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Autonomy Through Social Skill Development: A Camp Intervention for Young People with Spina Bifida

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LOYOLA UNIVERSITY CHICAGO

AUTONOMY THROUGH SOCIAL SKILL DEVELOPMENT:
A CAMP INTERVENTION FOR YOUNG PEOPLE WITH SPINA BIFIDA

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN CLINICAL PSYCHOLOGY

BY

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CHICAGO, ILLINOIS

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I'd like to thank the Kiwanis of Illinois for funding this project, the Spina Bifida Association of Illinois for their ongoing collaboration, and the many families who – year after year - make our research possible by making the time to complete questionnaires. Additionally, I'd like to thank Grayson Holmbeck for his mentorship and support throughout the course of this research, and the Chicago Healthy Adolescents Transition Study lab for their contributions to the study. Finally, I'd like to thank my parents for their generosity and encouragement throughout my graduate career, and my husband – Alex Shveyd – for his unwavering patience and understanding.

For my parents Joseph and Margaret Zurenda, with love and gratitude

Do not be daunted by the enormity of the world's grief. Do justly, now. Love mercy, now.
Walk humbly, now. You are not obligated to complete the work, but neither are you free
to abandon it.

The Talmud

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CHAPTER ONE

INTRODUCTION

Overview of the Study

In a culture where self-sufficiency is valued, living well means living independently. From this perspective, autonomy development is viewed as a process that individuals must negotiate to become optimally functioning adults (Greenfield, Keller, Fuligni, & Maynard, 2003; Guisinger & Blatt, 1994). In fact, research supports this notion, with autonomy during adolescence associated with positive outcomes during adulthood (Allen, Hauser, Eickholt, Bell, & O’Conner, 1994; Bier, Prince, Tremont, & Msall, 2005; Masten, 2005).

The process of becoming autonomous may be difficult for adolescents to negotiate for a number of reasons; for adolescents with chronic medical conditions, the process may be further complicated. However, research suggests that autonomy is no less important for this population, as findings derived from samples of young adults with various chronic medical conditions suggest that those who have achieved greater levels of autonomy report having a better quality of life (Bier et al., 2005; Wehmeyer, 1997; Wehmeyer & Schwartz, 1996). Autonomy attainment may be even more important for these individuals because the degree to which they can take care of their medical needs determines their ability to live apart from caregivers, partake in the workforce, and become financially independent.

Unfortunately, many individuals with chronic medical conditions do not achieve levels of independence for which they are capable (Sherman, Berling, & Oppenheimer, 1985; Blum, Resnick, Nelson, & St. Germain, 1991; Holmbeck et al., 2003; Peterson, Rau, Brown, & Cole, 1994).

Spina bifida is a congenital, multisystemic condition that requires intervention by neurology, urology, orthopedics, and occupational therapy (McLone & Ito, 1998). The physical manifestations associated with spina bifida – along with the complicated medical regimen they require - present multiple challenges to autonomy development. Meanwhile, spina bifida's cognitive and psychosocial correlates present additional obstacles. While recent advances in medicine have allowed for improved care of the physical aspects of spina bifida, psychology has lagged behind in addressing its cognitive and psychosocial features. Consequently, individuals with spina bifida are surviving longer into adulthood, but are not living as autonomously as possible. Research findings suggest that autonomy is especially underdeveloped in domains including self-care, mobility, and social skills (Bier, et al., 2005; Blum et al., 1991; Watson, 1991).

Pediatric psychology may play a role in promoting autonomy development in this population through the implementation of empirically-supported, developmentally-appropriate, and syndrome-specific interventions. However, there is currently a need for interventions that meet these criteria (Bauman, Drotar, Leventhal, Perrin, & Pless, 1997; Drotar, 1997). The current study was one attempt to meet this need. This study is one step in a line of intervention research designed to promote autonomy gains among young people with spina bifida. Its purpose is to evaluate a manual-based intervention as a part

of Camp Ability™, a one-week long overnight camp exclusively for children, adolescents, and young adults with spina bifida).

The following document is comprised of nine sections. First, spina bifida is described with regard to its physical, cognitive, and psychosocial correlates. Second, autonomy is defined in developmental-behavioral terms, and autonomy development is considered in the context of spina bifida and adolescence. Third, the literature on interventions for young people with chronic medical conditions is reviewed. Fourth, Camp Ability (i.e., the setting for the current intervention) is described, and an overview of findings from earlier interventions at the camp is provided. Fifth, previous intervention studies are critiqued, and changes to the current study are presented. Sixth, relevant outcome variables are discussed, and hypotheses are put forth. Seventh, the intervention and research protocol are described in terms of methods, materials, and measures. Eighth, statistical analyses are presented and results are reviewed. Finally, findings are considered in the context of the intervention literature, and ideas for future research are provided.

CHAPTER TWO

REVIEW OF THE LITERATURE

Spina Bifida: Etiology, Physical Correlates, and Management

Spina bifida is the most common of the neural tube defects, affecting 18 out of every 100,000 live births (Mathews, 2008). The defect occurs early in embryonic development (i.e., 20-25 days after conception), and results from a failure of the neural tube to form completely. Consequently, lesions occur at various parts of the spine. The lesion location determines the type of spina bifida, and also contributes to the severity of its manifestations. Myelomeningocele is the most common – and most severe - form (McLone & Ito, 1998).

In addition to lesion location, many other factors (i.e., individual, familial, socioeconomic, and healthcare) interact to create the wide range of variability that characterizes this condition (McLone & Ito, 1998; Wills, 1993). Despite this variability, spina bifida is typically associated with problems in brain development, urinary and bowel dysfunction, and physical limitations related to mobility. The purpose of the following section is to provide a brief description of the major physical correlates of this complex condition, with an emphasis on those that have implications for psychosocial functioning and autonomy development. Correlates related to brain development – some of the most common and most dangerous aspects of spina bifida – are described first.

The vast majority of individuals with spina bifida have an Arnold-Chiari II malformation – a deformity in the cerebellum that can result in death for newborns with

this condition. This malformation can also lead to hydrocephalus, which affects 80-90% of people with spina bifida (McLone & Ito, 1998). Hydrocephalus is the accumulation of cerebrospinal fluid in the ventricles of the brain. If left untreated, this accumulation can lead to increased intracranial pressure inside the skull, and consequently, enlargement of the head, spasticity, convulsions, scoliosis, weakness in the upper extremities, motor loss in the lower extremities, cognitive deficits, and even death (Wills, 1993). Fortunately, hydrocephalus can be managed through the insertion of a series of tubes and valves into the brain (i.e., a shunt). The shunt serves to drain excess cerebrospinal fluid, thus preventing further accumulation. However, shunts often malfunction, resulting in various symptoms including headaches, vomiting, seizures, lethargy, neck pain, and a decrease in sensory and motor functions. Other signs of malfunction include personality changes and decreased school performance (McLone & Ito, 1998). In the case of a shunt malfunction, immediate emergency attention is required. Individuals who are able to recognize the symptoms of a shunt malfunction, elicit emergency care, and inform medical professionals as to their medical history will be able to expedite intervention; those who are unable to do this will be at an extreme disadvantage in terms of having their healthcare needs met efficiently (McLone & Ito, 1998).

As a result of brain abnormalities, many individuals with spina bifida have cognitive impairments that interfere with self-care (McLone & Ito, 1998; Wills, 1993). These impairments typically manifest in the form of slightly low-average IQ scores, and specific cognitive deficits related to attention, memory, executive functioning, language pragmatics, problem-solving, and judgment (Fletcher, Dennis, & Northrup, 2000; McLone & Ito, 1998; Yeates, Enrile, Loss, Blumenstein, & Delis, 1995). Cognitive

impairments may interfere with social functioning as well. For example, attention problems may result in difficulty attending to conversations, asking follow-up questions, and changing topics appropriately, while deficits in language pragmatics may make it difficult to ascertain the implied meaning behind speech content (e.g., detecting sarcasm, appreciating humor). Likewise, impairments in judgment may prevent individuals from asking for assistance in appropriate ways (Wills, 1993). On a more basic level, deficits in executive functioning present challenges to carrying out complicated medical regimens.

The catheterization schedules and bowel programs that spina bifida management necessitates are particularly demanding aspects of the healthcare regimen, and working these interventions into daily routines requires memory, planning, organization, and time-management. However, as most people with spina bifida endure nerve damage that interferes with bladder and bowel functioning, self-catheterization and bowel management are a necessary part of self-care (McLone & Ito, 1998). These interventions are not only time-consuming; some of them also present health-related risks. For example, the regular use of catheters increases the likelihood that individuals will develop urinary tract infections (McLone & Ito, 1998). Social implications are notable as well, as odors resulting from bladder and bowel programs that are not handled properly are not expected to be tolerated by peers. This may lead to social isolation or teasing, thereby interfering with the formation of healthy peer relationships and negatively impacting self-concept. In light of these considerations, it is unsurprising that individuals with spina bifida cite difficulties with bladder and bowel programs as one of the most distressing aspects of their condition (McLone & Ito, 1998; King, Currie, & Wright, 1994; Watson, 1991). Interestingly, bladder and bowel care have also been identified as

one of the most delayed self-care skills among children with spina bifida, with most young people requiring assistance into adolescence and beyond (Blum et al., 1991; Watson, 1991).

The effects of nerve damage are not limited to bladder and bowel dysfunction; nerve damage can also result in paralysis and loss of sensation below the waist. Consequently, most people with spina bifida rely on braces and/or wheelchairs to maximize mobility, and many require the assistance of others with tasks that their able-bodied counterparts perform independently (e.g., getting in and out of bed, getting dressed, bathing; Bier et al., 2005).

In addition to interfering with activities of daily living, mobility issues are likely to impact social and vocational domains of functioning as well. For example, physical impairments may preclude children from traditional sports activities, and prevent adolescents from driving themselves to social gatherings. Furthermore, both children and adolescents with physical disabilities may be treated differently by peers and teachers than are their able-bodied counterparts (Hauser-Cram & Krauss, 2004; Thomas et al., 1985). Lower expectations of parents, teachers, and peers may be particularly detrimental to the autonomy development of children and adolescents as they may serve to limit the goals and aspirations people with spina bifida have for themselves, as well as reduce opportunities to cultivate autonomy skills (Eccles, Wigfield, & Schiefele, 1998; Wilson, 1992).

For young adults, physical impairments are likely to limit opportunities for employment as most jobs require some level of mobility, and employers may be more comfortable with employees who are independent in this respect (O'Mahar, 2010).

Individuals with visible physical disabilities may be perceived to be less capable or intelligent than they are in actuality (Hauser-Cram & Krauss, 2004; Thomas, Bax, & Smith, 1989); as a result, they may be less appealing to potential employers. Although people with spina bifida differ with regard to the degree of their physical impairment, it should be noted that relative gains in autonomy can be made for people of all abilities. For example, people who are wheelchair-bound may learn to initiate requests to be transferred rather than waiting for others to offer assistance (O'Mahar, 2010).

Autonomy Development and Spina Bifida: Conceptual Considerations

It is a basic tenant of psychology that no complex phenomenon can be explained by any single factor, and the process of autonomy development is no exception. No single factor determines how children will go on to negotiate the process of autonomy development; rather combinations of many factors may predict the “autonomy trajectory” upon which one embarks (Cicchetti & Rogosch, 2002). While some variables may function to keep an individual on the same trajectory, other factors may serve to steer that individual toward another path. For the purposes of the current research, the author takes a developmental-behavioral perspective, whereby a child’s autonomy trajectory is influenced not only by a constellation of risk and protective factors, but also by dynamic transactions among individuals, their caregivers, and the environment. Thus, the purpose of the intervention is to strengthen protective factors such that participants may become empowered to play an active role in shaping not only their medical care and health status, but also the quality of their relationships and their social lives. The current intervention strives to help individuals with spina bifida “transform the minus of the

handicap into the plus of compensation” (Rieber & Carton, 1993). In the following section, guiding definitions and perspectives are presented.

Definition of Autonomy

Autonomy is a broad term that refers to the thoughts, feelings, and behaviors that allow individuals to increase self-governing and self-regulation. It implies the ability to act according to one’s preferences, interests, and skills (Hill & Holmbeck, 1986; Wehmeyer, 1997; Wehmeyer & Schwartz, 1996). *Independence* is a term more narrow in scope, and often refers exclusively to the achievement of complete self-reliance (O’Mahar, 2010). In other words, autonomy connotes a developmental *process*, whereas independence refers to an *endpoint* of that process (O’Mahar, 2010). Individuals with spina bifida are variable with regard to the degree to which they can make autonomy gains, and some with severe physical and/or psychosocial impairments cannot be expected to achieve complete independence. For this reason, the term autonomy may be more appropriate when considered in terms of spina bifida (Bryant, Craik, McKay, 2005; Gill, 2005; Siperstein, Reed, Wolraich, & O’Keefe, 1990). However, for the purposes of the current study, the terms autonomy and independence are used interchangeably.

As physical limitations may preclude individuals with spina bifida from completing self-care tasks unaided, the context-dependent nature of autonomy is especially pertinent to a discussion of independence in this population. In the context of spina bifida – and other conditions associated with physical, cognitive, and/or psychological impairments - the achievement of autonomy *does not* refer to the ability to function without the help of others. On the contrary, autonomy may instead mean recognizing the need for assistance, identifying the appropriate source of support, and

asking for help accordingly. Likewise, autonomy does not suggest a sense of interpersonal detachment. Rather it implies the formation of developmentally-appropriate attachments, along with the ability to elicit support in a way that is effective in meeting needs, without being experienced as burdensome to friends and family.

Physical ability is only one of many contextual factors relevant to a discussion of autonomy development among people with spina bifida. While some of the other individual factors relate specifically to spina bifida (e.g., shunt status, lesion location), others apply to all people (e.g., age, developmental level, cognitive ability). Still other factors are determined by cultural standards and norms. Clearly, the concept of autonomy is both complex and subjective, and there are many vantage points from which it may be viewed. The concept of autonomy becomes even more complex when its various forms are considered (e.g., *behavioral autonomy*, *emotional autonomy*, *value autonomy*) (Holmbeck, 1994; Steinberg, 1985). One focus of the current research is on *healthcare autonomy*. Healthcare autonomy is a specific form of behavioral autonomy that refers to the skills and responsibilities associated with the successful implementation of one's healthcare regimen. Because successful management of spina bifida-related tasks greatly influences health status for people with spina bifida (and thus, the ability to function in other domains) healthcare autonomy takes precedence over other forms of behavioral autonomy for this population (Holmbeck, 1994; O'Mahar, 2010).

A Developmental-Behavioral Perspective on Autonomy

In keeping with the goal to empower participants to promote their own autonomy development through interactions with others, a developmental-behavioral perspective guides the current research. Unlike evolutionary psychological perspectives (that

emphasize hard-wired biological adaptations favoring the survival of the species; Buss, 1991), a developmental-behavioral perspective focuses on behaviors that can be altered at will. Unlike classical psychoanalytic perspectives (that emphasize intrapsychic structures and processes; Boesky, 1990), a developmental-behavioral approach targets specific social behaviors that are concrete and observable. Developmental-behavioral theorists emphasize the role of interpersonal relationships and their impact on the course of autonomy development (Holmbeck, 2002). Insofar as social skills involve behaviors that form the foundation of such relationships, a developmental-behavioral perspective is well-suited to inform an intervention aimed toward promoting healthcare autonomy through the advancement of social skills (Swanson & Malone, 1992).

Developmental-behavioral theorists view autonomy development as that which progresses - or remains stagnant - largely as a function of interpersonal relationships (Holmbeck, 2002). Likewise, they maintain that relationships both within the home (i.e., with parents) and outside of the home (i.e., with peers, teachers, coaches, and counselors) play important roles in facilitating – or impeding – the process of autonomy development (Holmbeck, 2002). The process of autonomy development is seen as a continuous one that occurs throughout the lifespan, manifesting itself in different ways throughout the course of development (Pardeck & Pardeck, 1990). For example, a two-year-old girl may assert her independence by refusing to eat her vegetables. Likewise, an elderly man may work to maintain his autonomy by refusing to surrender his driver's license, despite a diminishing ability to drive safely. However, for the purposes of the current intervention, autonomy development is viewed as a process that occurs primarily during adolescence.

Autonomy Development among Adolescents with Spina Bifida

Adolescence is a transitional period between childhood and adulthood that is marked by dramatic biological, psychological, and social changes (Adams, Montemayor, & Gullotta, 1996; Feldman & Elliott, 1990; Graber, Brooks-Gunn, & Petersen, 1996; Holmbeck & Updegrave, 1995). It is during this phase that the typically-developing young person may acquire a driver's license, set out to earn income, and begin searching for a long-term romantic partner (Holmbeck, 2002). These developmental tasks all prepare adolescents to leave the home of the family of origin and live as independent adults. Importantly, although the process of autonomy development is a continuous one, it is not linear in nature. Just as baffled parents remark on their adolescent's tendency to act mature one minute and then childlike the next, the entire lifespan may be construed as a series of advancements and regressions. Many people achieve autonomy successfully in their adult years to arrive – ultimately - at a state of dependency comparable to that experienced during infancy. Thus, the process of autonomy development can hardly be considered a simple or neat progression that culminates in independence.

Similarly, autonomy development does not occur at the same time or in the same manner for all people. Instead, multiple individual and environmental factors are likely to influence the rate, ease, and success with which individuals negotiate this process (Masten, 2005). Although there is currently little research regarding the specific autonomy trajectories of adolescents with chronic medical conditions, we do know that these trajectories can be altered dramatically – in either positive or negative directions – during this transitional phase (Holmbeck, 2002). Consequently, we see great variability with regard to how well individuals are able to negotiate the process of autonomy

development (Holmbeck, 2002). As discussed previously, physical and psychosocial limitations associated with spina bifida can compromise individuals' capacity to perform at a level consistent with that of their typically-developing peers (Hauser-Cram, Krauss, & Kersch, 2004). Meanwhile, demanding healthcare regimens, medical appointments, and hospitalizations may restrict opportunities to exercise independence (Holmbeck, 2002; Turnbull & Turnbull, 1985). While resilient children with adequate protective factors on their side pursue autonomy in spite of impediments, others find their resources overwhelmed by spina bifida demands. This may result in dependence on caregivers extending into the adult years.

Clearly, the ways by which a medical condition such as spina bifida affects a child's autonomy development are many and complex, and there is great variability in terms of the success with which adolescents traverse this process. However, as many young people with spina bifida encounter some difficulty as they set out to achieve independence (Bier et al., 2005; Holmbeck et al., 2003), there is a clear need for syndrome-specific, developmentally-appropriate interventions designed to promote autonomy development in this population. Unfortunately, few such curricula have been designed and implemented, and fewer still have been evaluated empirically.

Interventions for Young People with Chronic Medical Conditions: A Review

While there are many empirical investigations of interventions for children and adolescents, few are designed to address the needs of those with chronic medical conditions. Some have concluded that the need for methodologically sound interventions for this population is the most pressing issue currently facing pediatric psychologists (Bauman et al., 1997). Unfortunately, there is limited information relating to camp

interventions for people with spina bifida, and for people with chronic medical conditions more generally. The conclusions that can be drawn from those studies that have been done are limited by various methodological problems (e.g., failure to measure relevant health outcomes; Task Force on Community Preventative Services, 2002). That said, those interventions that have been designed for the population of people with spina bifida have largely focused on physical challenges such as self-catheterization, bowel training, and fine motor difficulties, and have been successful in leading to improvements in these areas (King et al., 1994; Watson, 1991).

Some interventions have included measurement of psychosocial outcomes as well. For example, findings from one investigation of a ten-week group exercise program for children with spina bifida revealed improvements in self-concept (Andrade, Kramer, Garber, & Longmuir, 1990). Despite this program's emphasis on physical variables (e.g., cardiovascular endurance and muscle strength), results are encouraging. Another intervention utilized a twelve-week psychoeducation group approach to address various aspects of psychosocial functioning for children with spina bifida. Findings indicated improvements in self-care tasks, but not in self-esteem or social skills (Engleman, Loomis, & Kleiback, 1994). King and colleagues (1997) took a more focused approach in the design of their intervention. Their ten-week group social skills training intervention for children with cerebral palsy and/or spina bifida revealed initial improvements in child-reported social acceptance; however, these results were not maintained at six month follow-up. Sherman, Berling, & Oppenheimer (1985) designed an intervention specifically to promote autonomy development among teenagers with spina bifida. Their intervention consisted of an eight-week (three days per week) summer

program in which adolescents identified goals and plans for attaining them. This program also included a support group for parents. Although the program was deemed effective on the grounds that most participants reported goal attainment, no statistical methods were employed to compare baseline and outcome data; consequently, firm conclusions cannot be drawn.

In sum, the research on interventions for young people with spina bifida is limited. Many studies neglect to address psychosocial aspects of the condition, or fail to measure outcomes adequately. Grayson Holmbeck, Ph.D. and his graduate student research team at Loyola University Chicago ventured to build upon this research not only by creating an intervention specifically with the physical and psychosocial correlates of spina bifida in mind, but also by evaluating it using sound methodological principles.

Camp Ability: Previous Programming

Supported by the Spina Bifida Association of Illinois (SBAIL), Camp Ability is an overnight camp designed exclusively for individuals with Spina Bifida. Although the camp has promoted independence as part of its mission since its inception in 2001, it was not until 2005 that the SBAIL sought assistance from Grayson Holmbeck, Ph.D. for an intervention guided by psychological theory and research. The camp is comprised of three separate week-long sessions for children (7-12 years), adolescents (13-17 years), and young adults (18 years and older) held at Camp Red Leaf in Illinois. The camp offers traditional camp activities such as swimming, horseback riding, canoeing, arts and crafts, talent shows, and campfires, with approximately one hour per day devoted to an “Independence Intervention.” For many children and adolescents, the experience of going away to overnight camp for the first time represents an important milestone; for

individuals with spina bifida, the experience may take on even more significance. In particular, it may represent the first time individuals have been away from home and apart from caretakers. As many individuals are dependent on caregivers to meet their healthcare needs, the experience of being away from home requires a shift of responsibility to campers themselves. In this sense, the camp experience is a potentially powerful experience for individuals with spina bifida insofar as it presents an opportunity to demonstrate their ability to take care of themselves without the assistance of parents. Additionally, it is likely to be one of the only times they are surrounded by others with spina bifida. This gives campers opportunities to share their experiences in living with spina bifida with others who may relate in a way able-bodied peers cannot. They may learn strategies for spina bifida management, and relating to others, and may even take on leadership roles in modeling healthcare and social skills. These are empowering experiences with the potential to alter the course of autonomy development in a positive way.

