

ASSESSING COMMUNITY REINTEGRATION IN ADOLESCENTS AND  
YOUNG ADULTS WITH SPINAL CORD INJURY: A DELPHI STUDY

A DISSERTATION  
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY  
IN THE GRADUATE SCHOOL OF THE  
TEXAS WOMAN'S UNIVERSITY

DEPARTMENT OF HEALTH STUDIES  
COLLEGE OF HEALTH SCIENCES

BY  
ROY RIVERA, JR., PT, DPT, CHES

DENTON, TEXAS

MAY 2013

TEXAS WOMAN'S UNIVERSITY  
DENTON, TEXAS


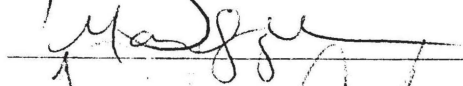
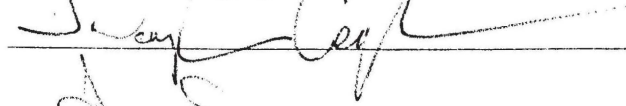
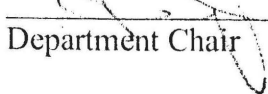
March 22, 2013

To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Roy Rivera, Jr., entitled "Assessing Community Reintegration in Adolescents and Young Adults with Spinal Cord Injury: A Delphi Study". I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Health Studies.

  
Dr. Marilyn Massey-Stokes, Major Professor

We have read this dissertation and recommend its acceptance:

  
  
  
  
Department Chair

Accepted:

  
Dean of the Graduate School

Copyright © Roy Rivera, Jr., PT, DPT, CHES, 2013

All rights reserved.

## ACKNOWLEDGEMENTS

I would like to start off by thanking my angel, my daughter, Isabella for watching her daddy take on his doctoral degree and dissertation from day one. I apologize for all those days that daddy could not play, take you to the park, or on long vacations because his studies got in the way. I also want to thank Jose for being my number one fan and biggest supporter throughout this journey. Together, we have managed to build a home, create a family, and overcome obstacles that would have otherwise been impossible alone.

Undoubtedly, I would have never come this far in my academic career without the love and guidance of my parents, Rogelio and Aidanela. Also, my brother, Fernando, served as a great inspiration to me because I have always strived to be the best role model for him in all that he does. My entire family has been instrumental in my academic, professional, and personal achievements, and I hope this final product makes them very proud.

My dearest friends that have become part of my extended family, thank you for your patience throughout my journey. Your continued support throughout this process means more to me than you might imagine. My dissertation committee, Drs. Massey-Stokes, Coyle, and Parker, has made this final stand challenging and fulfilling.

Last, but not least, I would like to thank God for giving me the health, strength, and will to complete this milestone. Now, the sky is the limit.

## ABSTRACT

ROY RIVERA, JR., PT, DPT, CHES

### ASSESSING COMMUNITY REINTEGRATION IN ADOLESCENTS AND YOUNG ADULTS WITH SPINAL CORD INJURY: A DELPHI STUDY

MAY 2013

The ability for adolescents and young adults (YA) with spinal cord injury (SCI) to reintegrate into the community and become contributing members of society is constantly challenged by both internal and external factors. In acute, sub-acute, and rehabilitative settings, allied health professionals are instrumental in helping these adolescents and YA with SCI reintegrate into the community by providing those physical, emotional, and psychosocial skills necessary for success. The purpose of this study was for a panel of allied health professionals to arrive at a consensus regarding the most effective multidisciplinary approach for helping adolescents and YA with SCI reintegrate into the community.

This study used the Delphi technique and was comprised of physical therapists (PT), occupational therapists (OT), and certified child life specialists (CCLS). The Delphi Panel was initially composed of 31 allied health professionals from various clinical practice settings across the United States; however, only 10 allied health professionals followed the study to completion. The Delphi study utilized three rounds of data collection. Round 1 gathered demographic data on participants and also contained three open-ended questions regarding defining community reintegration, identifying barriers to community reintegration, and the most effective treatment strategies for

community reintegration in adolescents and YA with SCI. For Round 2, participants were asked to rate their collective opinions from Round 1 on a 7-point Likert scale. Round 3 was a consensus and ranking survey of the opinions provided in the open-ended questions from Round 1.

Cain and Mittman's (2002) Diffusion of Innovation in Health Care theory with the ten critical dynamics was used to evaluate the findings. Successful completion of the Delphi study was defined as the group having reached at least 80% consensus with its self-generated ideas. In Round 2, the Delphi Panel reached 92% consensus, and in Round 3, this increased to 92.5% consensus. Findings indicated that the most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community is by providing education for caregivers and others about SCI.

## TABLE OF CONTENTS

COPYRIGHT.....	iii
ACKNOWLEDGEMENTS.....	iv
ABSTRACT.....	v
LIST OF TABLES.....	x
Chapter	
I. INTRODUCTION.....	1
Statement of Purpose.....	3
Research Question.....	3
Theoretical Perspective.....	3
Delimitations.....	4
Limitations.....	4
Assumptions.....	5
Definition of Terms.....	5
Importance of the Study.....	7
II. REVIEW OF LITERATURE.....	8
A Brief History of SCI.....	9
Trends in SCI.....	13
High-risk Behavior.....	15
Psychological Effects of SCI.....	17
Community Reintegration.....	18
Diffusion of Innovations in Health Care.....	23
Relative Advantage.....	24
Trialability.....	24
Observability.....	25
Communications Channels.....	25
Homophilous Groups.....	26
Pace of Innovation/Reinvention.....	27
Norms, Roles, and Social Networks.....	27
Opinion Leaders.....	28
Compatibility.....	28
Infrastructure.....	28

## LIST OF TABLES

Table	Page
1. Expert Panel Member Characteristics.....	49
2. Data Collection Summary.....	50
3. Emergent Themes Related to Community Reintegration for Adolescents and Young Adults with Spinal Cord Injury.....	53
4. Means, Medians, and Standard Deviations for Round 2 Items in Rank Order.....	57
5. Means, Medians, and Standard Deviations for Round 3 Items in Rank Order.....	63
6. Rounds 2 and 3 Comparison for Statistical Significance.....	70
7. Diffusion of Innovation in Health Care.....	80

## CHAPTER I

### INTRODUCTION

According to the Christopher and Dana Reeve Foundation (CDRF) (2011), there are approximately 6 million people in the United States living with paralysis. This is the equivalence of the combined populations of Los Angeles, CA, and Houston, TX, the second and fourth largest cities in the country, respectively (U.S. Census Bureau, 2010). Of these 6 million individuals with paralysis, approximately 23% are living with a spinal cord injury (SCI) (CDRF, 2011). SCI leads to the most devastating type of paralysis and has the potential to permanently affect functional mobility (FM) and quality of life (QOL).

The demographics of SCI have changed over the decades as recorded by the Model Spinal Cord Injury Systems (MSCIS) database. Two populations affected by SCI that are disproportionately distributed are adolescents and young adults (YA) aged 15 to 25. According to the Annual Report for the Spinal Cord Injury Model Systems, adolescents and YA comprise the largest age group with SCI totaling approximately 40% of all SCI cases from 1973 to 2009 (National Spinal Cord Injury Statistical Center, 2009).

Because of modern advances in medical care and availability of resources, trends in life expectancy after SCI demonstrate a reduction of mortality rate by 40% in the first two years post injury (Strauss, DeVivo, Paculdo, & Shavelle, 2006). Krause, DeVivo, and Jackson (2004) took a multifactorial approach and found that combinations of “health, economic, and psychosocial factors may make computations of life expectancy

more accurate” (p. 1764). If individuals with SCI are living longer, it is vital to ensure that QOL is maximized during and after the rehabilitative process so that they are able to reintegrate into the community and become active members of society. Thus, identifying barriers that hinder maximizing QOL in adolescents and YA with SCI is an important public health issue.

Research has shown that pursuing meaningful, self-enriching activities at work, home, and in the community is directly relevant to children’s QOL (Felce & Perry, 1992; Raphael, Brown, Renwick, & Rootman, 1996; Schalock, 1990, as cited in King et al., 2003). Likewise, Law et al. (2006) reported “children with physical disabilities are at increased risk of limitations to participation in everyday activities and [...] participation was less diverse in families with [...] lower-income, single-parent status, and lower respondent parent education” (para. 1). These studies demonstrated that transitioning to community reintegration is multifactorial and requires a multidisciplinary approach.

Adolescents and YA comprise the largest population of those with SCI; therefore, identifying barriers that hinder FM and maximizing QOL in adolescents and YA with SCI is an important public health issue. Addressing community reintegration for this population is vital because it impacts QOL and has a direct influence on physical, psychological, and social development. According to Kennedy, Lude, and Taylor (2006), “very few instruments have been designed to measure social participation comprehensively and even fewer are directly related to the SCI population” (p. 96). Moreover, there is a gap in the literature regarding SCI and community reintegration in this age group that needs to be addressed.

### **Statement of Purpose**

The purpose of this study is for a panel of allied health professionals, including physical therapists (PT), occupational therapists (OT), and certified child life specialists (CCLS), to arrive at a consensus regarding the most effective multidisciplinary approach for helping adolescents and YA with SCI reintegrate into the community.

### **Research Question**

What is the most effective multidisciplinary allied health approach for helping adolescents and YA with SCI reintegrate into the community?

### **Theoretical Perspective**

Cain & Mittman's (2002) adaptation of Everett M. Rogers' classic Diffusion of Innovations theory is the basis for the theoretical perspective in this study on assessing barriers to community reintegration in adolescents and YA with SCI. They describe the Diffusion of Innovations as "the process by which an innovation is communicated through certain channels over time among the members of a social system" (Cain & Mittman, 2002, p. 4).

Cain & Mittman (2002) adapted this philosophy to the modern health care system and developed the Diffusion of Innovations in Health Care (DIHC) theory that contains 10 critical dynamics of innovation diffusion: 1) relative advantage, 2) trialability, 3) observability, 4) communications channels, 5) homophilous groups, 6) pace of innovation/reinvention, 7) norms, roles, and social networks, 8) opinion leaders, 9) compatibility and 10) infrastructure.

### **Delimitations**

The delimitations for this study are as follows:

- 1) The study participants will be PT, OT, and CCLS with clinical practice experience treating adolescents and YA affected by paralysis secondary to SCI.
- 2) The various clinical practice settings represented in this study will include education/school-based facilities, inpatient rehabilitation hospitals, inpatient acute care hospitals, and outpatient clinics.
- 3) The study participants will be responding to survey questionnaires that pertain only to individuals between the ages of 15-25 with medical diagnoses of tetraplegia or paraplegia.

### **Limitations**

The limitations for this study are as follows:

- 1) The study participants will have at least 5 years of experience treating populations with SCI and different levels of education, ranging from undergraduate to post-professional degrees, respective to their professions and licenses/certifications.
- 2) Some participants will not be full-time clinicians practicing direct patient care.
- 3) The study participants will have a limited amount of time to respond to each survey round.
- 4) The study participants will represent a non-random sample of convenience drawn mostly from SCI and neurorehabilitative specialists; therefore, the results may not be generalized to other medical populations.

### **Assumptions**

The assumptions for this study are as follows:

- 1) The study participants will make no distinction between complete and incomplete SCI when they respond to survey questions.
- 2) Per American Spinal Injury Association (ASIA) assessment guidelines, the study participants will make no distinction between SCI classifications pertaining to the level of injury when responding to survey questions (ASIA, 2011).
- 3) The study participants will have access to their email both at home and work.
- 4) Based on their own professional experiences, the study participants will respond to the survey questions honestly and to the best of their abilities.

### **Definition of Terms**

- 1) Community reintegration: Broadly defined, community reintegration is “acquiring/resuming age-gender-culture appropriate roles/statuses/activities, including independence/interdependence in decision making and productive behaviors performed as multivaried relationships with family, friends, and others in natural community settings” (Dijkers, 1998, p. 5, as cited in Anderson, Krajci, & Vogel, 2003, p. 129.)
- 2) Formal activities: Formal activities are structured, extracurricular and often involve a coach or leader, e.g., youth groups, sports teams, music lessons, etc.
- 3) Informal activities: Informal activities are unstructured and usually initiated by the adolescent or YA, e.g., going to the movies, church, reading books, etc.

- 4) Paraplegia: Paraplegia is defined as a condition when “the level of SCI occurs below the first thoracic spinal nerve” (Apparelyzed, 2011, para. 4). It is important to note that individuals with paraplegia have full use of their arms and hands.
- 5) Participation: Participation is the involvement in formal or informal activities in adolescents and young adults outside of school or learning environments.
- 6) Quality of life (QOL): QOL as it relates to adolescents and YA is the “perception and evaluation of performance in relative life areas and its feeling related to problems in functioning [...] such as physical function, psychological state, social interaction, and somatic sensation, or cognitive, social, physical and emotional functioning” (Davis et al., 2006, p. 315).
- 7) Spinal cord injury (SCI): SCI is “the occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina), resulting in temporary or permanent sensory and/or motor deficit [...] and excludes intervertebral disc disease, vertebral injuries in the absence of spinal cord injury, nerve root avulsions and injuries to nerve roots and peripheral nerves outside the spinal canal, cancer, spinal cord vascular disease, and other non-traumatic spinal cord diseases” (National Spinal Cord Injury Statistical Center, n.d., para. 1).
- 8) Tetraplegia: Tetraplegia, also known as quadriplegia, is an “SCI above the first thoracic vertebra in which paralysis usually affects the cervical spinal nerves resulting in paralysis of all four limbs” (Apparelyzed, 2011, para. 3).

### **Importance of the Study**

Examining how a multidisciplinary team of allied health professionals view successful community reintegration in adolescents and YA with SCI will help aim future health education efforts to enhance participation in age-appropriate activities and QOL. Multidisciplinary collaboration is essential to maximize access to resources in this particular population. Collaborative relationships among health educators and allied health professionals such as PT, OT, and CCLS can bridge a significant gap that currently exists in helping adolescents and YA with SCI move from being homebound to successfully reintegrating into the community.

Obtaining input from allied health professionals who work directly with adolescents and YA with SCI will yield greater objectivity in terms of defining and identifying barriers to successful community reintegration of adolescents and YA without the influence of patient or caregiver biases, such as financial resources, emotional distress, challenges to obtaining durable medical equipment, etc., that could cloud the picture. Furthermore, a multidisciplinary definition of successful community reintegration is vital in developing goals, objectives, and strategies to address barriers.

Identifying and prioritizing barriers to successful community reintegration will provide valid information for setting measurable rehabilitative goals and objectives to allow for optimum use of health care resources and participant time in therapies as well as formal and informal activities. In turn, health educators can use this information for planning, implementing, and evaluating health promotion programs aimed at fostering successful community reintegration in adolescents and YA with SCI.

## CHAPTER II

### REVIEW OF LITERATURE

An SCI is “the occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina), resulting in temporary or permanent sensory and/or motor deficit [...] and excludes intervertebral disc disease, vertebral injuries in the absence of spinal cord injury, nerve root avulsions and injuries to nerve roots and peripheral nerves outside the spinal canal, cancer, spinal cord vascular disease, and other non-traumatic spinal cord diseases” (National Spinal Cord Injury Statistical Center, n.d., para. 1). The two most common manifestations characteristic of a SCI are conditions known as paraplegia and tetraplegia.

Paraplegia is defined as a condition when “the level of SCI occurs below the first thoracic spinal nerve” (Apparelyzed, 2011, para. 4). Because the level of the lesion occurs below the first thoracic nerve, individuals with paraplegia often have limited to full use of their upper extremities, including shoulders, forearms and hands. They can present with sensory, motor, or sensorimotor deficits preventing them from independent ambulation.

Tetraplegia, also known as quadriplegia, is an “SCI above the first thoracic vertebra in which paralysis usually affects the cervical spinal nerves resulting in paralysis of all four limbs” (Apparelyzed, 2011, para. 3). Because the level of the lesion is above the first thoracic vertebra, individuals with tetraplegia have either limited or no use of

their upper extremities and no use of their lower extremities. Often, these individuals can control the muscles of the head, neck, and face, although each individual case is unique.

Apart from sensory and motor deficits, individuals with SCI often experience a condition known as neurogenic bladder. Neurogenic bladder is defined as a condition in which a person lacks bladder control usually due to a brain, spinal cord, or nerve pathology (A.D.A.M. Medical Encyclopedia, 2012). Neurogenic bladder can be a potentially life-threatening condition if left untreated; however, recent advancements in medical technology, such as antibiotics, anticholinergic medications, catheterization, and surgical procedures, have “enhanced social continence and QOL and have prevented many of the complications that previously shortened life” (Donovan, 2007, p. 93).

### **A Brief History of SCI**

The documented history of SCI is more abundant in recent years; however, the earliest documented evidence of an individual with SCI can be found in the Edwin Smith surgical papyrus that dates back to approximately 2,500 B.C. (Donovan, 2007). According to Donovan (2007), the scroll was purchased in 1862 by an American Egyptologist, Edwin Smith, in Luxor, Egypt, and then translated by one of his colleagues. This particular document “contains descriptions of 48 traumatic cases, 6 involving the cervical spine, and 2 of those 6 are clearly injuries to the spinal cord” (Donovan, 2007, p. 85). The author of this script is thought to be Imhotep, the world’s first noted architect and physician, whose best-known writings were medical texts (New World Encyclopedia, 2008). Imhotep had no recommendations for the treatment of the two SCI cases in which he described as “an ailment not to be treated” (Donovan, 2007, p. 85).

This attitude towards SCI in the medical community has persisted even into more modern times. Documentation of the lives of some more recent historical figures who have suffered from SCI also proves that there was little to be done.

1. Lord Admiral Sir Horatio Nelson (1758–1805) was a British naval hero who lost his life at the battle of Trafalgar on October 20, 1805 from a sniper's bullet that entered his chest and spinal cord (Donovan, 2007). Upon being examined by the surgeon, Lord Nelson had no motion or feeling below his chest, and the surgeon was quoted as saying, "My Lord, unhappily for our country, nothing can be done for you" (Donovan, 2007, p. 86).
2. James A. Garfield (1831–1881), the 20th President of the United States, was shot by a delusional religious fanatic less than four months into his term (New World Encyclopedia, 2008). The bullet lodged into his conus medullaris, the terminal end of the spinal cord, resulting in paralysis of his legs and bowel and bladder functions. He eventually died 80 days later from complications secondary to his SCI (Donovan, 2007).
3. General George Patton (1885–1945), the commander of the United States' Seventh and then the Third Army during World War II, was involved in a motor vehicle crash only months after the conclusion of war in Europe and sustained a cervical SCI (Donovan, 2007). General Patton had knowledge on the condition and thus "refused all treatment and was reported to have died from a cardiovascular complication while still hospitalized" (Donovan, 2007, p. 86).

These examples help illustrate that Imhotep's precise description of SCI as "an ailment not to be treated" in roughly 2,500 B.C. held to be true in the more modern 19<sup>th</sup> and 20<sup>th</sup> centuries. It is worth noting, however, that documentation of SCI over time has significantly improved.

In 1936, the first SCI unit in the United States was founded in Boston City Hospital by Donald Munro (1898–1978), a neurosurgeon also known as the "father of paraplegia" who refused to accept the defeatist attitudes that surrounded the medical management of SCI (Eltorai, 2002, & Silver, 2005, as cited in Donovan, 2007). Munro's treatment approach was unique at the time in that he compartmentalized and addressed the whole person in multiple dimensions, such as neurological, urological, orthopedic, psychological, and social components. In addition, Munro was vital in coordinating rehabilitation efforts to improve self-care, mobility, and community reintegration, including educational and vocational pursuits (Donovan, 2007). This was not received well by his equally-educated and experienced colleagues; however, the success of his approach served as a model for future efforts.

In 1983, the University of Alabama (UAB) at Birmingham's Department of Rehabilitation Medicine received federal grants to establish a national SCI data reporting center, which has now become the world's largest SCI database (NSCISC, 2010). There are presently 14 SCI Model Systems (SCIMS) and four follow-up centers that assist in collecting and contributing data and statistics to the database. These model systems report demographics from age at time and cause of injury to longitudinal outcomes like

mortality. Studying these demographics helps to paint a bigger picture for the researcher and can help guide efforts for prevention and treatment.

