

# Happiness, Resilience, and Quality of Life among Individuals with Spinal Cord Injury

Report of Participant Responses  
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**DMC**  
Rehabilitation Institute  
of Michigan  
*always there.*



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# Happiness, Resilience, and Quality of Life Among Individuals with Spinal Cord Injury

## Purpose of the Report

1. To provide you – the participants – with information about study findings and results.
2. To clarify issues raised by both the study and its findings and to ask additional questions.
3. To get feedback from you to inform our interpretation of results and conclusions.

## Study Overview

While there is ample evidence that individuals with spinal cord injury (SCI) can experience a high quality of life, there is little understanding about how this happens. Research on adjustment after SCI has generally focused on identifying fixed characteristics such as race, resources, or personality that serve as risk factors or supports, as opposed to looking for factors that can be changed or modified. However, previous studies suggest that key events, experiences, and ways of thinking (cognitions) shape future decisions, behaviors and outcomes for individuals with SCI.

## Specific Goals

The objective of this investigation is to examine how what people think, the decisions they make, and the actions they take after SCI are associated with good adjustment and positive outcomes among individuals from both military and nonmilitary backgrounds. In particular, we proposed the following goals for the project:

*Goal 1:* Gather details about the cognitions, decisions, and behaviors of individuals with SCI after injury that may have been instrumental in promoting positive outcomes.

*Goal 2:* Analyze and compare data obtained from military and nonmilitary participants to determine similarities and differences, if any, in decisions, cognitions, and behaviors and their relationships to more global psychosocial and environmental factors and characteristics.

*Goal 3:* Interpret, summarize, and share project results with various stakeholders to facilitate the development of new assessments, interventions, and programs that enhance successful adjustment among individuals with new SCI.

## Impact

It is critical to identify the cognitions, decisions, and behaviors that are associated with successful adjustment among individuals with SCI in order to better inform treatment and improve outcomes for others. Information from this study will be used to develop interventions to support the adjustment of military personnel with SCI, including both direct patient programs and professional training modules, which can also be adapted for use by individuals not in the military.

## Study Design

This study is the second phase of a larger project funded by the Department of Defense entitled *Cognitions, Decisions, and Behaviors Related to Successful Adjustment among Individuals with SCI: A Qualitative Examination of Military and Nonmilitary Personnel*. (The first phase consisted of a survey completed by over 400 individuals.) The primary goal of this phase was to interview individuals with SCI from both military and nonmilitary backgrounds who experienced successful adjustment to SCI, defined as good emotional health, happiness, and participation in family or community activities.

## Recruitment Methods

Potential interview participants were those who responded to the Phase 1 survey and put their names and contact information. From the survey, information on military background, resources (household income and insurance coverage), and time since injury, as well as responses indicating successful or unsuccessful adjustment, were used to recruit a stratified (balanced) sample.

We used the Flourishing Scale as part of the survey in Phase 1 of the project to identify individuals who seemed to be doing well. This measure looks at how people see themselves in important areas such as relationships, self-esteem, purpose, and optimism. Individuals who scored in the top 50% of participants were categorized as “successful” and were invited to participate in Phase 2 of the study.

## Sample Characteristics

We completed a total of 60 interviews (29 military, 31 nonmilitary). Of those who were in the military, 10 were combat veterans, 19 receive VA benefits, and 22 receive care at a VA healthcare facility. Nine of the 29 injuries were service connected.

Ages ranged from 20 to 90 (the average age was 50.5). Only 9 of the interviewees were female, which is in line with the nationwide male-female split for SCI. Fifty-one of the participants were White, 4 were Black, 1 was Native Hawaiian, and 4 identified themselves as multiracial. Incomes ranged from less than \$20,000 per year to \$80,000 and over.

Twenty-seven were married or partnered, 18 were single, 13 were divorced, and 2 were widowed. The majority of participants live in suburban (22) or rural (28) areas; the other 10 live in urban areas. Everyone had at least a high school diploma or GED; most individuals (47) had at least some college, with 24 having a Bachelor's degree or higher. Most (40) were not employed.