Because there are so many different and interrelated aspects of spina bifida, there are many opportunities to make gains toward independence. In the section that follows, previous approaches (i.e., *The Toolbox Approach Addressing Independence, Social Skills, Emotional Wellness, and Self-Care; Cognitive Rehabilitation Approach*) will be outlined, and findings from previous research will be discussed to the extent that they informed the 2008 and 2009 interventions. Then, each of these interventions will be described.

2005 Camp Ability Intervention: A Toolbox Approach. Designed by Grayson Holmbeck, Ph.D. and three graduate students, this intervention was structured around five target domains such that each session addressed one of the following areas: *Taking*

Care of Your Relationships, Taking Care of Yourself, Living with Spina Bifida, Taking Care of Spina Bifida, and Taking Responsibility for Spina Bifida. The approach may be considered a toolbox approach insofar as each module was comprised of several different activities, with the interventionist choosing from among several activities for each session. Campers were separated into two groups of ten to twelve people, and the interventionist spent approximately one hour per day with each group. In addition to the five hours spent in intervention sessions throughout the week, campers met with counselors during the evenings to discuss progress toward healthcare goals. The interventionist was also available throughout the week to discuss any difficulties that came up throughout the week regarding goal attainment.

Throughout the camp sessions, the interventionist documented observations of camp. She noted that some campers were more engaged in the intervention activities than were others, with younger campers being more responsive than adolescent and young adult campers. With regard to goal setting, the interventionist observed that some goals were inappropriate (i.e., they were either too easy such that goals were achieved within one day of camp, or they were so difficult so as to be unrealistic given time constraints and/or level of physical limitation). These concerns were addressed in revisions made in the 2006 intervention. Conceptual concerns (e.g., lack of acknowledgement of cognitive limitations that interfere with autonomy development), and measurement concerns (e.g., lack of available medical information) were also addressed in revisions made to the 2006 intervention.

2006 Camp Ability Intervention: A Cognitive Rehabilitation Approach. By taking a cognitive rehabilitation approach to the Independence Intervention, the authors

of the 2006 curriculum made cognitive limitations the focus of the intervention.

Cognitive Rehabilitation Therapy is an intervention designed to help people with brain damage compensate for their cognitive deficits by addressing specific elements of brain functioning (e.g., attention, concentration, memory, problem-solving, initiation, awareness) (Cicerone et al., 2005). The researchers borrowed strategies from this approach and adapted them to target those neurocognitive deficits associated with spina bifida (e.g., language pragmatics, memory, problem-solving; O'Mahar, Holmbeck, Jandasek, & Zukerman, 2010). This intervention included a psychoeducation component designed to teach campers about spina bifida management. It also included an individual goals component that was created to help campers make progress toward healthcare goals. Findings indicated that participants showed improvements in some areas of psychosocial functioning, and made progress toward social goals.

2008 and 2009 Camp Ability Interventions: A Psychosocial Approach. The primary aim of the current study was to design and evaluate an Independence Intervention for young people with spina bifida. The focus of this study was on social skills. As discussed previously, social skills are important in terms of medical management (e.g., asking questions of healthcare providers, communicating with caregivers), school and work performance (e.g., asking for assistance or clarification as needed), and perhaps most obviously, relating with peers and family. Insofar as social skills underlie relationships with parents, peers, teachers, co-workers, and healthcare professionals, development of these skills will likely improve interpersonal functioning across arenas such as home, school, work, and medical care.

Components of the Current Intervention Curriculum. Designing a camp intervention for young people with spina bifida presents a host of challenges. To address these challenges, the authors of the current study borrowed from – and built upon - the work of previous researchers. The result is a curriculum that includes many elements shared by previous interventions, as well as several unique components. The defining components of the current curriculum are summarized below, and changes from previous interventions are emphasized.

The first defining component concerns the focus of the intervention. Whereas previous interventions targeted exercise habits (Andrade, 1990), spina bifida management (King et al., 1994; Watson, 1991), and cognitive deficits (O’Mahar et al., 2010), the current intervention was focused on both healthcare and psychosocial functioning as they relate to autonomy development. Although the emphasis of previous interventions was on aspects of spina bifida that are undoubtedly relevant to autonomous functioning, they may not have been perceived as important to individuals with spina bifida themselves; consequently, campers may have been relatively unmotivated to participate. Insofar as young people with spina bifida experience dissatisfaction with their social lives (McLone & Ito, 1998), they are likely to be motivated to engage in an intervention that has the potential to lead to improvement in this domain. The focus of the current curriculum was similar to that which was espoused in the 2005 “Toolbox Approach” described previously. However, in the current curriculum, psychosocial functioning was addressed in a more narrow sense: Whereas social skills, emotional wellness, and psychoeducation regarding depression were included in the Toolbox Approach, only observable social skill behaviors were addressed in the current curriculum.

Second, the current intervention was developmentally-informed, meaning that activities and exercises were designed to address the central developmental tasks of childhood, adolescence, and young adulthood. For example, the role plays designed for the 7-12 year-old group revolved around forming same-sex friendships and dealing with bullies, while the role plays for the adolescent and young adult groups were focused on negotiating more complex interpersonal situations and communicating with potential romantic partners. This approach is shared by at least two other previous curricula (Engleman et al., 1994; O'Mahar et al., 2010).

Third, like most of the interventions discussed previously (Andrade et al., 1990; O'Mahar et al., 2010; Sherman et al., 1985), the current intervention was created specifically with the demands of spina bifida in mind. For instance, role plays involved predicaments likely to be encountered by people with spina bifida (e.g., feeling excluded from an activity at school). Additionally, targeted social skills included those that have been identified as challenging for individuals with spina bifida (e.g., staying on topic during conversation). Also, like the O'Mahar et al. (2010) study, activities were sensitive to the cognitive limitations associated with spina bifida. Although typically-developing adolescents and young adults may be expected to benefit from interventions that require abstract reasoning, critical problem-solving, and perspective-taking (Holmbeck, Greenley, & Franks, 2004; Damon & Hart, 1982; Selman, 1980; Piaget, 1952), the cognitive abilities of many young people with spina bifida may not be on par with their typically-developing age-mates (Holmbeck et al., 1990). As such, a behavioral approach was taken for all three age groups. In particular, the intervention targeted behaviors that are specific and concrete, and thus can be demonstrated, modeled, and practiced. This

approach was thought to be more effective for a population of people likely to experience cognitive limitations, as compared with one that relies on more sophisticated cognitive operations (Holmbeck et al., 2004). It should be noted, however, that unlike the O'Mahar (2010) study, the current curricula did not address cognitive limitations explicitly (e.g., by teaching strategies for improving memory).

A fourth component of the current curriculum is a change that was made to previous programming in an effort to maximize camper satisfaction. This change relates to the presentation of material: Whereas previous interventions relied heavily on didactic approaches (O'Mahar et al. 2010), the current study featured games and group discussions to encourage campers' active participation. Additionally, role plays were used as a central part of the intervention. This technique has been identified in the literature as an engaging and effective way of teaching basic communication skills (Beck, 1995; Antony & Roemer, 2003). Camper and parent satisfaction – with the intervention specifically, and the camp more generally - was measured at Time 3 data collection.

As with previous camp programs (Sherman et al., 1985; O'Mahar et al., 2010), the current intervention includes a goal setting component. The goal setting and progress monitoring protocols used in the present study were borrowed and adapted from Kiresuk & Sherman's *goal attainment scaling procedures* (1968). Goal setting and progress monitoring were implemented as strategies for increasing motivation and collaboration among participants (Hill & Lambert, 2004). As these procedures reflect a client-centered and collaborative approach to intervention, they are viewed as especially appropriate for the evaluation of an Independence Intervention designed to empower young people to take ownership for their healthcare.

They are similarly well-suited for use with a sample of people with a condition as complex as spina bifida, as this strategy can help ensure clear goals and priorities for intervention, ensure the ongoing relevance of the goals, help maintain focus, and facilitate communication among the multiple providers involved in healthcare (King, McDougall, Palisano, Gritzan, & Tucker, 2007). These procedures are also appropriate for use with samples characterized by heterogeneity, as variance introduces error into findings and compromises power to detect significant results (Stuifbergen, Becker, Rogers, & Timmeran, 2000). Finally, goal attainment scaling procedures have been effective for a variety of populations (e.g., cognitively limited; Bailey & Simeonson, 1988) and in a range of settings (e.g., rehabilitation; Coughlan & Coughlan, 1999).

In previous Camp Ability program evaluations, measurement strategies adopted from goal attainment scaling procedures were used (O'Mahar et al., 2010). Because several problems were noted with regard to how these strategies were implemented in previous Camp Ability sessions, changes were made to the goal setting protocol. One problem observed during previous Camp Ability intervention evaluations was that participants identified goals that were inappropriate (i.e., too easy or too difficult to achieve over the course of a week, unrealistic with regard to participant's physical limitations). Since goals that are too easy or too difficult would prevent campers from having the experience of working toward a goal that is both challenging and realistic, it was deemed especially important that goals selected were appropriate for the campers' level of functioning. In an effort to standardize the goal setting procedure and limit goals to those that are potentially appropriate for all campers, the authors of the current intervention provided participants with a *Goal Bank* (see Appendix A) from which they

were to select goals for campers to work toward throughout the camp week. The *Goal Bank* featured a list of fifteen goals related to healthcare (i.e., “Healthcare Goals”) and twelve goals related to social skills (i.e., “Social Goals”) from which participants were to choose. The goal options were informed by the literature on healthcare-related challenges and social skill deficits associated with spina bifida (Bier, et al., 2005; Blum et al., 1991; Watson, 1991), as well as by goals identified during previous interventions at Camp Ability. Upon agreeing to participate, campers and parents were instructed to work to identify goals, and to provide ratings to appraise how close the participant was to meeting these goals (1=Not at all; 2=Minimally; 3=Somewhat; 4=Almost; 5=Completely). Campers were instructed to come to an agreement with their caregivers regarding one healthcare goal and one social goal, for a total of two goals per camper. However, ratings were provided independently, such that separate ratings were derived from campers and parents.

Another component of the current intervention involves counselor involvement in the intervention. At Camp Ability, each counselor is assigned two campers. As campers spend the majority of their time at camp with counselors, counselors are in a prime position to influence progress toward goals. In particular, counselors can provide support, help monitor progress toward goals, and facilitate transfer of skills to camp activities beyond the intervention. This transfer represents a preliminary step toward mastery of skills in campers’ lives apart from camp. Additionally, because the camp setting is an inherently social one, campers are constantly presented with opportunities to interact with peers; therefore counselors are able to assess skill development in a natural setting.

As counselor involvement was absent or limited in previous interventions (Engleman et al., 2004), the author of the current research built upon O'Mahar and colleagues' (2010) efforts to increase counselor involvement in camper progress. Counselors participated in the intervention sessions so that they would be aware of the targeted skills, and also met with campers daily to discuss their progress toward healthcare and social goals. During each meeting, campers and counselors worked together to assess progress during that day. For each day, they worked together to fill out a *Progress Monitoring Form* (see Appendix A). The *Progressing Monitoring Form* was designed by O'Mahar et al. (2010) not only to allow for quantitative tracking of progress, but also to help campers attend to, reflect on, and achieve insight into their own behaviors. This form was used to encourage campers to monitor their own progress, and address obstacles that impede progress. Counselors were instructed to play a supportive role during these meetings by reinforcing campers' efforts toward goal attainment (i.e., by offering praise).

Counselors were primarily college students, most of whom were working toward undergraduate degrees in health sciences, social sciences, or education. All counselors participated in training prior to the camp season. Training sessions occurred on two occasions. On both occasions, training related to progress monitoring was one component of a larger educational talk about medical and psychosocial correlates of spina bifida. Counselors were given information about basic principles of behavior modification (e.g., reinforcement, shaping, etc.), instruction regarding progress monitoring forms, and tips for "trouble-shooting" with campers. They were also provided with examples of ways to reinforce campers' efforts toward goal attainment. Counselors were also given

opportunities to ask questions about their role in the intervention, and were encouraged to talk with the interventionist about any questions or problems that may arise during the camp week. Because the author of the current study was interested in campers' goal progress as a pre- and post-treatment measure, only camper ratings from Time 1 (first day of camp), Time 2 (last day of the intervention), and Time 3 (1 month post-camp) were used; other ratings collected during daily meetings with counselors were used solely for the purpose of helping campers monitor their behavior so as to increase their progress toward goals.

Changes to the Current Intervention Evaluation. The current study featured several changes to the evaluation with regard to methodology, measurement, and analytic approach. First, whereas previous work relied on parent-report for an estimate of cognitive ability, standardized tests of cognitive ability were employed to supplement questionnaire data in the current study. This change represents a step toward a multi-method approach to the measurement of cognitive ability. As using multiple methods in data collection allows researchers to rule out alternative explanations for findings (e.g., common method bias, response bias), cognitive test administration was incorporated into the study in an effort to increase the validity of findings (Holmbeck, Li, Schurman, Friedman, & Coakley, 2002).

Second, a measure of group cohesion was included in the current study. Although previous research indicated that the alliance between campers and interventionists was not related to outcomes (O'Mahar, 2010), it was hypothesized that campers' overall sense of belonging among group members may predict the likelihood that campers would make more or less progress toward goals. This notion is supported by the literature, as group

cohesion has been identified as one of the most important small group variables in terms of its impact on therapeutic outcomes (Yalom & Leszcz, 2005).

Third, whereas previous evaluations relied solely on variable-centered approaches to measuring outcomes (O'Mahar et al., 2010), the current study included a person-centered approach as well. Variable-centered approaches to intervention research are useful in that they reveal mean levels of change for treatment groups, and allow for comparison among groups along outcome variables of interest. Likewise, they can be used to identify factors and processes that influence group differences (Cicchetti & Rogosch, 2002). In contrast, a person-centered approach can be used to identify the particular characteristics that distinguish participants who derive the most – and least – benefit from the intervention (Magnusson, 2003).

A person-centered approach is seen as an appropriate means for evaluating the current intervention for two reasons. First, the study sample was characterized by a high degree of variability in terms of demographic variables (e.g., age, SES), as well as spina bifida-related variables (e.g., physical, cognitive, and psychosocial correlates), and person-centered approaches are well-suited for highly heterogeneous groups. Second, ethical considerations and sample size limitations preclude the inclusion of a no-treatment comparison group; consequently the effects of the treatment group cannot be measured against a no-treatment control group. Because person-centered approaches examine differences *between* participants or characteristics of subgroups of participants *within* a group, multiple treatment groups are not required (Laursen & Hoff, 2006; Magnusson, 2003).

Person-centered approaches need not serve as an alternative to variable-centered approaches; instead they can serve a complementary function by offering another angle from which to examine data (Magnusson, 2003). As such, the author of the current study built upon previous intervention evaluations by employing both person-centered and variable-centered approaches in analyzing outcome data. Whereas variable-centered analyses were used to determine the impact of the intervention for the group as a whole, person-centered analyses were used to examine the characteristics of those individuals who derived the most - and least - benefit from the intervention.

Variables of Interest

Outcome Variables: Healthcare Autonomy and Psychosocial Functioning

Broadly speaking, the aim of the current intervention was to promote autonomy development. As discussed previously, autonomy development for people with spina bifida depends heavily on their ability to implement healthcare regimens effectively. Specifically, insofar as successful management of basic healthcare tasks contributes to one's health, it also impacts one's ability to make autonomy gains in the context of family, peers, and school. Therefore, *healthcare autonomy* – that is, the skills necessary for carrying out healthcare tasks, as well as the ability to take responsibility for completing these tasks – is of primary importance. Moreover, taking responsibility for healthcare tasks is likely to foster a sense of empowerment, and spur further attempts to achieve autonomy in other domains (McLone & Ito, 1998).

Healthcare autonomy for people with spina bifida also depends on one's ability to form and maintain supportive relationships with family members, peers, and healthcare professionals. For instance, a well-implemented healthcare regimen requires

communication with multiple people: While healthcare management for children may depend on their effective communication with parents, healthcare management for adolescents and young adults will likely rely on similarly effective communication with physicians, nurses, and insurance company representatives. Thus, across the lifespan, proficiency in social skills is necessary to facilitate healthcare-related interactions.

Likewise, for individuals across developmental levels, healthcare management may depend on one's ability to elicit support from family and peers. Accordingly, those social skills associated with the formation and maintenance of supportive relationships were targeted as part of the intervention as well, and components of *psychosocial functioning* were measured as outcome variables. For the purposes of this study, psychosocial functioning includes social skills (i.e., behaviors associated with effective communication and successful social interactions) and self-perceived social acceptance (i.e., campers' perceptions of acceptance by others). Both social skills and perception of social acceptance are seen as important factors that may help individuals with spina bifida take ownership for their physical well-being, and consequently, improve the quality of their healthcare.

Healthcare Autonomy. For the purposes of the current study, the general construct of *healthcare autonomy* is defined in terms of two distinct dimensions: 1) spina bifida-related *skills* (measured by the *Spina Bifida Independence Survey*) and 2) spina bifida-related *responsibilities* (measured by the *Sharing of Spina Bifida Management Responsibilities Survey*). Whereas spina bifida-related skills refer to whether individuals are *able* to perform healthcare tasks, spina bifida-related responsibilities refer to whether

individuals actually take responsibility for performing those tasks. In other words, the distinction between these constructs is the distinction between abilities and behaviors.

Both skills and responsibilities are necessary for healthcare autonomy. For instance, a 14-year-old boy may have the skills that would enable him to call a physician's office to schedule medical appointments, but in practice, his parents may take responsibility for scheduling such appointments. This boy would not be said to have achieved healthcare autonomy in terms of scheduling medical appointments because while he demonstrates skills that would allow him to carry out the task, he lacks the responsibility for doing so.

Research findings indicate that individuals with spina bifida lack healthcare autonomy in several areas. Catheterization, bowel management, and mobility have been identified as particularly challenging aspects of healthcare regimens (Bier, et al., 2005; Blum et al., 1991; Watson, 1991). In line with previous intervention research, it was expected that improvements in healthcare autonomy would follow participation in the current intervention (Engleman et al., 1994; O'Mahar et al., 2010; Sherman et al., 1985).

Psychosocial Functioning. While the term *psychosocial functioning* encompasses a broad range of cognitive, emotional, and behavioral functioning in relation to one's social environment, the author of the present study was most interested in two specific constructs that fall under the psychosocial functioning umbrella: *social skills* and *perceived social acceptance*. For the purposes of this study, social skills refer to those behaviors that may be observed objectively. In contrast, perceived social acceptance refers to one's own subjective experience of his or her social functioning. One aim of the current study was to assess change in social skills following an intervention designed to

target these skills. A second aim was to assess change in campers' perception of social acceptance following the intervention. Both social skills deficits and negative self-perceptions have been noted among people with spina bifida (Appleton et al., 1997; Hurley, Dorman, Laatsch, Bell, & D'Avignon, 1990). A brief summary of the literature related to social skills and self-perception in the population of young people with spina bifida is provided below.

Social skills include many specific and interrelated abilities that provide the foundation for interpersonal interaction and enable one to perform competently with regard to social tasks (Cavell, 1990). Although social skills include abilities related to social cognition (e.g., reading facial expressions, detecting sarcasm, identifying someone who is not trustworthy), and emotion regulation (e.g., controlling the impulse to tantrum in a public space), the emphasis of the current research is on those overt behaviors that are readily observed and measured. Social skills are immensely important as they allow us to navigate complex situations and communicate effectively. They determine – in large part – the ease with which we relate to others, as well as the success with which we are able to express ourselves (Cavell, 1990).

Cognitive correlates associated with spina bifida (e.g., deficits in language pragmatics, word-finding difficulties, attention problems) are likely to underlie problems in social functioning (Wills, 1993). Perhaps it is for this reason that children with spina bifida report smaller social networks and less support from peers as compared to children with chronic medical conditions that are not associated with cognitive deficits (Ellerton, Steward, Ritchie, & Hirth, 1996). The relative social isolation experienced by young people with spina bifida is likely to perpetuate difficulties with social skills, as children

and adolescents who lack exposure to peers do not have the benefit of learning and practicing these skills in the context of their age-mates.

While people with spina bifida may or may not have insight into their own social behaviors and how these contribute to their realities, children, adolescents, and young adults do report dissatisfaction with their social lives (McLone & Ito, 1998). Likewise, they report higher rates of loneliness than their typically-developing peers (Appleton et al., 1997). In terms of self-perception, people with spina bifida report lower ratings of athletic competence, body image satisfaction, and overall self-worth (Appleton et al., 1997). Perhaps unsurprisingly, they also report higher rates of depressed mood and suicidal ideation as compared to their typically-developing peers (Ammerman et al., 1998; Appleton et al., 1997).

Other Variables of Interest: Age, Cognitive ability, Perceived Cohesion

In addition to the outcome variables described above, the author of the present study examined the relation between outcomes and three variables: *age group*, *cognitive ability*, and *perceived cohesion*. These variables are discussed next.

Age Group. Adolescents and young adults were expected to make greater gains than would children. As discussed previously, autonomy issues are relevant to individuals in all phases of the lifespan; however, they are particularly salient for adolescents and young adults who are in the process of actively preparing to function as independent adults (Holmbeck, 1994). Therefore, it was expected that individuals in these age groups would be more engaged in the intervention and also more motivated to make gains. Consequently, they would be more likely to show greater improvements in healthcare autonomy, psychosocial functioning, and progress toward goal attainment for healthcare

and social goals. This hypothesis is consistent with research demonstrating that adolescents and adults tend to benefit more from interventions than do children (Kazdin, 2005; Kazdin & Weisz, 1998).

Cognitive Ability. Campers' ability to benefit from the intervention was expected to be related to their level of cognitive ability. Specifically, it was predicted that campers with higher levels of cognitive ability would benefit more from the intervention as demonstrated by greater advancement toward goal attainment for both healthcare and social goals. Although the intervention was designed with the cognitive limitations associated with spina bifida in mind, more learning was expected to take place for those who were better able to attend to, take meaning from, and remember the material presented. This hypothesis was guided by the intervention literature, which has shown that children and adolescents with higher IQs are more likely to benefit from interventions (Holmbeck, Neff, Greenley, & Franks, 1999; Kazdin, 2004; Swanson & Malone, 1992).