The active SCIMS are the following: 1) Alabama – UAB SCI Care System at UAB Spain Rehabilitation Center, 2) Colorado – Rocky Mountain Regional SCI System at Craig Hospital, 3) Georgia – Georgia Regional SCI System at Shepherd Center, 4) Illinois – Midwest Regional SCI Care System at Rehabilitation Institute of Chicago, 5) Massachusetts – New England Regional SCI Care System at Boston University Medical Center, 6) Michigan – University of Michigan SCI Model System at University of Michigan Medical Center, 7) New Jersey – Northern New Jersey SCI System at Kessler Institute for Rehabilitation, 8) New York – Mount Sinai SCI Model System at Mount Sinai Medical Center, 9) Ohio – Northeast Ohio Regional SCI System, 10) Pennsylvania – Regional SCI System of Delaware Valley at Thomas Jefferson University Hospital, 11) Pennsylvania – University of Pittsburgh Model System on SCI at University of Pittsburgh, 12) Texas – Texas Regional SCI System at TIRR Memorial Hermann, 13) Washington – Northwest Regional SCI System at University of Washington, and 14) Washington, DC – National Capital SCI Model System at National Rehabilitation Hospital.

The follow-up centers are the following: 1) Arizona – St. Joseph’s Medical Center, 2) California – Santa Clara Valley Medical Center, 3) Missouri – University of Columbia, and 4) Virginia – Medical College of Virginia (NSCISC, 2010).

## **Trends in SCI**

Although the population of those affected by SCI is diverse, there are common trends in those injured. Those at highest risk for experiencing SCI are males between the ages of 16 and 30 (Brain and Spinal Cord, 2011). Since 1973, the average age at the time of injury for individuals with SCI has increased from 29 years old ( $SD \pm 14$  years) to approximately 34 years old ( $SD \pm 16$  years), with males comprising 81% and females 19% of those affected (NSCISC, 2010). Caucasians comprise 67%, African Americans 23%, Native Americans 1%, Asian 2%, and others/unknown 7% of those individuals affected by SCI (NSCISC, 2010). Common risk factors for SCI onset include gender, age, race, and alcohol-intoxication (Krause, 2010).

A report by the CDRF (2011) indicated that paralysis appeared to be disproportionately distributed among African Americans and Native American minority communities when compared to a sample from the U.S. Census. The percentage of African Americans who reported having an SCI was approximately 16%, whereas the percentage of African Americans in the U.S. Census was approximately 12%. Also, the percentage of Native Americans who reported having an SCI was approximately 7%, whereas the percentage of Native Americans in the U.S. Census was approximately 1%. However, the percentage of Hispanics who reported having an SCI was approximately 13%, whereas the percentage of Hispanics in the U.S. Census was approximately 15% (CDRF, 2011). The percentage of Asian-Americans who reported having an SCI was not included in the report; however, the percentage of Asian-Americans that report suffering from some type of paralysis is approximately 0.3% (CDRF, 2011).

This same report concluded that the average household income for individuals with SCI is heavily skewed towards lower income brackets and significantly lower than the household income averages for the country as a whole (CDRF, 2011). A staggering 50% of individuals with SCI reported an average household income level of less than \$20,000; yet, according to the U.S. Census, the percentage of average households making less than \$20,000 is 22% (CDRF, 2011). Income plays an important role in the medical management of SCI because these conditions are very expensive to treat. Without the proper resources for acquiring medical treatments, equipment, and therapies, outcomes for survival and successful community reintegration are poor.

The leading causes of SCI have changed drastically over the years; whereas SCI secondary to violence has decreased as a result of decreased crime in the United States, SCI secondary to falls has increased as a result of an increase in the aging population (Jackson, Dijkers, DeVivo, & Poczatek, 2004). Motor vehicle accidents (MVA) remain the highest etiology for SCI (Lammertse, Jackson, & Sipski, 2004). NSCISC (2010) lists the top five injuries resulting in SCI as the following: 1) Auto accidents (34%), 2) Falls (21%), 3) Gunshot wounds (16%), 4) Diving accidents (6%), and 5) Motorcycle accidents (6%). It is also of interest to note that of all the documented SCI cases in the present database, approximately 10% are work related. The top five job census codes at time of SCI are the following: 1) precision production craft and repair (12.1%), 2) professions (8.0%), 3) handlers, equipment cleaners, helpers, and laborers (5.8%), 4) service, except protective and household (5.8%), and 5) executive, administrative, and manager (4.9%) (NSCIS, 2010).

A closer look at the statistics regarding the variable of level of education at time of injury reveals another noticeable trend that warrants attention. The highest levels of education at time of injury are the following: 8<sup>th</sup> Grade or less (9%), 9<sup>th</sup>-11<sup>th</sup> Grades (24%), High School Graduates or GED (48%), Associates (2%), Bachelors (6%), Masters (1%), Doctorates (1%), and others/unknown (9%) (NSCISC, 2010). These statistics further support that adolescents and YA are at higher risk than any other age groups, with approximately 81% of them acquiring an SCI with a high school level education or less at time of injury.

### **High-risk Behavior**

Risk taking plays a vital role in human behavior and has been the subject of numerous investigations, scholarly analyses, and policy debates (Byrnes, 1998; Slovic, Lichtenstein, & Fischhoff, 1988, as cited in Byrnes, Miller, & Schafer, 1999). Studies of gender differences in harmful risk-taking and antisocial behavior have suggested that male and female adolescents respond differently to situational stressors which may have direct impacts on mental health (Abbott-Chapman, Denholm, & Wyld, 2008).

A meta-analysis of 150 studies comparing high-risk behaviors between males and females revealed that male participants were more likely to take risks than female participants (Byrnes, Miller, & Schafer, 1999). This same study also reported that “males took more risks even when it was clear that it was a bad idea to take a risk [...] and the opposite was true for women and girls; that is, they seemed to be disinclined to take risks even in fairly innocuous situations or when it was a good idea to take a risk (e.g., intellectual risk taking on practice SATs)” (Byrnes, Miller, & Schafer, 1999, p. 378).

Young males were more likely than females to engage in “violent and drug-related antisocial acts such as physical fighting, suspension from school, property offences, damaging property, and being in contact with the criminal justice system” (Vassallo et al., 2002, as cited in Abbott-Chapman, Denholm, & Wyld, 2008, p. 133). Another study of gender differences in adolescent high-risk behavior, particularly drug use, found females were generally more highly monitored by parents than males; and males were more exposed to deviant peers, making them more likely to succumb to peer pressure and participate in those high-risk behaviors (Svensson, 2003, as cited in Abbott-Chapman, Denholm, & Wyld, 2008).

Abbott-Chapman, Denholm, & Wyld’s (2008) intergenerational study between parents and their teenage children concluded that there were significant gender differences with regard to males and underage drinking of alcohol, binge drinking, driving recklessly or speeding in cars, driving when drunk, smoking cigarettes, and watching pornographic videos. Females in their parental sample engaged in these activities far less than their male counterparts and far less than their daughters’ generation (Abbott-Chapman, Denholm, & Wyld, 2008).

The prevalence in high-risk behavior among males over females may contribute to the fact that males comprise 81% and females 19% of those individuals affected by SCI (NSCISC, 2010). It is unfortunate that the at-risk population is young males because human life expectancy rates have increased over the past 30 years, indicating that individuals affected by SCI are living longer. The average life expectancy of an individual acquiring an SCI affecting motor function at any level and resulting in non-

ventilator dependency at age 10 is roughly 62 years, at age 15 is 57 years, and at age 20 is 53 years (NSCISC, 2010). The consequences of SCI are devastating, and individuals and their families are often unable to cope with the physical, emotional, and socioeconomic stressors that accompany paralysis.

### **Psychological Effects of SCI**

After an SCI, individuals who were previously independent with activities of daily living, such as dressing, bathing, feeding, etc., are no longer able to do these things without assistance. Most often, these same individuals are unable to walk without assistance, varying from crutches to power wheelchairs, depending on the level and nature of their injuries. This drastic change in QOL promotes a variety of emotions like fear, anger, hopelessness, helplessness, and depression. Krause, Kemp, and Coker (2000) listed the greatest potential adverse emotional consequence as depression. Krause (1998) reported that an “individual’s subjective well-being will be strongly related to the extent to which he or she successfully adapts to the changes brought about by SCI” (p. 900). It is for this reason that depression is counterproductive to successful rehabilitation and community reintegration.

The new reality of living with a permanent disability, functional dependence, and an increased susceptibility to health complications requires psychological adjustment in order to change the basic framework for feeling, thinking, and behaving (Beck, 1995, as cited in Gontkovsky, Russum, & Stokic, 2006). Gontkovsky, Russum, and Stokic (2006) reported that this psychological adjustment occurs via exposure to new information and experiences, especially through formal education and therapeutic interventions during

acute inpatient rehabilitation. It is at this level of care that allied health professionals like PT, OT, and CCLS are introduced into the plan of care. PT, OT, and CCLS can help individuals with newly acquired SCI to adjust to a different way of life by incorporating their deficits and helping them to maximize their functional mobility.

### **Community Reintegration**

The World Health Organization (WHO) (2011) has defined a disability as an impairment limiting participation in and placing restrictions on activity. The term “disability” is complex in nature because it depicts the “interaction between features of a person’s body and features of the society in which he or she lives” (WHO, 2011, para. 2). However, this definition takes on a different tone for adolescents and YA with SCI because their participation in activities and interactions with society are very different from adults with SCI, especially when addressing FM and QOL. While taking FM and QOL into consideration, the challenge is to clearly define community reintegration for this age group, identify those barriers that prevent successful reintegration, and propose solutions to overcome these roadblocks.

A study by Law et al. (2006) concluded that there are obvious declines in recreational and extracurricular activity participation in children with disabilities when a shift towards socialization as children transition into adolescents should be occurring. As children transition into adolescents, frequency and intensity of participation in activities do not correlate directly with satisfaction of activities (Law et al., 2006). These declines in socialization and participation in recreational and extracurricular activities are due to barriers preventing community reintegration.

Davis et al. (2006) defined FM as “a child’s ability to perform daily activities that are essential to meet his or her basic needs, fulfill roles, and maintain health and well-being” (p. 313) and described QOL as the way a child feels. The WHO gives a more in-depth description for QOL and defines it as “an individual’s subjective perception of their satisfaction across various domains in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (The WHOQOL Group, 1994, as cited in Tsoi, Zhang, Wang, Tsang, & Lo, 2011, p. 21).

The extent to which people engage in FM and pursue their personal goals at work, home, and community is relevant to their sense of significance in everyday life and overall QOL (Felce & Perry, 1992, King, 2001, Raphael, Brown, Renwick, & Rootman, 1996, Schalock, 1990, Woodill, Renwick, Brown, & Raphael, 1994, as cited in King et al., 2003). From childhood to adolescence, participation in formal and informal activities becomes a vital component of socialization and learning for individuals. Formal activities are structured, extracurricular, and often involve a coach or leader, such as youth groups, sports teams, music lessons, etc.; and informal activities are unstructured and usually initiated by the adolescent or YA, such as going to the movies, attending church, reading books, etc.

King et al. (2003) reported that there is little concrete evidence, both qualitative and quantitative, about the main factors responsible for the decreased participation of children and adolescents with disabilities; therefore, they developed a conceptual model of factors affecting the participation of children with disabilities. This conceptual model is comprised of three domains that include community environment, the family, and the

child, and can further be broken down into predictive factors for participation in formal and informal activities. All of the domains and their predictive factors ultimately determine the outcome: participation in formal and informal activities or community reintegration.

The first domain is *environmental* and contains the following predictive factors:

1. Absence of physical and institutional barriers – This factor refers to the “absence of cost restrictions, policy barriers, or physical barriers in the community and to the presence of conveniently-located, accessible facilities as well as positive community attitudes with respect to inclusion” (King et al., 2003, p. 75).
2. Presence of supportive relationships for the child – This factor refers to positive, enabling relationships that the child has created with parents, other adults, peers, and friends.
3. Presence of supportive relationships for the parents – This factor refers to social support systems for parents to include other family members, friends, peers, and neighbors.

The second domain is *the family* and contains the following predictive factors:

1. Absence of financial and time impact on the family – The financial burden that parents take on when caring for a child with a disability can have a direct impact on money available for recreational activities or social events; also, labor intensive ADL routines may hinder the ability of parents to engage in

extracurricular events because there is less time and opportunity to do so (Perrin, 1986, as cited in King et al., 2003).

2. Supportive family demographic variables – This factor refers directly to the parents' education, employment, and family income, which all have been shown to directly influence involvement in formal and informal activities in children with disabilities (Garton & Pratt, 1991, as cited in King et al., 2003).
3. Supportive home environment – This factor refers directly to the “physical, mental, and social well-being of parents, the impact of a child with a disability on the family's social functioning, and how well the family functions as a unit” (King et al., 2003, p. 78).
4. Family preference for recreation – This refers to the willingness of parents to engage in the activity with the child so that they are performing as a unit.

The final domain is *the child* and contains the following predictive factors:

1. Child's self-perceptions of athletic and scholastic competence – This factor relates directly to the child's concept of their athletic and scholastic capabilities, which, in turn, has a direct impact on their self-perception of social acceptance.
2. Child's physical, cognitive, and communicative function – This factor refers to a child's “physical function, overall health, cognitive function, and receptive and expressive language” (King et al., 2003, p. 79). Because involvement in activities can be difficult for a child with a physical disabilities (Lightfoot, Wright, & Sloper, 1999, as cited in King et al., 2003), good function in these areas is

indicative of greater involvement and participation in community activities (Lepage, Noreau, & Bernard, 1998; Sloper et al., 1990, as cited in King et al., 2003).

3. Child's emotional, behavioral, and social function – This factor addresses the way that a child with disabilities interacts with his or her environment on an emotional and behavioral level. Feeling self-conscious or socially awkward can make involvement in activities difficult for a child (Lightfoot et al., 1999, as cited in King et al., 2003).
4. Child's activity preferences – This factor refers to the affinity of children with disabilities to participate in enjoyable activities, both formal and informal, which make them more likely to engage.

There is other supporting evidence concerning the more recent popularity of family-centered versus traditional, professional-centered approaches because the family-centered approach promotes the well-being of children and their caregivers through addressing the priorities of caregivers through well-designed interventions (King et al., 2004, Chiarello et al., 2010, Moberg-Wolff et al., 2010, as cited in Tsoi, Zhang, Wang, Tsang, & Lo, 2011).

The purpose of this model was for it to be used to guide research focusing on children with or without disabilities and for examining the determinants of children's overall participation in recreation and leisure activities or of specific types of participation activities, such as sports or clubs (King et al., 2003). The model's predictive factors can then be beneficial in the rehabilitative process to determine the best

plan of care to help adolescents and YA with SCI successfully reintegrate into the community.

Because allied health care professionals work closely with individuals affected by SCI to help them regain FM and QOL, it is vital that they tailor clinical goals and objectives to the individual's world outside of the rehabilitative setting. Empowering individuals with SCI with the knowledge and resources to transition back into their communities is essential. Defining successful community reintegration for adolescents and YA with SCI will help health professionals identify barriers and then find solutions for overcoming them. A collaborative treatment approach by a team of allied health care professionals can serve to reinforce goals and objectives that might overlap between disciplines. The diffusion and continuity of treatment across disciplines is vital to successful community reintegration.

### **Diffusion of Innovations in Health Care**

Rogers' Diffusion of Innovation theory has historically been defined "as the process by which innovation is communicated through certain channels over time among the members of a social system" (Rogers, 2010, p. 10). It consists of four main elements that include: innovation, communication channels, time, and the social system (Rogers, 2010). This model was adapted by Cain & Mittman (2002) and developed into the Diffusion of Innovations in Health Care (DIHC) theory.

Cain & Mittman's (2002) DIHC contains 10 critical dynamics of innovation diffusion: 1) relative advantage, 2) trialability, 3) observability, 4) communications

channels, 5) homophilous groups, 6) pace of innovation/reinvention, 7) norms, roles, and social networks, 8) opinion leaders, 9) compatibility and 10) infrastructure.

### **Relative Advantage**

Relative advantage is the perception that the benefits of adopting an innovation will outweigh the risks and that the innovation will be better than what it is replacing (Cain & Mittman, 2002). As perception of acquired benefits increases, so does the likelihood that the social group will adopt new innovations. Relative advantage can be conveyed as financial or economic profitability, social worth or prestige, educational value or enrichment, etc.

In the field of SCI and research, there have been a number of technological advancements. For example, the field of robotics is constantly evolving, and exoskeletons are proving to be viable options for increasing FM in individuals with SCI. Mikolajewska & Mikolajewski (2011) described an exoskeleton as a “distinctive kind of robot to be worn as an overall or frame, effectively supporting, or in some cases substituting for, the user’s own movements” (p. 227). The relative advantage of using a robot to stand and ambulate is greater than sitting in a wheelchair and propelling for mobility. Standing increases blood flow to the lower extremities, promotes healthy digestion, and relieves areas of skin pressure and soreness, making the relative advantage quite large to individuals with SCI.

### **Trialability**

Trialability is the ability to use or practice a new idea without having to invest or fully commit to it, thus making it more likely to adopt the innovation if there are positive

outcomes. For example, the aforementioned exoskeletons were first unveiled at rehabilitation conferences across the country. The rehabilitation professionals who attended these seminars and conferences were able to experience first-hand the new technology of robotics. This trialability provided the opportunity to use these particular robots and see them in action without actually investing in them.

### **Observability**

Observability is seeing and witnessing how an innovation works and then acknowledging that it is safe or can positively benefit a particular population, thus making it ideal for adoption (Cain & Mittman, 2002). The more obvious the benefits, e.g. better outcomes, greater functionality, improved performance, the more likely new users will want to adopt the innovation.

In the world of SCI, transportation is often an issue and barrier to community reintegration. Witnessing first-hand the technology of new technology on buses and public transportation systems that can accommodate individuals with SCI would make them more likely to use them. Observing lift equipment place someone into the vehicle would reassure potential users that it is safe and effective, thus making them more likely to use it as well.

### **Communications Channels**

This concept connotes that innovations are a social process, and ideas are diffused from one health care professional to another. Likewise, consumers have also become a large part of the communication channel passage for diffusion of innovations, mostly via the internet (Cain & Mittman, 2002). The internet has “sped up and democratized the

dissemination of medical information [...] and medical literature, traditionally the province of only trained professionals or the most diligent and educated consumer, has become open to all” (Cain & Mittman, 2002, p. 13).

Because the field of SCI is such a specialized field and niche in the rehabilitation community, communications channels are vital. Networking with rehabilitation professionals across the globe is vital for staying current with new ideas and rehabilitative technologies that can benefit individuals with SCI. Even more specialized are the areas of adolescents and young adults with SCI making communications channels particularly relevant.

### **Homophilous Groups**

Homophilous groups describe the similarities that the individuals adopting the innovation possess which will directly affect its speed and diffusion. Innovations will diffuse more readily across homophilous groups versus heterophilous groups (Cain & Mittman, 2002). For example, clinical physicians are generally a homophilous group, whereas health care administrators may be a mix of physicians and administrators without medical backgrounds.

The umbrella of allied health is an example of a homophilous group, regardless of the multiple disciplines that comprise it. PT, OT, CCLS, board certified music therapists (MT-BC) and recreational therapists (RT) are examples of allied health professionals who share similar goals when treating adolescents and YA with SCI.

### **Pace of Innovation/Reinvention**

Pace of innovation and or reinvention address the rate at which an idea evolves or does not evolve as it diffuses through the target community. Various innovations have the ability to evolve rapidly and adopt multiple facets to them, while others remain stale and are not so fast to change or adapt. For example, a product like a wheelchair cushion for a patient with SCI, which is an essential element for maintaining health and skin integrity, can be found in various forms. There are gel, air, water, etc., cushions that all essentially aim to do the same goal, provide pressure relief. However, because the goal is to protect skin integrity in individuals with SCI and various types of cushions are able to do this, the diffusion of innovation moves at a slower pace.

### **Norms, Roles, and Social Networks**

This is the relative idea that the diffusion of innovation is greater when one health care professional has a greater social network with other health care professionals. Ideas are more readily adopted when peers are actively involved in their dissemination and implementation.