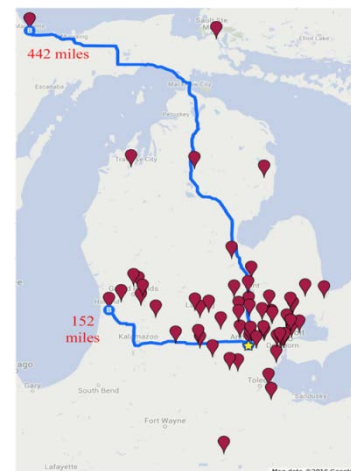
There was a range of injuries from between high cervical to S3, but the most frequent injury level (25) was between T1 and T12. Thirty-one had movement below their level injury and 37 had feeling below the level of injury. All but one person reported having health insurance. Medicare (31), employer health plan (21), and VA (17) were the most common sources of insurance. Most (48) rated their health as good, very good, or excellent.

## Interviews

Participants were interviewed in a comfortable location (primarily in their homes) with interviews lasting between 30 minutes to 3 ½ hours. A map of participants' locations is provided here.

The interview focused on the following questions:

- 1) Tell me about yourself and how you got to this point in your life.
- 2) In thinking about what you said, can you tell me about some of the high points?  
What about the low points?



- 3) How did you get to where you are now?
- 4) Tell me more about your background.
- 5) Now I want to find out more about how you thought about things immediately after your spinal cord injury and how you think about things now.
- 6) Were there specific actions which were consciously performed to advance priorities and promote health and quality of life?
- 7) In thinking about everything you have said during this interview, what things do you feel contribute most to your happiness or satisfaction with life?
- 8) Finally, what do you think is most important for those with new spinal cord injuries to be able to adjust and be successful?

### Background of Participants

In addition to the demographic information collected in the survey, participants also told us more about themselves during the interview. From this, we discovered that individuals who were identified as flourishing after SCI did not come from one specific type of background. They came from diverse areas of the country. Some were born in Michigan while others were from other regions of the country.

- *Right here in Detroit, Michigan. Yeah, right in Detroit, Michigan, bred.*
- *I grew up in New Jersey. In central Jersey.*

Some participants told us that they had moved around a number of times as a child. It may be that in doing so, they developed the ability to adapt to new situations – a skill that may have helped after their SCI.

- *I changed high schools every year. At the beginning of every year, I was a new kid in a different state.*
- *I used to live in every Southern state with my mother at the Air Force with my stepfather. You know, Georgia, North Carolina, South Carolina – I lived in Virginia, I've lived in New York....*

For the most part, our participants grew up in rural or suburban areas. The areas where they grew up may have impacted their relationships to other people.

- *Yeah, small town and, yeah, it was just a giant neighborhood. And I knew all the kids in the neighborhood. We all went to the same school.*
- *The friends I had ...set high standards for me ...and my parents sort of wanted me to—they didn't have a whole lot of money and I think they thought that if I'm going to be able to afford college—they wanted me to go to trade school, and even my dad had gone to business college.*

While many of the participants appeared to have grown up in supportive two-parent families, this was not universally the case. However, most of the individuals indicated that they felt safe and supported even if their parents were divorced. Relationships with siblings were also generally characterized as good.

- *Family support system in my younger years was very, very good. My parents got divorced after 25 years, so I was a college student when they divorced. So I had a two-parent household. Though we moved a lot, we were a family.*
- *When I grew up I was having a nuclear [family] – mother and father were married. ... We were really close. I had a very good childhood. In terms of when I was growing up, I didn't have that many problems. Went to school. I got along with my brothers and sisters. I have a younger brother and an older sister. We used to fight a lot, but we got pretty close as we got older. Oh. We had a lot of cousins. We pretty much grew up together, all of us.*

As evident above, many participants felt as if they had grown up with strong family ties and a strong support system.

- *Chaotic. I remember a lot of yelling and screaming. My parents were divorced—my parents got divorced when I was 16.*

Even those who discussed having experienced more challenges growing up were able to identify positive influences on their lives.

- *Maybe ... because I knew how bad my dad was, became an alcoholic, I didn't get much off my dad except operating equipment type thing. As far as the father figure he was terrible. But as a man he was awesome but that was end of that. But [my stepfather] told me what a man should be. ...So he treated me fine.*

## Socioeconomic Background

Being able to adjust to SCI did not appear to be associated with one particular socioeconomic background. Some participants described growing up poor, while others were in the middle or upper classes. Even those with less income and fewer resources, though, described having “enough” and feeling as if their actions made a difference, both in their own lives as well as in the lives of others.