Perceived Cohesion. It was expected that campers' ratings of perceived cohesion would predict the degree to which they benefit from the intervention. As group cohesion has been identified as one of the most important small group variables with regard to therapeutic gains (Yalom, 1995), it was predicted that those campers who perceived the intervention group to be relatively more cohesive would benefit more from the intervention in terms of healthcare and social goal progress.

Hypotheses

The primary aim of the current intervention was to increase independence by targeting healthcare autonomy and psychosocial functioning; accordingly, the following three sets of hypotheses refer to outcomes associated with these domains. The first set of hypotheses relates to improvements in healthcare autonomy. As mentioned previously, for people with spina bifida, healthcare autonomy depends not only on ability to perform healthcare tasks, but also willingness to take responsibility for completing them. Thus, this set of hypotheses includes separate predictions relating to both spina bifida-related *skills* and *responsibilities*. Hypothesis 1a refers specifically to spina bifida-related *skills*. It was hypothesized that parent-reported spina bifida-related skills will improve significantly from Time 1 to Time 3. The *Spina Bifida Independence Survey* was used to assess change in this regard. Hypothesis 1b refers to spina bifida-related *responsibilities* (i.e., whether campers take responsibility for performing various spina bifida-related tasks). It was predicted that significant improvements will be seen in parent-reported spina bifida-related responsibilities from Time 1 to Time 3. The *Sharing of Spina Bifida Management Responsibilities* questionnaire was used to measure change over time. Hypothesis 1c states that campers will make significant progress toward their individual healthcare goals. This hypothesis was tested separately for campers and parents, using Likert-scale ratings on *Progress Monitoring* forms. For campers, it was predicted that significant improvements will be seen from Time 1 to Time 2, but significant improvements will not be observed from Time 2 to Time 3. For parents, it was predicted that significant improvements will be seen from Time 1 to Time 3.

The second set of hypotheses refers to improvements in psychosocial functioning. Psychosocial functioning was assessed in three ways: 1) parent-report of general social skills (*Social Skills Measure*), 2) camper-report of self-perceived social acceptance (*Harter Self-Perception Profile for Children; Harter Self-Perception Profile for Adolescents*), and 3) camper- and parent-report of progress made toward individual social goals (*Progress Monitoring Form*). Hypothesis 2a states that camper social skills will improve significantly from Time 1 to Time 3. This hypothesis was tested using parent ratings of social skills on the *Social Skills Measure* at Time 1 and Time 3. (Time 2 data were not collected from parents.) The second hypothesis relating to psychosocial functioning refers to self-perception of social acceptance. Specifically, Hypothesis 2b states that camper self-perceived social acceptance will improve significantly from Time 1 to Time 2, and will remain stable from Time 2 to Time 3. Hypothesis 2c states that campers will make significant progress toward their individual social goals. This hypothesis was tested separately for parents and campers, using Likert-scale ratings on *Progress Monitoring* forms. For campers, it was predicted that significant improvements would be seen from Time 1 to Time 2, but no significant improvements would be seen from Time 2 to Time 3. For parents, it was predicted that significant improvements would be seen from Time 1 to Time 3.

The above hypotheses were tested using a variable-centered approach to explore the relation between intervention and outcomes. A person-centered approach was used to determine the extent to which age group, cognitive ability, and group cohesion were related to progress toward goal attainment. Hypotheses 3a, 3b, and 3c state that these three variables (i.e., age group, cognitive ability, and group cohesion) will distinguish

those campers who made a significant amount of progress toward goals from those campers who made little or no progress toward goals. In particular, adolescents and young adults were expected to be more likely to fall within the “High Progress” group than the “Low/No Progress” group as compared with children. Likewise, higher levels of cognitive ability and greater ratings of perceived cohesion were expected to predict membership in the “High Progress” outcome group. All hypotheses in this set were tested separately for healthcare goals and social goals, and according to camper- and parent-report.

CHAPTER THREE

METHOD

Participants

Participants were young people with spina bifida who attended a week-long overnight summer program at Camp Ability. This program was funded by the Spina Bifida Association of Illinois (SBAIL), and took place at Camp Red Leaf in Illinois. Separate camp sessions were conducted for three age groups: Ability A (children ages 7 to 12 years), Ability B (adolescents ages 13 to 17 years), and Ability C (young adults ages 18 to 41 years).

Power Analysis

To ensure that the sample size would allow for the detection of meaningful effects, a power analysis was conducted. The statistical treatment for the current study included analysis of variance (which requires a sample of approximately 64 participants to detect medium effect sizes at the p-value of < 0.05) and logistic regression (which requires a sample of approximately 50 participants per predictor variable to detect medium effects sizes at the p-value of < 0.05) (Cohen, 1992; Hsieh, Block, & Larsen, 1998). This was a realistic target sample size given the number of campers who were enrolled in Camp Ability during previous camp seasons. To increase the sample size (and allow for meaningful statistical analyses), the current study included participants from two camp sessions (i.e., 2008 and 2009 sessions).

Sample Recruitment

Upon enrollment in camp, campers and parents were sent letters in which the research protocol and intervention components were described. Campers and parents were also contacted via telephone by research assistants. The purpose of the telephone calls was three-fold: 1) to ensure that the letter was received, 2) to provide more information about the intervention, and 3) to offer an opportunity for campers and parents to ask questions. Because the Independence Intervention was a part of the Camp Ability curriculum, campers necessarily took part; however, participation in the research component was optional and voluntary.

Sample Participation and Retention

For the 2008 camp year, participation rates for the three age groups at Time 1 were as follows: Ability A= 88% (22 of 25 campers); Ability B = 93% (27 of 29 campers); and Ability C = 96% (27 of 28 campers). Commonly stated reasons for non-participation were lack of time or interest. Retention rate at Time 2 was 96% of those who participated at Time 1. (At Time 2, researchers came to the camp and collected data from campers directly. One camper from Ability A was not retained at Time 2 because he returned home after the first day of camp.) The retention rate at Time 3 was as follows: Ability A = 55% (12 out of 22); Ability B = 63% (17 out of 27); Ability C = 78% (21 out of 27). Campers who were retained at Time 3 did not differ from those who were not retained on demographic variables including socioeconomic status, ethnicity, age, gender, and medical severity. (Please see Table 1.)

Table 1: Attrition Analysis

Variable	T3 m(sd)	No T3 m(sd)	t	P
SES	43.88(13.21)	45.90(12.80)	.63	.53
Age	17.61(7.55)	15.69(5.71)	-1.27	.21
Previous Camp Attendance	3.99(4.04)	3.48(4.30)	-.52	.61
Cognitive Ability	84.08(17.60)	77.85(16.11)	-1.53	.13
Medical Severity	7.81(1.26)	7.11(2.27)	-1.85	.07

For the 2009 camp year, participation rates for the three age groups at Time 1 were as follows: Ability A= 90% (28 of 31 campers); Ability B = 89% (25 of 28 campers); and Ability C = 76% (19 of 25 campers). Once again, commonly stated reasons for non-participation were lack of time or interest. Retention rate at Time 2 was 97% of those who participated at Time 1. (Two campers from Ability B declined participation at Time 2, though one of these campers resumed participation at Time 3.) Retention rate at Time 3 was as follows: Ability A = 68% (19 out of 28); Ability B = 72% of parents (18 out of 25) and 68% of campers (17 out of 25); Ability C = 89% (17 out of 19).

Increasing Sample Size (2008 and 2009 Camp Sessions)

To compensate for the small sample size and low retention rate at Time 3 for 2008, participants from the 2009 camp session were added to the dataset employed in the current study. Campers from the 2009 camp season included two types of campers: 1) those who *had not* participated in the 2008 camp intervention (i.e., “new campers”) and 2) those who *had* participated in the 2008 camp intervention (i.e., “veteran campers”). The 2009 campers who had not participated in the 2008 camp intervention were automatically included in the dataset. This resulted in the addition of 26 “new campers” to the dataset. For campers who participated in the intervention during both camp

sessions, decisions regarding which data to include were made on a case-by-case basis (i.e., by comparing the amount of data available for each camp year). If the amount of data collected from a given participant during the 2008 camp year was *equivalent or greater than* that which was collected in the 2009 camp session, then only the 2008 data for that participant were included in the dataset. If the amount of data collected during the 2008 camp season was *less than* that which was collected during the 2009 camp season, then only the 2009 data were included. *In no case was both 2008 and 2009 data included for a single individual.* Case-by-case decisions resulted in changes that affected the data employed for 16 veteran campers (i.e., 2009 data was substituted for 2008 data in the cases of 16 participants). In sum, after all new 2009 campers had been added and all 2009 data were substituted per the guidelines described above, the sample size of the original dataset was increased by 26 participants, and the amount of data available for analysis was increased for 16 veteran campers.

Participants from the 2009 camp session did not differ from those who took part in the 2008 camp session on demographic variables including socioeconomic status, ethnicity, age, gender, cognitive ability, and medical severity. With regard to other variables of interest, significant differences were seen in Time 1 spina bifida-related skills (i.e., campers in the 2008 session were rated as having mastered significantly *fewer* spina-bifida-related skills at Time 1 than campers in the 2009 session), Time 3 ratings of spina bifida-related responsibilities (i.e., campers in the 2008 session took on significantly *more* spina bifida-related responsibilities at Time 3 than campers in the 2009 session), and Time 3 parent-reported intervention satisfaction (i.e., parents of campers in the 2008 session were significantly *less* satisfied with the intervention at Time 3 than

were parents of campers in the 2009 session). For those analyses featuring the three variables characterized by significant differences across the 2008 and 2009 camp sessions, *camp session* was included as a covariate.

In sum, in an effort to compensate for the small sample size and low retention rate that characterized the original 2008 intervention evaluation, data derived from participants in the 2009 intervention evaluation were added to the 2008 dataset. Statistical analyses were used to compare 2008 and 2009 participants on all relevant variables. When significant differences were detected, these differences were controlled for by entering *camp session* as a covariate in analyses involving these variables.

Table 2: T-Tests Comparing 2008 and 2009 Camp Sessions on Relevant Variables

Variable	2008 m(SD)	2009 m(SD)	T	p
SES	45.11(12.47)	43.69(13.98)	.465	.643
SB Severity	7.63(1.66)	7.52(1.71)	.289	.773
Previous Camp	3.60(4.05)	4.08(4.22)	-.527	.600
IQ Proxy	80.95(17.91)	83.37(16.69)	-.625	.534
T1 SB Skills*	64.38(27.70)	79.27(26.90)	-2.318	.023
T3 SB Skills	74.92(22.71)	76.59(24.02)	-.252	.801
T1 SB Responsibilities	1.98(.44)	1.97(.40)	.102	.919
T3 SB Responsibilities*	2.52(.39)	2.20(.37)	2.97	.005
T1 Social Skills	3.41(.76)	3.59(.56)	-1.052	.296
T3 Social Skills	3.50(.67)	3.60(.63)	-.552	.583
Camp Satisfaction (C)	4.11(.74)	4.39(.62)	-1.63	.108
Intervention Satisfaction (C)	3.86(.82)	4.21(.67)	-1.87	.066
Camp Satisfaction (P)	4.25(.81)	4.40(.84)	-.594	.556
Intervention Satisfaction (P)*	3.35(.81)	3.94(.75)	-2.28	.033

*These measures were not administered to parents of Ability C campers; these analyses refer only to Ability A & B.

While the recruitment strategies used in the 2009 camp season were equivalent to those used in the 2008 camp session, some changes were made to retention strategies in an effort to decrease sample attrition. These changes relate to the reimbursement and Time 3 follow-up protocol, and are discussed in more detail in the *Design and Procedure* section.

The Intervention Evaluation: Design and Procedure

As noted above, participants who took part in two similar summer camp intervention evaluations administered during two consecutive summers were included in the dataset used for the current study. Both interventions were designed through a collaboration between the SBAIL and Grayson Holmbeck, Ph.D., as well as graduate students and interventionists involved with previous Camp Ability programs. Although the two intervention evaluations were very similar, they differed with regard to several important details, which are emphasized throughout the following description. Unless otherwise stated, it may be assumed that the 2008 and 2009 intervention evaluations were equivalent.

Intervention Design

The 2008 and 2009 intervention evaluations were similar not only in terms of the intervention approach employed, but also with regard to the study design, procedures, and measures used. The interventions shared a common purpose (i.e., promoting autonomy) as well as a common approach (i.e., spina bifida-specific, developmentally-informed, manual-based). The interventions were equivalent in terms of setting and structure: Both took place as a part of the Camp Ability program (at Camp Red Leaf), and each camp year consisted of three week-long camp sessions, separated

according to age (child, 8 - 12 years; adolescent, 13 - 18 years; and young adult, 19 - 41 years). Both the 2008 and 2009 interventions were comprised of two major components: *group treatment* and *individual goals*.

Group Treatment. The format of group treatment sessions was equivalent for both the 2008 and 2009 interventions. The group treatment component included five sessions (one session per day, one hour per session). Groups were comprised of eight to ten campers, with one interventionist leading sessions. Counselors were present throughout these sessions. For both the 2008 and 2009 interventions, manuals were created in an effort to standardize the interventions across age-group sessions, and to ensure that targeted skills were taught explicitly and reliably. While the manuals employed in 2008 and 2009 were similar, they differed in some ways.

Both manuals included descriptions of activities, as well as scripts for interventionists to follow. Questions for discussion were included as well. The manuals were similar in that both were skills-based, with material presented in the form of games role plays, and group discussions. Both manuals included adaptations to reflect the developmental issues likely to be most salient for the three age groups. While adaptations for the three age groups were included in a single manual for the 2008 intervention, three separate manuals were created for the 2009 intervention. Although the manuals shared a common emphasis and many overlapping activities and exercises, they featured several important differences with regard to content and structure. In particular, the 2008 intervention (i.e., *Autonomy Through Social Skill Development: An Independence Intervention for Young People with Spina Bifida*) focused specifically on spina bifida management and social skills, and was framed in terms of five domains:

Communicating About Yourself, Communicating About Spina Bifida, Communicating With Family, Communicating With Peers, and Communicating at School and Work. (See Table 3).

Table 3: Outline of Activities for 2008 Intervention Curriculum

Monday	<p><i>“Communicating About Yourself”</i></p> <ul style="list-style-type: none"> - Collage about you/Introductions - Psychoeducation about communicating and sharing personal info - Link between social skills and autonomy
Tuesday	<p><i>“Communicating About Spina Bifida”</i></p> <ul style="list-style-type: none"> - Jeopardy game to review knowledge of spina bifida - Discussion about sharing information about spina bifida
Wednesday	<p><i>“Communicating with Family”</i></p> <ul style="list-style-type: none"> - Family Feud game - Psychoeducation about effective conflict resolutions skills - Discussion about family conflict
Thursday	<p><i>“Communicating with Peers”</i></p> <ul style="list-style-type: none"> - Psychoeducation about bullying, being left out, and spina bifida - Role plays involving bullying and being left out
Friday	<p><i>“Week in Review/Communicating at School and Work”</i></p> <ul style="list-style-type: none"> - Review of skills learned throughout the week - Discussion of how they apply at school/work to promote autonomy

Meanwhile, the 2009 manual (i.e., *A Camp Curriculum Addressing Independence, Social Skills, Emotional Wellness, and Self-Care*) was structured around five topics: *Taking Care of Relationships, Taking Care of Yourself, Living with Spina Bifida, Taking Care of Spina Bifida, and Taking Care of Your Future.* (Please refer to Table 4.) Notably, this manual differed from the 2008 manual in that it provided numerous options with regard to psychoeducation, group discussion, role play, and other activities from which the interventionist could choose from.

Both manuals addressed healthcare autonomy and psychosocial functioning, but differed in terms of how they addressed these topics. In terms of healthcare autonomy, both versions of the intervention included a “Jeopardy” game designed to review knowledge about spina bifida. However, the 2009 version also included a didactic

component in which information about spina bifida was presented in terms of each body system affected. Additionally, the 2009 version included a session devoted to the

Table 4: Outline of Activities for 2009 Intervention Curriculum

Monday	<p>“Taking Care of Relationships”</p> <ul style="list-style-type: none"> • Psychoeducation <ul style="list-style-type: none"> - Rules of Friendships; Communication Basics • Group Discussion
Tuesday	<p>“Taking Care of Yourself”</p> <ul style="list-style-type: none"> • Psychoeducation <ul style="list-style-type: none"> - Feelings; Coping Strategies; Depression • Activity
Wednesday	<p>“Living with Spina Bifida”</p> <ul style="list-style-type: none"> • Psychoeducation <ul style="list-style-type: none"> - Sexuality - Identifying feelings associated with spina bifida
Thursday	<p>“Taking Care of Spina Bifida”</p> <ul style="list-style-type: none"> • Psychoeducation <ul style="list-style-type: none"> - Anatomy and physiology of spina bifida - Self-catheterization
Friday	<p>“Taking Care of Your Future”</p> <ul style="list-style-type: none"> • Group Discussion <ul style="list-style-type: none"> - Transfer of responsibility - Questions for the doctor

medical transition from pediatric healthcare to adult healthcare. This addition was included in response to focus groups co-led by Grayson Holmbeck, Ph.D. and David McClone, M.D. (specialist in neurosurgery related to spina bifida). These focus groups were conducted with young people with spina bifida, and this transition emerged as a prominent challenge affecting many adolescents and young adults with spina bifida. As these focus groups took place after the 2008 manual was created, information from the focus groups did not influence its content, but transcriptions were created to inform future intervention curricula (including that which would be designed for 2009).

In terms of psychosocial functioning, the 2008 manual focused specifically on social skills. In contrast, the 2009 version targeted psychosocial functioning in a more

general sense: While this version included some explicit teaching of social skills, it also included a session devoted to emotional wellness. In particular, the emotional wellness session included in the 2009 intervention manual featured psychoeducation regarding feelings, as well as exercises designed to teach coping skills and relaxation strategies, and to improve self-esteem.

In sum, the 2008 and 2009 interventions shared considerable overlap in terms of structure, content, and presentation of material. However, there were some notable differences between the group curricula. In particular, the 2009 curriculum included a module relating to the transition from pediatric to adult medical care that was not featured as part of the 2008 intervention. Additionally, the 2009 curriculum addressed psychosocial functioning in a general sense, while the 2008 curriculum focused more narrowly on social skills. Although both curricula included modules devoted to healthcare autonomy and psychosocial functioning, the 2008 curriculum placed more focus on the latter, while the 2009 curriculum emphasized the former.

Individual Goals. Both the 2008 and 2009 interventions featured an individual goals component whereby campers worked toward one healthcare goal and one social goal throughout the week at camp. There were two facets of the individual goals component: *goal setting* and *progress monitoring*. The *goal setting* element occurred as part of Time 1 data collection. Campers and parents were asked to work together to select one healthcare goal and one social goal to work toward during the week at camp. (For young adult campers in the 2009 intervention, parents were not involved in the goal setting process because they were not recruited for participation in the study.) Goals were selected from a *Goal Bank* that included 15 healthcare goal options and 12 social goal

options. Once goals were selected, campers and parents were instructed to rate the degree to which these goals were being met at that time. Separate ratings were provided by campers and parents, and ranged from “1 = Not at all meeting this goal” to “5 = Completely meeting this goal.”

The second facet of the individual goals component was *progress monitoring*. This occurred throughout the week at camp during brief daily progress monitoring sessions with counselors. Counselor training involved education regarding spina bifida (including its physical, cognitive, and social correlates). As a part of this training, counselors were provided with information about the intervention evaluation, as well as their role in completing *Progress Monitoring Forms* (Appendix A), which were given to counselors as a means of helping them guide discussions and facilitate progress toward goal attainment. Positive reinforcement (i.e., praise) was emphasized, and suggestions regarding trouble-shooting were provided.

During daily progress monitoring sessions, counselors worked individually with campers to discuss progress made toward healthcare and social goals. Campers were asked to reflect on their progress with counselors, and then provide ratings on a scale of 1 to 5 (1 = Not at all meeting this goal; 5 = Completely meeting this goal). Campers also provided ratings independently as a part of Time 1, Time 2, and Time 3 data collection. (Parents provided such ratings as part of Time 1 and Time 3 data collection as well.)

Data Collection Procedure

The data collection procedure featured the same general structure and protocol for both the 2008 and 2009 intervention evaluations. For both intervention evaluations, camper data were collected at three time points: one month prior to camp (i.e., Time 1),

after the final group treatment session (i.e., Time 2), and one month after camp (i.e., Time 3). For participants from all three age groups in the 2008 camp year, parent data were collected at two time points (T1 and T3). This protocol was the same for children and adolescent participants in the 2009 intervention evaluation; however, parents of young adult campers were not recruited for the 2009 intervention evaluation. Therefore parent-report of healthcare autonomy, psychosocial functioning, and goal attainment are not available for 2009 participants. This change to the recruitment protocol has several implications in terms of the data available for analysis; these are highlighted in the *Measures* and *Results* sections.

For both the 2008 and 2009 intervention evaluations, Time 1 data collection began one month prior to camp. Time 1 questionnaires were mailed to families' homes, along with a letter explaining the intervention and research protocol. Informed consent forms were included as well. Time 1 questionnaire packets included measures of demographic information and spina bifida severity. Likewise, they included baseline measures of healthcare autonomy and psychosocial functioning. Campers and parents were also asked to discuss and agree upon one healthcare goal and one social goal for the camper to work toward throughout the week, and to provide baseline ratings of goal attainment. Questionnaires were returned via post (in the self-addressed stamped envelope), or in person (i.e., during camper "check-in/drop-off" on the first day of camp). Many campers and parents neither returned Time 1 questionnaires via post, nor brought completed questionnaires to camp. These participants filled out questionnaires during camper check-in/drop-off.

Time 2 data collection occurred on the last day of the intervention. At this time, only camper data were collected. Camper questionnaire measures included those administered during Time 1, as well as measures of intervention group functioning. Counselors and research assistants were available to assist campers with questionnaires as needed. Time 3 data collection took place approximately one month after camp, at which point camper and parent questionnaire packets were sent via post to family homes. Follow-up phone calls were made to ensure receipt of the packets, and to provide an opportunity to answer questions. Time 3 questionnaire packets were the same as Time 1 packets, with one addition: Time 3 packets included *Feedback Forms* relating to satisfaction with Camp Ability. This measure was designed to gather quantitative and qualitative data pertaining to satisfaction with the camp in general, and the intervention in particular. *Feedback Forms* were included in questionnaire packets for both campers and parents.