Allied health professionals who are actively involved in treating patients with SCI at neurorehabilitation centers are more likely to adopt innovations and pass them onto other neurorehabilitative specialists via media, conferences, etc. This common ground of networking makes the diffusion of innovation easier and more credible to those practicing with target populations.

## **Opinion Leaders**

Opinion leaders are those individuals who directly affect the diffusion of innovations because they have greater media exposure, have higher incomes or education levels, or wider social networks (Cain & Mittman, 2002). They are vital vectors in the transmission of ideas across various forums because of their knowledge, expertise, popularity, or networking abilities.

In his lifetime, Christopher Reeves served as an opinion leader for the field of SCI through research, education, and charity. His celebrity status combined with first-hand experience with a traumatic SCI resulting in tetraplegia led him to be in the limelight insofar as media exposure was concerned. The Reeve Foundation's mission is to cure SCI by funding innovative research and improve the QOL for people living with paralysis through grants, information, and advocacy (CDRF, 2012).

## **Compatibility**

Compatibility can best be described as the ability of an innovation to be compatible with existing technologies or interventions already in place. If the innovation is consistent with the adopter's existing value system, past experiences, and immediate needs, the more likely it is to be integrated (Cain & Mittman, 2002).

## **Infrastructure**

In order for an innovation to be implemented into a culture, there needs to be an existing infrastructure that can support its adoption. For example, in order for individuals with SCI to try new wheelchair technologies, there must be an established relationship

with a PT or OT for recommendation. This individual will most likely be a current patient of the therapist.

## CHAPTER III

### METHODOLOGY

#### **Procedure for Collection and Treatment of Data**

The primary purpose of this study was for a panel of multidisciplinary allied health professionals to arrive at a consensus regarding the most effective clinical approach for helping adolescents and YA with SCI reintegrate into the community. The Delphi technique was selected as the methodology for this mixed methods study. This method is designed to utilize structured group surveying in multiple rounds to gather expert opinion on the target topic and eventually reach consensus. In the final round of surveying, participants were also given an option to provide rationale for their final decisions.

#### **Research Design**

A mixed-methods design was used as the research design for this study. Creswell (2009) defined mixed methods research design as the following:

Mixed methods research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases in the research process. As a method, it focuses on collecting, analyzing, and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches in combination

provides a better understanding of research problems than either approach alone.  
(p. 5).

There are both advantages and limitations to all types of research study design. Because mixed methods data collection involves gathering both quantitative and qualitative data, the limitations of one can neutralize or cancel out the other (Creswell, Clark, Gutmann, & Hanson, 2003). Greene and Clark argued that in the social sciences, because “social phenomena are so complex, different kinds of methods are needed to understand these complexities” (as cited in Creswell, Clark, Gutmann, & Hanson, 2003, p. 211). This allows for a multifaceted approach, view, and triangulation of data to create stronger inferences than using a single, stand-alone method.

### **The Delphi Method**

The Delphi technique is a widely used and accepted mixed-method study design in which the researcher gathers data from a particular sample of participants within their specific domain of expertise with the ultimate goal being consensus or convergence of ideas on a topic. The technique is designed to organize group communication processes which aim to achieve a convergence of opinion on a specific real-world issue where there is an incomplete state of knowledge or lack of agreement (Powell, 2003).

The Delphi method was originated by the RAND Corporation in the 1950s and developed to collect a consensus among a group of experts on a particular topic (Okoli & Pawlowski, 2004). Since its development, there have been a variety of modified methods developed and tested throughout the research literature. Linston and Turoff listed some common characteristics of the Delphi method that are present, even in modified versions,

to include: 1) “feedback of individual contributions of information and knowledge,” 2) “assessment of group judgment or view,” 3) “opportunity for individuals to revise views,” and 4) a “degree of anonymity for the individual responses” (as cited in Okoli & Pawlowski, 2004).

There are three types of Delphi techniques: conventional, real-time or modified, and policy. A conventional Delphi is a classical form in which an initial questionnaire is sent out to a panel of experts and subsequent questionnaires or rounds are based on results of the first (De Villiers, De Villiers, & Kent, 2005). The real-time or modified Delphi is described as a similar process to the conventional method; however, the process takes place during the course of a meeting where the researcher immediately summarizes responses to obtain a conclusion. A policy Delphi is a forum for ideas where an informed group presents options supported by evidence rather than have a group reach a consensus (Clayton, 1997; Crisp et al., 1997, Linstone & Turoff, 1975; Moore, 1987, as cited in De Villiers, De Villiers, & Kent, 2005).

### **Selection of the Expert Panel and Sample Size**

There is presently no set of standards that exist for the selection of Delphi panel participants because each research question is unique to the specific issue being studied (Hsu, 2007). One of the main attributes of a panel is its expertise and or knowledge-ability on a particular topic. Jairath and Weinstein (1994) proposed that participants should be experts in their fields who present current knowledge and perceptions on the particular topic or issue (as cited in Powell, 2003). Jolson and Rossow (1971) found that accuracy increased as rounds progressed with expert groups, but did not increase for

inexpert ones (as cited in Rowe & Wright, 1999). The challenge then becomes identifying expert versus inexpert groups and characteristics. A team of physicians versus college students might be an expert group when discussing a particular medical topic. However, given a change in topic to college football games and predictions, the college students might now be considered the experts. Rowe & Wright (1999) argued the value of the measure of expertise rather than the role of the experts that are being utilized in the Delphi Panel.

Insofar as sample size is concerned, the literature demonstrates a wide range of numbers from 10 to 1685, and “guidance suggests that numbers of participants will vary according to the scope of the problem and resources available” (Delbecq, et al. 1975, Fink et al. 1991, Hasson, et al. 2000, as cited in Powell, 2003, p. 378). Murphy et al. (1998) contended that “there is very little actual empirical evidence on the effect of the number of participants on the reliability or validity of consensus processes” (p. 37). Increasing the sample size of participants is not particularly beneficial because it affects processes within groups, and participation then becomes unequal (Murphy et al., 1998). Delbecq, Van de Ven, and Gustafson (1975) recommended that researchers use the minimally sufficient number of panelists necessary and suggest that 10 to 15 is sufficient if the background of the panelists are homogenous (as cited in Hsu, 2007).

### **Advantages and Disadvantages**

There are both advantages and disadvantages to using the Delphi method for collecting data, and the literature provides extensive reasoning for both. Insofar as advantages go, the nature of electronic communication helps to cut researchers’ costs,

time, and effort in the data collection phase (Fink et al., 1984, as cited in De Villiers, De Villiers, & Kent, 2005). The Delphi method is also ideal for international participation because it is without geographical limitations (De Villiers, De Villiers, & Kent, 2005; Jones et al. 1992, as cited in Powell, 2003). The feedback generated from the various rounds stimulates new ideas and is highly motivating and educational for participants (Pill, 1971, Stokes 1997, as cited in Powell, 2003). Likewise, there is a component of anonymity of participants which allows for decreased bias and increased participation whereby individuals might feel less threatened to report their opinions when they know that other colleagues or peers are not judging them.

One major disadvantage of the Delphi technique is the imposition of preconceptions on respondents (De Villiers, De Villiers, & Kent, 2005). Also, poor techniques of summarizing and presenting the group response by the researcher can be problematic (De Villiers, De Villiers, & Kent, 2005). It is important for the researcher to recognize that the participant is playing a consultative role and not a passive one when responding. The decision of open-ended versus closed questions should be carefully thought out because limiting the participants discourages alternate views and disagreements that could potentially enrich the data collection process (Goodman, 1987, Linstone & Turoff, 1975, as cited in De Villiers, De Villiers, & Kent, 2005). Others have argued that taking a consensus approach leads to watered down versions of the best opinion (Sackman, 1975, as cited in Powell, 2003). These disadvantages can be overcome by encouraging the Delphi panel to provide their opinions or disagreements with the statements made.

## Setting

This conventional Delphi study was conducted via the World Wide Web, and data was collected via *PsychData*, a secure, reliable website designed to meet IRB standards for ethical research and the protection of participant confidentiality via Secure Sockets Layer (SSL) data encryption and Secure Survey Environment (PsychData, n.d.). This internet resource allows the researcher to collect data into one central database without compromising the identity of participants and allowing them to access it whenever it is convenient to them. Participants had the option of using either their work or personal computers to participate, and they were encouraged to use personal computers and home internet access to avoid the possibility of others accessing their information or responses. The researcher used a personal, private password-protected computer and network in a secure office.

Fricker and Schonlau (2002) reported that internet surveys and questionnaires conducted via the World Wide Web are increasingly popular and advantageous because of three assumptions: (1) Internet-based surveys are much cheaper to conduct, (2) Internet-based surveys are faster, and (3) when combined with other survey modes, Internet-based surveys yield higher response rates than conventional survey modes alone. Another advantage is that the internet provides access to unique populations, groups, and individuals who otherwise would be difficult to reach through other channels (Garton, Haythornthwaite, & Wellman, 1999, Wellman, 1997, as cited in Wright, 2005).

Conversely, two main disadvantages that may hamper the use of Internet-based questionnaires in epidemiologic research have been described as: 1) relatively high

nonresponse rates compared with traditional modes of data collection, and 2) concerns regarding the reliability and validity of the data obtained (Van Gelder, Bretveld, & Roeleveld, 2010). Self-selection bias is another major limitation of survey research as some individuals are more likely than others to complete online surveys and questionnaires (Stanton, 1998, Thompson et al., 2003, Wittmer et al., 1999, as cited in Wright, 2005).

### **Population and Sample**

The target population and study participants were initially PT, OT , CCLS, and MT-BC with at least 5 years of clinical practice experience treating adolescents and YA affected by paralysis secondary to SCI. However, after completion of the study, it was discovered that no MT-BC actually participated; therefore, this group was excluded from results and discussion.

PT, OT, and CCLS from health care institutions across the United States were asked to identify the most effective multidisciplinary allied health approach for helping adolescents and YA with SCI reintegrate into the community. The data collection spanned a timeframe from August 3 to October 17, 2012. A timeline of data collection can be seen in Table 2.

The American Physical Therapy Association, American Occupational Therapy Association, and Child Life Council websites were primary resources used to identify clinicians, rehabilitation facilities, and educational institutions that specialize primarily in treatment of the target population. Various websites had direct email and contact information for clinicians, whereas others regarded email addresses as private. Social

media and non-profit organization sites, e.g. Linked In, Facebook, and Christopher and Dana Reeve Foundation, were also used as means to recruit panel members. *PsychData* hyperlinks to Round 1 of the study were placed in online blogs and bulletin boards specifically targeting PT, OT, and CCLS.

The study participants had varying certifications and levels of education, ranging from undergraduate to post-professional degrees respective to their professions and national credentialing requirements. The various clinical practice settings of the allied health professionals participating in this study included education/school-based facilities, inpatient rehabilitation hospitals, inpatient acute care hospitals, and outpatient clinics. Some of the study participants were not be full-time clinicians involved in direct patient care because they were in academic settings. The study participants represented a national non-random sample of convenience drawn mostly from pediatric specialists; therefore, the results were not be generalized to other populations such as adults and older adults with SCI.

Institutional Review Board (IRB) approval through Texas Woman's University (TWU) was obtained prior to initiation of the study (Appendix A), and an invitational email was sent out to various allied health professionals asking for their participation in the study (Appendix B). Inclusion criteria were included in the email, and expectations for participation were also clearly communicated. The researcher encouraged participants to pass the invitation email onto other colleagues or peers who worked closely with adolescents and YA with SCI so as to create a more homogenous sample.

## **Physical Therapists**

The American Physical Therapy Association (APTA) (2012) defined PT as:

Physical therapists are highly-educated, licensed health care professionals who can help patients reduce pain and improve or restore mobility - in many cases without expensive surgery and often reducing the need for long-term use of prescription medications and their side effects (para. 1).

PT must obtain a graduate masters or doctoral degree from an accredited institution in the United States and pass a national board exam before they are allowed to legally practice.

The scope of PT varies, and there are many areas of specialty. The American Board of Physical Therapy Specialties (ABPTS) (2012) offers board-certification in eight specialty areas of physical therapy: 1) Cardiovascular and Pulmonary, 2) Clinical

Electrophysiology, 3) Geriatrics, 4) Neurology, 5) Orthopedics, 6) Pediatrics, 7) Sports, and 8) Women's Health. The ABPTS (2012) established this specialty program “to provide formal recognition for physical therapists with advanced clinical knowledge, experience, and skills in a special area of practice and to assist consumers and the health care community in identifying these physical therapists” (para. 2).

## **Occupational Therapists**

The American Occupational Therapy Association (AOTA) (2012) defines OT as:

Occupational therapists help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations). Common occupational therapy interventions include helping children with disabilities to participate fully in school and

social situations, helping people recovering from injury to regain skills, and providing supports for older adults experiencing physical and cognitive changes (para. 1).

OT must obtain a graduate masters or doctoral degree from an accredited institution in the United States and pass a national board exam before they are allowed to legally practice. The scope of OT varies; and their services include home, workplace, or school assessments, adaptive equipment screening, and family guidance and education. OT are most often recognized for their expertise and attention to a holistic approach in which activities of daily living (ADL) are the focal point for patients (AOTA, 2012).

### **Certified Child Life Specialists**

The Child Life Council (CLC) (2012) defines certified child life specialists as:

Child life specialists are experts in child development, who promote effective coping through play, preparation, education, and self-expression activities. They provide emotional support for families, and encourage optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization. Understanding that a child's wellbeing depends on the support of the family, child life specialists provide information, support and guidance to parents, siblings, and other family members. They also play a vital role in educating caregivers, administrators, and the general public about the needs of children under stress (para. 1).

CCLS are found in a variety of health care settings, and their levels of education range from undergraduate to doctorate. Most health care facilities require a certification in which a national exam must be passed; however, this is not always a requirement.

### **Other Allied Health Professionals**

There are a number of other allied health care professionals who work with the target population of adolescents and YA with SCI. Some of these include music therapists, recreational therapists, and speech language pathologists. As mentioned previously, music therapists were included in the inclusion criteria; however, none actually participated in the study.

### **Protection of Human Subjects**

As previously mentioned, the TWU IRB approved commencement of the study (Appendix A), and the invitation email (Appendix B) contained a hyperlink to the *PsychData* survey website where an IRB approved consent form (Appendix C) was embedded. Potential participants were provided with an explanation and purpose of the research study, a description of the procedures, potential risks, and participation benefits. There was also information regarding contacting the principal investigator, research advisor, and TWU Office of Research and Sponsored Programs.

The principle investigator (PI) explained that there was a potential risk of loss of confidentiality in all email, downloading, and internet transactions. Confidentiality was protected to the extent that was allowed by law. *PsychData* protected each participant's identity and kept his/her information anonymous from the researcher and other participants as well. Participants registered with *PsychData* and provided their email

addresses and a self-generated password. The PI stored this information in a file that was separate from the survey data and accessed it only to resend data for Rounds 2 and 3.

The PI did not make any attempts to match email addresses with survey responses.

The PI downloaded the survey data from *PsychData* to his personal computer for the purpose of data analysis only, with no participant identification. The PI computer and network access was password-protected and also had an assigned password allowing access to *PsychData*. The PI clearly communicated to the participants that the registration data file will be deleted from *PsychData* upon analysis and completion of the study; at that time, the PI will access email addresses in order to send participants a link to the final abstract of the study findings. Any survey results that are presented or published will include only collective responses.

### **Instrument**

Because the Delphi technique does not utilize any specific tool for data collection, the instrument was user-created based on the research question at hand. Since the purpose of this study was for a panel of multidisciplinary allied health professionals to arrive at a consensus regarding the most effective clinical approach for helping adolescents and YA with SCI reintegrate into the community, the initial round of questions targeted defining and identifying barriers to community reintegration. Round 1 of the Delphi study included the following questions (Appendix E):

- 1) How would you define successful community reintegration as it relates to adolescents and YA with SCI?

- 2) In your opinion, what are the most critical barriers to community reintegration in adolescents and YA with SCI?
- 3) In your opinion, what is the most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community?

A demographic questionnaire (Appendix D) was included prior to advancing to the Round 1 questions above in order to determine if the inclusion criteria for data collection was satisfied.

### **Data Collection and Treatment of Data**

The first communication letter that the researcher emailed to participants outlined the purpose of the study, a description of the procedures, potential risks, and participation benefits. A hyperlink to access the *PsychData* website was also included. The email subject was titled, “Call to research! Assessing Community Reintegration in Adolescents and Young Adults with SCI”, and the researcher briefly introduced himself as a TWU doctoral candidate. Once participants completed Round 1 of the study, email correspondence, whether or not they participated in Round 2, continued with those participants up until completion of the study or the end of Round 3. Reminder emails were sent to maximize study participation and discourage attrition.

### **Round 1 – Opinion Generation, Merging, and Classification**

Round 1 sought to gather demographic information on the participants. The demographic form not only sorted inclusion from exclusion criteria but also served to gather education and workforce data. For example, the demographic survey addressed

occupation, sex, age, race, ethnicity, highest degree earned, employment status, and practice setting. Frequency distribution and percentages were calculated for demographic information given the initial small sample size of 31 participants. Once the demographic information was completed, the participants were advanced to another survey where the three aforementioned research questions were provided. The panelists were not given a minimum or a maximum number of characters or words for answering; however, they were encouraged to answer concisely and efficiently in conveying their expert opinions.

At completion of Round 1, all the generated statements were gathered and placed into separate Microsoft Office 2010 Excel spreadsheets by questions and anonymous participant number. Through the process of thematic content analysis, a Microsoft Office 2010 Word document was generated to merge and categorize responses. These themes that recurred were tallied and grouped so as to prevent duplication. A doctoral educated statistician, external to the study and highly experienced in mixed-method designs, provided feedback throughout the thematic content analysis for comparison. All themes were included in Round 2 even if they did not recur so that panelists could critique and determine their significance to the corresponding question. The grammar, wording, and ideas were preserved as much as possible for the development of Round 2.

The 31 panel members who participated in Round 1 generated a total of 161 responses for all 3 research questions. Question 1 contained 16, question 2 contained 12, and question 3 contained 16 themes, respectively, once duplications were merged. Overall, 161 responses were condensed into 44 themes.

## **Round 2 – Likert Scale and Ratings**

Round 2 of the Delphi study involved the panelists' ratings by level of importance for each of the thematic statements generated from Round 1 (Appendix F). The statements were grouped to their specific questions and placed in random order so as not to bias any of the responses. The 7-point Likert scale used for collecting ordinal level data was the following: 1 = Strongly disagree with the statement, 2 = Disagree with the statement, 3 = Somewhat disagree with the statement, 4 = Neither agree nor disagree with the statement, 5 = Somewhat agree with the statement, 6 = Agree with the statement, and 7 = Strongly agree with the statement.

SPSS version 19 was used to analyze the data from Round 2. Measures of central tendency (means and medians) and variation (standard deviations) were calculated for each statement to examine agreement among Round 2 participants. The mean can be defined as the arithmetic average of the set and can be greatly affected by extreme values; therefore, it is accompanied by other measures of central tendency and variation to provide a more complete and accurate description (Columbia University, n.d.). The median is defined as the middle value when observations are ordered from smallest to largest and is insensitive to extreme values (Columbia University, n.d.). The standard deviation is defined as the average amount by which scores in a distribution differ from the mean, ignoring the sign of the difference and can sometimes be defined as the average distance between any score in a distribution and the mean of the distribution (Price, 2000). Agreement with each statement occurred when ratings converged around a mean. When the standard deviation of a statement increased, this was indicative of disagreement

or a greater level of rating dispersion. For example, if the mean of a statement response was 6 and the standard deviation was  $\pm 3$ , then there was disagreement because the responses were widely dispersed. However, the same mean of 6 with a standard deviation of 1 is indicative of greater agreement with the response.

### **Round 3 – Realignment of Responses and Analysis**

Round 3 of the Delphi study involved the panelists' re-ratings by level of importance for each of the statements generated from Round 2 given the means, medians, and standard deviations for each response. The 7-point Likert scale used for collecting ordinal level data was identical to that of Round 2 described above.