- *We lived on the east side of Des Moines, which is the poor side of town, but never felt want for anything even though we didn't have a whole lot of money.*
- *Upper class. I mean my dad was doing well at [his company] ... We never had to want for anything....*
- *[I grew up] during the Depression. My dad worked in a steel mill.*

## Education

All of the participants graduated from high school or earned a GED. Some had attended college to varying degrees. Many of those who stopped after high school stated that they had done so not because of a lack of intelligence but because they were not interested in school and did not apply themselves.

- *Just the normal problems. I was really a good kid. I think I got a couple detentions here and there.... All the teachers liked me and respected me 'cause I knew what I was doing and I just didn't put the effort into doing it.... Any time I was tested, [they'd say] "You're really smart. You just don't put any effort into it."*

## Personality

Many participants described themselves as outgoing, active, and social.

- *Well, I was just a fun-loving guy—still am [laughs]—and I just hung out with friends, did the normal things [like] party, went to concerts—what your average early 20-year-old would do.... I was working at a store and, um, had recently moved out, and was just doing the normal thing, like partying all the time.*



Others described being entrepreneurial:

- *Back then all you could burn – I mean all they heated their homes with was coal. So when you heat a home with coal you got all the ashes, so everybody had a pile of ashes in their backyard, and there was a city dump which was probably about a mile or so away, and I would haul people’s ashes for ten cents a load with a wagon. I’d put like two bushel baskets of ashes on it, and I got ten cents for hauling them to the dump. And the other thing, I’d go out – I cut people’s grass, but I didn’t make too much doing that, I got 25 cents an hour for cutting grass.*

Some participants described themselves as athletes while growing up and appeared to associate benefits from that type of activity and role.

- *I’ve always been an athlete, I played three sports in college and I had a scholarship offer for wrestling and football at one school. I could have played—I tried out and made the baseball team at [my university]. So yeah, I was always in athletics and I miss that a lot!*
- *I had played pretty competitive ice hockey from the time I was 12 through college and then loved football. Like to watch football. Still play softball. Still play sled hockey. Did all those things growing up and always went on family vacations.*

Others just described themselves as active, particularly in participating in outdoor activities.

- *I used to be very active – very, very active. I liked to run around and liked to drink beer and hunt and fish. I would consider myself pretty active before the accident. I rode a bicycle and yeah, I was very active. Fished – I had friends that fished and we’d always go fishing on our days off and stuff like that. Then shooting, reloading.*

## Religious Upbringing

Religion played different roles for different people in this study. Some individuals were raised in religious families while others were not.

- *I grew up not having a whole lot of spirituality or religion in my life. ...So my mom and dad decided “We’re not going to have our kids brought up in any certain religion; we’re going to let them do what they want” because they didn’t want us*

*kids to go through anything like that when we were starting to settle down and start our own families.*

- *Well, I was raised up Baptist. Sunday morning, Sunday night, Wednesday, Tuesday prayer. The whole summer camp – the whole everything. But I don't know, there was so much of it that I just veered away from it when I got out of the house. It was always present – [I was] always aware, and I do believe.*

## **Cognitive Flexibility**

Participants in this study were given the Stroop test, a measure of mental sharpness and flexibility. They were first presented with the Color Task to assess reading accuracy. The second task, the Color-Word Task was used to show how quickly and accurately they were able to take in the information they saw and give us the information we were looking for, which was the color of the word. The higher the score, the better. Overall, the scores were pretty similar to what is found in the general population. Our findings suggest that individuals who have been successful with adjusting to their SCI generally have a good level of cognitive flexibility which allows them to problem-solve and deal with new situations and environments.

## **Social Support**

Participants' responses on a standardized measure of social support (the Interpersonal Support Evaluation List, or ISEL 12) appear to support the importance of people in their lives. The ISEL-12 measures the extent to which respondents feel they have people to socialize with or provide them with emotional or practical support. The higher the score, the more social support that person believes he or she has. Our participants' scores were only slightly higher than the normative sample, which is consistent with the operational definition we used for success after SCI (that is, to flourish). Moreover, it seems to suggest that most participants felt they had people they could count on when they really needed it.

## **Background Values and Habits**

Participants in our study mentioned specific values, habits, and lessons they learned while growing up that they felt were important in making them the person they were. Many participants displayed a strong sense of practicality and self-reliance. This was particularly true if they grew up on a farm or in rural areas.