For both the 2008 and 2009 intervention evaluations, participants received monetary reimbursement. However, the protocol differed with regard to the reimbursement schedule, as well as the total amount of money given for participation. For the 2008 intervention evaluation, individual participants (i.e., campers and parents) received a “lump sum” of \$10 upon receipt of each Time 3 questionnaire packet. For the 2009 intervention, families were given \$10 per “set” of questionnaire packets, in two installments. Upon receipt of Time 1 questionnaire packets, \$10 was provided; upon receipt of Time 3 packets, \$20 was provided. In the few instances where some portion of a “set” was not completed or returned (e.g., parents returned Time 3 questionnaire packets while their children declined participation at Time 3), reimbursement was decreased accordingly. For

example, in the case that a parent Time 3 questionnaire packet was returned without a camper Time 3 questionnaire packet, Time 3 reimbursement was reduced to \$10 (instead of \$20).

For both evaluations, a brief assessment of cognitive ability was administered to campers. This assessment took place at the camp, and was administered by trained research assistants. Each camper met with a research assistant for testing one time during the camp week, for approximately 15 minutes. Every effort was made to ensure that campers did not miss scheduled camp activities due to testing. The tests administered are described in more detail in the following section. For 2009 “veteran campers” (who participated in the intervention evaluation after having participated in the 2008 session), assessments of cognitive ability were not repeated in 2009. Given that data related to cognitive ability was not expected to change substantially over the course of a single year, data collected as part of the 2008 session were considered to be an adequate reflection of campers’ cognitive ability in 2009.

Measures

In the following section, questionnaire and testing instruments are organized by construct. These include: *demographic and medical information*, *cognitive ability*, *healthcare autonomy* (i.e., spina bifida-related skills, spina bifida-related responsibilities), *psychosocial functioning* (i.e., social skills, self-perception of social acceptance), *goal attainment* (i.e., healthcare goal progress, social goal progress) and *intervention group: functioning and evaluation* (i.e., perceived cohesion, sociometrics, intervention satisfaction). Copies of measures can be found in Appendix A. Measures are

described in detail below, and differences between measures used in the 2008 and 2009 evaluations are emphasized. (Please refer to Table 5 for a summary of measures.)

Demographics and Medical Information (T1). For children and adolescent participants in both the 2008 and 2009 intervention evaluations (and for young adults in the 2008 intervention), parents reported on demographic variables such as age, ethnicity, gender, education level, employment status. Parent education level and employment status formed the basis of family SES calculations (Hollingshead, 1975).

Medical information included four medical variables: lesion level (sacral, lumbar, thoracic), type of spina bifida (myelomeningocele, lipomeningocele, other) total number of shunt surgeries, and ambulation (ankle-foot orthoses, knee-ankle-foot orthoses, hip-knee-ankle-foot orthoses, and wheelchair). Taken together, these medical variables were used to calculate a composite score of spina bifida severity. To compute composite scores, response options for the four medical variables were assigned a number as follows: lesion level (sacral=1, lumbar=2, thoracic=3), myelomeningocele type of spina bifida (no=1, yes=2), shunt status (no=1, yes=2), and ambulation status (no assistance/ankle-foot orthoses=1, knee-ankle-foot orthoses/hip-knee-ankle-foot orthoses=2, wheelchair=3). Calculation of scores yielded sums between 4 and 10, with higher scores indicating greater severity. Past research has yielded high levels of internal consistency for calculating condition severity in this manner (Hommeyer, Holmbeck, Wills, & Coers, 1999).

For young adult campers in the 2009 camp session, demographic and medical information was collected from campers themselves. However, the nature of the demographics gathered was different in that information relating to parents' educations

and jobs was not collected from these campers. Therefore, it was not possible to calculate family SES for young adult campers from the 2009 camp year. (The medical information collected, however, was the same as that which was collected from parents in the 2008 camp year. Consequently, it was possible to calculate medical severity scores for these campers.)

Cognitive Ability. Two methods were used to assess cognitive ability: questionnaires (i.e., Swanson Nolan And Pelham-Fourth Edition; SNAP-IV) and cognitive testing (i.e., selected subtests from the Wechsler Abbreviated Scale of Intelligence; WASI and the Diagnostic Analysis of Nonverbal Abilities; DANVA). Although cognitive ability was assessed using these three measures, only the data derived from the WASI was analyzed as part of the current study.

The SNAP-IV (Swanson et al. 1995) rating scale is a parent-report questionnaire that was used to measure symptoms related to Attention Deficit Hyperactivity Disorder (ADHD) in campers. This measure included 18 items (9 related to attention abilities; 9 related to hyperactivity and impulsivity), and response options are presented on 4-point scales (0=Not at All; 1=Just a Little; 2=Quite a Bit; 3=Very Much). A mean score calculated across all items provided an index of ADHD-like symptoms in campers. Mean scores can range from 0 – 3, with higher scores indicating more difficulty. The SNAP-IV has been shown to have adequate internal consistency, and can satisfactorily distinguish among individuals with attention problems of varying degrees (Bussing et. al., 2008). Because parents of young adult campers were not recruited for participation in the 2009 intervention evaluation, young adult campers completed this measure (and thus reported on their own attention abilities) for this session.

The Wechsler Abbreviated Scale of Intelligence (WASI; Vocabulary and Matrix Reasoning subtests) was used to estimate cognitive ability. The WASI is a brief measure of cognitive ability that is based on the Wechsler Adult Intelligence Scale and the Wechsler Intelligence Scale for Children. The WASI is often used to estimate global intelligence in research and clinical settings that allow little time for assessment, as well as for populations of people with physical or intellectual impairments that preclude the completion of a full battery (Homack & Reynolds, 2007; Stano, 2004). The test is comprised of four subtests that have been shown to provide strong correlations with global intelligence. Two of these are verbal (i.e., Vocabulary; Similarities), while the others are nonverbal (i.e., Matrix Reasoning; Block Design). The WASI has been normed on a large, nationally representative sample of people ages 6-89 years, including people with mental retardation, learning disabilities, and brain injuries. It has been shown to have high reliability for both children and adults, as well as for samples of people in rehabilitation settings. Moreover, it has been shown to have adequate construct validity (including content validity and concurrent validity). For the purpose of measuring global intelligence in a brief timeframe (i.e., 15 minutes), 2 subtests were selected for use in the current study: Vocabulary and Matrix Reasoning. The Vocabulary subtest is comprised of 42 items (i.e., 4 pictures; 38 words), and requires examinees to provide definitions for items of increasing difficulty. The Matrix Reasoning subtest was designed to measure nonverbal abstract reasoning ability. It consists of 24 items of increasing difficulty. Each item features a design, with one portion of the design missing; examinees are required to complete the design by choosing from among five response

options. Each item targets one of four types of nonverbal reasoning: pattern completion, classification, analogy, and serial reasoning (Homack & Reynolds, 2007; Stano, 2004).

The *Diagnostic Analysis of Nonverbal Abilities* (DANVA-2) is comprised of three subtests: Child Facial Expressions, Child Paralanguage, and Child Postures. The DANVA-2 Child Facial Expressions subtest (i.e., DANVA-2-CF) was used in the proposed study as a measure of receptive nonverbal processing skills, as these skills are seen as underlying social skill development. This subtest consists of a series of 24 photographs of child facial expressions. Half of these photographs feature male faces, and half feature female faces. The series features an equal number of low and high intensity happy, sad, angry, and fearful faces. Examinees are given two seconds to look at each photograph, and then are asked: “Is this a happy, sad, angry, or fearful face?” Each correct response earns one point, with higher scores indicating greater nonverbal processing ability. This subtest has been shown to have adequate reliability and construct validity (including internal consistency, convergent validity, discriminative validity, and criteria validity; Nowicki & Duke, 1994).

Healthcare Autonomy. The *Spina Bifida Independence Survey* (SBIS; Time 1 & Time 3) was administered to assess mastery of self-care skills. Wysocki and colleagues (2006) originally designed the independence survey for use with pediatric diabetes populations, and were consulted during the process of measure adaptation. After this consultation, items were changed to reflect self-care tasks relevant to spina bifida management. The adapted measure includes 48 items, all of which refer to healthcare regimens for people with spina bifida (e.g., “Can your child . . . identify appropriate professionals for specific problems?,” “Can your child . . . properly insert catheter?”). For

the 2008 camp year, parents completed this measure for all three age groups. For the 2009 camp year, parents completed this measure for the child and adolescent groups, while campers completed the measure in the young adult group.

The camper version of the SBIS was equivalent in terms of item content; only the wording of item stems was changed to reflect the fact that campers were answering questions about themselves (i.e., “Can your child . . .” was changed to “Can you . . .”). For both camper and parent versions of the SBIS, informants chose from “yes,” “no,” “not sure,” and “not applicable” to indicate whether specific skills had been mastered. For analyses, a ratio score was calculated based on the total number of “yes” responses to the total number of “no” responses. This ratio provided information regarding the degree to which campers had mastered tasks relevant to their needs. “Not sure” responses were not included in the ratio because such answers indicated ambiguity as to whether the camper could manage the task. “Not applicable” responses were also excluded because they indicated tasks that were not relevant for particular campers. For analyses, the ratio of “yes” to “no” responses was multiplied by 100 so that data transformations could be completed. Therefore, scores ranged from 0 to 100, with 100 indicating that the camper had mastered all spina bifida-related tasks that were relevant for that camper.

To address the difference in measure administration across the 2008 and 2009 camp seasons, the decision was made to exclude 2009 young adult camper-reported SBIS data from the dataset employed. This decision was made for two primary reasons: 1) the original decision for supplementing the 2008 dataset with 2009 data was made so as to increase power, and the addition of 2009 young adult camper-reported SBIS data would not have had a substantial effect in this regard, 2) combining data reported by different

informants contaminates the variable of interest, thereby decreasing the measure's validity (Holmbeck, et al., 2002). Therefore, 2009 young adult camper-reported SBIS data were not included in the dataset used in the current study. As a result, analyses based on SBIS data included only parent-reported data for 2008 children, adolescents, and young adults, and 2009 children and adolescents.

Whereas the SBIS refers to whether individuals are *capable* of completing tasks, the *Sharing of Spina Bifida Management Responsibilities Survey* (SSBMR; Time 1 & Time 3) refers to whether individuals actually take responsibility for completing them. In particular, the SSBMR was administered to assess changes in functional autonomy related to self-care tasks. For the 2008 intervention evaluation, the SSBMR was administered to parents of campers in all three age groups at Times 1 and 3. In the 2009 intervention evaluation, the SSBMR was administered to parents of campers in the child and adolescent groups only. Because parents of young adult campers were not included in the 2009 intervention evaluation, the SSBMR was administered to young adult campers themselves.

Like the SBIS, the SSBMR was based on a questionnaire designed for use with pediatric diabetes samples (Anderson, Auslander, Jung, Miller, & Santiago, 1990), and was adapted to reflect those responsibilities associated with spina bifida management. The SSBMR requires respondents to indicate who has responsibility (Child, Equal, Parent, or N/A) for 34 spina bifida-related tasks. Higher scores indicate a greater level of camper responsibility, while lower scores indicate a greater level of parental responsibility.

As with the 2009 young adult camper-reported SBIS data, 2009 young adult parent-data were not available, and camper-reported SSBMR data were not included in the dataset used in the current study. Again, this decision was made because the advantage of including these data (i.e., a slight increase in power) was outweighed by the methodological problems it would introduce (i.e., a decrease in the measure's validity). Consequently, analyses based on SSBMR data included 2008 parent-reported data for children, adolescents, and young adults, and 2009 parent-reported data for children and adolescents.

Psychosocial Functioning. The *Social Skills Measure* (Parent-Report: Time 1 & Time 3) is a measure of social skills that was constructed specifically for the current study to reflect those specific skills the intervention manual was designed to target. Items were based on the literature related to social skills deficits associated with spina bifida (McLone & Ito, 1998; Wills, 1993). The *Social Skills Measure* is comprised of 26 items related to interpersonal functioning, and includes both verbal and nonverbal behaviors. Respondents were asked to rate campers on a scale from 1 - 5 (1= Never; 3=Half of the Time; 5=Always). This measure was filled out by parents at Times 1 and 3. Once again, young adult participants in the 2009 intervention evaluation completed this measure as their parents were not included in the study.

Self-Perceived Social Acceptance (Camper-Report: Time 1, Time 2, & Time 3) was measured using *Harter's Self-Perception Profile for Children* (SPPC; Harter, 1985) and *Harter's Self-Perception Profile for Adolescents* (SPPA; Harter, 1988). Both versions of the measure have been shown to have adequate psychometric properties (including convergent and discriminant validity) and have been classified as well-established

measures by the evidence-based assessment task force (Holmbeck et al., 2008). Items from the adolescent version were modified slightly for the young adult intervention group, such that the word “teenagers” was changed to “young adults.”

The SPP for Children was designed for use with 8 - 13 year-olds. In its entirety, the SPP for Children is comprised of 36 items that make up one Global Self-Worth subscale and five domain-specific subscales (Scholastic Competence, Athletic Competence, Physical Appearance, Behavioral Conduct, and Social Acceptance). Each item consists of two contradictory statements, and requires respondents to decide which statement more accurately describes them. Then, respondents must indicate whether the chosen statement is “really true” or “sort of true” for them. A subscale score is determined by calculating the mean of all items that make up a given subscale, with higher scores indicating greater levels of competence in that domain. In keeping with the intervention evaluation’s emphasis on social functioning, only the Social Acceptance subscale was employed.

The SPP for Adolescents is similar to the SPP for Children with regard to item format; however it features 51 items comprising one Global Self-Worth subscale and eight domain specific subscales (Scholastic Competence, Athletic Competence, Physical Appearance, Job Competence, Behavioral Conduct, Romantic Appeal, Close Friendships, and Social Acceptance). For the purposes of the current study, only the Social Acceptance subscale was used. As with the SPP for children, a score was calculated using means of items that comprise the subscale, with higher scores indicating a greater level of perceived competence.

Goal Attainment. *Goal Progress* (Camper-Report: Time 1, Time 2, & Time 3; Parent-Report: Time 1 & Time 3) was calculated based on ratings provided on *Progress*

Monitoring Forms. For 2008 and 2009 children and adolescents, and 2008 young adults, campers and parents worked *cooperatively* at Time 1 to identify one healthcare goal and one social goal chosen from a *Goal Bank*. (For 2009 young adults, campers chose goals independently, as their parents were not recruited for participation.) Goals selected for inclusion in the *Goal Bank* were informed by the literature on spina bifida, and derived from those identified by campers and parents during previous camp sessions. For children and adolescents, the goal options were equivalent across the 2008 and 2009 camp sessions. However, slight modifications were made to the original 2008 *Goal Bank* for 2009 young adults. In particular, two options were added to the healthcare goal choices (i.e., “Develop a personal nutrition plan;” “Develop a personal exercise plan”), and one option was omitted (i.e., “Eat more fruits and vegetables”). With regard to social goal options, one option was added to the social goal choices (i.e., “Practice job interviewing skills”), and one option was omitted (“Improve table manners”).

After having identified two goals to work toward, participants *independently* rated the degree to which campers had attained the goals thus far on Likert-type scales (1-5, with higher scores indicated greater degrees of goal attainment). The *Progress Monitoring Forms* employed were identical across the 2008 and 2009 camp seasons. Campers rated their progress on these forms at Times 1, 2, and 3, and parents (of all campers in 2008 session, and of children and adolescents in the 2009 session) rated progress at Times 1 and 3.

Intervention Group: Functioning and Evaluation. Bollen & Hoyle’s (1990) *Perceived Cohesion Scale* (PCS; Camper-Report: Time 2) was employed to assess individuals’ perception of themselves within the intervention group, as well as their sense

of the group as a whole. This measure was designed to assess two underlying dimensions of cohesion: *sense of belonging* (e.g., “I am happy to be a part of this group”) and *feelings of morale* (e.g., “This group is the best anywhere”). This measure consists of six items, and requires respondents to rate each on a 5-point Likert-Type Scale (1=Strongly Disagree to 5=Strongly Agree). High scores indicated greater levels of perceived cohesion. Adequate reliability and validity have been demonstrated for use in both small and large groups, and in a variety of populations (Bollen & Hoyle, 1990; Chin et al., 1999). The *Satisfaction with Camp Experience Feedback Form* (SCEFF; Camper-Report: Time 3; Parent-Report: Time 3) was administered to assess camper and parent satisfaction with the intervention, as well as with the general camp experience.

Table 5: Measures

Construct	Measure	Time	Informant
Demographics	Demographic and Medical Information	1	P [†]
Cognitive Ability	Swanson Nolan And Pelham-4 th Editions (SNAP-IV)	1	P [†]
	Diagnostic Analysis of Verbal Abilities (DANVA)	1	C
	Wechsler Abbreviated Scale of Intelligence (WASI)	1	C
	Subtest 1: Matrix Reasoning Subtest 2: Vocabulary		
Healthcare Autonomy	Spina Bifida Independence Survey (SBIS)	1,3	P [†]
	Sharing of Spina Bifida Management Responsibilities (SSBMR)	1,3	P [†]
	Goal Bank and Progress Monitoring (Healthcare Goals)	1,2,3	C, P*
Psychosocial Functioning	Harter's Self-Perception Profile for Children/Adolescents (SPPC/A)	1,2,3	C
	Social Skills Measure (SSM)	1,3	P [†]
	Goal Bank and Progress Monitoring (Social Goals)	1,2,3	C, P*
Group Functioning and Evaluation	Personal Cohesion Scale (PCS)	2	C
	Feedback Form: Satisfaction with Camp Experience	3	C, P [†]

Note. Time refers to the wave of data collection from which the measure will be drawn for the current analyses. Informant refers to the person who completed the questionnaire (C=Camper, P=Parent).

** Parent data were only collected for Time 1 and Time 3.*

† Parent data were not collected for 2009 young adult campers.

Statistical Treatment

Preliminary Analyses. Several steps were taken to prepare the data for analysis. Frequencies were examined to ensure that all values fell within scale parameters. Then, outliers were identified and considered. In cases where outliers indicated invalid responses, data were re-coded as missing. Then, group means and standard deviations were calculated. (See Table 6.)

Normality of variables was assessed according to guidelines presented by Tabachnick & Fidell (2001). Skewness analyses were conducted for all variables (see Table 7). Z-scores were calculated using the formula $[S-0/s_s]$; where S = value reported for skewness, and s_s = the standard error for skewness]. Variables that were negatively skewed were first reflected so that subsequent data transformations could be conducted. The following variables were reflected because they were negatively skewed: Time 3 Spina Bifida-Related Skills (Parent-Report) and Camp Satisfaction (Parent-Report). Those variables with z-score values at 3.3 or higher were transformed using a square-root transformation. This value was chosen because it represents a conservative cut-off value ($p < 0.001$) for skewness (Tabachnick & Fidell, 2001). Square root transformations were applied to the following variables characterized by z-scores exceeding 3.3: age, number of shunt surgeries, previous camp experience, Time 2 perceived cohesion, Time 3 spina bifida-related skills, and Time 3 camp satisfaction (parent-report). If skewness values were inadequate following square-root transformations, then logarithmic transformations were conducted (Tabachnick & Fidell, 2001). Logarithmic transformations were applied to the following variables characterized by z-scores that continued to exceed 3.3 after square root transformations: number of shunt surgeries, Time 2 perceived cohesion, and Time 3

camp satisfaction (parent-report). After these transformations, skewness was adequately decreased to acceptable levels for all variables with the exception of Time 2 *perceived cohesion*. Although skewness was reduced significantly for this variable, it continued to exceed the acceptable cut-off point after both square root and logarithmic transformations. However, because it approached the cut-off, the decision was made to include it in analyses. The advantages and disadvantages of this decision are considered in the *Discussion*. To maintain consistency across time points and informants, some normally distributed variables were transformed as well (i.e., Time 1 *spina bifida-related skills*, Time 3 *camp satisfaction* (camper-report), Time 3 *intervention satisfaction* (camper- and parent-report)). (For skewness values and transformations, please refer to Table 7.)

Data derived from camp sessions 2008 and 2009 were compared on all relevant variables. T-tests were used to determine whether significant differences existed between the two sessions. (These findings are reported in Table 2.) In cases where significant differences were found to exist between the 2008 and 2009 camp sessions (i.e., Time 1 *spina bifida-related skills*, Time 3 *spina bifida-related responsibilities*, and Time 3 parent-report of *intervention satisfaction*), subsequent analyses featuring these variables included *camp session* as a covariate. Chronbach's Scale Alphas were computed for all measures and all alphas were adequate (i.e., $\alpha > 0.6$), with the exception of the adolescent /young adult version of the Time 1 Harter Social Scale (for both adolescent and young adult campers) and the Time 3 Harter Social Scale (for adolescents only). For these scales, two items were dropped (i.e., "Some teenagers/young adults are able to make really close friends; "Some teenagers/young adults are very hard to like"). The removal of these two items increased Chronbach's Scale Alphas to acceptable levels. (Please refer to Table 8.)