SPSS version 19 was used to re-analyze the data from Round 3. Measures of central tendency (means and medians) and variation (standard deviations) were calculated for each statement to examine agreement among Round 3 participants. Because of the small sample size ( $N = 10$ ) and because the data was negatively skewed, potential differences between ratings in Rounds 2 and 3 for each question were examined using non-parametric Wilcoxon Signed Ranks tests.

### **Summary**

This chapter addressed the methods that were employed during the study and identified the mixed-methods research design, setting, population and sample, IRB protection of human subjects, instruments, data collection processes, and treatment of the data. The purpose of this study was for a panel of multidisciplinary allied health professionals to arrive at a consensus regarding the most effective clinical approach for helping adolescents and YA with SCI reintegrate into the community. The Delphi

technique was utilized for structured group surveying in multiple rounds to gather expert opinion on the target topic and achieve consensus.

## CHAPTER IV

### RESULTS

#### **Introduction**

The purpose of this study was for a panel of allied health professionals to arrive at a consensus regarding the most effective multidisciplinary approach for helping adolescents and YA with SCI reintegrate into the community. This study utilized a Delphi Panel of allied health professionals requiring three rounds of data collection. All communication was done electronically via *PsychData*, and each round was analyzed using measures of central tendency and non-parametric Wilcoxon Signed Ranks tests.

#### **Characteristics of Delphi Panel Members**

The initial panel of experts consisted of 31 allied health professionals. Demographic data from these experts was collected during Round 1 of the study. The same participants from Round 1 were invited to participate in two subsequent rounds, with 10 participants choosing to remain in the study for the next two rounds. Demographic information pertaining to the sample for Round 1 and the sample for Rounds 2 and 3 will be reported in this chapter.

For Round 1 of data collection, 28 of the 31 participants chose to provide some demographic information. There was a mean age of 36.93 years ( $SD = 7.77$ , range between 26 and 55 years). As shown in Table 1, there were 28 females (100.0%) and no reported males. For ethnicity, the majority of the sample (96.4%) was not Hispanic or Latino; and for race, the majority of the sample was White (92.9%). For highest degree

earned, the majority of the sample reported having a baccalaureate degree (46.4%), closely followed by Master's degree (39.3%).

With regards to current occupation, 26.7% were PT, 16.7% were OT, 53.3% were CCLS, and 3.3 % were from other occupations. Most participants reported that they worked full time (96.4%), indicating that they worked 35 or more hours per week. Participants reported working at a variety of different facilities: acute care hospitals (28.6%), sub-acute care rehab hospitals (21.4%), health system or outpatient facilities or clinics (14.3%), skilled nursing facilities/extended care facilities (3.6%), home health care (7.1%), academic institutions (7.1%), research centers (3.6%), and other types of facilities (14.3%).

For Rounds 2 and 3 of data collection, 10 of the 31 participants from the initial sample chose to continue their participation. There was a mean age of 37.11 years ( $SD = 7.56$ , range between 28 and 50 years). As shown in Table 1, there were 9 females (100.0%) and no reported males. For ethnicity and race, 100% of the sample was not Hispanic or Latino (i.e., 100% of the sample was White). The most represented highest degree earned reported by the sample reported having a baccalaureate degree (40.0%), followed by Master's degree (20.0%) and Clinical Doctorate (20.0%).

With regards to current occupation, 50.0% were PT, 40.0% were CCLS, and 10.0% were OT. All participants (100%) reported that they worked full time. Participants reported working at a variety of different facilities: acute care hospitals (20.0%), sub-acute care rehab hospitals (20.0%), health system or outpatient facilities or

clinics (20.0%), skilled nursing facilities/extended care facilities (11.1%), academic institutions (20.0%), and other types of facilities (10.0%).

For Round 1, frequencies not summing to 31 and percentages not summing to 100 reflect missing data. For Round 2, frequencies not summing to 10 and percentages not summing to 100 reflect missing data.

Table 1.  
*Expert Panel Member Characteristics*

	Round 1		Rounds 2 & 3	
	Frequency	%	Frequency	%
Sex				
Female	28	100.0	10	100.0
Ethnic Origin				
Hispanic or Latino	1	3.6	—	—
Not Hispanic or Latino	27	96.4	9	100.0
Race				
White	26	92.9	10	100.0
Other	2	7.1	—	—
Highest Degree Earned				
Baccalaureate Degree	13	46.4	4	40.0
Master's Degree	11	39.3	2	20.0
PhD or Equivalent (e.g., EdD, DSc, ScD)	1	3.6	1	10.0
Clinical Doctorate (e.g., DPT, OTD)	2	7.1	2	20.0
PhD (or Equivalent) and Clinical Doctorate	1	3.6	1	10.0
Current Occupation				
Physical Therapist	8	26.7	5	50.0
Occupational Therapist	5	16.7	1	10.0

(Continued)

Child Life Specialist	16	53.3	4	40.0
Current Employment Status				
Full-Time	27	96.4	10	100.0
Part-Time	1	3.6	—	—
Current Facility/Institution				
Acute Care Hospital	8	28.6	2	20.0
Sub-Acute Rehab Hospital (Inpatient)	6	21.4	2	20.0
Health System or Hospital-Based Outpatient Facility or Clinic	4	14.3	2	20.0
Skilled Nursing Facilities/Extended Care Facilities	1	3.6	1	10.0
Patient's Home/Home Health Care	2	7.1	—	—
Academic Institution (Post-Secondary)	2	7.1	2	20.0
Research Center	1	3.6	—	—
Other (Please Specify)	4	14.3	—	—

*Note.* For Round 1, frequencies not summing to 31 and percentages not summing to 100 reflect missing data. For Round 2, frequencies not summing to 10 and percentages not summing to 100 reflect missing data.

Table 2.  
*Data Collection Summary*

Date	Activity	Appendices
8/3/12	Survey placed on <i>PsychData</i> . Site prepared and tested.	-
8/3/12	Email invitations sent to allied health professionals to participate in Round 1.	B
8/3/12 – 8/24/12	Round 1 data collected.	E
8/29/12 – 9/7/12	Round 2 instrument developed. Instrument placed on <i>PsychData</i> .	-

(Continued)

---

9/10/12	Invitations sent to registered Round 1 allied health professionals to participate in Round 2.	G
9/17/12	Reminder email for Round 2.	H
9/10/12 – 9/24/12	Round 2 data collected.	F
9/27/12 – 10/2/12	Round 3 instrument developed and placed on <i>PsychData</i> .	-
10/3/12	Invitations sent to registered Round 1 panelists to participate in Round 3.	J
10/11/12	Reminder email for Round 3.	K
10/17/12	<i>PsychData</i> site closed. Data analysis initiated.	-

---

In Round 1, participating allied health professionals were asked to generate open-ended opinion statements on the following research questions:

- 1) How would you define successful community reintegration as it relates to adolescents and YA with SCI?
- 2) In your opinion, what are the most critical barriers to community reintegration in adolescents and YA with SCI?
- 3) In your opinion, what is the most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community?

Round 1 generated a total of 31 panelists between August 3 and August 24, 2012.

Initially, only 14 days were to be given to each round for data collection; however, the deadline for Round 1 was extended by seven days to allow for a greater preliminary sample size. Demographic data and characteristics of panel members were analyzed using descriptive statistics, and their responses to the research questions above were

analyzed using content analysis. Rounds 2 and 3 resulted in a total of 10 panel members completing the study. These final rounds collected ordinal level data and were analyzed using measures of central tendency and levels of dispersion (i.e., mean, median, and standard deviation).

### **Content Analysis**

Once Round 1 was complete, the data was downloaded from *PsychData* and compiled into three separate Excel spreadsheets by research question. Each research question's individual responses were examined in depth for themes, and categories were created to consolidate any of those that were recurring. A tally was kept for each identified theme to prevent duplication and ensure that all responses and ideas were included. A doctoral educated statistician, external to the study and highly experienced in mixed method designs, provided feedback throughout the thematic content analysis for comparison. All themes were included in Round 2 even if they did not recur so that panelists could critique and determine their significance to the corresponding question. The grammar, wording, and ideas were preserved as much as possible for the development of Round 2 (See Table 3.).

---

Table 3.

*Emergent Themes Related to Community Reintegration for Adolescents and Young Adults With Spinal Cord Injury*

---

Question 1:

Successful community reintegration as it relates to adolescents and YA with SCI means that they...

1. Have a good social support system (i.e. family, friends, and community)
2. Have necessary adaptive equipment/durable medical equipment
3. Are able to go back to school
4. Participate in recreational/leisure and/or group social activities
5. Have an established health care team (i.e. primary physician, neurologist, allied health, mental health)
6. Have few physical/environmental barriers to achieve community mobility
7. Independently complete activities of daily living (ADL)
8. Address social stigmas including bullying and promote public awareness for SCI
9. Achieve self-acceptance of their disability
10. Become successfully employed
11. Live independently
12. Have autonomy with medical decisions
13. Establish a committed relationship
14. Have reliable transportation
15. Become financially secure
16. Have a good bowel and bladder program

Question 2:

The most critical barriers to community reintegration in adolescents and YA with SCI include...

1. Lack of financial support and/or unemployment
2. Physical/environmental barriers including lack of transportation
3. Poor social support systems
4. Dealing with stigmas/biases of disability
5. Poor self-acceptance resulting in depression and inability to cope
6. Lack of adequate adaptive equipment/durable medical equipment

---

(Continued)

- 
7. Decreased autonomy/independence because of overbearing family members wanting to help
  8. Poor advocacy for SCI issues
  9. Inability to finish education
  10. Having to learn bowel and bladder programs
  11. Lack of participation in extracurricular activities
  12. Fatigue with activities

Question 3:

The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...

1. Providing psychosocial support (i.e. support groups, networking with others, and life –long counseling)
  2. Breaking down social barriers (i.e. advocating for SCI)
  3. Role playing for task-specific goal achievement
  4. Attending school visits and/or actively participating in classroom activities
  5. Participating in multi-disciplinary approaches, team meetings, and collaborative work (i.e. co-treatments, consulting social workers)
  6. Providing education for caregivers and others about SCI
  7. Establishing a bowel and bladder program
  8. Providing financial resources
  9. Promoting patient autonomy with health care decisions
  10. Providing transportation resources
  11. Supporting mobility for achieving ADL (i.e. providing wheelchair management clinics)
  12. Providing therapies and treatments in their own environments
  13. Assisting with finding employment
  14. Assisting in their community/environment problem solving
  15. Establishing Life Care Planners to help individuals with SCI navigate associated issues over the lifespan
  16. Effective approach does not exist
-

## **Results**

### **Round 1**

The 31 panel members who participated in Round 1 generated a total of 161 responses for all three research questions. Question 1 contained 16, question 2 contained 12, and question 3 contained 16 themes, respectively, once duplications were merged. Overall, 161 responses were condensed into 44 themes.

### **Round 2**

A total of 10 participants from Round 1 responded to Round 2. During Round 2, participants were asked to rate their agreement with a series of statements generated from the collective responses of allied health professionals during Round 1 of this study. No additional demographic information was obtained during Round 2. On September 10, 2012, registered participants from Round 1 were sent private email invitations to participate in Round 2.

The instrument used during Round 2 reintroduced the statements that were developed during Round 1 to participants in Likert-scale format. There were 16 statements related to the first fill-in-the-blank question: "Successful community reintegration as it relates to adolescents and YA with SCI means that they...". There were 12 statements related to the second fill-in-the-blank question: "The most critical barriers to community reintegration in adolescents and YA with SCI include...". Also, there were 16 statements related to the third fill-in-the-blank question: "The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...". Thus,

participants responded to a total of 44 statements by indicating their agreement with each statement on a 7-point Likert scale (from 1 = *strongly disagree* to 7 = *strongly agree*). SPSS version 19 was used to analyze the data from Round 2. Measures of central tendency (means and medians) and variation (standard deviations) were calculated for each statement to examine agreement among Round 2 participants.

As shown in Table 4, participants expressed overall agreement with statements generated during Round 1 for the first question (i.e., “Successful community reintegration as it relates to adolescents and YA with SCI means that they...”). The highest level of agreement attained was with the statement “have necessary adaptive equipment/durable medical equipment” ( $M = 6.70$ ,  $Mdn = 7.00$ ,  $SD = .48$ ). The lowest amount of agreement attained was with the statement “live independently” ( $M = 4.40$ ,  $Mdn = 4.50$ ,  $SD = 1.26$ ). In fact, the mean score for this statement was just above the midpoint (4), which would indicate that participants neither agreed nor disagreed with the statement.

For the second question (i.e., “The most critical barriers to community reintegration in adolescents and YA with SCI include...”), participants continued to express overall agreement with the statements. The highest level of agreement attained was for the statement “physical and/or environmental barriers, including lack of transportation” ( $M = 6.50$ ,  $Mdn = 6.50$ ,  $SD = .53$ ). There were few statements with which, on average, participants tended to express that they only somewhat agreed, including the following: “decreased autonomy and/or independence because of overbearing family members who wish to help” ( $M = 5.30$ ,  $Mdn = 6.00$ ,  $SD = .95$ ), “inability to finish education” ( $M = 5.30$ ,  $Mdn = 5.50$ ,  $SD = 1.16$ ), “having to learn bowel

and bladder programs” ( $M = 5.30$ ,  $Mdn = 5.00$ ,  $SD = 1.25$ ), and “fatigue with activities” ( $M = 5.3$ ,  $Mdn = 5.00$ ,  $SD = .67$ ). For each of the questions, the general consensus indicated that participants somewhat agreed with the statements.

Finally, participants expressed overall agreement (for the most part) with the statements for the third question (i.e., “The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...”). One exception to this pattern was for the statement “an effective approach does not exist” ( $M = 2.78$ ,  $Med = 2.00$ ,  $SD = 1.79$ ), with which, on average, participants expressed that they somewhat disagreed.

Table 4.  
*Means, Medians, and Standard Deviations for Round 2 Items in Rank Order*

	N	Mean	Mdn	SD	Min	Max
<b>Successful community reintegration as it relates to adolescents and YA with SCI means that they...</b>						
Have necessary adaptive equipment/durable medical equipment.	10	6.70	7.00	.48	6	7
Have established health-care teams (i.e., primary physician, neurologist, allied health, mental health).	10	6.50	6.50	.53	6	7
Participate in recreational/leisure and/or group social activities.	10	6.40	6.50	.70	5	7
Have good social support systems (i.e., family, friends, and communities).	10	6.30	7.00	1.25	3	7

(Continued)

Have few physical/environmental barriers to achieve community mobility.	10	6.30	6.00	.67	5	7
Are able to go back to school.	10	6.20	6.50	1.03	4	7
Have reliable transportation.	10	6.10	6.00	.88	5	7
Have autonomy with medical decisions.	10	6.00	6.00	1.05	4	7
Have good bowel and bladder programs.	10	6.00	6.00	1.05	4	7
Achieve self-acceptance of their disability.	10	5.70	6.00	.95	4	7
Address social stigmas, including bullying, and promote public awareness for SCI.	10	5.40	5.50	1.17	4	7
Independently complete activities of daily living (ADL).	10	5.00	6.00	1.83	2	7
Become successfully employed.	10	5.00	5.00	1.05	3	6
Become financially secure.	10	5.00	5.00	1.05	4	7
Establish committed relationships.	10	4.50	4.00	.97	3	6
Live independently.	10	4.40	4.50	1.26	2	6

**The most critical barriers to community reintegration in adolescents and YA with SCI include...**

Physical and/or environmental barriers, including lack of transportation.	10	6.50	6.50	.53	6	7
Poor social support systems.	10	6.40	6.00	.52	6	7
Lack of adequate adaptive equipment and/or durable medical equipment.	10	6.30	6.00	.67	5	7
Lack of financial support and/or unemployment.	10	6.20	6.00	.79	5	7

(Continued)

Poor self-acceptance resulting in depression and inability to cope.	10	6.20	6.50	.92	5	7
Dealing with stigmas and/or biases of disability.	10	6.10	6.00	.99	4	7
Lack of participation in extracurricular activities.	10	5.80	6.00	1.23	3	7
Poor advocacy for SCI issues.	10	5.40	5.50	1.26	3	7
Decreased autonomy and/or independence because of overbearing family members who wish to help.	10	5.30	6.00	.95	4	6
Inability to finish education.	10	5.30	5.50	1.16	3	7
Having to learn bowel and bladder programs.	10	5.30	5.00	1.25	3	7
Fatigue with activities.	10	5.30	5.00	.67	4	6

**The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...**

Providing education for caregivers and others about SCI.	9	6.78	7.00	.44	6	7
Providing therapies and treatments in their own environments.	9	6.78	7.00	.44	6	7
Assisting in their community/environment problem-solving.	9	6.67	7.00	.50	6	7
Providing psychosocial support (i.e., support groups, networking with others, and life-long counseling).	9		7.00	.73	5	7

(Continued)

Participating in multidisciplinary approaches, team meetings, and collaborative work (i.e., co-treatments, consulting social workers).	9	6.44	6.00	.53	6	7
Establishing bowel and bladder programs.	9	6.44	7.00	.73	5	7
Providing transportation resources.	9	6.44	7.00	.73	5	7
Supporting mobility for achieving ADL (i.e., providing wheelchair management clinics).	9	6.44	6.00	.53	6	7
Breaking down social barriers (i.e., advocating for SCI).	9	6.33	6.00	.71	5	7
Promoting patient autonomy with health-care decisions.	9	6.33	6.00	.71	5	7
The establishment of Life Care Planners to help individuals with SCI navigate associated issues over the lifespan.	9	6.33	7.00	1.12	4	7
Attending school visits and/or actively participating in classroom activities.	9	5.89	6.00	.93	4	7
Assisting with finding employment.	9	5.89	6.00	.93	5	7
Role-playing for task-specific goal achievement.	9	5.78	6.00	.67	5	7
Providing financial resources.	9	5.33	6.00	1.41	2	7
An effective approach does not exist.	9	2.78	2.00	1.79	1	5

---

*Note.* One participant did not evaluate statements related to the third question.

### Round 3 – Statistical Ranking of Mean Scores

A total of 10 participants from Rounds 1 and 2 responded to Round 3. For Round 3, participants were asked to re-rate each statement after observing and considering the group's overall values for means and standard deviations from Round 2. No additional demographic information was collected during Round 3. Measures of central tendency (means and medians) and variation (standard deviations) were calculated for each statement to examine agreement among Round 2 participants.

As shown in Table 5, participants expressed overall agreement with the statements generated during Round 1 for the first question, with the addition of information about the mean, standard deviation, and range of scores from Round 2 for each statement. The highest level of agreement attained was with the statement “participate in recreational/leisure and/or group social activities (Mean = 6.40,  $SD = .70$ , range between 5 and 7),”  $M = 6.70$ ,  $Mdn = 7.00$ ,  $SD = .48$ . This was closely followed by the leading statement from Round 1: “have necessary adaptive equipment/durable medical equipment (Mean = 6.70,  $SD = .48$ , range between 6 and 7),”  $M = 6.50$ ,  $Mdn = 6.50$ ,  $SD = .53$ . Consistent with Round 2, the lowest amount of agreement attained was for the statement “live independently (Mean = 4.40,  $SD = 1.26$ , range between 2 and 6),”  $M = 4.11$ ,  $Mdn = 5.00$ ,  $SD = 1.36$ . In fact, the mean score for this statement was just above the midpoint (4), which would indicate that participants neither agreed nor disagreed with the statement.

