copies of this letter. Please sign one indicating your choice and return in the enclosed envelope. The other copy is for your records. Thank you for your consideration.

Sincerely,

Briana Terrill

Student Researcher

Yes, I, _____ consent/allow my child _____ to participate in this research project.

No, I, _____ do not consent/allow my child _____ to participate in this research project.

Signature of Parent

Date

Appendix G

Child Assent Permission Form



UNIVERSITY of NEW HAMPSHIRE

Identifying Gaps in Perceived Ability

Assent Form

My name is Briana. I am trying to learn about **how you and your parents decide about health** because I want to understand better. If you would like, you can be in my study.

If you decide you want to be in my study, you will **answer some questions** I have in an **interview**. The **interview will be taped by a machine**, but after I write down what you say, the **tapes will be destroyed**.

The **risks in this study are minimal**. The **benefits of this study are that it can help me understand how you choose things about your health**.

Other people will not know if you are in my study. I will put things I learn about you together with things I learn about other teens so no one can tell what things came from you. When I tell other people about my research, I will not use your name, so no one can tell who I am talking about.

Your parents or guardian have to say it's OK for you to be in the study. After they decide, **you get to choose if you want to do it too**. If you don't want to be in the study, no one will be mad at you. If you want to be in the study now and change your mind later, that's OK. **You can stop at any time**.

My telephone number is **(603)689-6312**. You can call me if you have questions about the study or if you decide you don't want to be in the study any more.

I will give you a copy of this form in case you want to ask questions later.

Sincerely,

Briana Terrill
Student Researcher

Appendix G (Continued)

Agreement

I have decided to be in the study even though I know that I don't have to do it. Briana has answered all my questions.

Signature of Study Participant

Date

Signature of Researcher

Date

Appendix H



UNIVERSITY of NEW HAMPSHIRE

Briana L. Terrill
Junior Undergraduate Honors Nursing Student
The University of New Hampshire
27 Forest Rd.
Hudson, NH 03051
(603)689-6312
Blk34@unh.edu

February 23, 2011

Dear Parents of Campers at Camp Allen,

My name is Briana, and I am a junior undergraduate nursing student at the University of New Hampshire in Durham. I will be conducting research during this summer 2011 at Camp Allen. The purpose of this study is to find out how young adults with disabilities perceive their health decision abilities. In addition the purpose is also to determine what parent's perceive their child's ability to make health decisions are. My intent is to improve the overall health of young adults with disabilities by examining how they make decisions about their health.

You and your child are invited to participate in this research! Participation is entirely voluntary and there will be no penalty if you do not wish to participate. You will not receive any compensation for your participation. There are minimal risks to you and your child if you decide to participate in this study. If you agree to participate you will be asked to complete a **questionnaire that will take approximately 20 minutes**. While you are completing the survey, I will **interview your child for approximately 20 minutes** asking questions about exercise. These interviews will be voice recorded. You may decide to stop participating at any time without penalty.

You and your child's confidentiality will be maintained at all times. After the voice recordings have been transcribed, they will be destroyed. All documents will be in a locked cabinet in my professor's office. After this research has been analyzed, it will be properly destroyed.

If you have any questions about this research project or would like more information before, during, or after the study, you may contact Briana Terrill, (603)689-6312 blk34@unh.edu. If you have questions about your rights as a research subject, you may contact Dr. Julie Simpson in UNH Research Integrity Services at 603-862-2003 or Julie.simpson@unh.edu to discuss them.

Thank you very much for your time and consideration. I appreciate your willingness to participate in this survey.

Thank You,

Briana Terrill

Appendix I

University of New Hampshire

Research Integrity Services, Service Building
51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

23-May-2011

Terrill, Briana Lee
Nursing, Hewitt Hall
Woodside Apts. I, 6L
27 Forest Road
Hudson, NH 03051

IRB #: 5133

Study: Identifying the Gaps in Perceived Ability: Promoting the Health of Young Adults with Disabilities

Approval Date: 06-Apr-2011

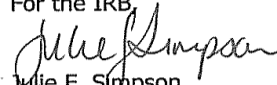
The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study.