Table 6: Means, Standard Deviations, and Scale Ranges

Variable	Time	Measure	N	M (SD)	Range
SES	1	Parent Report	77	43.69(13.98)	17-66
Camper Age	1	Parent Report	94	16.96(7.00)	7-41
Severity Index	1	Parent Report	86	7.58(1.68)	2-10
Previous Camp Experience	1	Parent Report	83	3.82 (4.11)	0-19
Full-Scale IQ	1	WASI	81	82.09	55-114
Healthcare Goal Progress	2	Camper Report	82	1.45 (1.42)	-3- 4
Healthcare Goal Progress	3	Parent Report	43	0.91(1.06)	-1-3
Social Goal Progress	2	Camper Report	79	1.17 (1.15)	-2-4
Social Goal Progress	3	Parent Report	44	0.61 (0.95)	-2-2
SB Skills	1	Parent Report	78	69.66 (28.19)	6-100
SB Skills	3	Parent Report	51	75.67 (23.09)	21-100
SB Responsibilities	1	Parent Report	78	1.98 (0.42)	1-3
SB Responsibilities	3	Parent Report	51	2.37 (0.41)	1-4
Social Skills	1	Parent Report	77	3.48 (0.08)	2-5
Social Skills	3	Parent Report	51	3.54 (0.09)	2-5
Self-Perception of Social Acceptance	1	Camper Report (Ch)	38	2.63(0.61)	2-4
Self-Perception of Social Acceptance	1	Camper Report (Ad)	50	2.90(0.69)	1-4
Self-Perception of Social Acceptance	2	Camper Report (Ch)	36	2.82(0.71)	2-4
Self-Perception of Social Acceptance	2	Camper Report (Ad)	50	2.90(0.69)	1-4
Self-Perception of Social Acceptance	3	Camper Report (Ch)	23	2.93(0.58)	2-4
Self-Perception of Social Acceptance	3	Camper Report (Ad)	36	2.87(0.63)	2-4
Perceived Cohesion	2	Camper Report	89	4.32 (0.89)	1-5
Camp Satisfaction	3	Camper Report	61	4.26 (0.69)	3-5
Camp Satisfaction	3	Parent Report	40	4.34 (0.82)	1-5
Intervention Satisfaction	3	Camper Report	61	4.05 (0.76)	2-5
Intervention Satisfaction	3	Parent Report	38	3.71(0.82)	2-5

Table 7: Skewness Values and Transformations

Construct	Variable	Skewness	Z-Score	Square Root Trans	Log Trans
Demographic Information	Age	1.26	5.02	3.23	1.35
	SES	-0.41	-1.49		
	Severity Index				
	# of Shunt Surgeries	4.58	17.22	5.77	2.69
	Camp Experience	1.37	5.19	0.43	
Cognitive Ability	Cognitive Ability	-0.01	-0.04		
Goal Progress	Healthcare Goal (C)	0.75	2.76		
	Healthcare Goal (P)	-0.11			
	Social Goal (C)	-0.05			
	Social Goal (P)	-0.07			
Healthcare Autonomy	**T1 SB Skills	-0.75	-2.76	0.21	
	*T3 SB Skills	-1.20	-4.81		
	T1 SB Responsibilities	-0.06	-0.22		
	T3 SB Responsibilities	-0.08	-0.23		
Psychosocial Functioning	T1 Social Acceptance	0.21	0.80		
	T2 Social Acceptance	-0.04	-0.14		
	T3 Social Acceptance	0.69	2.23		
	T1 Social Skills	0.04	0.15		
	T3 Social Skills	-0.03	-0.10		
Cohesion	Perceived Cohesion	-2.04	7.98	5.90	4.04
Satisfaction	Camp Satisfaction (C)	-0.68	-2.22	1.40	0.63
	Camp Satisfaction (P)	-2.44	-6.53	4.60	2.85
	Intervention Satisfaction (C)	-0.70	-2.30	0.83	0.40
	Intervention Satisfaction (P)	-0.44	-1.15	0.07	0.91

Table 8: Chronbach's Scale Alphas

	Scale	Ability A	Ability B	Ability C	Sample
Time 1	WASI	.590	.688	.656	.688
	SNAP-IV (P)	.938	.819	.904	.918
	Social Skills	.964	.921	.967	.952
	Harter Social Scale: Child	.601	N/A	N/A	.601
	Harter Social Scale: Adol/YA	N/A	.830	.699	.780
Time 2	Perceived Cohesion	.825	1.00	.955	1.00
	Harter Social Scale:Child	.768	N/A	N/A	.768
	Harter Social Scale: Adol/YA	N/A	.736	.750	.742
Time 3	Social Skills	.957	.961	.936	.954
	Harter Social Scale: Child	.726	N/A	N/A	.726
	Harter Social Scale: Adol/YA	N/A	.730	.666	.689
	Satisfaction with Camp (C)	.654	.728	.855	.770
	Satisfaction with Camp (P)	.961	.645	.854	.923
	Satisfaction with Intervention (C)	.856	.905	.942	.902
	Satisfaction with Intervention (P)	.842	.728	.903	.929

Main Effects Analyses. For all main effects analyses, omnibus tests for repeated measures ANOVAs were conducted to determine whether significant changes occurred with regard to three categories of outcomes: 1) healthcare autonomy, 2) psychosocial functioning, and 3) goal attainment. Specifically, it was predicted that significant improvements in healthcare autonomy (i.e., spina bifida-related skills, spina bifida-related responsibilities) and psychosocial functioning (i.e., social skills, perceived social acceptance) would be observed following the intervention (i.e., Hypotheses 1a, 1b, 2a, and 2b respectively). Likewise, it was predicted that participants would make significant progress toward both healthcare and social goals (i.e., Hypotheses 1c and 2c

respectively). For those variables that were measured at three time points (i.e., perceived social acceptance, camper-reported healthcare and social goal ratings), it was expected that gains would increase between Time 1 and Time 2, and would remain stable from Time 2 to Time 3. In cases where three data collection time points were available and significant results were detected, post-hoc probing was used to identify the specific time points during which change occurred.

Person-centered Analyses. To understand the impact of age group, cognitive ability, and perceived cohesion on outcome, person-centered analyses were conducted. Specifically, Hypotheses 3a, 3b, and 3c state that these three variables (i.e., age group, cognitive ability, and perceived cohesion) will distinguish between those campers who made a substantial amount of progress toward their goals (e.g., a 2-point or greater improvement on Likert scales) and those campers who made little progress toward their goals (e.g., less than a 2-point improvement on Likert scales). It was predicted that membership in the adolescent and young adult age groups would increase the likelihood that campers would make a substantial amount of progress toward goals (Hypothesis 3a). Likewise, it was predicted that campers who obtained higher scores on a measure of cognitive ability would be more likely to achieve a substantial amount of progress toward goals (Hypothesis 3b). Finally, it was expected that campers who rated the intervention group as being more cohesive would be more likely to achieve a substantial amount of progress toward goals (Hypothesis 3c).

Before these hypotheses were tested, “Goal Progress” variables were created for healthcare and social goals. Binary logistic regression analyses were then used to examine whether select variables would predict membership in “high progress” or

“low/no progress” outcome groups (i.e., camper-reported healthcare goal progress, parent-reported healthcare goal progress, camper-reported social goal progress, and parent-reported social goal progress). Camper outcome data and parent outcome data were analyzed separately.

Decisions regarding cut-off points were made for each of the four progress variables. These decisions were made with both practical and conceptual issues in mind, following analysis of frequency and descriptive data. Examination of these data revealed that a sizeable number of campers rated their progress toward goal attainment as a “4” (i.e., “Almost Reaching This Goal”) out of “5” (i.e., “Completely Reaching This Goal”) on Time 1 *Progress Monitoring Forms*. For Time 1 healthcare goals, 11 campers provided ratings of “4;” for Time 1 social goals, 19 campers provided ratings of “4.” These high Time 1 ratings are problematic for several reasons – most notably, the 5-point scale does not leave adequate room for gains beyond one point for these participants (i.e., it would not be possible for campers who began at a “4” to be placed in a “high progress” group when “high progress” is defined as improvement by two or more points). To complicate matters further, excluding these campers from the analysis was not a feasible option because this would have reduced the sample size such that power to detect results would have been diminished substantially. After a careful consideration of multiple factors, the decision was made to compute progress variables based on a less stringent cut-off for those campers who began at a “4.” This adjustment was carried out for both progress variables based on camper-report such that for campers who provided goal ratings of “4” at Time 1, “high progress” was defined as a 1-point increase, while “low/no progress” was defined as less than 1-point increase. For all other campers,

“high progress” was defined as an increase of 2 points or greater and “low progress” was defined as less than a 2-point increase. (Because Time 1 goal ratings of “5” suggest that an inappropriate goal was selected; the few participants who provided Time 1 ratings of “5” were excluded from person-centered analyses. This resulted in the exclusion of three participants for analyses involving healthcare goals, and four participants for analyses involving social goals.)

For outcome variables based on parent-report, decisions regarding cut-points were made according to the practical necessity of having an adequate number of participants in both “high progress” and “low progress” groups, as well as a conceptual issue relating to the Time 3 data collection point used to calculate variables (as opposed to Time 2 for campers). In particular, given the greater amount of time that passed between Time 1 and Time 3, it made conceptual sense to use a less stringent cut-point for analyses based on parent goal ratings to account for some loss of gains that may have occurred between Time 2 and Time 3. Therefore, for outcome variables based on parent-report, “high progress” was defined as an increase of 1-point or greater, while “low/no Progress” was defined as less than 1-point increase. (Unlike campers, no parents rated goal progress as “5” at Time 1, so there was no need to exclude participants from these analyses.)

Table 9: Ns for “High Progress” and “Low/No Progress” Outcome Groups

	High Progress	Low/No Progress	Total N
Camper Healthcare Goal Progress	47	32	79
Camper Social Goal Progress	41	34	75
Parent Healthcare Goal Progress	28	16	44
Parent Social Goal Progress	25	18	43

CHAPTER FOUR

RESULTS

Main Effects Analyses

For all main effects analyses, omnibus tests for repeated measures ANOVAs were used to determine whether there were significant improvements following the camp intervention. Only those participants who completed data at all time points were included in these analyses. Analyses were run separately for camper-report and parent-report. Results of the omnibus tests for main effects are presented in Table 10.

For analyses based on camper-report, it was hypothesized that variables of interest would change between Time 1 and Time 2, and would remain stable between Time 2 and Time 3. For analyses based on parent-report, it was hypothesized that variables would change from Time 1 to Time 3. (Parent data were not collected at Time 2.) Two sets of main effect hypotheses were tested: 1) healthcare autonomy and 2) psychosocial functioning.

The first set of main effects analyses refers to *healthcare autonomy* (i.e., spina bifida-related skills and spina bifida-related responsibilities). (Recall that parent-reported data relating to these two variables were not collected for the 2009 young adult sample; therefore, these campers are not included in the analyses described below.) The first analysis tested Hypothesis 1a: *Spina bifida-related skills will improve significantly from Time 1 to Time 3. Camp session* was entered as a covariate for this analysis because a significant difference was found when the variable was compared across the 2008 and

2009 sessions. Findings did not support this hypothesis, as no significant change was detected from Time 1 to Time 3 ($F = 1.55$; $p = .22$). The second analysis tested Hypothesis 1b: *Campers will take on significantly more spina bifida-related responsibilities from Time 1 to Time 3*. Again, *camp session* was entered as a covariate due to the significant difference detected when this variable was compared across the 2008 and 2009 sessions. Counter to the author's hypothesis, findings did not reveal a significant change from Time 1 to Time 3 ($F = 3.85$; $p = .06$). It should be noted, however, that significant increases in both spina bifida-related skills and responsibilities were detected when 2009 child and adolescent data were excluded from the dataset ($F = 4.15$; $p < .05$; $F = 19.31$; $p < .0001$, respectively).

The next two tests examined Hypothesis 1c: *Campers will make significant progress toward individual healthcare goals*. For parent-report, it was predicted that significant progress toward healthcare goals would occur from Time 1 to Time 3. For camper-report, it was predicted that significant progress would be made from Time 1 to Time 2, and no further gains would be made from Time 2 to Time 3. In general, findings provided support for these hypotheses. According to parent- and camper-report, campers made significant progress toward healthcare goals from Time 1 to Time 3 ($F = 31.19$; $p < .001$; $F = 25.04$; $p < .001$, respectively).

For analyses featuring three time points, post-hoc paired t-tests were conducted to determine the point at which the change occurred. For camper-reported healthcare goal attainment, t-tests revealed a significant increase from Time 1 to Time 2 ($t = -9.23$; $p < .001$), and a significant decrease from Time 2 to Time 3 ($t = 2.99$; $p = 0.004$). Despite this

significant decrease, the “net gain” of goal progress was maintained as confirmed by a comparison of Time 1 and Time 3 goal ratings ($t = 5.51; p < .0001$).

The second set of analyses refers to psychosocial functioning. The first analysis tested Hypothesis 2a: *Parent-reported social skills will improve significantly from Time 1 to Time 3*. Contrary to this hypothesis, findings suggest that social skills did not improve from Time 1 to Time 3 ($F = 1.82; p = .18$). The second analysis in this set tested Hypothesis 2b: *Camper-reported self-perception of social acceptance will improve significantly from Time 1 to Time 2, and will remain stable from Time 2 to Time 3*. Because the child and adolescent/young adult versions of the social acceptance measure were comprised of different items, two separate analyses were run. For children and adolescents/young adults, results indicated that self-perception of social acceptance did not change significantly over time ($F = .37; p = .69; F = 2.72; p = .08$, respectively). The final two tests in this set examined Hypothesis 2c: *Campers will make significant progress toward individual social goals*. For parent-report, it was predicted that significant progress toward social goals would occur from Time 1 to Time 3. According to parent-report, significant progress was made toward social goals from Time 1 to Time 3 ($F = 18.54; p < .001$). For camper-report, it was predicted that significant progress would be made from Time 1 to Time 2, and no further gains would be made from Time 2 to Time 3. According to camper-report, significant changes in social goal attainment were observed ($F = 26.30; p < .001$). Post-hoc paired t-tests were performed for camper-reported social goal attainment, and results indicate a significant increase in goal attainment from Time 1 to Time 2 ($t = -9.08; p < 0.001$). No significant change was detected between Time 2 and Time 3 ($t = 0.88; p = .38$).

Table 10: Main Effects

Construct	Variable	N	T1 <i>m(sd)</i>	T2 <i>m(sd)</i>	T3 <i>m(sd)</i>	F	ES
Healthcare Autonomy	SB Independence Survey (P) †	50	6.55(2.68)	N/A	5.37(2.26)	1.55	.03
	Management of SB Responsibilities (P)	50	2.01(.40)	N/A	2.36(.41)	3.85	.07
	Individual SB Goals (P)	43	2.26	N/A	3.16	31.19***	.43
	Individual SB Goals (C)	51	2.63(1.02)	3.98(.99)	3.43(1.12)	25.04***	.51
Psychosocial Functioning	Social Skills (P)	50	3.46(.66)	N/A	3.54(.66)	1.82	.04
	Social Acceptance: Child Version (C)	23	2.71(.65)	2.84(.77)	2.79(.68)	.371	.02
	Social Acceptance: Adol./Young Adult (C)	32	2.97(.64)	3.00(.61)	2.85(.66)	2.72	.15
	Individual Social Goals (P)	44	2.75(.69)	N/A	3.36(.87)	18.54***	.30
	Individual Social Goals (C)	48	2.90(.93)	3.98(1.00)	3.88(1.08)	26.30***	.53

(C) Denotes Camper-Report; (P) Denotes Parent-Report; ES = Effect Size; † denotes reflected variables

* $p < .05$; ** $p < .01$; *** $p < .001$

In sum, results from main effects analyses derived from broad-based measures of functioning were consistent: Significant findings were not detected on these measures of healthcare autonomy (i.e., spina bifida-related skills or responsibilities) or psychosocial functioning (i.e., overall social skills or self-perceived social acceptance). With regard to individual goals, results were more promising: Findings suggest significant progress toward goal attainment for both healthcare and social goals, and according to both camper- and parent-report. To better understand the conditions related to goal attainment, person-centered analyses were conducted next.

Person-Centered Analyses

Person-centered analyses were used to gain another perspective on data.

Hypotheses 3a, 3b, and 3c state: *Age group, cognitive ability, and perceived cohesion will distinguish between those campers who make varying degrees of progress toward goals* (i.e., “high progress” and “low/no progress”). To test this hypothesis, and thus, gain a better understanding of that which characterizes those campers who benefit the most (and least) from the intervention, logistic regression analyses were performed. To do this, several steps were taken. First, four *Goal Progress* variables were created (i.e., one for camper-reported healthcare goals, one for parent-reported healthcare goals, one for camper-reported social goals, and one for parent-reported social goals). For camper-report, progress was defined as the difference between the Time 1 Progress Monitoring and Time 2 Progress Monitoring. For campers, progress was defined in terms of change from Time 1 to Time 2 to capitalize on the substantially lower attrition rate at Time 2 (as compared to Time 3) and thereby, maximize power. For parent-report, progress was defined as the difference between Time 1 Progress Monitoring and Time 3 Progress

Monitoring. Then two levels (i.e., “high progress” and “low/no progress”) were created for each of the four progress variables according to the procedure described previously. (Please refer to the *Statistical Treatment* section for details regarding the method of choosing cut-off points for high and low/no progress groups).

Four sets of logistic regression analyses were computed for each of three predictor variables (i.e., age group, cognitive ability, and perceived cohesion) and four outcome variables (i.e., camper- and parent-reported healthcare goal progress; camper- and parent-reported social goal progress). Therefore, a total of 12 logistic regression analyses were performed. Results are provided below.

Age Group. Analyses featuring age group as a predictor variable were not found to be significant for any of the four outcome variables (see Table 11). When camper- and parent-reported healthcare goal progress were analyzed as outcome variables, the model fit was not significant ($\chi^2 = 1.89, p = .39$; $\chi^2 = .83, p = .66$). Likewise, when camper- and parent-reported social goal progress were analyzed as outcome variables, the model fit was not significant ($\chi^2 = .42, p = .81$; $\chi^2 = .55, p = .76$).

Table 11: Logistic Regression Analysis of Age Group

Outcome Variable	<i>N</i>	χ^2	<i>P</i>
Healthcare Goal Progress (C)	79	1.89	.39
Healthcare Goal Progress (P)	43	.83	.66
Social Goal Progress (C)	79	.42	.81
Social Goal Progress (P)	44	.55	.76

Cognitive Ability. Analyses featuring cognitive ability as a predictor variable were not found to be significant for any of the four outcome variables (see Table 12). When camper- and parent-reported healthcare goal progress were analyzed as outcome variables, the model fit was not significant ($\chi^2 = .36, p = .85$; $\chi^2 = .61, p = .44$). Likewise,

when camper- and parent-reported social goal progress were analyzed as outcome variables, the model fit was not significant ($\chi^2 = .02, p = .89$; $\chi^2 = .03, p = .86$).

Table 12: Logistic Regression Analysis of Cognitive ability

Outcome Variable	<i>N</i>	χ^2	<i>P</i>
Healthcare Goal Progress (C)	70	1.89	.39
Healthcare Goal Progress (P)	36	.83	.66
Social Goal Progress (C)	66	.02	.89
Social Goal Progress (P)	37	.03	.86

Perceived Cohesion. Analyses featuring perceived cohesion as a predictor variable were not found to be significant for any of the four outcome variables (see Table 13). When camper- and parent-reported healthcare goal progress were analyzed as outcome variables, the model fit was not significant ($\chi^2 = 0.11, p = .74$; $\chi^2 = 3.06, p = .08$). Likewise, when camper- and parent-reported social goal progress were analyzed as outcome variables, the model fit was not significant ($\chi^2 = .07, p = .41$; $\chi^2 = .48, p = .49$).

Table 13: Logistic Regression Analysis of Perceived Cohesion

Outcome Variable	<i>n</i>	χ^2	<i>P</i>
Healthcare Goal Progress (C)	77	.11	.74
Healthcare Goal Progress (P)	43	3.06	.08
Social Goal Progress (C)	73	.07	.41
Social Goal Progress (P)	44	.48	.49

Descriptive and Frequency Data: Age Group, Cognitive Ability, and Cohesion

Standardized Testing of Cognitive Ability. Results from standardized testing of cognitive ability revealed several important findings. First, 2-factor IQ scores derived from the WASI were calculated as a proxy measure of cognitive ability. In the sample employed, the mean proxy IQ score was 82.01, which places the average camper in the low end of the Low Average range of functioning. Moreover, scores ranged from below

55 (Mild Mental Retardation, and the lowest possible score for this instrument) to 114 (the high end of the Average range). Adolescents and young adults performed at the Borderline range of functioning with an average score of 75.84. Adolescent and young adult scores were significantly lower than the average proxy IQ score in the child group, $t = 2.28, p < 0.05$.

Goals. Frequency data relating to goal selection were examined for healthcare and social goals. All goals included in the *Goal Bank* were selected by at least one camper. The most commonly selected healthcare goals for the overall group was “Catheterize Regularly” (27%), followed by “Improve Swimming Skills” (11%), “Exercise Regularly” (10%), “Eat Fruits and Vegetables” (10%), and “Drink Water” (10%). The most commonly selected social goals were “Ask for help when needed” (20%), “Contribute to Conversation” (15%), “Speak Clearly” (11%), “Share Personal Information Appropriately” (9%), and “Assert Self Appropriately” (7%). Please refer to Table 14 and Table 15 for additional data relating to goal selection. With regard to goal progress, descriptive data were examined to determine the percentage of campers for whom progress increased, decreased, or stayed the same. These data are provided in Table 16.

Table 14: Frequency of Healthcare Goal Selection

Healthcare Goal	Frequency	Percentage
Catheterizes regularly	25	26.6
Practices swimming skills	10	10.6
Eats fruits and vegetables	9	9.6
Drinks enough water	9	9.6
Exercises regularly	9	9.6
Showers independently	7	7.4
Completes self-care tasks	5	5.3
Completes bowel program	4	4.3
Develop a nutrition plan	3	3.2
Catheterizes hygienically	2	2.1
Performs skin checks	2	2.1
MACE	1	1.1
Takes medication	1	1.1
Develop an exercise plan	1	1.1
Walks to meals/activities	1	1.1

Table 15: Frequency of Social Goal Selection

Social Goal	Frequency	Percentage
Asks for help	19	20.2
Contributes to conversation	14	14.9
Speaks clearly	10	10.6
Shares personal info	8	8.5
Asserts self	7	7.4
Greets others	6	6.4
Stays on topic	5	5.3
Asks follow-up questions	4	4.3
Users nonverbal cues	4	4.3
Initiates conversations	4	4.3
Practices interview skills	3	3.2
Maintains personal space	1	1.1
Introduces self	1	1.1

Table 16: Percentages of Campers Who Made Progress Toward Goals

	Progressed	Regressed	Stayed the Same
Healthcare Goal	71.9	7.3	20.7
Healthcare Goal	58.2	7.0	34.9
Social Goal (C)	77.2	7.6	13.9
Social Goal (P)	63.6	11.4	22.7

Camper and Parent Satisfaction. The final group of analyses was based on responses to a *Feedback Form* completed by campers and parents. Descriptive statistics are presented in Table 17. Responses ranged from 1 (“Strongly Disagree”) to 5 (“Strongly Agree”), with higher numbers indicating more favorable perceptions. Findings suggest that both campers and parents viewed the camp experience and the intervention program positively. T-tests were conducted to compare participant satisfaction with the intervention to their satisfaction with the camp in general. Results indicate that both campers and parents viewed the camp experience significantly more favorably than the independence program ($t = 2.31$; $p = 0.02$ for camper-report; $t = 3.98$; $p < .0001$ for parent-report). (Please refer to Table 17.)