For the second question, participants continued to express overall agreement with the statements. Consistent with Round 2, the highest level of agreement attained was for

the statement “physical and/or environmental barriers, including lack of transportation (Mean = 6.50,  $SD = .53$  range between 6 and 7),”  $M = 6.33$ ,  $Mdn = 6.00$ ,  $SD = .71$ . There were few statements with which, on average, participants tended to express that they only somewhat agreed, including the following statements: “decreased autonomy and/or independence because of overbearing family members who wish to help (Mean = 5.30,  $SD = .95$ , range between 4 and 6),”  $M = 5.33$ ,  $Mdn = 5.00$ ,  $SD = .87$ ; “lack of participation in extracurricular activities (Mean = 5.80,  $SD = 1.23$ , range between 3 and 7),”  $M = 5.33$ ,  $Mdn = 6.00$ ,  $SD = .87$ ; “inability to finish education (Mean = 5.30,  $SD = 1.16$ , range between 3 and 7),”  $M = 5.25$ ,  $Mdn = 6.00$ ,  $SD = 1.39$ ; “fatigue with activities (Mean = 5.30,  $SD = .67$ , range between 4 and 6),”  $M = 5.22$ ,  $Mdn = 5.00$ ,  $SD = .97$ ; “lack of financial support and/or unemployment (Mean = 6.20,  $SD = .79$ , range between 5 and 7),”  $M = 5.00$ ,  $Mdn = 5.00$ ,  $SD = .87$ ; and “having to learn bowel and bladder programs (Mean = 5.30,  $SD = 1.25$ , range between 3 and 7),”  $M = 4.67$ ,  $Mdn = 4.00$ ,  $SD = 1.41$ . For each of the questions, the general consensus indicated that participants somewhat agreed with the statements.

Finally, participants expressed overall agreement (for the most part) with the statements for the third question. As in Round 2, one exception to this pattern was for the statement “an effective approach does not exist (Mean = 2.78,  $SD = 1.79$ , range between 1 and 5),”  $M = 3.44$ ,  $Med = 3.00$ ,  $SD = 2.07$ , a statement with which, on average, participants expressed that they somewhat disagreed.

Table 5.

*Means, Medians, and Standard Deviations for Round 3 Items in Rank Order*

	N	Mean	Mdn	SD	Min	Max
<b>Successful community reintegration as it relates to adolescents and YA with SCI means that they...</b>						
Participate in recreational/leisure and/or group social activities (Mean = 6.40, <i>SD</i> = .70, range between 5 and 7).	10	6.70	7.00	.48	6	7
Have necessary adaptive equipment/durable medical equipment (Mean = 6.70, <i>SD</i> = .48, range between 6 and 7).	10	6.50	6.50	.53	6	7
Have good social support systems (i.e., family, friends, and communities; Mean = 6.30, <i>SD</i> = 1.25, range between 3 and 7).	10	6.10	6.00	.32	6	7
Are able to go back to school (Mean = 6.20, <i>SD</i> = 1.03, range between 3 and 7).	10	6.00	6.00	1.15	3	7
Have few physical/environmental barriers to achieve community mobility (Mean = 6.30, <i>SD</i> = .67, range between 5 and 7).	10	6.00	6.00	.82	4	7
Have autonomy with medical decisions (Mean = 6.00, <i>SD</i> = 1.05, range between 4 and 7).	9	5.89	6.00	1.27	3	7
Have reliable transportation (Mean = 6.10, <i>SD</i> = .88, range between 5 and 7).	9	5.89	6.00	.60	5	7

(Continued)

Have established health-care teams (i.e., primary physician, neurologist, allied health, mental health; Mean = 6.50, <i>SD</i> = .53, range between 6 and 7).	10	5.80	6.00	.79	4	7
Have good bowel and bladder programs (Mean = 6.00, <i>SD</i> = 1.05, range between 5 and 7).	10	5.70	6.00	1.16	4	7
Address social stigmas, including bullying, and promote public awareness for SCI (Mean = 5.40, <i>SD</i> = 1.17, range between 4 and 7).	9	5.33	5.00	1.22	4	7
Achieve self-acceptance of their disability (Mean = 5.70, <i>SD</i> = .95, range between 4 and 7).	10	5.30	5.50	1.06	4	7
Become successfully employed (Mean = 5.00, <i>SD</i> = 1.05, range between 3 and 6).	9	4.89	5.00	1.62	2	7
Independently complete activities of daily living (ADL; Mean = 5.00, <i>SD</i> = 1.83, range between 2 and 7).	10	4.80	4.50	1.40	3	7
Become financially secure (Mean = 5.00, <i>SD</i> = 1.05, range between 4 and 7).	9	4.67	5.00	1.12	2	6
Establish committed relationships (Mean = 4.50, <i>SD</i> = .97, range between 3 and 6).	9	4.22	4.00	1.20	2	6
Live independently (Mean = 4.40, <i>SD</i> = 1.26, range between 2 and 6).	9	4.11	5.00	1.36	2	6

(Continued)

---

**The most critical barriers to community reintegration in adolescents and YA with SCI include...**

Physical/environmental barriers including lack of transportation (Mean = 6.50, <i>SD</i> = .53 range between 6 and 7).	9	6.33	6.00	.71	5	7
Lack of adequate adaptive equipment/durable medical equipment (Mean = 6.30, <i>SD</i> = .67, range between 5 and 7).	9	6.22	6.00	.67	5	7
Poor social support systems (Mean = 6.40, <i>SD</i> = .52, range between 6 and 7).	9	6.11	6.00	.60	5	7
Poor self-acceptance resulting in depression and inability to cope (Mean = 6.20, <i>SD</i> = .92, range between 5 and 7).	9	6.00	6.00	.71	5	7
Dealing with stigmas/biases of disability (Mean = 6.10, <i>SD</i> = .99, range between 4 and 7).	9	5.78	6.00	.97	4	7
Poor advocacy for SCI issues (Mean = 5.40, <i>SD</i> = 1.26, range between 3 and 7).	9	5.67	6.00	.71	5	7
Decreased autonomy and/or independence because of overbearing family members who wish to help (Mean = 5.30, <i>SD</i> = .95, range between 4 and 6).	9	5.33	5.00	.87	4	7

---

(Continued)

Lack of participation in extracurricular activities (Mean = 5.80, <i>SD</i> = 1.23, range between 3 and 7).	9	5.33	6.00	.87	4	6
Inability to finish education (Mean = 5.30, <i>SD</i> = 1.16, range between 3 and 7).	8	5.25	6.00	1.39	2	6
Fatigue with activities (Mean = 5.30, <i>SD</i> = .67, range between 4 and 6).	9	5.22	5.00	.97	3	6
Lack of financial support and/or unemployment (Mean = 6.20, <i>SD</i> = .79, range between 5 and 7).	9	5.00	5.00	.87	3	6
Having to learn bowel and bladder programs (Mean = 5.30, <i>SD</i> = 1.25, range between 3 and 7).	9	4.67	4.00	1.41	3	7

**The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...**

Providing education for caregivers and others about SCI (Mean = 6.78, <i>SD</i> = .44, range between 6 and 7).	9	6.56	7.00	.53	6	7
Providing therapies and treatments in their own environments (Mean = 6.78, <i>SD</i> = .44, range between 6 and 7).	9	6.56	7.00	.53	6	7
Assisting in their community/environment problem solving (Mean = 6.67, <i>SD</i> = .50, range between 6 and 7).	9	6.44	6.00	.53	6	7

(Continued)

Providing transportation resources (Mean = 6.44, <i>SD</i> = .71, range between 5 and 7).	9	6.33	6.00	.50	6	7
Supporting mobility for achieving ADL (i.e., providing wheelchair management clinics; Mean = 6.44, <i>SD</i> = .53, range between 6 and 7).	9	6.33	6.00	.71	5	7
Providing psychosocial support (i.e., support groups, networking with others, and life-long counseling; Mean = 6.44, <i>SD</i> = .73, range between 5 and 7).	9	6.22	7.00	.97	5	7
Breaking down social barriers (i.e., advocating for SCI; Mean = 6.33, <i>SD</i> = .71, range between 5 and 7).	9	6.22	6.00	.67	5	7
Participating in multidisciplinary approaches, team meetings, and collaborative work (i.e., co-treatments, consulting social workers; Mean = 6.44, <i>SD</i> = .53, range between 6 and 7).	9	6.22	6.00	.67	5	7
Promoting patient autonomy with health-care decisions (Mean = 6.33, <i>SD</i> = .71, range between 5 and 7).	9	6.22	6.00	.67	5	7
Establishing Life Care Planners to help individuals with SCI navigate associated issues over the lifespan (Mean = 6.33, <i>SD</i> = 1.12, range between 4 and 7).	9	6.00	6.00	.71	5	7

(Continued)

Attending school visits and/or actively participating in classroom activities (Mean = 5.89, <i>SD</i> = .93, range between 4 and 7).	9	5.89	6.00	1.05	4	7
Establishing bowel and bladder programs (Mean = 6.44, <i>SD</i> = .73, range between 5 and 7).	9	5.89	6.00	1.17	4	7
Providing financial resources (Mean = 5.33, <i>SD</i> = 1.41, range between 2 and 7).	9	5.67	6.00	.50	5	6
Assisting with finding employment (Mean = 5.89, <i>SD</i> = .93, range between 5 and 7).	9	5.33	5.00	.71	4	6
Role-playing for task-specific goal achievement (Mean = 5.78, <i>SD</i> = .67, range between 5 and 7).	9	5.22	5.00	.83	4	7
Effective approach does not exist (Mean = 2.78, <i>SD</i> = 1.79, range between 1 and 5).	9	3.44	3.00	2.07	1	7

---

*Note.* One participant did not evaluate all statements.

Because of the small sample size ( $N = 10$ ) and because the data was negatively skewed, the researcher examined potential differences between ratings in Rounds 2 and 3 for each question using non-parametric Wilcoxon Signed Ranks tests. As shown in Table 6, the results revealed a significant difference between ratings in Rounds 2 and 3 for the item “lack of financial support and/or unemployment,”  $Z = 2.16, p = .031$ . Participants provided slightly more negative ranks at Round 3 ( $M = 5.00, Mdn = 5.00, SD = .87$ ) than

they did at Round 2 ( $M = 6.20$ ,  $Mdn = 6.00$ ,  $SD = .79$ ). There was also a significant difference between ratings in Round 2 and 3 for the item “have established health-care teams (i.e., primary physician, neurologist, allied health, mental professional),”  $Z = 1.93$ ,  $p = .053$ . Participants provided slightly more negative ranks at Round 3 ( $M = 5.80$ ,  $Mdn = 6.00$ ,  $SD = .79$ ) than they did at Round 2 ( $M = 6.50$ ,  $Mdn = 6.50$ ,  $SD = .53$ ).

Nevertheless, participants agreed overall with the statements for both items at both Rounds 2 and 3. There were no additional differences between ratings in Rounds 2 and 3. Thus, participants tended to rate items similarly overall, even when presented with information regarding means and standard deviations.

It is also noteworthy that if they changed their ratings during the different rounds, participants were asked to explain how or why they did so. The majority of participants did not respond to this question. One participant fairly consistently indicated an inability to recall her previous ratings. Of the few responses that were obtained, one participant indicated feeling differently about some items depending on the age of the patients, explaining that employment and independent living may be important for adults but not adolescents. Another participant indicated that social support was a tool but not necessary for reintegration. Finally, one participant indicated that Internet access may be a viable option for ensuring that the necessary equipment is available to reintegrate.

Table 6.  
Rounds 2 and 3 Comparison for Statistical Significance

	N	Mean	Mdn	SD	Z	p
<b>Successful community reintegration as it relates to adolescents and YA with SCI means that they...</b>						
Have good social support systems (i.e., family, friends, and community).					.90	.366
Round 2	10	6.30	7.00	1.25		
Round 3	10	6.10	6.00	.32		
Have necessary adaptive equipment/durable medical equipment.					.82	.414
Round 2	10	6.70	7.00	.48		
Round 3	10	6.50	6.50	.53		
Are able to go back to school.					.35	.726
Round 2	10	6.20	6.50	1.03		
Round 3	10	6.00	6.00	1.15		
Participate in recreational/leisure and/or group social activities.					1.00	.317
Round 2	10	6.40	6.50	.70		
Round 3	10	6.70	7.00	.48		
Have established health-care teams (i.e., primary physician, neurologist, allied health, mental health)					1.93	.053
Round 2	10	6.50	6.50	.53		
Round 3	10	5.80	6.00	.79		
Have few physical/environmental barriers to achieve community mobility					1.13	.257
Round 2	10	6.30	6.00	.67		
Round 3	10	6.00	6.00	.82		

(Continued)

Independently complete activities of daily living (ADL).					.25	.799
Round 2	10	5.00	6.00	1.83		
Round 3	10	4.80	4.50	1.40		
Address social stigmas, including bullying, and promote public awareness for SCI.					.36	.720
Round 2	10	5.40	5.50	1.17		
Round 3	9	5.33	5.00	1.22		
Achieve self-acceptance of their disability.					.74	.462
Round 2	10	5.70	6.00	.95		
Round 3	10	5.30	5.50	1.06		
Become successfully employed.					.21	.832
Round 2	10	5.00	5.00	1.05		
Round 3	9	4.89	5.00	1.62		
Live independently.					.17	.864
Round 2	10	4.40	4.50	1.26		
Round 3	9	4.11	5.00	1.36		
Have autonomy with medical decisions.					.00	1.000
Round 2	10	6.00	6.00	1.05		
Round 3	9	5.89	6.00	1.27		
Establish committed relationships.					.29	.773
Round 2	10	4.50	4.00	.97		
Round 3	9	4.22	4.00	1.20		
Have reliable transportation.					.33	.739
Round 2	10	6.10	6.00	.88		
Round 3	9	5.89	6.00	.60		
Become financially secure.					.07	.942
Round 2	10	5.00	5.00	1.05		
Round 3	9	4.67	5.00	1.12		

(Continued)

---

Have good bowel and bladder programs.					.72	.470
Round 2	10	6.00	6.00	1.05		
Round 3	10	5.70	6.00	1.16		

**The most critical barriers to community reintegration in adolescents and YA with SCI include...**

Lack of financial support and/or unemployment.					2.16	.031
Round 2	10	6.20	6.00	.79		
Round 3	9	5.00	5.00	.87		

Physical and/or environmental barriers, including lack of transportation.					.82	.414
Round 2	10	6.50	6.50	.53		
Round 3	9	6.33	6.00	.71		

Poor social support systems.					1.00	.317
Round 2	10	6.40	6.00	.52		
Round 3	9	6.11	6.00	.60		

Dealing with stigmas and/or biases of disability.					.79	.429
Round 2	10	6.10	6.00	.99		
Round 3	9	5.78	6.00	.97		

Poor self-acceptance resulting in depression and inability to cope.					.36	.720
Round 2	10	6.20	6.50	.92		
Round 3	9	6.00	6.00	.71		

Lack of adequate adaptive equipment and/or durable medical equipment.					.00	1.000
Round 2	10	6.30	6.00	.67		
Round 3	9	6.22	6.00	.67		

Decreased autonomy and/or independence because of overbearing family members who wish to help.					.26	.792
Round 2	10	5.30	6.00	.95		

---

(Continued)

Round 3	9	5.33	5.00	.87		
Poor advocacy for SCI issues.					.65	.518
Round 2	10	5.40	5.50	1.26		
Round 3	9	5.67	6.00	.71		
Inability to finish education.					.00	1.000
Round 2	10	5.30	5.50	1.16		
Round 3	8	5.25	6.00	1.39		
Having to learn bowel and bladder programs.					1.56	.119
Round 2	10	5.30	5.00	1.25		
Round 3	9	4.67	4.00	1.41		
Lack of participation in extracurricular activities.					.79	.429
Round 2	10	5.80	6.00	1.23		
Round 3	9	5.33	6.00	.87		

**The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...**

Fatigue with activities.					.28	.783
Round 2	10	5.30	5.00	.67		
Round 3	9	5.22	5.00	.97		
An effective approach does not exist.					.51	.608
Round 2	9	2.78	2.00	1.79		
Round 3	9	3.44	3.00	2.07		
Providing psychosocial support (i.e., support groups, networking with others, and life-long counseling).					.14	.890
Round 2	9	6.22	7.00	.97		
Round 3	9	6.44	7.00	.73		
Breaking down social barriers (i.e., advocating for SCI).					.28	.783
Round 2	9	6.33	6.00	.71		
Round 3	9	6.22	6.00	.67		

(Continued)

---

Role-playing for task-specific goal achievement.					1.19	.236
Round 2	9	5.78	6.00	.67		
Round 3	9	5.22	5.00	.83		
Attending school visits and/or actively participating in classroom activities.					.33	.739
Round 2	9	5.89	6.00	.93		
Round 3	9	5.89	6.00	1.05		
Participating in multidisciplinary approaches, team meetings, and collaborative work (i.e., co-treatments, consulting social workers).					1.00	.317
Round 2	9	6.44	6.00	.53		
Round 3	9	6.22	6.00	.67		
Providing education for caregivers and others about SCI.					1.34	.180
Round 2	9	6.78	7.00	.44		
Round 3	9	6.56	7.00	.53		
Establishing bowel and bladder programs.					1.28	.202
Round 2	9	6.44	7.00	.73		
Round 3	9	5.89	6.00	1.17		
Providing financial resources.					.41	.680
Round 2	9	5.33	6.00	1.41		
Round 3	9	5.67	6.00	.50		
Promoting patient autonomy with health-care decisions.					.00	1.000
Round 2	9	6.33	6.00	.71		
Round 3	9	6.22	6.00	.67		
Providing transportation resources.					.58	.564
Round 2	9	6.44	7.00	.73		
Round 3	9	6.33	6.00	.50		
Supporting mobility for achieving ADL (i.e., providing wheelchair management clinics).					.33	.739

---

(Continued)

Round 2	9	6.44	6.00	.53		
Round 3	9	6.33	6.00	.71		
Providing therapies and treatments in their own environments.					1.41	.157
Round 2	9	6.78	7.00	.44		
Round 3	9	6.56	7.00	.53		
Assisting with finding employment.					.74	.461
Round 2	9	5.89	6.00	.93		
Round 3	9	5.33	5.00	.71		
Assisting in their community/environment problem-solving					1.00	.317
Round 2	9	6.67	7.00	.50		
Round 3	9	6.44	6.00	.53		
The establishment of Life Care Planners to help individuals with SCI navigate associated issues over the lifespan					.69	.492
Round 2	9	6.33	7.00	1.12		
Round 3	9	6.00	6.00	.71		

### Summary

In this chapter, the researcher reported the findings from the three rounds of this study. Demographic characteristics of allied health professionals that were obtained during Round 1 were described. Details were also provided about how the consensus quantitative instrument was developed from the qualitative items pertaining to each of three questions (i.e., “Successful community reintegration as it relates to adolescents and YA with SCI means that the...”; “The most critical barriers to community reintegration in adolescents and YA with SCI include...”; “The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...”). The level of importance of the

agreement in both Rounds 2 and 3 with the statements that were generated in response to the questions during Round 1. The primary exception to this pattern was with the statement “an effective approach [to help adolescents and YA with SCI successfully reintegrate into the community] does not exist.” During both Rounds 2 and 3, participants expressed that they mildly disagreed with this statement. There were also some statements with which participants were more neutral (i.e., closer to the midpoint), such as the statements that pertained to establishing committed relationships and living independently.

In addition to examining participants’ agreements with the statements at a descriptive level, we also examined potential changes between the ratings for Rounds 2 and 3 (when participants had the means and standard deviations from Round 2 to consider as well). Overall, there were more similarities than there were differences between the ratings from Rounds 2 and 3. Still, participants provided slightly more negative ratings at Round 3 for the items “lack financial support and/or unemployment.” Additionally, ratings were somewhat lower in Round 3 for the item “have established health-care teams.” Nevertheless, participants generally agreed overall with these statements.

## CHAPTER V

### CONCLUSIONS AND RECOMMENDATIONS

#### **Introduction**

The purpose of this study was for a panel of allied health professionals to arrive at a consensus regarding the most effective multidisciplinary approach for helping adolescents and YA with SCI reintegrate into the community. This study utilized the conventional Delphi technique, and the panel was initially composed of 31 allied health professionals in the fields of physical therapy, occupational therapy, and child life services from various clinical practice settings across the United States; however, only 10 allied health professionals followed the study to completion. The research question being addressed was, “What is the most effective multidisciplinary allied health approach for helping adolescents and YA with SCI reintegrate into the community?” In order to better understand the research question being addressed, it was crucial to first define successful community reintegration and identify barriers to community reintegration as they related to adolescents and YA with SCI.

The Delphi panel generated a number of opinions and ideas over the course of three rounds. Successful completion of the Delphi study was defined as the group having reached at least 80% consensus among panelists (Ulschak, 1983, as cited in Hsu & Stanford, 2007). In Round 2, the Delphi Panel reached 92% consensus; and in Round 3, this increased to 92.5% consensus. This increase in consensus percentage is indicative of increased convergence on topic ideas or opinions, an indication of a successfully run

Delphi study (De Villiers, De Villiers, & Kent, 2005). This chapter is a discussion of the findings by the Delphi panel and also addresses the implication of these findings on health care educators and providers. Limitations to the study as well as recommendations for future studies are also presented.