Approval is granted to conduct your study as described in your protocol for one year from the approval date above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. (This document is also available at <http://unh.edu/research/irb-application-resources>.) Please read this document carefully before commencing your work involving human subjects.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,


Julie F. Simpson
Director

cc: File
Dinapoli, Pamela
Akerman, Peter

Appendix J

	Parent's Scores										
	1	2	3	4	5	6	7	8	9	10	AGG
Q1	5	1	5	2	5	2	1	2		3	26
Q2	1	3	5	4	4	2	1	1		2	23
Q3	4	4	5	3	4	2	1	4		2	29
Q4	4	3	5	2	4	4	2	5		2	31
Q5	5	3	2	2	3	4	1	2		2	24
Q6	3	1	5	1	3	2	1	4		3	23
Q7	4	3	5	4	5	2	1	2		2	28
Q8	2	2	5	1	5	2	1	2		3	23
Q9	2	3	5	2	3	3	1	2		3	24
Average	3.3333 33	2.5555 56	4.6666 67	2.3333 33		2.5555 56	1.1111 11	2.6666 67		2.4444 44	25.6666 667
Q10	5	2	2	5	4	4	1	1		4	28
Q11	1	2	2	1	1	1	1	1		4	14
Q12	1	4	3	1	2	4	1	1		4	21
Q13	5	4	2	1	1	5	1	2		3	24
Q14	4	3	2	1	1	2	1	1		2	17
Q15	4	5	2	4	2	4	1	5		4	31
Q16	4	3	2	2	2	3	1	5		4	26
Q17	1	2	1	0	0	2	1	1		1	9
Q18	2	5	3	4	1	5	1	5		1	27
Q19	5	4	1	2	2	5	5	5		5	34
Average	3.2	3.4	2	2.1	1.6	3.5	1.4	2.7		3.2	23.1
Q20	1	4	2	2	4	2	3	2		2	22
Q21	1	4	3	3	4	2	4	4		5	30
Q22	4	1	2	3	5	3	3	1		3	25
Q23	4	4	5	4	5	3	1	5		1	32
Q24	1	4	3	3	3	2	3	3		3	25
Q25	2	4	3	5	5	4	3	4		3	33
Q26	2	4	2	3	4	2	2	4		2	25
Q27	2	4	3	3	4	2	1	3		1	23
Average	2.52	3.64	2.6	3.01	3.7 6	2.85	2.64	3.37		2.82	26.875

Appendix K

<i>Perceived Benefits of Action</i>	Frequency
<i>Individual Sports</i>	19
<i>Reason for exercise: Fun/Happy/Excitement</i>	8
<i>Outside exercise</i>	7
Socialization	6
Team Sports	6
Reason for exercise: Health	6
Alternative forms of exercise: Swinging, Wii video games, role playing, pushing grocery carts, catching frogs	6
Reason for Exercise: Does not want to be fat	2
Motivator: Creativity	2
Reason for exercise: Makes you calm	2
Motivator: Parental influence/encouragement	2
Motivated to exercise: Air conditioned basement and equipment	1
Reason for exercise: "Because you have to"	1
Reason for exercise: To not be a "couch potato"	1
Reason for exercise: to prevent boredom	1
Reason for exercise: It just happens	1
Reason for exercise: Feeling powerful in certain martial art positions	1
Reason for exercise: Repetition/ Routine	1
Motivation to exercise: A "Game" like atmosphere	1
Reason for exercise: Improving skill in a sport	1
Motivator: Playing a sport since he was 10 years old	1
Motivator: Scoring a lot of points in a game	1
Motivator: Coach & Practice	1
<i>Perceived Barriers of Action</i>	
<i>Altered Time Perception</i>	10
<i>Barrier to exercise: Bad weather (rain, extreme cold/heat)</i>	5
<i>Feeling sick</i>	4
Barrier to exercise: Parental attitude	3
Limited area or equipment for recreational needs	2
Barrier to exercise: Feeling tired	2
Barrier to exercise: Lack of interest	2
Barrier to exercise: Difficult exercises "stairs, push ups"	2
Barrier to exercise: Conflict with other activities	1
Barrier to exercise: Injury	1
Type of exercise: does not like team sports	1
Barrier to exercise: "Im lazy"	1
Barrier to exercise: Playing with someone not good at basketball	1

Barrier to exercise: A coach who pushes you	1
Barrier to exercise: The time of the day	1
Perceived Self-Efficacy	
<i>Knowing limits: Decreasing or changing intensity or activity in order to overcome barrier</i>	6
<i>Overcoming barriers: Desire to exercise (including alternative forms)</i>	4
<i>Overcoming barriers: Would still play outside if it was poor weather</i>	4
Understanding limits: Drinking water when it is hot	3
Overcoming Barriers: Pushing through difficulties (Exercise even if hurt, tired)	3
Overcoming Barriers: Perceiving that all the hard work will make the “team” better	1
Overcoming barriers: Understanding that scoring a lot of points in a basketball game was because his coach pushed him to practice.	1