Table 17: Satisfaction with Camp Ability and the Independence Intervention

	Camp	Intervention	T
Campers	4.26(.69)	4.04(.76)	2.31*
Parents	4.33(.84)	3.71(.82)	3.98**

* Indicates significance at the $p < .05$ level

**Indicates significance at the $p < .0001$ level

Additionally, one exploratory analysis relating to intervention satisfaction was done. In particular, logistic regression analyses were conducted to determine whether camper satisfaction with the intervention predicted the likelihood that campers would make more or less progress toward goals. Findings indicated that intervention satisfaction did not distinguish between campers who made high and low levels of progress toward individual healthcare or social goals ($\chi^2 = .268$, $p = .91$; $\chi^2 = .446$, $p = .73$, respectively).

CHAPTER FIVE

DISCUSSION

Overview

The purpose of the present study was to design and evaluate an Independence Intervention for children, adolescents, and young adults with spina bifida. The primary aim of the intervention was to promote autonomy development among participants. Two components comprised the intervention: 1) group treatment, and 2) individual goals. Although analyses did not reveal significant findings on broad-based measures of healthcare autonomy or psychosocial functioning, significant results were found for both individual healthcare and social goals. In the following discussion, interpretations for findings are offered in light of the intervention literature. Then, key components of the curriculum and evaluation are reviewed and critiqued in the context of pertinent quantitative findings and qualitative observations. Lastly, limitations of the study are summarized and ideas for future intervention evaluations are proposed.

Findings: Interpretations and Explanations

It was the author's aim to build upon previous camp intervention research to create a spina bifida-specific intervention evaluation. With regard to curriculum, the author's objective was to promote *healthcare autonomy* and *psychosocial functioning* in an enjoyable and satisfying camp atmosphere. In terms of evaluation, the author's goal was to expand upon previous intervention work by using a person-centered approach to explore the role of age group, cognitive ability, and perceived cohesion in terms of their

relation with outcomes. Additionally, efforts were made to improve the goal setting protocol. In the section that follows, findings are discussed in terms of these themes. First, findings relating to curriculum objectives are considered. Specifically, findings related to *healthcare autonomy*, *psychosocial functioning*, and *participant satisfaction* are discussed. Then, findings related to evaluation objectives are considered. This section includes a discussion of findings pertinent to *age group*, *cognitive ability*, and *perceived cohesion*.

Curriculum Aims: Healthcare Autonomy, Psychosocial Functioning, & Satisfaction

Spina Bifida-Specific: Findings Related to Healthcare Autonomy. As described previously, *spina bifida-related skills* refer to the degree to which campers are able to perform various healthcare tasks, whereas *spina bifida-related responsibilities* refer to the extent to which campers fulfill the responsibility for completing these tasks. Both are necessary components of healthcare autonomy. Likewise, both are required for campers to make progress toward individual healthcare goals.

It was hypothesized that improvements in both skills and responsibilities would be seen from Time 1 to Time 2, and no further change would be seen from Time 2 to Time 3. Similarly, it was predicted that significant progress toward healthcare goals would be observed from Time 1 to Time 2, and no change would be seen from Time 2 to Time 3. To test these hypotheses, repeated measures ANOVAs were run on data derived from two broad-based, spina bifida-specific outcome measures of healthcare autonomy and one measure of progress toward individual healthcare goals.

Significant improvements on broad-based measures of healthcare autonomy were not detected when 2008 and 2009 were analyzed together with *Camp Session* entered as a

covariate. However, significant findings in both skills and responsibilities were detected when 2009 data were excluded from analyses and only 2008 data were examined. Additionally, significant progress toward individual healthcare goal attainment was observed, according to both camper- and parent-report. Furthermore, for those outcomes that were measured at three time points (i.e., camper-reported healthcare goal progress), significant progress was made between Time 1 and Time 2, after which a significant loss in gains was observed at Time 3 follow-up. While such a decline is inconsistent with the proposed hypotheses – and furthermore, suggests the need for more strategies to increase skill transfer and maintenance - the pattern is consistent with that which would be expected if the intervention was, in fact, producing the change. However, in the absence of a control group, this hypothesis cannot be supported or refuted.

Findings related to Time 2 healthcare goals are consistent with findings from previous Camp Ability intervention evaluations (O’Mahar et al., 2010) as well as findings from other more time-intensive intervention evaluations (Engleman et al., 1994; Sherman et al., 1985). Taken together, these findings suggest that both short-term (i.e., 1-week) and longer-term (i.e., 12-week) camp interventions can be effective in promoting mastery and application of healthcare skills in a sample of young people with spina bifida. However, whether gains can be maintained beyond 1-month follow-up is less clear.

Notwithstanding the significant “net gain” in healthcare goal progress that was maintained from Time 1 to Time 3 in the present study, the significant loss of gains between Time 2 and Time 3 is concerning because it suggests the possibility that further deterioration may occur with greater passage of time. This concern is based on previous research demonstrating that some gains are lost at 6-month follow-up (King et al., 1994).

The significant loss between Time 2 and Time 3 is inconsistent with findings from the O'Mahar et al. (2010) study that demonstrated maintenance of healthcare goal gains at 1-month follow-up. Notably, the O'Mahar et al. intervention was characterized by a greater emphasis on the cognitive deficits associated with spina bifida and included the explicit teaching of strategies to improve memory of intervention material (e.g., use of mnemonics, memory diaries, etc.). As these strategies are likely to have contributed to the maintenance of gains at Time 3 follow-up, they should be incorporated into future interventions with this population.

Social Skills: Findings Related to Psychosocial Functioning. *Psychosocial functioning* is a broad term referring to a range of cognitive, emotional, and behavioral factors in relation to one's social environment. The author of the present study was particularly interested in two specific constructs that fall under the psychosocial functioning umbrella: *social skills* and *perceived social acceptance*. In the context of the present study, psychosocial functioning refers to social skills (i.e., behaviors as observed and reported by parents) and perceived social acceptance and (i.e., thoughts and feelings associated with relations to peers). While the former aspect of psychosocial functioning refers to the relatively objective parental observations of behaviors, the latter refers to subjective experiences related to one's own sense of belonging among peers. Both are important aspects of psychosocial functioning. The author of the present study was also interested in progress toward individual social goals.

It was hypothesized that improvements in *social skills*, *perceived social acceptance*, and *progress toward individual social goals* would occur following the intervention. To test these hypotheses, repeated measures ANOVAs were conducted on

data derived from two broad-based outcome measures of psychosocial functioning:

Social Skills Measure (parent-report), *Harter Self-Perceived Social Acceptance* (camper-report), as well as on a more specific measure of progress toward individual social goals.

As with findings related to healthcare autonomy, findings pertaining to psychosocial functioning were mixed: While broad-based measures of psychosocial functioning did not yield significant results, significant progress was observed with regard to individual social goals. The former (non-significant) results are discussed first.

Significant findings were not detected with regard to overall social skills. There are several possible explanations for the lack of significant findings. Again, it is possible that the small sample size of current study prevented the detection significant findings due to a loss of power (Aiken & West, 1991; Cohen, 1992). While small sample size is problematic for other analyses included in this study (including those that revealed significant results) – as well as studies of young people with chronic health conditions more generally (Drotar, 1997) – sample size was a particularly salient issue for analyses relating to social skills because they depended on retention of parent participants at Time 3. As the sample of parent participants declined substantially by Time 3 (and parent-reported data were not available for 2009 young adult campers), analyses that relied on these data were compromised by a substantial loss of power. Another possible interpretation relates to the measure employed. Although the *Social Skills Measure* offered the benefit of having been designed to address those specific deficits associated with spina bifida, and further, to precisely reflect those skills targeted in the current intervention, the psychometric properties of this measure are unknown. Without having knowledge of its psychometric properties, it remains possible that this measure does not

feature adequate reliability and/or validity. Thus, significant findings may have been detected had an established social skills measure (i.e., with adequate validity and reliability) been employed instead.

While it is possible that significant findings would have been detected had a psychometrically-established social skills measure been employed, the lack of significant findings regarding social skills is consistent with results from at least one other intervention evaluation (Engleman et al., 1994). Thus, it is possible that the lack of significant findings related to overall social skills were not observed because long-lasting, broad-based changes in social skill functioning require longer-term, more intensive, or more systemic interventions.

Given that significant changes were not observed for those behaviors that were targeted directly in the current intervention, it is perhaps unsurprising that significant changes were not seen in a relatively subjective and intra-psychic aspect of psychosocial functioning that was not addressed directly in the context of this intervention. Specifically, significant increases were not observed for perceived social acceptance – for either the child or adolescent/young adult sub-samples. Notably, these analyses were considerably underpowered to detect significant results. As mentioned previously, different items comprised the two versions of the measure employed (i.e., child and adolescent/young adult versions). As running a single analysis including two measures comprised of different items would have compromised the validity of findings, analyses were run separately for two “sub-samples” (i.e., child and adolescent/young adult). The decision to divide the sample in accordance with the different versions of the measure

resulted in a substantial loss of power, which may account for the lack of significant findings.

Nonetheless, this pattern of findings is consistent with results from other camp intervention evaluations that did not reveal improvements in psychosocial functioning (Engleman, et al., 1994; O'Mahar, 2009). The replication of these findings in the current study thus adds support to the possibility that short-term, skills-based, behaviorally-oriented interventions may be ill-suited to effect change for more intra-psychic areas of functioning. Longer-term interventions designed to directly target such areas may be required for significant changes to be observed. It is also possible that improvements in social acceptance (and other more intra-psychic domains not addressed in this study) may occur beyond the 1-month post-intervention data collection point used in the current study (Rachman, 1999). Perhaps if campers had more time to garner the benefits of behavioral gains, improvements in intra-psychic aspects of psychosocial functioning would follow.

Notably, the lack of significant findings with regard to perceived social acceptance is inconsistent with findings from two studies suggesting transient improvements in self-perception (Andrade et al., 1990; King et al., 1997). Variations across curricula, methodologies, and measurement may have contributed to these divergent findings. For instance, both of these interventions involved substantially longer-term and more intensive interventions as compared to the current intervention (i.e., 10-weeks as compared to 1-week), which may have accounted for the different findings obtained. While this interpretation makes intuitive sense, treatment "strength" has not been well-studied or established as a moderator of treatment outcomes (Kazdin,

2005). However, in the small pool of studies related to interventions for young people with chronic health conditions, longer-term, higher-intensity interventions are generally associated with positive outcomes (Andrade, 1990; Engleman et al., 1994; King et al., 1997).

As compared with findings based on broad-based measures of psychosocial functioning, findings derived from the individual social goals component of the intervention were more promising. These data demonstrate significant increases in progress toward social goals between Time 1 and Time 2 according to both camper- and parent-report. Furthermore, unlike findings related to healthcare goal progress, gains made with regard to social goal progress were maintained at follow-up. These findings are consistent with conclusions drawn by Sherman and colleagues (1985) in their study of goal attainment among participants in a spina bifida-specific camp intervention. Findings from the current study strengthen Sherman et al.'s findings not only by replicating their results, but also by using statistical analyses to do so.

The consistency with which significant findings were detected on the individual goals component of the current intervention suggests that this component is an effective means of intervention. Likewise, it is possible that more focused outcome measures are more likely to reveal significant changes following time-limited interventions. As such, small-scale, short-term, skills-based interventions may be more aptly evaluated by skills measures that are proportional to the intervention. The measure of goal attainment employed in the current study is one example of this type of measure. In sum, focused outcome measures are well-suited to small-scaled, focused intervention efforts.

Satisfaction for Campers and Parents. Lastly, the author sought to create a curriculum that was satisfactory for both campers and parents. Satisfaction was measured by a *Feedback Form*, which elicited both quantitative and qualitative data. Findings from quantitative analyses indicated that camper- and parent-ratings of both the intervention in particular, and the camp as a whole, were highly positive.

Additionally, participant satisfaction with the intervention was compared to participant satisfaction with the camp in general. Findings indicated a significant difference between the degree to which participants were satisfied with the intervention and the camp, with both campers and parents reporting less satisfaction with the intervention than with the camp. This pattern is consistent with findings from previous Camp Ability intervention evaluations (O’Mahar et al., 2010). Taken together, these findings underscore one challenge of administering an intervention in the context of a summer camp: From the perspective of participants, time spent doing intervention activities may be viewed as time *not* spent engaging in more traditional camp activities such as swimming, canoeing, and horseback riding. Thus, even the most engaging intervention activities may be a “tough sell” to campers insofar as these activities may be seen as infringing on time spent engaging in more appealing recreational pastimes.

Additionally, a major draw of Camp Ability is the opportunity it presents for campers to enjoy the traditional pastimes that able-bodied young people routinely enjoy. Furthermore, campers are able to enjoy these activities in the company of their peers who share similar challenges. This may represent one of the only times when campers feel “normal” in using braces to ambulate or a catheter to eliminate. Thus, despite efforts to maintain a positive, strengths-based approach to intervention, group sessions may be

experienced as something of a comedown whereby campers are required to recall the ways in which they are different from the population at large, and moreover, anticipate the challenges they will face upon returning home. When considered from this perspective, the significant difference between intervention ratings and camp ratings becomes less striking than the extremely positive ratings given the intervention.

Despite these remarkably positive ratings, the quantitative data derived from *Feedback Forms* do not tell the whole story; qualitative data warrant consideration as well. Although the limited number of comments provided on this measure precluded their qualitative analysis, several noteworthy remarks are discussed in the *Future Directions* section.

Evaluation Aims: Findings Related to Age, Cognitive Ability, and Cohesion

Several changes to previous Camp Ability intervention evaluations were made with regard to methodology. In particular, the author of the current study supplemented variable-centered analyses with person-centered analyses. This approach was chosen in an effort to identify the particular characteristics distinguishing participants who derived the most – and least – benefit from the intervention. Person-centered analyses were employed to better understand whether *age group, cognitive ability, and perceived cohesion* would differentiate between campers who make greater and lesser amounts of progress toward goals.

Counter to hypotheses, significant findings were not detected for any of these three variables as they pertained to either healthcare or social goal progress. Taken together, the lack of findings relating to these variables may be explained by measurement and methodological factors. For example, the 5-point Likert-type scale on

which goal progress was tracked may not have allowed enough room to capture an adequate amount of variability, thereby limiting the likelihood of detecting results (Tabarnick & Fidell, 2001). This may have been especially problematic for those campers who provided advanced Time 1 ratings (i.e., “4 - Almost Meeting This Goal”). Likewise, some campers rated themselves at “5 – Completely Meeting Goal” at Time 1, creating a situation whereby they were left with no room for improvement (and thus were excluded from analyses). This resulted in a diminished sample size.

The small sample size that was included in this analysis – especially for parent-reported goal progress (which relied on retention at Time 3 in order for inclusion to be possible) may have limited the author’s ability to detect significant findings relating to person-centered analyses as well. As binary logistic regression typically demands at least 50 participants per predictor variable in order to have adequate power to detect medium effect sizes (Hsieh et al., 1998), analyses may have lacked sufficient power to uncover significant results.

The above explanations refer to measurement, methodological, and statistical issues that apply to all the person-centered logistic regression analyses conducted in the current study. There are other possible explanations that apply to the particular predictor variables examined in these analyses. A discussion of these explanations is featured below.

Age Group. It was hypothesized that age group would be significantly associated with progress toward goal attainment, with older campers making greater progress than younger campers. Findings from the current study did not support this hypothesis.

Despite the lack of significant findings related to age group and goal progress, analysis of

frequency and descriptive data regarding progress revealed interesting findings related to a small percentage of campers who actually declined on measures of goal progress.

Although these analysis were exploratory in nature (and so were not hypothesis-driven), findings were inconsistent with that which might have been expected.

Perhaps the most surprising finding was that a small but notable percentage of campers in the adolescent group made no progress – or actually regressed - with regard to goal attainment. In particular, 30 – 42% of campers were reported to have made no progress with regard to healthcare goal attainment, while 22 – 34% were reported to have made no progress with regard to social goal attainment. (Ranges reflect differences between camper- and parent-report.) The percentage of campers who regressed was actually greater for the adolescent group, which may reflect some version of rebellion akin to that which is thought to occur in the population of adolescents with diabetes (Kazak, 2002; Spirito & Kazak, 2005; Timms & Lowes, 1999). Nonetheless, this finding runs counter to studies demonstrating that adolescents tend to make greater gains from intervention than do children (Kazdin, 2005; Kazdin & Weisz, 1998).

Cognitive Ability. Whereas previous interventions relied on parent-report of attention abilities as a proxy for cognitive ability (O'Mahar et al., 2010), the current project included a brief battery of cognitive ability to supplement parent-reports. This represents a step toward a multimethod approach, and serves to decrease method error and reporter bias (Holmbeck et al., 2003). Additionally, the measure used in the current study tapped various aspects of cognitive ability (i.e., vocabulary and visual-spatial reasoning). While the current assessment method is hardly a comprehensive assessment

of intelligence, it represents a step toward a more standardized (and thus valid) estimation of cognitive ability.

That said, findings from logistic regression analyses did not reveal a significant relationship between cognitive ability and progress toward goal attainment. Despite the lack of significant findings related to cognitive ability and outcomes, the standardized testing of cognitive ability employed in this study allowed for comparison of functioning in our sample relative to the population at large. Findings from cognitive testing indicated that the present sample was more cognitively impaired – on average – than the population of people with spina bifida in general (Holmbeck et al., 1990), and this discrepancy was especially sizeable for the older campers in the sample. The greater impairment seen among older campers (especially young adults) is unsurprising given that summer camp attendance is an activity usually associated with children and teenagers. The very fact that young adults were in attendance may suggest a developmental and/or cognitive lag.

As many campers return to Camp Ability year after year - with participants in the current sample having attended, on average, four previous Camp Ability sessions - information relating to cognitive ability may be used to inform future curricula such that the intervention is more closely tailored to suit the needs of its participants. This type of tailoring may be especially important for the young adult group, as impairments were the most sizeable in this group. Ideas relating to how findings from cognitive testing may inform accommodations made to future curricula are discussed in the *Future Directions* section.

Perceived Cohesion. As part of person-centered analyses, the author considered the impact of perceived cohesion. As group cohesion has been regarded as one of the

most important small group variables (Yalom & Leszcz, 2005), it was hypothesized that higher levels of perceived cohesion would be associated with greater gains in functioning.

Contrary to this author's hypotheses, findings derived from a logistic regression analysis indicated that perceived cohesion was not significantly related to goal progress outcomes. There are many possible explanations for these findings, several of which relate to the means by which this construct was measured. For one, the psychometric properties of the *Perceived Cohesion Scale* may have prevented detection of significant findings. In particular, the majority of campers provided very high ratings on all items that comprised the scale; as a result, the measure failed to yield adequate variability. This may have precluded the detection of significant findings (Tabachnick & Fidell, 2001).

Additionally, while the consistently high ratings suggest that campers experienced their intervention groups as highly cohesive, this explanation runs counter to observations that took place throughout the camp week. In addition to observations made by interventionists and counselors that campers often did not engage one another without prompting from staff, Time 2 data collection revealed that many campers did not know fellow group members' names in order to fill out a sociometric measure. While this may reflect cognitive limitations associated with spina bifida (e.g., memory problems) (Dennis, Landry, Barnes, & Fletcher, 2006; Yeates, et al., 1995), it remains difficult to imagine a highly cohesive group comprised of people who do not know each others' names. As such, it seems more plausible that some other factor (or factors) contributed to the positive skew of the data. For instance, a social desirability effect may have occurred whereby campers responded in a way they perceived to be acceptable rather than

according to how they truly experienced the group. This explanation may be especially applicable to those campers who required staff assistance in completing the forms (as staff was certainly privy to campers' responses in these cases) (Nederhof, 1985).

However, as social desirability was not measured as part of the current study, it was not possible to test these hypotheses.

Another possible explanation for the lack of significant findings regarding cohesion relates not to the measure per se, but to the means by which it was administered. Although the *Perceived Cohesion Scale* was intended to capture campers' experience of the intervention group as a whole (i.e., throughout all five sessions throughout the week), it was only measured at a single time point (i.e., Time 2 data collection, after the final intervention session on the sixth day of camp). Consequently, data derived from this measure may have reflected campers' feelings about the group only at the moment in time during which it was administered. Because it was administered only at a single time point, it may be inadequate to capture the flavor of campers' experiences throughout the week (Burlingame, MacKenzie, & Strauss, 2004). Additionally, the timing of administration (i.e., shortly after the final intervention session, and before campers would return home to their families) may have biased responses toward being more positive (though less accurate regarding perceived cohesion throughout the week as a whole).

In sum, the lack of significant findings regarding cohesion may have reflected the measure employed or the means by which the measure was administered. Other ideas for measurement of cohesion are discussed in the *Future Directions* section.

Goals Component: Exploratory Analyses and Qualitative Observations

The goal setting and progress monitoring protocols used in the present study were borrowed from Kiresuk & Sherman's *goal attainment scaling procedures* (1968). As described previously, these procedures were considered to be appropriate for use with the current sample for a variety of reasons. Not only have they been shown to be effective for cognitively limited populations (Bailey & Simeonson, 1988) and in a range of settings (Coughlan & Coughlin, 1999), they also lend themselves to use with heterogeneous samples (Stuifbergen et al., 2000). In particular, the individualized nature of goal attainment scaling procedures can help minimize some of the variance (and thus error) inherent in data derived from heterogeneous samples, thereby preserving power to detect significant results. This was a particularly salient issue in the current study, as the small sample size and high attrition rate made it necessary to preserve what power remained.

Previous Camp Ability intervention evaluations featured measurement strategies based on goal attainment scaling procedures (O'Mahar et al., 2010). However, O'Mahar and colleagues (2010) noted that goals chosen by participants were often inappropriate for the intervention evaluation (e.g., too easy to achieve, difficult to observe and measure). In response to this observation, a *Goal Bank* was included in the questionnaire measures. The *Goal Bank* served to limit goal options to those that can be readily observed and measured, and also facilitated quantitative analyses of goal choice. Frequency data related to goal choice revealed several popular goal options. The most commonly selected healthcare goal was "Catheterize regularly," with 27% of the overall sample selecting this goal to work toward. While this is consistent with tasks identified in the literature as the most challenging for this population (Bier et al., 2007; Blum, Resnick et

al., 1991; Watson, 1991), the current study features the first known analysis of goal type among young people with spina bifida.