### **Discussion of Findings**

Community reintegration is often a goal of rehabilitation and described as a QOL measure. However, the definitions for community reintegration vary across the literature, and a definite gap exists in defining community reintegration for adult age groups, much less adolescents and YA. Dijkers (1998) defined community reintegration as “after/with physical impairment or disability is acquiring/resuming age-gender-culture appropriate roles/statuses/activities, including independence/interdependence in decision making and productive behaviors performed as part of multivaried relationships with family, friends, and others in natural community settings” (p. 5). The author attempted to cover all age-groups by stating “age-appropriate” activities; however, it is vital to know what “age-appropriate” means to adolescents and YA. The Delphi panel sought to explore this concept further.

The Delphi panelists defined the top three factors for successful community reintegration for adolescents and YA with SCI as being able to participate in recreational/leisure and/or group social activities, having necessary adaptive equipment/durable medical equipment, and having good social support systems. It is interesting to note that the panel of allied health professionals included “having necessary adaptive equipment/durable medical equipment” as part of successful community

reintegration. The allied health care professionals recognized that mobility plays a vital role in community reintegration and QOL, whereas the aforementioned definition did not address this.

Identifying barriers to community reintegration has also proven to be challenging because very often it is multifactorial. The Delphi Panel identified the three most critical barriers to community reintegration in adolescents and YA with SCI as physical/environmental barriers, including lack of transportation, lack of adequate adaptive equipment/durable medical equipment, and poor social support systems.

The Delphi panelists concluded that the top three most effective multidisciplinary approaches that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community include providing education for caregivers and others about SCI, providing therapies and treatments in the young people's own environments, and assisting them with community/environment problem solving.

### **Theoretical Perspective**

Cain and Mittman's (2002) Diffusion of Innovation in Health Care theory with the 10 critical dynamics was used to evaluate the findings of the research question as seen in Table 7. Each response generated by the Delphi panel was paired with one or more of the critical dynamics found in Cain and Mittman's (2002) Diffusion of Innovation in Health Care theory. Further exploration into the possibility of implementing these interventions was explored and analyzed.

Communications channels, infrastructure, along with norms, roles, and social networks were the three most common dynamics pertaining to the best multidisciplinary approach for treating adolescents and YA with SCI. Communication between health care providers and across disciplines in already established health care systems were listed as the best treatment approaches.

Table 7.  
*Diffusion of Innovation in Health Care*

<i>Critical Dynamics</i>	
<b>The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes...</b>	
Providing psychosocial support (i.e. support groups, networking with others, and life –long counseling)	Norms, Roles, and Social Networks
Breaking down social barriers (i.e. advocating for SCI)	Opinion Leaders, Communication Channels
Role playing for task-specific goal achievement	Norms, Roles, and Social Networks
Attending school visits and/or actively participating in classroom activities	Observability, Infrastructure
Participating in multi-disciplinary approaches, team meetings, and collaborative work (i.e. co-treatments, consulting social workers)	Homophilous Groups
Providing education for caregivers and others about SCI	Communications Channels
Establishing a bowel and bladder program	Relative Advantage
Providing financial resources	Relative Advantage

(Continued)

Promoting patient autonomy with health care decisions	Norms, Roles, and Social Networks
Providing transportation resources	Infrastructure, Communications Channels
Supporting mobility for achieving ADL (i.e. providing wheelchair management clinics)	Trialability, Infrastructure
Providing therapies and treatments in their own environments	Compatibility, Pace of Innovation/Reinvention
Assisting with finding employment	Communications Channels
Assisting in their community/environment problem solving	Compatibility, Infrastructure
Establishing Life Care Planners to help individuals with SCI navigate associated issues over the lifespan	Norms, Roles, and Social Network, Trialability
Effective approach does not exist	-

### **Relative Advantage**

Relative advantage is the perception that the benefits of adopting an innovation will outweigh the risks and that the innovation will be better than what it is replacing (Cain & Mittman, 2002). As perception of acquired benefits increases, so does the likelihood that the social group will adopt new innovations. Relative advantage can be conveyed as financial or economic profitability, social worth or prestige, educational value or enrichment, etc.

“Establishing a bowel and bladder program” was one relative advantage for successful community reintegration identified by the Delphi Panelists. Bowel and bladder programs and schedules are crucial for participating in social and community

activities because the inability to void can cause a host of medical problems for the individual with SCI. The relative advantage of adopting a regular bowel and bladder program outweighs the hassle of using diapers and possibly ending up in awkward social scenarios.

Also, “providing financial resources” for adolescents and YA with SCI empowers them to explore options for durable medical equipment, transportation, etc., that they would have otherwise been unable to access. These resources can include private organizations, educational institutions, and government-sponsored assistive programs. This empowerment could lead to successful community reintegration by promoting independence through mobility.

### **Trialability**

Trialability is the ability to use or practice a new idea without having to invest or fully commit to it, thus making it more likely to adopt the innovation if there are positive outcomes. For example, “supporting mobility for achieving ADL (i.e. providing wheelchair management clinics)” and “establishing life care planners to help individuals with SCI navigate associated issues over the lifespan” are two ways trialability can lead to successful community reintegration.

Often times, wheelchair clinics are pro bono services offered by PT and OT where recommendations are made for the best or newest innovations on the market insofar as mobility products are concerned. Attending these clinics is often free so the investment is very low risk while benefits can potentially be great. Life care planning can also be very beneficial to adolescents and YA with SCI because it enables them to set attainable

short- and long-term goals that can help speed up the process of community reintegration. Life care planners often have nursing backgrounds and help coordinate different levels of care for individuals with disabilities from scheduling physician appointments to job acquisition.

### **Observability**

Observability is seeing and witnessing how an innovation works and then acknowledging that it is safe or can positively benefit a particular population, thus making it ideal for adoption (Cain & Mittman, 2002). The more obvious the benefits, e.g. better outcomes, greater functionality, improved performance, the more likely new users will want to adopt the innovation.

“Attending school visits and/or actively participating in classroom activities” was listed by the Delphi panelists as a successful approach to community reintegration and can be categorized into observability. Allowing an adolescent or YA with SCI to matriculate into the classroom after a catastrophic injury promotes independence and gives the individual a sense of normalcy. Having peer-to-peer contact in a positive learning and nurturing environment is essential for both emotional and social maturation. Observing these positively reinforcing attitudes and behaviors is beneficial for all those involved and can help to adopt the notion of re-matriculation post SCI.

### **Communications Channels**

This concept connotes that innovations are a social process, and ideas are diffused from one health care professional to another. Likewise, consumers have also become a large part of the communication channel passage for diffusion of innovations, mostly via

the internet (Cain & Mittman, 2002). The internet has “sped up and democratized the dissemination of medical information [...] and medical literature, traditionally the province of only trained professionals or the most diligent and educated consumer, has become open to all” (Cain & Mittman, 2002, p. 13).

Responses that addressed communications channels were “breaking down social barriers (i.e. advocating for SCI)”, “providing education for caregivers and others about SCI”, “ providing transportation resources”, and “assisting with finding employment”. Each of these responses involves communication processes between healthcare professionals before innovations are ultimately passed down to adolescents or YA with SCI. For example, a YA with SCI looking for employment at a local library would require a PT conferencing with a social worker or health educator to determine the needs of the individual, e.g. type of transportation required, special needs accessibility of the potential employment facility, etc.

### **Homophilous Groups**

Homophilous groups describe the similarities that the individuals adopting the innovation possess that will directly affect its speed and diffusion. Innovations will diffuse more readily across homophilous groups versus heterophilous groups (Cain & Mittman, 2002). For example, clinical physicians are generally a homophilous group, whereas health care administrators may be a mix of physicians and administrators without medical backgrounds.

“Participating in multi-disciplinary approaches, team meetings, and collaborative work (i.e. co-treatments, consulting social workers)” describes a homogenous group of

health care providers who play a specific role in the care of an individual. This homophilous group of health care providers, each with his or her own particular expertise, helps to shape the innovation for the adolescent or YA with SCI because they know what most of the immediate and future needs of the individual will be.

### **Pace of Innovation/Reinvention**

Pace of innovation and or reinvention address the rate at which an idea evolves or does not evolve as it diffuses through the target community. Various innovations have the ability to evolve rapidly and adopt multiple facets to them, while others remain stale and are not so fast to change or adapt.

“Providing therapies and treatments in their own environments” is not a common practice for adolescents and YA with SCI. There are multiple factors to consider, such as liability, transportation, lack of resources, etc., that make treating these individuals in their home environments difficult. The pace of diffusion of this particular innovation has been and continues to be slow as the majority of health care providers are not willing to adopt it.

### **Norms, Roles, and Social Networks**

This is the relative idea that the diffusion of innovation is greater when one health care professional has a greater social network with other health care professionals. Ideas are more readily adopted when peers are actively involved in their dissemination and implementation. This theme appeared the most throughout the Delphi panelists’ responses.

“Providing psychosocial support (i.e. support groups, networking with others, and life-long counseling,” “role playing for task-specific goal achievement,” “promoting patient autonomy with health care decisions,” and “establishing Life Care Planners to help individuals with SCI navigate associated issues over the lifespan” are innovations best served by diffusion through networks from one health care professional to another. Providing means for health care professionals to communicate ideas for treatment with one another and then passing this information down to adolescents and YA with SCI is an important concept and a very popular approach. For example, there are internet websites and blogs dedicated to allied health professionals who share information about case scenarios asking for feedback from others. This allows the health care professional to get recommendations from peers and even the target population on ideas for treatment approaches.

### **Opinion Leaders**

Opinion leaders are those individuals who directly affect the diffusion of innovations because they have greater media exposure, have higher incomes or education levels, or wider social networks (Cain & Mittman, 2002). They are vital vectors in the transmission of ideas across various forums because of their knowledge, expertise, popularity, or networking abilities.

“Breaking down social barriers (i.e. advocating for SCI)” was the one response that alluded to opinion leaders. Again, as previously mentioned, the CDRF is a prime example of an organization that supports advocating for and helping individuals with SCI across the nation. Because Christopher Reeves had such a strong celebrity presence

during his lifetime, his foundation serves to bring awareness to and find solutions for individuals with SCI. The CDRF's website has resources to help individuals with SCI acquire the following: 1) information on the best rehabilitation centers that specialize in paralysis, 2) health insurance coverage to maximize benefits, 3) social security and disability benefits, 4) information on clinical trials and research in the field of SCI, 5) funding for rehabilitation equipment, and 6) coping strategies for adjustment and depression (CDRF, 2012).

### **Compatibility**

Compatibility can best be described as the ability of an innovation to be compatible with existing technologies or interventions already in place. If the innovation is consistent with the adopter's existing value system, past experiences, and immediate needs, the more likely it is to be integrated (Cain & Mittman, 2002).

“Providing therapies and treatments in their own environments” and “assisting in their community/environment problem solving” are two examples of compatibility. By working with adolescents and YA with SCI in their own environments, the health care provider is able to use interventions and processes already in place and modify them to meet the needs of the individual. The more compatible the treatments or changes, the more likely the adolescent or YA with SCI will be to adopt them.

Unfortunately, lack of resources, including staffing and professional liability issues, make it difficult for health care providers to provide therapies in home environments. This continues to be an ongoing challenge for this particular population because ongoing therapy services are vital for positive outcomes.

## **Infrastructure**

In order for an innovation to be implemented into a culture, there needs to be an existing infrastructure that can support its adoption. For example, “providing transportation resources,” “supporting mobility for achieving ADL (i.e. providing wheelchair management clinics,” and “assisting in their community/environment problem solving” are all scenarios where existing systems in place must be present for innovations to diffuse to the target population. Existing transit systems and health care facilities equipped to handle individuals with SCI must be established before a transition to community reintegration occurs.

## **Implications**

The Delphi panelists concluded with 92.5% accuracy that the top three most effective multidisciplinary approaches that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community include providing education for caregivers and others about SCI, providing therapies and treatments in their own environments, and assisting in their community/environment problem solving.

First, providing education for caregivers and others about SCI was the most agreed-upon recommendation. The implications of this finding are vital for health care professionals, including health educators. Each specific discipline has its unique contributions to the plans of care for adolescents and YA with SCI. For example, PT educate patients and caregivers on safety in bed mobility, transferring from one surface to another, and wheelchair mobility/propulsion; OT educate on ADL, bowel and bladder

programs, and community reintegration; and CCLS educate on emotional coping strategies and ways to socially interact with others.

Second and third, providing therapies and treatments in their own environments and assisting in their community/environment problem solving were two other recommendations by panelists that received high agreement. Being able to see an adolescent or YA with SCI in his or her home environment is powerful for health care professionals because they become aware of those economic, social, and physical barriers that keep the individual from successfully reintegrating into the community. Witnessing first-hand those barriers that hinder these young people can be vital to helping them overcome those obstacles.

Identifying these barriers, determining a plan of care, implementing a particular treatment or approach, and then evaluating outcomes in the home environment or community environment is a key health care advantage to these adolescents and YA with SCI. Allowing them to experience first-hand the effects of the treatment experience in their realms may foster self-efficacy to help them overcome many of the barriers.

The results of this study help to hone in on the importance of education in this particular population, which in turn, can lead them to opportunities for finding resources, acquiring durable medical equipment, and successfully reintegrating into the community.

### **Health Educators**

The Seven Areas of Responsibility for a Health Educator are a comprehensive set of competencies and sub-competencies that define the role of the health education specialist (National Commission for Health Education Credentialing, 2008). These areas

include: 1) Assess Needs, Assets and Capacity for Health Education, 2) Plan Health Education, 3) Implement Health Education, 4) Conduct Evaluation and Research Related to Health Education, 5) Administer and Manage Health Education, 6) Serve as a Health Education Resource Person, and 7) Communicate and Advocate for Health and Health Education.

Assessing the needs of the target population helps health educators plan interventions to assist adolescents and YA with SCI and their caregivers achieve their goals. For example, the health educator can develop a tool to assess both the adolescent's or YA's and caregiver's levels of knowledge on various topics that are identified as barriers to community reintegration. Identifying gaps in the knowledge base can then lead the health educator to plan and implement the appropriate interventions to address this deficiency. Once these interventions have been implemented, the health educator can evaluate the outcomes by comparing objective measures from baseline to end result to determine its effectiveness.

For example, if the barrier to community reintegration is inadequate funding for durable medical equipment (e.g., seating and wheelchairs), then the health educator can serve as a resource person by connecting these individuals and their caregivers with funding resources. The health educator can also host a monthly or quarterly support group meeting for adolescents and YA with SCI in order to build networks and advocate for their health and quality of life.

Health educators can use their knowledge on the topic of community reintegration and SCI to collaborate with appropriate allied health professionals in promoting health

and quality of life for adolescents and young adults with SCI. Joint efforts between health educators, PT, OT, and CCLS will help increase and maximize functional outcomes for young people with SCI in various domains, including physical, emotional, psychosocial, and socioeconomic. Health educators are in prime position to provide broad-spectrum education to adolescents and YA with SCI and their caregivers. In educating the caregivers and other allied health care professionals, health educators can play a vital role as ambassadors who communicate and advocate for health and health education targeting young people with SCI.

### **Study Limitations**

There were limitations observed in this study. Initially, the study's target sample was to consist of PT, OT, CCLS, and MT-BC. However, after Round 1 was generated, it was discovered that no MT-BC participated in the Delphi panel. Because MT-BC are part of the multidisciplinary team and contribute to the rehabilitation process for adolescents and YA with SCI, the absence of input by MT-BC is a threat to the generalizability of results to the multidisciplinary allied health team approach in the treatment of adolescents and YA with SCI. Likewise, the results of the 10 Delphi panelists cannot be generalized to represent opinions of all allied health care professionals who work with adolescents and YA with SCI.

Another limitation to the study is that OT were underrepresented because only one OT followed the study to completion; and although the entire group consisted of allied health professionals, there was a mixed group of professions within the group. This heterogeneous panel consisting of PT, OT, and CCLS could be seen as a threat to

the reliability of the study because Delphi panels ideally are composed of homogenous groups. However, one could argue that the umbrella of allied health is the thread that homogenizes the panel.

Attrition was a threat to the internal validity of the study because a total of 21 participants dropped out between Rounds 1 and 3. However, this did not have a profound impact on the study because a sample size of 10 panelists is within the recommended range in the current literature (Delbecq, Van de Ven, & Gustafson, 1975, as cited in Hsu, 2007).

### **Implications for Future Research**

This study generated a multitude of questions that need to be explored in order to further contribute to the knowledge base concerning QOL and community reintegration in individuals with SCI across the lifespan. Recommendations for further study include examining the following questions:

1. What types of recreation/leisure activities and/or group social activities are appropriate for adolescents and YA with SCI?
2. What adaptive equipment/durable medical equipment is necessary for adolescents or YA with SCI to achieve successful community reintegration?
3. How do good social support systems promote successful community reintegration in adolescents and YA with SCI?
4. How can physical/environmental barriers, including lack of transportation, be addressed in adolescents and YA with SCI to allow for successful community reintegration?

5. What is the best approach at providing education for caregivers and others about SCI?
6. How can providing therapies and treatments in their own environments and community settings empower adolescents and YA with SCI to successfully reintegrate?
7. What is the best order of interventions for adolescents and YA with SCI to successfully reintegrate into the community?

Future studies utilizing a real-time Delphi technique could include participant focus groups of individuals with SCI and/or their caregivers. Having focus groups would reduce the threat of attrition because all necessary information could be gathered in one visit as opposed to three or more. Also, the opinions and viewpoints of the target population could be compared against those of allied health care professionals and assessed for commonalities.

### **Summary**

The purpose of this conventional Delphi Study, guided by Cain and Mittman's (2002) Diffusion of Innovation in Health Care Theory's 10 critical dynamics, was for a panel of allied health professionals to arrive at a consensus regarding the most effective multidisciplinary approach for helping adolescents and YA with SCI reintegrate into the community. Data was obtained from a final Delphi Panel consisting of 10 members during three rounds and analyzed using both qualitative and quantitative methods.

This chapter included a discussion of the study findings, identified parallels between these findings and by Cain and Mittman's (2002) Diffusion of Innovation in

Health Care Theory, presented limitations of the study, and offered recommendations for future studies. Understanding the implications of SCI to adolescents and YA will enable health educators and allied health professionals to tailor their health promotion and treatment approaches to meet the needs of this unique population.

## REFERENCES

- Abbott-Chapman, J., Denholm, C., & Wyld, C. (2008). Gender differences in adolescent risk taking: Are they diminishing?: An Australian intergenerational study. *Youth & Society, 40*, 131-154.
- A.D.A.M. Medical Encyclopedia. (2012). *Neurogenic bladder*. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001761>
- American Board of Physical Therapy Specialties. (2012). *About specialist certification*. Retrieved from <http://www.abpts.org/Certification/About/>
- American Occupational Therapy Association. (2012). *About occupational therapy*. Retrieved from <http://www.aota.org/Consumers.aspx>
- American Physical Therapy Association. (2012). *Who are physical therapists?* Retrieved from <http://www.apta.org/AboutPTs/>
- American Spinal Injury Association. (2011). *International standards for classification of spinal cord injury*. Retrieved from [http://www.asia-spinalinjury.org/publications/59544\\_sc\\_Exam\\_Sheet\\_r4.pdf](http://www.asia-spinalinjury.org/publications/59544_sc_Exam_Sheet_r4.pdf)
- Anderson, C. J., Krajci, K. A., & Vogel, L. C. (2003). Community integration among adults with spinal cord injuries sustained as children or adolescents. *Developmental Medicine and Child Neurology, 45*, 129-134.  
doi:10.1017/S0012162203000239
- Apparelyzed. (2011). *Types of paralysis: Quadriplegia (tetraplegia) and paraplegia*. Retrieved from <http://www.apparelyzed.com/paralysis.html>

- Brain and Spinal Cord. (2011). *Spinal cord injury*. Retrieved from  
<http://www.brainandspinalcord.org/spinal-cord-injury.html>
- Byrnes, J. P, Miller, D. C., & Schafer, W. D. (1999). Gender differences in risk taking. *Psychological Bulletin*, 125, 367-383.
- Cain, M., & Mittman, R. (2002). *Diffusion of Innovation in Health Care*. Retrieved from  
<http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/D/PDF%20DiffusionofInnovation.pdf>
- Christopher and Dana Reeve Foundation. (2011). *One degree of separation: Paralysis and spinal cord injury in the United States*. Retrieved from  
<http://www.christopherreeve.org/atf/cf/%7B3d83418f-b967-4c18-8ada-adc2e5355071%7D/8112REPTFINAL.PDF>
- Christopher and Dana Reeve Foundation. (2012). *About us*. Retrieved from  
<http://www.ccrpf.org/>
- Columbia University. (n.d.). *Measures of central tendency*. Retrieved from  
<http://iridl.ldeo.columbia.edu/dochelp/StatTutorial/MCT/>
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3<sup>rd</sup> ed.). Lincoln, NE: Sage Publications.
- Creswell, J. W., Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 209-240). Thousand Oaks, CA: Sage.

- Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Graham, H. K., Mehmet-Radji, O., & Boyd, R. (2006). Paediatric quality of life instruments: A review of the impact of the conceptual framework on outcomes. *Developmental Medicine & Child Neurology*, 48, 311–318. doi:10.1017/S0012162206000673
- Dijkers, M. (1998). Community integration: Conceptual issues and measurements approaches in rehabilitation research. *Top Spinal Cord Injury Rehabilitation*, 4, 1-15.
- Donovan, W. H. (2007). Spinal cord injury: Past, present, and future. *Journal of Spinal Cord Medicine*, 30, 85-100.
- Fricker, R. D., & Schonlau, M. (2002). Advantages and disadvantages of internet research surveys: Evidence from the literature. *Field Methods*, 14, 347-367. doi:10.1177/152582202237725
- Gontkovsky, S. T., Russum, P., & Stokic, D. S. (2007). Perceived information needs of community-dwelling persons with chronic spinal cord injury: Findings of a survey and impact of race. *Disability and Rehabilitation*, 29, 1305-1312.
- Hsu, C., & Stanford, B. A. (2007). The Delphi technique: Making sense of consensus. *Practical Assessment, Research & Evaluation*, 12, 1-8.
- Jackson, A. B., Dijkers, M., DeVivo, M. J., & Poczatek, R. B. (2004). A demographic profile of new traumatic spinal cord injuries: Change and stability over 30 years. *Archives of Physical Medicine & Rehabilitation*, 85, 1740-1748.

- Kennedy, P., Lude, P., & Taylor, N. (2006). Quality of life, social participation, appraisals and coping post spinal cord injury: A review of four community samples. *Spinal Cord*, 44, 95-105.
- King, G., Lawm, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, 23, 63-90. doi:10.1080/J006v23n01\_05
- Krause, J. S. (2010). Risk for subsequent injuries after spinal cord injury: A 10-year longitudinal analysis. *Archives of Physical Medicine & Rehabilitation*, 91, 1741-1746.
- Krause, J. S., DeVivo, M. J., & Jackson, A. B. (2004). Health status, community integration, and economic risk factors for mortality after spinal cord injury. *Archives of Physical Medicine & Rehabilitation*, 85, 1764-1773.
- Krause, J. S., Kemp, B., & Coker, J. (2000). Depression after spinal cord injury: Relation to gender, ethnicity, aging, and socioeconomic indicators. *Archives of Physical Medicine & Rehabilitation*, 81, 1099-1109.
- Lammertse, D. P., Jackson, A. B., & Sipski, M. L. (2004). Research from the Model Spinal Cord Injury Systems: Findings from the current 5-year grant cycle. *Archives of Physical Medicine & Rehabilitation*, 85, 1737-1739.
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., . . . Hanna, S. (2006). Patterns of participation in recreational and leisure activities among

- children with complex physical disabilities. *Developmental Medicine and Child Neurology*, 48, 337-342.
- Mikolajewska, E., & Mikolajewski, D. (2011). Exoskeletons in neurological diseases: Current and potential future applications. *Advances in Clinical and Experimental Medicine*, 20, 227-233.
- Murphy, M. K., Black, N., Lamping, D. L., McKee, C. M., Sanderson, C. F., Askham, J., & Marteau, T. (1998). Consensus development methods and their use in clinical guideline development. *Health Technology Assessment*, 2, 1-88.
- National Commission for Health Education Credentialing. (2008). *Responsibilities and competencies for health education specialists*. Retrieved from <http://www.nchec.org/credentialing/responsibilities>
- National Spinal Cord Injury Statistical Center. (2010). *Annual report for the spinal cord injury model systems: Public version*. Retrieved from [https://www.nscisc.uab.edu/public\\_content/pdf/2009%20NSCISC%20Annual%20Statistical%20Report%20-%20Complete%20Public%20Version.pdf](https://www.nscisc.uab.edu/public_content/pdf/2009%20NSCISC%20Annual%20Statistical%20Report%20-%20Complete%20Public%20Version.pdf)
- National Spinal Cord Injury Statistical Center. (n.d.). *Definition of spinal cord injury*. Retrieved from [https://www.nscisc.uab.edu/public\\_content/nscisc\\_database/definition\\_eligibility.aspx](https://www.nscisc.uab.edu/public_content/nscisc_database/definition_eligibility.aspx)
- New World Encyclopedia. (2008). *Imhotep*. Retrieved from <http://www.newworldencyclopedia.org/entry/Imhotep>
- New World Encyclopedia. (2008). *James Garfield*. Retrieved from [http://www.newworldencyclopedia.org/entry/James\\_Garfield#Assassination](http://www.newworldencyclopedia.org/entry/James_Garfield#Assassination)

- Okoli, C., & Pawlowski, S. D. (2004). The Delphi method as a research tool: An example, design considerations and applications. *Information & Management*, 42, 15-29. doi:10.1016/j.im.2003.11.002
- Powell, C. (2003). The Delphi technique: Myths and realities. *Journal of Advanced Nursing*, 41, 376-382. doi:10.1046/j.1365-2648.2003.02537.x
- Price, I. (2000). *Standard deviation*. Retrieved from [http://www.une.edu.au/WebStat/unit\\_materials/c4\\_descriptive\\_statistics/standard\\_deviation.htm](http://www.une.edu.au/WebStat/unit_materials/c4_descriptive_statistics/standard_deviation.htm)
- PsychData. (2013). *Features*. Retrieved from <http://www.psychdata.com/content/features.asp>
- Skulmoski, G. J., Hartman, F. T., & Krahn, J. (2007). The Delphi method for graduate research. *Journal of Information Technology Education*, 6, 1-21.
- Strauss, D. J., DeVivo, M. J., Paculdo, D. R., & Shavelle, R. M. (2006). Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 87, 1079-1085.
- Tsoi, W. S., Zhang, L. A., Wang, W. Y., Tsang, K. L., & Lo, S. K. (2011). Improving quality of life of children with cerebral palsy: A systematic review of clinical trials. *Child: Care, Health and Development*, 38, 21-31. doi:10.1111/j.1365-2214.2011.01255.x
- U.S. Census Bureau. (2010). *United States Census 2010: Interactive population map*. Retrieved from <http://2010.census.gov/2010census/popmap/>

- Van Gelder, M. M., Bretveld, R. W., & Roeleveld, N. (2010). Web-based questionnaires: The future in epidemiology? *American Journal of Epidemiology*, 172, 1292-1298. doi:10.1093/aje/kwq291
- World Health Organization. (2011). *Health topics: Disabilities*. Retrieved from <http://www.who.int/topics/disabilities/en/>
- Wright, K. B. (2005). Researching internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*, 10, article 11.

## APPENDIX A

### TWU IRB Approval Letter



**Institutional Review Board**  
Office of Research and Sponsored Programs  
P.O. Box 425619, Denton, TX 76204-5619  
940-898-3378 FAX 940-898-4416  
e-mail: IRB@twu.edu

July 10, 2012

Mr. Rogelio Rivera, Jr.  
8935 Andante Drive  
Houston, TX 77040

Dear Mr. Rivera, Jr.:

*Re: Assessing Community Reintegration in Adolescents and Young Adults with Spinal Cord Injury:  
A Delphi Study (Protocol #: 17059)*

The above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp and a copy of the annual/final report are enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. The signed consent forms and final report must be filed with the Institutional Review Board at the completion of the study.

This approval is valid one year from June 1, 2012. Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. If you have any questions, please contact the TWU IRB.

Sincerely,

Dr. Kathy DeOrnellas, Chair  
Institutional Review Board - Denton

enc.

cc. Dr. Gay James, Department of Health Studies  
Dr. Marilyn Massey-Stokes, Department of Health Studies  
Graduate School

## **APPENDIX B**

### **Delphi Panel Invitation Letter**

## Delphi Panel Invitation Letter

To: Allied Healthcare Professional

Subject: Call to research! Assessing Community Reintegration in Adolescents and Young Adults with SCI

Body of Letter:

Attention all physical therapists (PTs), occupational therapists (OTs), music therapists (MTs), and child life specialists (CCLS):

My name is Roy Rivera, and I am a doctoral student in the Health Studies department at Texas Woman's University (TWU). I would like to invite you, as an allied health professional, to take part in a research study that I am conducting called "Assessing Community Reintegration in Adolescents and Young Adults with Spinal Cord Injury: A Delphi study". I am under the guidance of my advisor, Dr. Marilyn Massey-Stokes, and we can both be reached at the phone numbers and email addresses listed below if you have any questions.

The purpose of this study is for a panel of multidisciplinary allied health professionals to arrive at a consensus regarding the most effective clinical approach for helping adolescents and YA with SCI reintegrate into the community. Examining how a multidisciplinary team of allied health professionals view successful community reintegration in adolescents and YA with SCI will help aim future health education efforts to enhance quality of life and participation in age-appropriate activities. Identifying and prioritizing barriers to community reintegration in adolescents and YA with SCI will provide valid information for setting measurable rehabilitative goals to allow for optimum use of health care resources and participant time in therapies, recreational, and leisure activities. In turn, health educators can use this information for planning, implementing, and evaluating health promotion programs aimed at fostering successful community reintegration in adolescents and YA with SCI.

If you consent to participate in this study, you will be asked to complete a series of 3 to 4 questionnaires, approximately 3 to 4 weeks apart, that will be embedded in PsychData, a secure, reliable website designed to meet IRB standards for ethical research and the protection of participant confidentiality via Secure Sockets Layer (SSL) data encryption and Secure Survey Environment. Your time commitment is 30 minutes to 1 hour per questionnaire with a maximum cumulative time commitment of between 1.5 and 4 hours. At no point in time will your identity be revealed. Also, participation in this study is voluntary and you may stop and withdraw from the study at any time without consequences. You will only be asked to participate in this study one time.

We hope that you participate in this research study. At the end of the study, you will be

able to access an end of survey standard conclusion page or custom URL redirect via PsychData. If you have questions about the study, you may contact me, the PI at twudelphi@gmail.com or (713)725-5464, or my advisor, Dr. Marilyn Massey-Stokes at mmasseystokes@mail.twu.edu or (940)898-2863. If you have questions about your rights as a participant in this research or the way this study is being conducted, you may contact Texas Woman's University Office of Research and Sponsored Programs at IRB@twu.edu or (940)898-3378.

Thank you for your time and for your interest in participating in this study. Please feel free to ask me any questions applicable to the research study. You may also forward this email to any peers, friends, or colleagues that might be interested in participating as well.

Research study link: <https://www.psychdata.com/s.asp?SID=149737>

-----

Dr. Roy Rivera, Jr., PT, DPT, CHES  
Physical Therapist and Certified Health Education Specialist

## APPENDIX C

### Approved TWU Consent Form

Approved TWU Consent Form

TEXAS WOMAN'S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH

Title: Assessing Community Reintegration in Adolescents and Young Adults with Spinal Cord Injury: A Delphi Study

Investigator: Roy Rivera, Jr., PT, DPT, CHES.....twudelphi@gmail.com 713/725-5464

Advisor: Marilyn Massey-Stokes, EdD...mmasseystokes@mail.twu.edu 940/898-2863

Explanation and Purpose of the Research:

You are being invited to participate on a multidisciplinary allied health professional Delphi panel in a research study by Dr. Roy Rivera regarding community reintegration in adolescents and young adults (YA) with spinal cord injury (SCI). The purpose of this study is for a panel of multidisciplinary allied health professionals to arrive at a consensus regarding the most effective clinical approach for helping adolescents and YA with SCI reintegrate into the community. We expect to enroll a combined total of 40 allied health professionals in this study from disciplines to include physical therapy (PT), occupational therapy (OT), music therapy (MT), and child life specialists (CLS).

Description of Procedures:

All participants in this study must meet the minimum criteria of being clinical practitioners for at least 5 years and have experience with treating adolescents and YA between the ages of 15-25 affected by SCI. Discipline-specific additional criteria are as follows:

- PT must have a bachelor's, master's, clinical doctorate and/or terminal doctoral degree and be board certified to practice physical therapy in their respective state.
- OT must have a bachelor's, master's, clinical doctorate and/or terminal doctoral degree and be board certified to practice occupational therapy in their respective state.
- MT must have a bachelor's, master's and/or terminal doctoral degree and be board certified (MT-BC) to practice music therapy in their respective state.
- CLS must have a bachelor's, master's and/or terminal doctoral degree and be a Certified Child Life Specialist (CCLS) by the Child Life Council.

For this study, the principal investigator (PI) will ask the participant to complete a series of questionnaires that will be embedded in *PsychData*, a secure, reliable website designed to meet IRB standards for ethical research and the protection of participant confidentiality via Secure Sockets Layer (SSL) data encryption and Secure Survey Environment. The study will include three to four rounds of questions spread out over a total of 3 to 4

months. Round 1 will inquire about general demographic information and open-ended qualitative statements to three questions regarding community reintegration in adolescents and YA with SCI. A master list of Round 1 responses will be created and sorted by key words, main ideas, or emerging themes. Round 2 will take the results of Round 1 and have the participants read each statement on the list and rate it on a 5-point Likert scale. Panel members will also be encouraged to add additional comments or ask for clarification on the listed statements. Round 3 will then take the results from Round 2 and provide participants an opportunity to rank their preference of responses from most to least important. Your time commitment is 30 minutes to 1 hour per questionnaire with a maximum cumulative time commitment of between 1.5 and 4 hours.

### Potential Risks

There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. Confidentiality will be protected to the extent that is allowed by law. *PsychData* will protect the participant's identity and keep his or her information anonymous to the researcher and other participants as well. Participants will register with *PsychData*, giving their email address and a password created by them. This information will be stored in a file that is separate from the survey data. It will be accessed only for resending data for Rounds 2 and 3. The PI will not make any attempts to match it with survey responses. The registration data file will be deleted from *PsychData* upon analysis and completion of the study when the email is accessed to send a link to the final abstract of the study findings. The survey data will be downloaded from *PsychData* to the PI's computer for the purpose of data analysis only with no participant identification. The PI's computer and network access is password protected, and he also has an assigned password allowing him to access *PsychData*. Any survey results that are presented or published will include only collective responses.

In order to directly minimize the loss of time for your participation, the PI will streamline the first questionnaire using direct simple questions and avoiding complex or compound questions. Also, all subsequent rounds will require you to list in rank order your responses from the previous round. This ranking method will help ease the burden of time commitment. *PsychData* allows for the participant to exit the survey at any time and access it again if the time commitment becomes a burden and causes you fatigue. You may withdraw from the study at any time.

To avoid the possibility of coercion, the PI will tell all potential and active participants that participation is voluntary and they may withdraw from the study at any time.

The PI will try to prevent any problem that could happen because of this research. However, Texas Woman's University does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

### Participation and Benefits

Your participation in this study is voluntary. You do not have to be in this study if you do not want to be. The only direct benefit of this study to you is that at the completion of the study a summary of the results will be made available to you via a link through *PsychData*.

Examining how a multidisciplinary team of allied health professionals view successful community reintegration in adolescents and YA with SCI will help aim future health education efforts to enhance quality of life and participation in age-appropriate activities. Identifying and prioritizing barriers to community reintegration in adolescents and YA with SCI will provide valid information for setting measurable rehabilitative goals to allow for optimum use of health care resources and participant time in therapies, recreational, and leisure activities. In turn, health educators can use this information for planning, implementing, and evaluating health promotion programs aimed at fostering successful community reintegration in adolescents and YA with SCI.

### Questions Regarding the Study

If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

Your consent to participate in this study is demonstrated in your participation as *PsychData* survey instructions are designed to indicate informed consent for participation. Thank you for your participation in this study that is designed to contribute to the knowledge base on community reintegration in adolescents and YA with SCI.

### Informed Consent

Please note that by clicking on the option that you agree to participate in this study, you are indicating your informed consent to participate in this study. If you have read and understand the above statements, please click on either "Yes, agree to participate" or "No, do not agree to participate". Agreement to participate will take you to the demographic followed by the three initial study questions. Before proceeding, please print a copy of the consent form to retain for your records. If you do not agree to participate, simply close this Internet address with the consent form.

## APPENDIX D

### Demographic Questionnaire

## Demographic Questionnaire

Instructions: Please answer the following to the best of your abilities. Please only choose one option for each questions from those presented.

Please indicate your current occupation. Select only one below.

Physical Therapist  
Occupational Therapist  
Music Therapist  
Child Life Specialist

Please indicate your sex:

Male  
Female

Please indicate your age in years.

20-25 years  
26-30 years  
31-35 years  
36-40 years  
41-45 years  
46-50 years  
51-55 years  
56-60 years  
61-65 years  
66+ years

Which of the following best describes your race?

American Indian or Alaska Native  
Asian  
Black or African American  
Native Hawaiian or Other Pacific Islander  
White

Which of the following best describes your ethnic origin?

Hispanic or Latino  
Not Hispanic or Latino

What is the highest earned degree (or degrees) you hold in any area of study? (Select only one.)

Baccalaureate degree  
Master's degree  
PhD (or equivalent, e.g. EdD or ScD)  
DPT or OTD  
PhD (or equivalent) and DPT or OTD  
Other

Using a total of 35 or more hours per week (at your primary position) as the definition of 'full-time', which one of the following describes your current employment status?

Full-time salaried  
Part-time salaried  
Full-time self employed  
Part-time self employed  
Full-time hourly  
Part-time hourly  
Retired  
Unemployed/not seeking work  
Unemployed/seeking full-time employment  
Unemployed/seeking part-time employment

Which of the following best describes the type of facility or institution in which you currently do all or most of your work (your primary position)?

Acute care hospital  
Subacute rehab hospital (inpatient)  
Health system or hospital-based outpatient facility or clinic  
Private outpatient office or group practice  
SNF/ECF/ICF  
Patient's home/home care  
School system (preschool/primary/secondary)  
Academic institution (post-secondary)  
Health and wellness facility  
Research center  
Industry  
Other (please specify): \_\_\_\_\_

APPENDIX E  
Delphi Round 1

## Delphi Round 1

### TEXAS WOMAN'S UNIVERSITY

#### DELPHI ROUND 1

Please answer the following questions to the best of your abilities based on professional interactions and experiences with adolescents and young adults (YA) with spinal cord injury (SCI) in clinical settings. Note that there is not a minimum or maximum length for your answer; however, it is encouraged that your answers are concise and efficient at conveying your expert opinion.

When answering the following questions, you should make no distinction between complete and incomplete or classifications pertaining to the mechanism, time, or level of SCI.

- 1) How would you define successful community reintegration as it relates to adolescents and YA with SCI?
- 2) In your opinion, what are the most critical barriers to community reintegration in adolescents and YA with SCI?
- 3) In your opinion, what is the most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community?

APPENDIX F  
Delphi Round 2

## Delphi Round 2

This questionnaire includes a series of statements of your personal opinions on three questions concerning community reintegration in relation to adolescents and young adults (YA) with spinal cord injury (SCI). These statements represent the collective opinions of those allied health professionals who responded to the first round of this Delphi study. The statements are arranged in random order under their representative questions.