In terms of social goals, the most commonly selected goals were: “Asking for help” (20%), “Contributing to conversation” (15%), and “Speaking clearly and audibly” (11%). The popularity of these goal choices reflects the challenging nature of these tasks for many people in this population, and additionally, may speak to participants’ awareness of how important they are with regard to autonomy. Findings may be useful for guiding future group treatment sessions such that treatment can be more effectively tailored to suit the needs of the sample. This possibility is discussed more in the *Future Directions* section.

The *Goal Bank* seemed to be a positive step in the direction of limiting goals to those that are potentially appropriate for the purposes of the intervention. However, the number of participants who endorsed goals they had reportedly already met – or nearly met – suggests that there is room for improvement with regard to the goal setting protocol. In particular, for future interventions, instructions may be modified such that participants are told explicitly to identify more challenging goals. Additionally, increased monitoring by research assistants and camp staff could help to ensure appropriate goal setting procedures for participants who fill out Time 1 questionnaires at the Independence Intervention “check-in station” during camp drop-off.

Observations throughout the course of the current study indicated that additional changes made to the goal component of the curriculum may further improve both the curriculum and its evaluation. For instance, observations suggest there was variability with regard to participant adherence to the goal setting and progress monitoring protocol;

deviations may have resulted in decreased progress toward goal attainment. As outlined in the *Goal Bank* instructions, campers and parents were to work together to choose goals when they received Time 1 questionnaires (i.e., one-month prior to camp), and then mail the completed questionnaires via post. However, many participants selected goals and filled out their questionnaires while at the Independence Intervention “check-in station” during camper “drop-off.” While this variability is problematic insofar as it introduced method error into the data, it provided the author with the valuable opportunity to observe the goal setting process in vivo.

One problem that was observed was a lack of collaboration between campers and parents. For instance, campers in all three age groups set goals for themselves without consulting parents. This may have resulted in goals that are less objectively appropriate for campers. For example, campers with limited insight into the nature of their needs may have identified goals that do not pertain to them, or are too easy (or difficult) to achieve. This hypothesis is consistent with findings from descriptive data showing that several campers selected goals they perceived to have already attained or were very close to attaining.

In some cases, parents selected goals without eliciting input from campers. This scenario is problematic for at least two reasons. For one, it runs counter to the very mission of the intervention (i.e., to promote independent functioning). Two, it may result in goals that are less subjectively meaningful for campers. For instance, a parent may identify a goal that a camper does not believe is important, and therefore, is not motivated to work toward. Furthermore, the very fact that a parent identified the goal without consulting the camper may negatively impact camper motivation to work toward the

goal. In this scenerio, campers may use the goal component of camp as an arena within which to rebel against parents, as is thought to occur in populations of adolescents who do not adhere to their diabetes regimens (Timms & Lowes, 1999; Kazak, 2002; Spirito & Kazak, 2005). Some version of this phenomenon may occur in populations of adolescents with spina bifida, which could have affected outcomes in the current study. For example, this phenomenon may account for the substantial percentage of campers who did not make progress toward goals, as well as those who actually regressed with regard to goal attainment. Interestingly, the percentage of campers who fell into these categories was significantly greater in the adolescent group. As adolescence is a time during which young people may be more inclined to exert their will against their parents (Timms & Lowes, 1999), this finding is consistent with what would be expected if regression regarding goal attainment is indicative of teenage rebellion.

If campers experience pressure to change – without feeling like they are actively involved in the process – they are likely to resist intervention efforts. This resistance decreases the likelihood of behavior change (Brehm & Brehm, 1981; Miller, Benefield, & Tonigan, 1993; Miller & Moyers, 2005) and is likely to be a particularly powerful issue for participants in the current study. Unlike individuals who are motivated to seek out therapy by the experience of distress and/or the desire for change, participants did not enroll in the Independence Intervention for such reasons. In fact, they didn't seek out the intervention at all; rather they enrolled in a summer camp that happened to have an intervention as one component. This is one challenge to administering an intervention in a camp context, and makes both gauging and inspiring motivation particularly important.

To be consistent with the intervention mission of empowering young people to become more autonomous - and to identify goals that are both objectively important and subjectively meaningful - the goal setting component must be a collaborative effort between campers and parents. As participants who are engaged in the intervention process are more likely to experience greater improvements on outcome measures (Orlinsky, Rønnestad, & Willutzki, 2004), ensuring this collaboration will be essential in maximizing the effectiveness of future interventions. This collaboration may be especially important for those campers who have limited insight into the nature of their problems, a rebellious streak, or both. The degree to which this collaboration is important may depend on a given camper's age and developmental level, as well as the particular dynamics that characterize his or her family. This idea is elaborated upon in the *Future Directions* section.

As with the goal setting protocol, progress monitoring procedures could be further standardized in an effort to increase goal attainment and intervention effectiveness. Efforts were made to increase counselor training and involvement in the individual goals component of the current intervention. However, feedback from parents, campers, counselors, and the interventionist suggests that more intensive counselor training and support may be necessary to maximize effectiveness. For instance, on the Time 3 *Feedback Form*, one camper in the young adult group noted he was "babied" by counselors at camp. As such comments were not subjected to statistical analysis, it is unknown as to whether they reflect biased perceptions and reports of isolated campers, a more systemic issue indicating a need for greater counselor training, or some

combination of both. However, these comments certainly suggest a need for further exploration regarding campers' perceptions of their relationships with camp staff.

Therapy outcome research suggests that therapeutic alliance plays an important role in promoting change for participants (Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003), with some stating that this bond is the most important component linking process to outcome (Orlinksky et al., 2005). As such, it is possible that relationships between campers and camp personnel may play a similarly important role in promoting progress toward goals. This may hold especially true for relationships between campers and the individual counselors who work with them on a daily, one-on-one basis.

Future studies may include feedback forms that elicit more specific comments regarding camper and parent opinions of interventionists, counselors, and the intervention more generally. As one aim for the intervention was to be developmentally-informed, this is especially important with regard to perceptions that campers are treated in a developmentally-appropriate manner. An Independence Intervention administered within the context of a camp environment that does not consistently promote developmentally-appropriate autonomy is unlikely to be effective.

A more intense approach to counselor training may remedy these concerns. More specifically, training with regard to spina bifida, developmental norms, and behavior modification may need to be increased. Because counselors' backgrounds and experiences varied greatly – and did not necessarily include courses in psychology or education - it cannot be assumed that they were selected for their positions because of some working knowledge of behavioral modification practices. Future efforts may be directed toward increasing the quality of time counselors spent with campers. Likewise,

these efforts should be measured in terms of their effectiveness. Such ideas are discussed in more detail in the *Future Directions* section.

Future Directions

From the above critique, several prominent themes emerge. Directions for future curricula and evaluation are organized around these themes in the section that follows. In this section, ideas for future curricula and evaluation are discussed as they relate to 1) group structure and dynamics, 2) involvement of camp, family, school and medical systems, and 3) spina bifida-specificity and developmental appropriateness.

“Regrouping:” Group Context and Process

Despite substantial gains made toward goal attainment, findings suggest a need to capitalize on the group aspect of camp such that increases in overall psychosocial functioning are promoted more effectively. Additionally, contrary to previous intervention research, perceived cohesion did not appear to impact outcomes significantly. Descriptive data that contrasted with qualitative observations indicated a need for alternative means of measurement. Taken together, findings and qualitative observations suggest the need for: 1) a different approach to promoting social skill development as part of group treatment, 2) a different approach to measuring the impact of the group and its potential effect on outcomes.

Given that the individual goals component of the intervention seemed to be an effective way of both promoting goal attainment and detecting change, it is worthwhile to consider whether elements from this component may be incorporated into the group treatment curriculum. For example, the collaboration involved in choosing goals and monitoring progress toward goals may have been motivating for campers; therefore,

some version of these processes may be effective in the group treatment context. For instance, campers could work as a group to identify “group goals” to work toward throughout the camp week. Research supports the use of group goals, and performance has shown to be superior when individuals work toward both group and individual goals (O’Leary-Kelly, Martocchio, & Frink, 1994; Crown & Rosse, 1995).

Group goals may be incorporated into treatment sessions such that groups are formed according to, for example, the top five goals individual campers and parents select from a goal bank at Time 1. In this way, treatment sessions could be tailored more closely to individual needs and more time could be spent focusing on those skills most relevant to particular campers. It could also give groups a sense of shared purpose, thereby increasing a sense of teamwork and cohesion. This sense of cohesion would be bolstered by continued collaboration toward shared goals and collective reinforcement for effort and progress. This would serve to increase camper interaction while providing group incentives to achieve goals, foster a sense of accountability for making progress toward them, and make intervention sessions more fun (Slavin, 1995). Treatment groups could function as “teams” and compete against other treatment groups at camp. This would capitalize on the camp setting, be consistent with the spirit of summer camp, and contribute to camper satisfaction. It would also exploit the combined effect of competition and cooperation (i.e., intergroup competition) as a means for increasing motivation, performance, and enjoyment (Tauer & Harackiewicz, 2004).

Additionally, the significant findings regarding goal progress suggest that the collaborative process involved in working one-on-one with counselors may have been effective in promoting gains toward individual goals. Therefore, this idea may be

“borrowed” from the goal component of the intervention with the intention of increasing effectiveness of the group treatment component. For instance, a peer mentorship component could be incorporated whereby lower functioning campers are paired with higher functioning campers who serve as mentors with regard to spina bifida-related and social issues. Those campers who are more comfortable interacting with others on a one-on-one basis may be more able to benefit from intervention provided in the context of a mentorship relationship than in the context of a group treatment. Findings from cognitive ability assessments may be used to inform partnerships such that higher functioning participants can model social skills for lower functioning campers. Furthermore, as peer modeling has been established as an effective means for producing behavioral change – especially when models are perceived as similar to observers (Bandura & Walters, 1963; Bandura, 1986; Schunk, 1987; Werts, Caldwell, & Wolery, 1996) – this type of partnership is likely to be effective in promoting progress.

With regard to evaluation of group variables, findings from the current study suggest a need for measures that more aptly capture the flavor of the group interaction. In light of previous research highlighting the importance of cohesion (Yalom, 1995), the lack of significant results detected with regard to this construct raises questions regarding its measurement in the current study. For instance, the questionnaire employed was a measure of *perceived* cohesion, and relied on camper-report. It’s possible that relatively objective measures may be more revealing with regard to the relationship between group cohesion and outcomes. Similarly, it may be that individuals are not well-suited to report on group variables. Instead, group treatment sessions may be recorded, coded for group interactions, and analyzed systematically. A structured observational system such as the

Systemic Multiple Level Observation of Groups (SYMLOG) (Bales & Cohen, 1979) could be used to provide a more objective perspective, while capturing the gestalt of the group. This type of measure would encapsulate overall interactions among all members of the group - and throughout all sessions of the week - thereby reducing method biases discussed previously. Such measures would allow for the analysis of a true group variable in terms of its impact on treatment outcome. Insofar as the current research focused on “person-centered analyses” whereby characteristics of participants and participant perceptions were used to predict outcomes, future researchers may employ “group-centered analyses” whereby characteristics of the group are analyzed in terms of their relation to individual and group outcomes.

Alternatively, group variables may be measured another way. Although data derived from the sociometric measure employed in the current evaluation was deemed invalid due to observations made during administration and the quality of the data collected, some other version of a sociometric measure may be employed during future sessions. In particular, sociometric measures of group standing may be adapted to accommodate the cognitive deficits associated with this spina bifida. For instance, measures that include pictures of peers have been used in samples of young children and have been effective in overcoming memory problems that might interfere if completion relied on name recognition alone (McCandless & Marshall, 1957; Asher, Singleton, Tinsely, Hymel, 1979).

Lastly, future evaluation efforts should feature control groups such that alternative explanations regarding participant change may be eliminated and causal conclusions can be drawn. This type of undertaking could involve multi-site studies whereby outcomes

derived from participants in the Camp Ability intervention are compared to outcomes obtained from participants who attend similar camp programs that do not feature an intervention component. Alternatively, within the context of Camp Ability, participants could be assigned to a “no treatment control condition.” These campers would partake in all camp activities with the exception of the intervention, and then would be compared to those participants who did partake in the intervention. This would allow for a better understanding the impact of the intervention as compared to the general camp experience. Finally, Camp Ability participants could take part in only one component of the intervention (e.g., group treatment sessions or individual goal component). This would enable researchers to identify those components of the intervention that are most highly associated with positive outcomes. Identification of these factors would allow for more efficient use of intervention resources (Kazdin & Weisz, 1998).

“It Takes a Village:” More Emphasis on Integration of Systems

It is a tenant of community psychology that the most effective interventions are those in which an individual’s entire system is involved. Research supports this notion in general child and adolescent populations (Koocher & Pedulla, 1977; Kazdin & Weisz, 1998; Kazdin, 2004) and in populations of young people with chronic health conditions (Satin et al., 1989; Kazak, 1992; Spirito & Kazak, 2005; Stark et al., 1994; Quittner, Drotar, Iveres-Landis, Slocum, Seidner, & Jacobsen, 2000; Wysocki et al., 1999).

Findings from the current research suggest that campers who made significant progress toward healthcare goals throughout the week at camp lost some of these gains upon returning home. These losses suggest a need for greater systemic support of skill transfer and maintenance. This type of shift would necessarily increase the intensity (i.e.,

“dose”) of the intervention in an effort to maximize positive change. Although it stands to reason that “higher strength” treatments would be more effective in maximizing positive outcomes, few studies test variations of treatment strength (Kazdin, 2005). However, in the small pool of studies related to interventions for young people with chronic health conditions, longer-term, higher-intensity interventions do seem to be associated with positive outcomes (Andrade, 1990; Engleman et al., 1994; King et al., 1997).

There are several ways by which greater systemic support may be promoted in the context of a camp intervention. These include changes made in the camp, family, school, and medical domains, and are discussed in the section that follows.

Camp System. A true camp independence intervention would not merely take place within the context of a camp, it would involve the entire camp system such that all camp activities are aimed toward actively targeting autonomy-related skills, and all camp personnel are invested in promoting autonomy gains. In this way, intervention aims would be incorporated seamlessly into the general camp structure.

This type of approach would serve to increase the intensity of the intervention, as targeted skills would be taught and rehearsed not only during the one-hour long intervention sessions, but throughout the entire camp day. For example, camper demonstration of targeted social skills would be monitored by counselors during camp activities, and immediate feedback would be provided. In this way, the intervention sessions would become the context in which skills practiced throughout the day are taught and rehearsed in an explicit and concerted effort; however, observation, monitoring, and reinforcement would occur throughout the entire camp day. One model for this type of integrated program is the Summer Treatment Program, whereby

individualized treatment strategies are applied continuously, camper behavior is monitored throughout the camp day, and campers are provided with feedback regularly (Pelham & Fabiano, 2008; Pelham et al., 2005).

Family System. Another way of maximizing intervention effectiveness is to incorporate parents into the program as has been done in camp interventions for children with ADHD (Pelham, Fabiano, Gnagy, Greiner, & Hoza, 2005; Pelham & Fabiano, 2008) and interventions for young people with diabetes (Satin, LaGreca, Zigo, & Skylar, 1989; Wysocki et al., 1999; Anderson, Brackett, & Laffel, 2000), cystic fibrosis (Stark, Powers, Jelalian, Rape, & Miller, 1994), and obesity (Marcus, Levine, Kalarchran, & Wisniewski, 2003). This type of involvement is likely to facilitate skill transfer and prevent the loss of gains post-intervention.

Research suggests that parent involvement is an essential feature shared among successful intervention programs (Kazak, 2002; Kazak & Clarke, 1986). The Summer Treatment Program, for example, is notable for its weekly training program in which parents are taught to reinforce changes made at camp such that positive changes can be transferred and maintained (Pelham et al., 2005). Other interventions that have demonstrated positive outcomes include a family component as well (Satin et al., 1989; Wysocki et al., 1999; Quittner, 2000; Anderson et al., 2000, Stark et al., 1994; Marcus et al., 2003).

While the notion of a parent training component at an overnight camp designed for a sample characterized by considerable variation in age and functioning raises numerous theoretical and practical questions, several parents in the current sample expressed the wish to be involved in the intervention on *Feedback Forms*. This opinion

was shared by some campers in the context of focus groups, who cited a need for parent-training. Thus qualitative reports suggest that some parents are interested in being included in the Independence Intervention, and some campers would be supportive of their inclusion. More systematic research is needed to gauge parents' interest in - and commitment to - becoming involved in the intervention. Campers' opinions would be important to consider as well.

Provided that participants would be agreeable to increased parent involvement, there are several ways by which parents may be included in the intervention. For instance, they may be included in the context of psychoeducation sessions provided during camper "drop-off" on the first day of camp, and then again during camper "pick-up" on the last day of camp. This second session may be used to inform parents about their camper's progress toward individual goals and provide concrete strategies for maintaining progress upon returning home. To increase motivation and commitment related to goal maintenance, interventionists could facilitate a discussion between campers and parents regarding how they will work together to ensure that campers continue to make progress. Additionally, interventionists could follow-up with phone-calls to family homes to monitor progress and provide guidance as needed.

School System. Although involving schools in a summer camp intervention may seem to be an ambitious undertaking, it is not necessarily so. Importantly, school involvement need not be complex or burdensome to teachers. It may instead be as simple as reaching out and making contact with teachers or guidance counselors to make them aware of individual students' goals and progress. For instance, summaries of intervention goals, progress, and challenges encountered throughout the camp week could be sent to

teachers or guidance counselors. Many of the campers in the current sample are likely to have special education services in place due to classifications of “orthopedically impairment,” learning disabilities, etc. Therefore, a summary of intervention aims could be incorporated into campers’ individualized education plans. This simple outreach effort would make teachers aware of the issues involved in a camper’s autonomy development and would provide them with the opportunity to reinforce desirable behavior. This outreach effort would also serve the purpose of modeling for parents the importance of advocating for their children through an open dialogue with school personnel.

Medical System. As discussed previously, the medical system is an important one for young people with chronic health conditions such as spina bifida. Establishing a “network of care” for young adults with spina bifida has been called “the greatest challenge in Medicine today” (Bowman, McLone, Grant, Tomita, & Ito, 2001). Although medical issues were addressed implicitly in the intervention manual, more time and concrete instruction regarding navigation of medical systems is essential for this population. These ideas are discussed in more detail in the following section (i.e., *Increasing Spina Bifida-Specificity and Developmental Appropriateness*).

In terms of the evaluation of the Independence Intervention, input from medical professionals would be a valuable addition to future research. Findings from the current study suggest a need for such information as much of the data regarding medical variables (e.g., lesion level, type of spina bifida) was left blank, thereby making it difficult to consider variables such as medical severity. Data collected from medical professionals or from medical chart review would help alleviate this problem.

Increasing Spina Bifida-Specificity and Developmental Appropriateness

In order for future interventions to be truly spina bifida-specific and developmentally-informed, several gaps in the current intervention must be addressed. In particular, the 2008 curriculum did not feature a component on the transition from pediatric healthcare to adult healthcare. This issue is pressing for adolescents and young adults who are in the process of negotiating the shift from pediatric to adult care clinics, and demands a place in future curricula. The reason this issue is so vital to this cohort of young people with spina bifida is that this is the first cohort to have survived into adulthood. This presents a systemic problem in healthcare because most adult-care physicians lack experience in dealing with issues unique to spina bifida. Although adult physicians will eventually gain facility with spina bifida management, at present, the onus is on individuals with spina bifida to present to healthcare facilities with a working knowledge of the problems associated with their condition, and the ability to articulate this knowledge to medical staff such that needs are attended to in a timely manner. While this may be seen as a burden for patients to carry, it may also be viewed as an opportunity for autonomy development. As such, it is a critical issue that would be well-suited to discussion as part of an Independence Intervention.

Because skills related to medical care are so vital to autonomous functioning for people with spina bifida, future curricula may include exercises designed to facilitate this transition. Content included in this module should address not only the practical components involved in transitioning (e.g., communicating about spina bifida), it should also present the opportunity to discuss the emotional issues surrounding this transition.

This is a matter that should not be underestimated, as many young people with spina bifida express emotional attachments to their pediatricians (McLone & Ito, 1998).

A second developmentally-salient healthcare issue for adolescents and adults concerns the issue of sexual health. Despite the critical nature of this issue, it was not addressed as part of the current curriculum. For instance, the biological changes associated with puberty were not addressed in the adolescent groups. Likewise, sexual relationships were not discussed in the young adult group. These topics inevitably breed value-laden controversies that arise whenever sexual education is discussed (e.g., contraceptive use, abortion), and raise several practical questions (would parents enroll their adolescents in a camp that featured a sex education component?). Future efforts may be directed toward answering these questions and resolving these controversies, as sexual education is a vital component of autonomy development for adolescents and young adults with spina bifida.

Conclusions

The current study is an important step in a larger program of research devoted to the design, implementation, and evaluation of an Independence Intervention for young people with spina bifida. Findings with regard to individual goals were especially promising and suggest that the process of choosing goals and monitoring progress toward them is an effective means of intervention for this population. Likewise, findings indicate that modest outcome measures may be best-suited for evaluation of small-scale, time-limited interventions. In order to maximize benefit from such interventions, future programs should move in the direction of more group-focused, systemic curricula that address the unique needs associated with spina bifida.

APPENDIX
MEASURES

Demographic Information

-
1. Camper gender (*circle one*) Male Female

 2. Camper age: _____

 3. Camper ethnicity (*e.g. Caucasian, African American, Hispanic*): _____

 4. **Your** gender (*circle one*) Male Female

 5. Check the highest level of education that **you** completed:
 1. ___ Some grade school
 2. ___ Finished grade school
 3. ___ Some high school
 4. ___ Finished high school
 5. ___ Business or technical school
 6. ___ Some college
 7. ___ Finished college
 8. ___ Attended graduate school or professional school after college
 9. ___ Received a professional degree
 10. ___ I am currently enrolled in the following: _____

 6. Check the highest level of education that your **SPOUSE / SIGNIFICANT OTHER** completed:
 1. ___ Some grade school
 2. ___ Finished grade school
 3. ___ Some high school
 4. ___ Finished high school
 5. ___ Business or technical school
 6. ___ Some college
 7. ___ Finished college
 8. ___ Attended graduate school or professional school after college
 9. ___ Received a professional degree
 10. ___ S/he is currently enrolled in the following: _____

 7. What is **your** current EMPLOYMENT status? (*please circle one*)
 - a. Full-time homemaker (does not work outside the home)
 - b. Retired
 - c. On disability from work
 - d. Employed part-time
 - e. Employed full-time
 - f. Other (please explain): _____

8. If **you** are EMPLOYED part-time or full-time, please describe your job:
- Where do you work? _____
 - What kind of work do you do? _____
 - How many hours per day do you work? _____

9. What is your **SPOUSE / SIGNIFICANT OTHER's** current EMPLOYMENT status?

(Please circle one.)

- Full-time homemaker (does not work outside the home)
- Retired
- On disability from work
- Employed part-time
- Employed full-time
- Other (Please explain): _____

10. If your **SPOUSE / SIGNIFICANT OTHER** is EMPLOYED part-time or full-time, please describe his/her job:

- Where does s/he work?

- What kind of work does s/he do?

- How many hours per day does s/he work?

11. What is your family's total yearly income? (Please circle one.)

- | | |
|---------------------------|---------------------------|
| 1. Under \$10,000 | 12. \$110,000 - \$119,999 |
| 2. \$10,000 - \$19,999 | 13. \$120,000 - \$129,999 |
| 3. \$20,000 - \$29,999 | 14. \$130,000 - \$139,999 |
| 4. \$30,000 - \$39,999 | 15. \$140,000 - \$149,999 |
| 5. \$40,000 - \$49,999 | 16. \$150,000 - \$159,999 |
| 6. \$50,000 - \$59,999 | 17. \$160,000 - \$169,999 |
| 7. \$60,000 - \$69,999 | 18. \$170,000 - \$179,999 |
| 8. \$70,000 - \$79,999 | 19. \$180,000 - \$189,999 |
| 9. \$80,000 - \$89,999 | 20. \$190,000 - \$199,999 |
| 10. \$90,000 - \$99,999 | 21. Over \$200,000 |
| 11. \$100,000 - \$109,999 | |

Previous Camp Experience Information

- The total number of times camper has attended Camp Ability is ____
(Note: If this is their first year, please put 0)

Spina Bifida Related Information

1. Type of Spina Bifida (*Please circle one*):

Occulta Lypomeningocele Meningocele Myelomeningocele

2. Lesion Level (*Please circle one*):

Thoracic Lumbar Sacral

3. Total Number of Shunt Surgeries _____

4. Ambulation: _____

(*For example: Ankle-foot orthoses, knee-ankle-foot orthoses, hip-knee-ankle-foot orthoses, and wheelchair*)

The SNAP-IV Teacher and Parent Rating Scale
James M. Swanson, Ph.D., University of California, Irvine, CA 92715

For each item, check the column that best describes this CAMPER:

	Not At All	Just A Little	Quite A Bit	Very Much
1. Often fails to give close attention to details or makes careless mistakes in schoolwork or tasks	_____	_____	_____	_____
2. Often has difficulty sustaining attention in tasks or play activities	_____	_____	_____	_____
3. Often does not seem to listen when spoken to directly	_____	_____	_____	_____
4. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties	_____	_____	_____	_____
5. Often has difficulty organizing tasks and activities	_____	_____	_____	_____
6. Often avoids, dislikes, or reluctantly engages in tasks requiring sustained mental effort	_____	_____	_____	_____
7. Often loses things necessary for activities (e.g., toys, school assignments, pencils, or books)	_____	_____	_____	_____
8. Often is distracted by extraneous stimuli	_____	_____	_____	_____
9. Often is forgetful in daily activities	_____	_____	_____	_____
10. Often fidgets with hands or feet or squirms in seat	_____	_____	_____	_____
11. Often leaves seat in classroom or in other situations in which remaining seated is expected	_____	_____	_____	_____
12. Often runs about or climbs excessively in situations in which it is inappropriate	_____	_____	_____	_____
13. Often has difficulty playing or engaging in leisure activities quietly	_____	_____	_____	_____
14. Often is "on the go" or often acts as if "driven by a motor"	_____	_____	_____	_____
15. Often talks excessively	_____	_____	_____	_____
16. Often blurts out answers before questions have been completed	_____	_____	_____	_____
17. Often has difficulty awaiting turn	_____	_____	_____	_____
18. Often interrupts or intrudes on others (e.g., butts into conversations/games)	_____	_____	_____	_____

GOAL BANK

Based on goals identified by campers in previous years at camp, we have come up with a list of goals to help campers name 2 goals to work on during their week at camp. Together, please discuss what goals are important and challenging enough to work on during the entire week at camp.

Please circle one healthcare goal and one social goal below.

Healthcare Goals: Please circle 1 healthcare goal to work on during the week at camp.

Adhere to regular exercise regimen	Take medication without reminders
MACE regularly without reminders	Shower independently
Perform skin checks without reminders	Drink water with meals
Walk to each meal/activity	Practice swimming skills
Perform skin checks without reminders	Adhere to bowel program
Catheterize regularly without reminders	Improve table manners
Catheterize in a hygienic way	Eat more fruits and vegetables
Perform self-care tasks without reminders (For example: Comb hair, brush teeth)	

Social Goals: Please circle 1 social goal to work on during the week at camp.

Greet others appropriately	Initiate conversations appropriately
Ask appropriate follow-up questions during conversation	Stay on topic during conversation
Share personal information appropriately	Change subject appropriately
Ask for help/clarification when needed	Assert self appropriately
Use <i>verbal</i> cues to demonstrate that s/he is listening	Contribute to conversation
Use <i>nonverbal</i> cues to demonstrate that s/he is listening (For example: Eye contact)	Speak clearly and audibly

PROGRESS MONITORING

Please copy the goals that you circled on the previous page.

Although we asked you to identify goals together, please rate the goals independently from each other. In other words, it is okay if parents and campers do not agree as to the degree to which a goal is being reached.

GOAL 1: _____

Rate the degree to which you are currently reaching this goal. (Circle one number.)

- 1 = Not at all reaching this goal
- 2 = Minimally reaching this goal
- 3 = Somewhat reaching this goal
- 4 = Almost reaching this goal
- 5 = Completely reaching this goal

GOAL 2: _____

Rate the degree to which you are currently reaching this goal. (Circle one number.)

- 1 = Not at all reaching this goal
- 2 = Minimally reaching this goal
- 3 = Somewhat reaching this goal
- 4 = Almost reaching this goal
- 5 = Completely reaching this goal

Spina Bifida Independence Survey

Instructions: For each of the following spina bifida skills, please check “YES” if your camper has mastered that skill, “NO” if your camper has not mastered that skill, or “NOT SURE” if you do not know. Mastery of a given skill means that your camper can perform it correctly without any kind of help from another person. Please remember that we are interested in what your camper is able to do and not in what he or she actually does. Try to ignore your camper’s cooperation with treatment as you fill out this survey. If the skill is not relevant to your camper’s medical management, please mark “N/A.” If you are not sure about whether your camper is able to do the skill, please mark “NOT SURE.”

<u>Can your camper:</u>	<u>Yes</u>	<u>No</u>	<u>Not Sure</u>	<u>N/A</u>
1. Recognize symptoms of hydrocephalus/shunt malfunction and tell someone else about it (e.g., headache, change in appetite, deterioration in school performance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Notice changes in health (e.g., weight gain, skin, stool)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Ask for help for health-related issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Identify appropriate professionals for specific problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Arrange for transportation to and from a health care facility if such a clinic visit is necessary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Take medications appropriately (e.g., timing, dose)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Fill prescriptions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Recognize and discard expired medication products	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. State each type of medication he/she uses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. State the reasons why it is especially important for an individual with spina bifida to follow a healthy diet (e.g., bowel functioning)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<u>Can your camper:</u>	<u>Yes</u>	<u>No</u>	<u>Not Sure</u>	119 <u>N/A</u>
11. Identify foods that are important to include in his/her diet (e.g., fiber and calcium-rich foods) and foods to avoid (e.g., chocolate, cheese)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Maintain a healthy diet, including appropriate fluid intake	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Perform a physical exercise routine on a regular basis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Understand the benefits of exercise for an individual with spina bifida	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Maneuver in and out of his/her wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Maintain wheelchair and orthotic devices and use them properly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Dress him/herself independently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Bath him/herself independently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. State different products that may contain latex.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Conduct daily skin checks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Understand why skin care is especially important for individuals with spina bifida (e.g., pressure sores, infection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Protect skin from potential damage (e.g., extreme temperature, cuts)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Recognize skin warning signs (e.g., redness, swelling, fever, blister and sores)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Understand why skin care is especially important for individuals with spina bifida (e.g., pressure sores, infection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Recognize symptoms of a urinary tract infection (e.g., fever, stomach ache, smelly and/or cloudy urine, or blood in urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<u>Can your camper:</u>	<u>Yes</u>	<u>No</u>	<u>Not Sure</u>	<u>120 N/A</u>
26. State catheterization steps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Conduct each catheterization step correctly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Wash hands and genital area before catheterizing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Remember and gather appropriate catheterization equipment (e.g., catheter, lubricant)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Lubricate and hold catheter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Properly insert catheter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Know when and how to remove catheter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Store used catheters properly, in a dry environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Clean, discard, and replace catheters as needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Remember to complete catheterization regularly, every 2-4 hours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Understand the importance of hygiene and how it relates to care of catheterization and bowel management equipment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Recognize bowel warning signs (e.g., diarrhea, constipation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Use suppositories, enemas, stool softeners, and/or laxatives correctly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Understand the importance of a regular toileting time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<u>Can your camper:</u>	<u>Yes</u>	<u>No</u>	<u>Not Sure</u>	121 <u>N/A</u>
40. Clean up after his/herself, if a bowel or urinary accident occurs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Prevent constipation through daily monitoring of stool and bowel functioning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Understand that spina bifida causes the bowel not to work in the same way as in typically developing individuals and that special bowel programs help individuals with spina bifida achieve continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Participate in choosing a bowel program that will achieve continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Learn steps of a bowel program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Carry out steps of a bowel program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Understand the consequences of not following a bowel program (e.g., soiled clothing, social consequences)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Understand health risks of choosing not to do a bowel program (e.g., skin breakdown, increased wetness, shunt malfunction, and colon cancer)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Call a nurse or doctor for help if bowel accidents, diarrhea, or constipation occur.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Sharing of Spina Bifida Management Responsibilities

For each of the following parts of spina bifida care, choose the number of the answer that best describes the way you handled things at home **during the last month**.

CAMPER-Camper took or initiated responsibility for this almost all of the time, by him/herself.

EQUAL-Parent(s) and camper shared responsibility for this about equally.

PARENT-Parent(s) took or initiated responsibility for this almost all of the time.

N/A- Not Applicable. This does not describe a part of your camper's spina bifida care.

Who Has Responsibility?

	<u>CAMPER</u>	<u>EQUAL</u>	<u>PARENT</u>	<u>N/A</u>
1. Remembering day of clinical appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Making appointments with doctors.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Talking with doctors about medical questions and requests (e.g., medication refill).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Explaining absences from school/work to teachers or other personnel.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Telling teachers/supervisors about spina bifida.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Telling relatives about spina bifida.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Telling camper's friends about spina bifida.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Remembering to take medication, as prescribed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Who Has Responsibility?

	<u>CAMPER</u>	<u>EQUAL</u>	<u>PARENT</u>	<u>N/A</u>
9. Checking expiration dates on medical supplies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Taking proper care of my wheelchair and braces.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Wearing orthotics (braces) as prescribed by doctor/physical therapist.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Getting around in wheelchair from place to place inside of the home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Getting around in wheelchair from place to place outside of the home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Getting in and out of wheelchair.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Taking care of basic needs (e.g., bathing, dressing).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Avoiding products that may contain latex, if allergic to latex.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Protecting his/her skin from temperature, textures, and injury.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Conducting daily skin checks.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Taking medications for urinary tract infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Noticing differences in urine that could indicate a urinary tract infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Who Has Responsibility?

	<u>CAMPER</u>	<u>EQUAL</u>	<u>PARENT</u>	<u>N/A</u>
21. Remembering to catheterize regularly, every 2-4 hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Washing hands and genital area before catheterizing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Gathering appropriate catheterization equipment (e.g., catheter, lubricant)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Lubricating catheter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Properly inserting catheter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Draining bladder completely and removing catheter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Cleaning, storing, and discarding catheterization equipment properly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Following a regular physical exercise routine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Remembering to eat foods with lots of fiber and avoiding other foods (e.g., chocolate).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Remembering to drink lots of fluid.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Taking suppositories, enemas, stool softeners, or laxatives as needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Maintaining a regular bowel toileting time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Cleaning up after him/herself, if an accident occurred.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Monitoring bowel functioning by keeping a log.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SSM

Please rate camper with regard to how often s/he demonstrates the following skills in a manner that is appropriate for his/her developmental level.

- | | | | | | |
|--|-------|---|------------------|---|--------|
| 1.) Greets others appropriately | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 2.) Introduces him/herself appropriately | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 3.) Initiates conversations appropriately | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 4.) Stays on topic during conversations | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 5.) Contributes to conversation (i.e., one-on-one) | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 6.) Contributes to conversation in groups | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 7.) Is able to maintain a conversation (i.e., can keep a conversation going) | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 8.) Uses <i>nonverbal</i> cues to demonstrate that s/he is listening (e.g., eye contact) | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 9.) Uses <i>verbal</i> cues to demonstrate that s/he is listening to the person speaking | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |
| 10.) Reads <i>verbal</i> cues accurately | 1 | 2 | 3 | 4 | 5 |
| | Never | | Half of the Time | | Always |

- 11.) Reads *nonverbal* cues accurately (e.g., body language such as gestures)
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 12.) Reads facial expressions accurately
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 13.) Asks appropriate follow-up questions during conversation
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 14.) Disagrees respectfully
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 15.) States opinions clearly
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 16.) Is able to negotiate
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 17.) Is able to compromise
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 18.) Is able to stand up for him/herself
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 19.) Shares personal information appropriately
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 20.) Changes subject of conversation appropriately
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 21.) Asks for help/clarification when needed
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |

- 22.) Ends conversation appropriately
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 23.) Maintains appropriate eye contact
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 24.) Sees things from other peoples' points of view
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 25.) Uses good social judgment
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |
- 26.) Expresses feelings appropriately
- | | | | | |
|-------|---|------------------|---|--------|
| 1 | 2 | 3 | 4 | 5 |
| Never | | Half of the Time | | Always |

Thank you for completing these questionnaires! Apart from the goals questionnaire, we would like to know how independently the camper was in completing the forms. There is no right or wrong answer to this; we understand the campers have different levels of ability to answer questions on their own.

On average, please rate the degree to which you assisted the camper with the questionnaire. (Circle one number.)

- | | | | | |
|--|---|-----------------------------------|---|---|
| 1 | 2 | 3 | 4 | 5 |
| Camper
completed
questionnaires
independently | | We each
contributed
equally | | I completed the
questionnaires for
the camper |

Harter-Ch

Sample Sentence

	Really True For Me	Sort Of True For Me	Sample Sentence	Sort Of True For Me	Really True For Me		
(a)	_____	_____	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T.V.	<u>X</u>	_____
2.	_____	_____	Some kids find it <i>hard</i> to make friends	BUT	Other kids find it's pretty <i>easy</i> to make friends	_____	_____
8.	_____	_____	Some kids have <i>a lot</i> of Friends	BUT	Other kids <i>don't</i> have very many friends	_____	_____
14.	_____	_____	Some kids would like to have a lot more friends	BUT	Other kids have as many friends as they want	_____	_____
20.	_____	_____	Some kids are always doing things with <i>a lot</i> of kids	BUT	Other kids usually do things by <i>themselves</i>	_____	_____
26.	_____	_____	Some kids wish that more people their age liked them	BUT	Other kids felt that most people their age <i>do</i> like them	_____	_____
32.	_____	_____	Some kids are <i>popular</i> with others their age	BUT	Other kids are <i>not</i> very popular	_____	_____

Harter-Adolescent Report

	Really True For Me	Sort Of True For Me	Sample Sentence		Sort Of True For Me	Really True For Me
(a)	_____	_____	Some teenagers like to go to movies in their spare time.	BUT	Other teenagers would rather go to sports events.	<u>X</u> _____
2.	_____	_____	Some teenagers find <i>hard</i> to make friends	BUT	For other teenagers it's pretty easy.	_____ _____
8.	_____	_____	Some teenagers are able to make really close friends	BUT	Other teenagers find it hard to make really close friends	_____ _____
11.	_____	_____	Some teenagers have a lot of friends.	BUT	Other teenagers don't have very many friends.	_____ _____
17.	_____	_____	Some teenagers do have a close friend they can share secrets with	BUT	Other teenagers do not have a really close friend they can share secrets with	_____ _____
20.	_____	_____	Some teenagers are very hard to like	BUT	Other teenagers are really easy to like	_____ _____
26.	_____	_____	Some teenagers wish they had a really close friend to share things with	BUT	Other teenagers <i>do</i> have a close friend to share things with	_____ _____
29.	_____	_____	Some teenagers are popular with others their age	BUT	Other teenagers are not very popular	_____ _____
35.	_____	_____	Some teenagers find it hard to make friends they can really trust.	BUT	Other teenagers are able to make close friends they can really trust	_____ _____

Really True For Me Sort Of True For Me

Sort Of True For Me Really True For Me

38. _____ _____ Some teenagers feel that they are socially accepted. BUT Other teenagers wished that more people their age accepted them _____ _____

44. _____ _____ Some teenagers *don't* have a friend that is close enough to share really personal thoughts with BUT Other teenagers do have a close friend that they can share personal thoughts and feelings with _____ _____

PCS

The following statements refer to how you feel about the “Independence Intervention” you took part in this week at camp. Please read each statement and circle the option that best describes your feelings.

I feel that I belong to this group.

Strongly disagree Slightly disagree Neither disagree nor agree Slightly agree Strongly agree

I am happy to be a part of this group.

Strongly disagree Slightly disagree Neither disagree nor agree Slightly agree Strongly agree

I see myself as part of this group.

Strongly disagree Slightly disagree Neither disagree nor agree Slightly agree Strongly agree

This group is one of the best anywhere.

Strongly disagree Slightly disagree Neither disagree nor agree Slightly agree Strongly agree

I feel that I am a member of this group.

Strongly disagree Slightly disagree Neither disagree nor agree Slightly agree Strongly agree

I am content to be a part of this group.

Strongly disagree Slightly disagree Neither disagree nor agree Slightly agree Strongly agree

SDS

For each group member listed in the first column, check one of the 5 boxes. Please be honest, and remember that your responses will not be shared with anyone.

	1 Would like to have him/her as one of my best friends	2 Would like to have him in my group but not as a close friend	3 Would like to be with him/her once in a while, but not often or for a long time	4 Don't mind him/her being in our group, but I don't want anything to do with him/her	5 Wish he/she weren't in our group
Camper 1					
Camper 2					
Camper 3					
Camper 4					
Camper 5					
Camper 6					
Camper 7					
Camper 8					
Camper 9					
Camper 10					

WHAT DID YOU THINK? – CAMPER REPORT
CAMP ABILITY 2008

We would like to know what your camp experience was like this year. It will help us know what things should stay the same and what things could change next year. This form asks general questions about the camp in one section and questions about your daily Independence Program meetings with [*Interventionist's Name*] in another. Please be honest in your responses, and thank you for completing this form!

Please choose a number from 1 to 5 for each of the following questions.

GENERAL CAMP EXPERIENCE... (NOT the meetings with [<i>Interventionist's Name</i>]).						
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1.	I enjoyed the camp activities.	1	2	3	4	5
2.	I got to do all the things I wanted to do at camp.	1	2	3	4	5
3.	The same activities should be done next year.	1	2	3	4	5
4.	My counselor helped me to get the most out of my week at camp.	1	2	3	4	5
5.	I want to return to camp next year.	1	2	3	4	5
In the space below or on the back of this sheet, write any comments that you have about camp this year. (E.g., Things you liked, thing you didn't like, and what should be done next year.)						
DAILY INDEPENDENCE MEETINGS WITH [<i>Interventionist's Name</i>]...						
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1.	I enjoyed the meetings with _____.	1	2	3	4	5
2.	I felt comfortable with the topics we discussed with _____.	1	2	3	4	5
3.	I wish we had more time for the meetings with _____ each day.	1	2	3	4	5
4.	The meetings with _____ helped me learn more about taking care of spina bifida.	1	2	3	4	5
5.	The meetings with _____ helped me to learn to do things more independently.	1	2	3	4	5
6.	I feel more confident about talking with people because of the things that we did with _____.	1	2	3	4	5
7.	The same activities should be done next year.	1	2	3	4	5
In the space below or on the back of this sheet, please write any comments that you have about the meetings with [<i>Interventionist's Name</i>]. (E.g., Things you liked, thing you didn't like, and what should be done next year.)						

WHAT DID YOU THINK? – PARENT REPORT
CAMP ABILITY 2008

We would like to get your feedback about camp and the independence program this year. It will help us know what things should stay the same and what things could change next year. This form asks general questions about the camp in one section and questions about the independence program in another. Please be honest in your responses, and thank you for completing this form!

Please choose a number from 1 to 5 for each of the following questions.

<i>GENERAL CAMP EXPERIENCE... (NOT the Independence Program).</i>						
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1.	My child enjoyed the camp activities.	1	2	3	4	5
2.	My child got to do all the things he/she wanted to do at camp.	1	2	3	4	5
3.	I think the same activities should be done next year.	1	2	3	4	5
4.	My child's counselor helped him/her to get the most out of the week at camp.	1	2	3	4	5
5.	I want my child to return to camp next year.	1	2	3	4	5
In the space below or on the back of this sheet, write any comments that you have about camp this year (e.g., Things you/your child liked, didn't like, and what should be done next year.)						
<i>INDEPENDENCE PROGRAM</i>						
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1.	My child enjoyed the independence activities with [Interventionist's Name].	1	2	3	4	5
2.	The independence program targeted issues relevant for my child.	1	2	3	4	5
3.	My child seems to have benefited from the independence program.	1	2	3	4	5
4.	I have seen an improvement in my child's level of independence.	1	2	3	4	5
5.	The same independence activities should be done next year.	1	2	3	4	5
In the space below or on the back of this sheet, please write any comments that you have about the independence program (e.g., Things you/your child liked, didn't like, and what should be done next year.)						

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