In this second round, you are asked to rate the level of your agreement with each statement. There is no right or wrong answer. The rating you select will be based on the Likert scale below and should reflect your own personal opinions on each statement. None of your responses will be personally identifiable or linked to you.

### **Please choose just one for each response:**

- 1 = **Strongly disagree** with the statement
- 2 = **Disagree** with the statement
- 3 = **Somewhat disagree** with the statement
- 4 = **Neither agree nor disagree** with the statement
- 5 = **Somewhat agree** with the statement
- 6 = **Agree** with the statement
- 7 = **Strongly agree** with the statement

Q1) Successful community reintegration as it relates to adolescents and YA with SCI means that they \_\_\_\_\_.

- Have a good social support system (i.e. family, friends, and community)
- Have necessary adaptive equipment/durable medical equipment
- Are able to go back to school
- Participate in recreational/leisure and/or group social activities
- Have an established health care team (i.e. primary physician, neurologist, allied health, mental health)
- Have few physical/environmental barriers to achieve community mobility
- Independently complete activities of daily living (ADL)
- Address social stigmas including bullying and promote public awareness for SCI
- Achieve self-acceptance of their disability
- Become successfully employed
- Live independently
- Have autonomy with medical decisions
- Establish a committed relationship
- Have reliable transportation
- Become financially secure
- Have a good bowel and bladder program

Q2) Critical barriers to community reintegration in adolescents and YA with SCI include \_\_\_\_\_.

- Lack of financial support and/or unemployment
- Physical/environmental barriers including lack of transportation
- Poor social support systems
- Dealing with stigmas/biases of disability
- Poor self-acceptance resulting in depression and inability to cope
- Lack of adequate adaptive equipment/durable medical equipment
- Decreased autonomy/independence because of overbearing family members wanting to help
- Poor advocacy for SCI issues
- Inability to finish education
- Having to learn bowel and bladder programs
- Lack of participation in extracurricular activities
- Fatigue with activities

Q3) The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes \_\_\_\_\_.

- Providing psychosocial support (i.e. support groups, networking with others, and life –long counseling)
- Breaking down social barriers (i.e. advocating for SCI)
- Role playing for task-specific goal achievement
- Attending school visits and/or actively participating in classroom activities
- Participating in multi-disciplinary approaches, team meetings, and collaborative work (i.e. co-treatments, consulting social workers)
- Providing education for caregivers and others about SCI
- Establishing a bowel and bladder program
- Providing financial resources
- Promoting patient autonomy with health care decisions
- Providing transportation resources
- Supporting mobility for achieving ADL (i.e. providing wheelchair management clinics)
- Providing therapies and treatments in their own environments
- Assisting with finding employment
- Assisting in their community/environment problem solving
- Establishing Life Care Planners to help individuals with SCI navigate associated issues over the lifespan
- Effective approach does not exist

## APPENDIX G

### Round 2 Email

## Round 2 Email

Subject: Research Study Round 2 - Assessing Community Reintegration in Adolescents and Young Adults with SCI

Dear Research Participant,

Thank you for participating in Round 1 of "Assessing Barriers to Community Reintegration in Adolescents and Young Adults with Spinal Cord Injury: A Delphi Study". In Round 2, you will be asked to complete a questionnaire that includes a series of statements of your personal opinions on three questions concerning community reintegration in relation to adolescents and young adults (YA) with spinal cord injury (SCI). These statements represent the collective opinions of those allied health professionals who responded to the first round of this Delphi study. The statements are arranged in random order under their representative questions. In Round 2, you are asked to rate the level of your agreement with each statement. There is no right or wrong answer. The rating you select will be based on a 7-point Likert scale and should reflect your own personal opinions on each statement. None of your responses will be personally identifiable or linked to you.

Thank you again for participating in this study. Please complete all Round 2 responses no later than Friday, September 21, 2012.

### RESEARCH LINK:

<https://www.psychdata.com/s.asp?SID=149396>

-----

Dr. Roy Rivera, Jr., PT, DPT, CHES  
Physical Therapist and Certified Health Education Specialist

## APPENDIX H

### Round 2 Reminder Email

## Round 2 Reminder Email

Subject: \*\*\* REMINDER EMAIL Research Study Round 2 \*\*\*

Please complete Round 2 of the survey if you haven't done so already. The link will remain open until Friday, September 21, 2012. As of today, 20% of participants have completed Round 2. If you are one of them, thank you and please disregard this reminder.

### RESEARCH LINK:

<https://www.psychdata.com/s.asp?SID=149396>

Dear Research Participant,

Thank you for participating in Round 1 of "Assessing Barriers to Community Reintegration in Adolescents and Young Adults with Spinal Cord Injury: A Delphi Study". In Round 2, you will be asked to complete a questionnaire that includes a series of statements of your personal opinions on three questions concerning community reintegration in relation to adolescents and young adults (YA) with spinal cord injury (SCI). These statements represent the collective opinions of those allied health professionals who responded to the first round of this Delphi study. The statements are arranged in random order under their representative questions. In Round 2, you are asked to rate the level of your agreement with each statement. There is no right or wrong answer. The rating you select will be based on a 7-point Likert scale and should reflect your own personal opinions on each statement. None of your responses will be personally identifiable or linked to you.

Thank you again for participating in this study. Please complete all Round 2 responses no later than Friday, September 21, 2012.

### RESEARCH LINK:

<https://www.psychdata.com/s.asp?SID=149396>

-----

Dr. Roy Rivera, Jr., PT, DPT, CHES  
Physical Therapist and Certified Health Education Specialist

**APPENDIX I**  
**Delphi Round 3**

### Delphi Round 3

This questionnaire includes a series of statements of your personal opinions on three questions concerning community reintegration in relation to adolescents and young adults (YA) with spinal cord injury (SCI). These statements represent the collective opinions of those allied health professionals who responded to the first round of this Delphi study. The statements are arranged in random order under their representative questions.

Completion of Round 3 should take approximately 15 to 20 minutes. Completion is requested by October 17, 2012. Round 3 of this study is being provided to you in a similar manner as Round 2 on the PsychData website. The opinion statements will include the group's mean, standard deviation (SD) and range of responses. The mean represents the group's opinion of that particular statement. The SD represents the amount of disagreement about that statement among the group. The range will give you the range of responses for each item. I am requesting that you re-rate your opinion on the importance of each item. This allows you the opportunity to change your mind regarding your own opinion. I have included a free response box after each item. Please indicate how you changed your mind and in what way.

In this third round, you are asked to rate the level of your agreement with each statement. There is no right or wrong answer. The rating you select will be based on the Likert scale below and should reflect your own personal opinions on each statement. None of your responses will be personally identifiable or linked to you. Please also respond in the free response block after each question as to how and why you changed your mind on your ratings of each of the items.

#### **Please choose just one for each response:**

- 1 = **Strongly disagree** with the statement
- 2 = **Disagree** with the statement
- 3 = **Somewhat disagree** with the statement
- 4 = **Neither agree nor disagree** with the statement
- 5 = **Somewhat agree** with the statement
- 6 = **Agree** with the statement
- 7 = **Strongly agree** with the statement

Q1) Successful community reintegration as it relates to adolescents and YA with SCI means that they \_\_\_\_\_.

- Have a good social support system (i.e. family, friends, and community)
- Have necessary adaptive equipment/durable medical equipment
- Are able to go back to school
- Participate in recreational/leisure and/or group social activities

- Have an established health care team (i.e. primary physician, neurologist, allied health, mental health)
- Have few physical/environmental barriers to achieve community mobility
- Independently complete activities of daily living (ADL)
- Address social stigmas including bullying and promote public awareness for SCI
- Achieve self-acceptance of their disability
- Become successfully employed
- Live independently
- Have autonomy with medical decisions
- Establish a committed relationship
- Have reliable transportation
- Become financially secure
- Have a good bowel and bladder program

Q2) Critical barriers to community reintegration in adolescents and YA with SCI include \_\_\_\_\_.

- Lack of financial support and/or unemployment
- Physical/environmental barriers including lack of transportation
- Poor social support systems
- Dealing with stigmas/biases of disability
- Poor self-acceptance resulting in depression and inability to cope
- Lack of adequate adaptive equipment/durable medical equipment
- Decreased autonomy/independence because of overbearing family members wanting to help
- Poor advocacy for SCI issues
- Inability to finish education
- Having to learn bowel and bladder programs
- Lack of participation in extracurricular activities
- Fatigue with activities

Q3) The most effective multidisciplinary approach that an allied health professional can take to help adolescents and YA with SCI successfully reintegrate into the community includes \_\_\_\_\_.

- Providing psychosocial support (i.e. support groups, networking with others, and life –long counseling)
- Breaking down social barriers (i.e. advocating for SCI)
- Role playing for task-specific goal achievement
- Attending school visits and/or actively participating in classroom activities
- Participating in multi-disciplinary approaches, team meetings, and collaborative work (i.e. co-treatments, consulting social workers)

- Providing education for caregivers and others about SCI
- Establishing a bowel and bladder program
- Providing financial resources
- Promoting patient autonomy with health care decisions
- Providing transportation resources
- Supporting mobility for achieving ADL (i.e. providing wheelchair management clinics)
- Providing therapies and treatments in their own environments
- Assisting with finding employment
- Assisting in their community/environment problem solving
- Establishing Life Care Planners to help individuals with SCI navigate associated issues over the lifespan
- Effective approach does not exist

## APPENDIX J

### Round 3 Email

### Round 3 Email

Subject: FINAL ROUND - Assessing Community Reintegration in Adolescents and Young Adults with SCI

RESEARCH LINK:

<https://www.psychdata.com/s.asp?SID=150711>

Dear Research Participant,

Thank you very much for your participation in Round 1 and/or 2 of the Delphi study aimed at gaining consensus on statements concerning community reintegration in relationship to adolescents and young adults with spinal cord injury. I am now asking for your participation in Round 3 to complete the study.

In Round 3, you are asked to rate the level of your agreement with each statement. There is no right or wrong answer. The rating you select will be based on the Likert scale from the previous round and should reflect your own personal opinions on each statement. None of your responses will be personally identifiable or linked to you.

Completion of Round 3 should take approximately 15 to 20 minutes and is requested by October 15, 2012. Round 3 of this study is being provided to you in a similar manner as Round 2 on the Psychdata website. The opinion statements are a reflection of those responses to Round 2 and will include the group's mean, standard deviation (SD) and range. The mean represents the group's opinion of that particular statement. The standard deviation represents the amount of disagreement about that statement among the group. The range will give you the range of responses for each item. I am requesting that you re-rate your opinion on the importance of each item, although your opinion may remain the same. This allows you the opportunity to change your mind regarding your own opinion after seeing the way others have responded. I have included an optional free response box after each item so that you may indicate how or why you changed your mind.

RESEARCH LINK:

<https://www.psychdata.com/s.asp?SID=150711>

Thank you again for contributing to the body of literature on adolescents and young adults with SCI.

-----

Dr. Roy Rivera, Jr., PT, DPT, CHES  
Physical Therapist and Certified Health Education Specialist

## APPENDIX K

### Round 3 Reminder Email

### Round 3 Reminder Email

Subject: LAST CALL -- Delphi Study

RESEARCH LINK:

<https://www.psychdata.com/s.asp?SID=150711>

Dear Research Participant,

Thank you very much for your participation in Round 1 and/or 2 of the Delphi study aimed at gaining consensus on statements concerning community reintegration in relationship to adolescents and young adults with spinal cord injury. I am now asking for your participation in Round 3 to complete the study. If you have already responded to this email, thank you and please disregard.

In Round 3, you are asked to rate the level of your agreement with each statement. There is no right or wrong answer. The rating you select will be based on the Likert scale from the previous round and should reflect your own personal opinions on each statement. None of your responses will be personally identifiable or linked to you.

Completion of Round 3 should take approximately 15 to 20 minutes and is requested by midnight, October 15, 2012. Round 3 of this study is being provided to you in a similar manner as Round 2 on the Psychdata website. The opinion statements are a reflection of those responses to Round 2 and will include the group's mean, standard deviation (SD) and range. The mean represents the group's opinion of that particular statement. The standard deviation represents the amount of disagreement about that statement among the group. The range will give you the range of responses for each item. I am requesting that you re-rate your opinion on the importance of each item, although your opinion may remain the same. This allows you the opportunity to change your mind regarding your own opinion after seeing the way others have responded. I have included an optional free response box after each item so that you may indicate how or why you changed your mind.

RESEARCH LINK:

<https://www.psychdata.com/s.asp?SID=150711>

Thank you again for contributing to the body of literature on adolescents and young adults with SCI.

-----

Dr. Roy Rivera, Jr., PT, DPT, CHES  
Physical Therapist and Certified Health Education Specialist

Appendix L  
Curriculum Vitae

# Dr. Roy Rivera, Jr., PT, DPT, CHES

---

<b>OBJECTIVE</b>	An opportunity to utilize my didactic and clinical experience in allied health, rehabilitation, wellness, and health studies for the completion of Texas Woman's University's Doctorate of Philosophy in Health Studies	
<b>EDUCATION</b>	<b>Texas Woman's University</b>	<b>Denton, TX</b>
	Doctorate of Philosophy in Health Studies	
	<i>Concentration: Community/Population Health</i>	
	Anticipated Date of Graduation: May 2013	
	<b>Rocky Mountain University of Health Professions</b>	<b>Provo, UT</b>
	Doctor of Physical Therapy	
	December 2007	
	<b>University of Texas Medical Branch</b>	<b>Galveston, TX</b>
	Master of Physical Therapy	
	December 2005	
	<b>Southwestern University</b>	<b>Georgetown, TX</b>
	Baccalaureate of Arts in Biology	
	December 2002	
<b>EMPLOYMENT HISTORY</b>	<b>Crōm Rehabilitation, LLC</b>	
	8935 Andante Dr., Houston, TX 77040, Ph: 713.725.5464	
	<i>CEO and Director of Rehabilitation</i> – [September 2012 – Present]	
	<b>Cross Country Education</b>	
	9020 Overlook Blvd, Ste. 140, Brentwood, TN 37027, Ph: 615.331.4422	
	<i>Faculty</i> – [July 2009 – Present]	
	<b>Supplemental Health Care</b>	
	2100 West Loop South, Suite 1525, Houston, TX 77027, Ph: 713.965.9998	
	<i>Contract Senior Physical Therapist</i> – [June 2007 – present]	
	<b>AccuCARE Therapy Services</b>	
	15211 Heather Mist Court, Cypress, TX 77433, Ph: 832.277.5556	
	<i>Home Health Rehabilitation</i> – [November 2006 – June 2007]	
	<b>TIRR Rehabilitation Centers at Town and Country</b>	
	700 Town and Country Blvd., Ste. 2490, Houston, TX 77024, Ph: 713.722.0156	
	<i>Outpatient Orthopedic, Aquatic, and Neurologic rehabilitation</i> – [December 2005 – November 2006]	
	<b>University of Texas Medical Branch Acute Care for the Elders Unit</b> [2003] – Galveston, TX	
<b>CLINICAL INTERNSHIPS/ RESIDENCIES</b>	<b>Concentra Urgent Care</b> [2004] – Houston, TX	
	<b>HealthSouth Rehabilitation Hospital of Miami</b> [2004] – Kendall, FL	
	<b>University of Texas MD Anderson Cancer Center</b> [2005] – Houston, TX	
	<b>University Medical Center Brackenridge</b> [2005] – Austin, TX	
<ul style="list-style-type: none"><li>Each clinical internship/residency consisted of a four- to eight-week affiliation with both patient care and teaching experiences in specialization tracks to include: geriatrics, occupational medicine, sports medicine and rehabilitation, neurologic oncology, and trauma/wound care.</li></ul>		

# Dr. Roy Rivera, Jr., PT, DPT, CHES

---

## RESEARCH/ PUBLICATIONS

- Rivera, R. (2013). *Assessing Community Reintegration in Adolescents and Young Adults with Spinal Cord Injury: A Delphi Study*. (Unpublished doctoral dissertation). Texas Women's University, Denton, TX.
- Rivera, R. (2009). *Therapeutic modalities in rehabilitation*. Brentwood, TN: Cross Country Education.
- Rivera, R. (2007). *Identifying, assessing and decreasing falls in homebound older adults: An evidence-based case series report* (Unpublished doctoral dissertation). Rocky Mountain University of Health Professions, Provo, UT.
- Rivera, R., Harrison, J., Whitehead, M. (2005). *The correlation of subjective and objective balance measures to the ability of older adults to maintain dynamic balance during challenged gait* (Unpublished master's thesis). University of Texas Medical Branch, Galveston, TX.

## COURSE INSTRUCTION/ LECTURES

A three part series approved by the Texas Physical Therapy Association that includes: **“Ethics for Rehabilitation Professionals”, “Professional Development and Ethical Responsibility in Rehabilitation”, and “Professionalism in Physical Therapy: A Modern, Evidence-based Approach”**

- The three-part series of lectures is designed specifically for physical therapists, physical therapist assistants, occupational therapists, and occupational therapist assistants. The objectives of these courses are the following: to define ethics and establish a foundational knowledge base for clinical decision-making; examine the American Physical Therapy Association's Code of Ethics and Guide for Professional Conduct; describe legal standards of conduct and discuss ramifications for violations as outlined in the Texas Board of Physical Therapy Examiner's Practice Act and Physical Therapy Rules; identify, critically analyze, and problem solve through compromising case scenarios; and define professionalism as it applies to healthcare and establish those core values vital to the practice of physical and occupational therapy.

### **“Therapeutic Modalities in Rehabilitation”**

- This national lecture series is designed specifically for physical therapists, physical therapist assistants, occupational therapists, occupational therapist assistants, athletic trainers, massage therapists, nurses, and chiropractors. The objectives of this course are the following: to assess the most commonly used modalities, their mechanisms of action and those physiologic changes that occur when applied; identify pathology-dependent indications, contraindications and precautions for the application of physical agents; utilize an efficient screening process for sorting through the literature to determine those studies of highest power and significance to clinical application; and discuss the development of modern modalities and implications for future research.

## PROFESSIONAL DEVELOPMENT

- “Diagnosis and Management of the Neurologic Shoulder” – Julie Jennings, PT [2009]  
“Governmental Affairs and Ethics” – Patricia Bolli Nelson, PT [2007]  
“Strength Training Program Design” – International Weightlifting Association [2006]  
“Management of Rotator Cuff Injuries” – Charles Metzger, MD [2006]  
“An Overview of Cervical Spine Surgeries and Physical Therapy Interventions” – Alex Valadka, MD, Lance Langland, PT, and Colette Pientok, PT [2006]

## CERTIFICATIONS

- Certified Health Education Specialist (CHES)** – National Commission for Health Education Credentialing, Inc., Certification #18760  
**Certified Strength Training Specialist (CSTS)** – International Weightlifting Association [2006]  
**Basic Life Support for Healthcare Providers (CPR & AED)** – American Heart Association [2003 – Present]  
**Heartsaver Pediatric First Aid** – American Heart Association [2009 – Present]

# Dr. Roy Rivera, Jr., PT, DPT, CHES

---

<b>LICENSURE</b>	Texas Board of Physical Therapy Examiners – License #1166310
<b>PROFESSIONAL MEMBERSHIPS</b>	American Physical Therapy Association [2003 – Present] Texas Physical Therapy Association [2003 – Present] American Public Health Association [2011] – <i>Chiropractic Health Care Section Member</i>
<b>AWARDS</b>	“Star Award” – Supplemental Health Care’s Outstanding Clinical Practitioner [2009]
<b>REFERENCES</b>	<p><b>Marilyn Massey-Stokes, EdD, CHES, FASHA, IC®</b> Associate Professor, Department of Health Studies – Texas Woman’s University PO Box 425499, Denton, TX 76204-5499 Ph: 940.898.2863 mmasseystokes@twu.edu</p> <p><b>Sue Evans, PTA</b> Physical Therapist Assistant – Supplemental Health Care 2100 West Loop South, Suite 1525, Houston, TX 77027 Ph: 281.744.7997 sevens0320@yahoo.com</p> <p><b>Terence Chang, MD</b> Family Practice Physician, Physicians at Sugar Creek – Memorial Hermann Hospital System 14023 Southwest Fwy., Sugar Land, TX 77478 Ph: 713.927.9731 terencechangmd@gmail.com</p>