## **Respect people**

- *And that's how they raised me is to respect people and so, yeah, I want to respect them in what they ask me to do.*

## **Work ethic**

- *And I think having a strong work ethic. I grew up working my whole life.*
- *But I was fortunate enough to be doing stuff when I was probably too young to be doing it. ...When I grew up, once you were big enough to reach the clutch pedal on the tractor well, you drove on the bailer. That's what you did.*

## **Military Background**

Many of our participants verbalized clear values and skills they'd learned while serving in the military that wound up being particularly useful in managing their SCI. In particular, the following key messages or expectations associated with the military were articulated.

## **Accountability**

- *Well yeah, I mean, they hold people accountable for what they do a lot more than the civilian world does.*

## **Attitudes**

- *Just the attitude that you can get things done and never give up and things like that. That's why I still belong to the VFW and all the guys there that – most of the guys I hang around with are Marines and we all had that same attitude. That's the Marine Corps attitude that nothing will hold you back and not to give up. Get things accomplished. That's probably the same in life. Working... and doing all the other stuff is the training I had back then, and your fellowship with your friends and colleagues and stuff like that. That's real necessary.*

## **Communication**

- *I don't think I was ever a good communicator.... I wouldn't say that I was a bully, but I definitely would not back down and I think that was the result of not being*

*able to communicate. So you have to make that transition in life and I think the military helped with that.*

### **Confidence**

- *Yeah, buddy, I went and got some plain clothes, so I've always done extra for everybody for that kind of thing.... I've always volunteered for anything that had to be done in the military but it gives yourself confidence. It really builds you up.*

### **Cooperation**

- *How to work together, how to be a man, how to think for yourself, how to, you know, how to basically treat other people, how to live together in a – as much as I hate other people – learn how to collaborate with others and when you have to be right there with them all the time. But it gave me structure. It gave me a little sense of how to be polite. You had to – that's where you got your no sir, yes sir, yes ma'am, and that kind of thing – ...that all comes from it.*

### **Coping Strategies**

- *Improvise, adapt, and overcome.*
- *The army taught me how to be patient. Hurry up and wait....*

### **Discipline**

- *I think discipline and following authority is one of the things that stuck with me through the military.*
- *You got to learn to take orders. If you are not the type of person who wants to take orders, you ain't going to make it. Because you ain't the boss!*

### **Goal Setting**

- *It is kind of like mission-focused, I guess you would call it, and then you kind of set a goal for yourself, and you aim towards it, and you work towards it, and sometimes when you get to the goal you are really not sure what to do, but you work towards a goal.*

## **Independence**

- *It was definitely a growing up. I kind of looked at it later and said, "It should almost be a requirement for every kid to go through this." Makes them grow up real fast and realize that it's not just a big old game. It's real life. You've got to work, you've got to compete with other people and you're not judged by...like the famous Martin Luther King. You're judged by what you do, not by what you look like or who you know, for the most part.*

## **Integrity**

- *Teamwork, integrity. I'm a big person on integrity. Say what you mean, mean what you say, and if you say you're going to do something, you need to do it.*

## **Leadership**

- *Lots of things. How to read people. That's the biggest thing, how to read people.*
- *Probably some leadership skills, because when you're running a squad you've got some things there and I guess maybe the most would probably be learning the different personalities of people and how to lead them. What motivates one person doesn't motivate another person. You've got to get different people different ways to get them to do – get them in line to do what they're doing and try to pull them along with the group.*

## **Listening**

- *I still remember the stuff today and listening to my doctors. When I had to listen to my drill sergeants and all that, [it] kind of got me on the path to listen to my doctors because I always thought I had a better plan, but I don't.*

## **Organization**

- *The way I keep things, the way I keep organized, the routines – kind of incorporated you know do certain things certain ways. And the results you get are all valuable teaching tools....*
- *I think I'm a bit more organized, a little bit more ordered. Like I said, I wasn't in all that long, but I do find myself organizing, especially supplies and stuff, kind of making sure I have enough of -- even at the shop here, the sandpaper and the*

*paint, you know, I've got it all organized in cabinets and stuff, and I didn't used to do that before. I don't know if that came from the military or just from necessity, but I do find myself more organized than I used to be. It used to be I, you know -- because I used to -- I'd throw everything in the toolbox, and it was where it was.*

### **Perseverance**

- *Well I think it was kind of reinforced that if you work hard and put your mind to it, you can do just about anything and you will be rewarded.*
- *I can say in the military I did develop – and me being as timid as I was and going to the military – that might have even started some of my strengths as well because of how the drill sergeants would yell. They'd stomp, they'd – irate idiots as I call them – but at the end of the day when I figured it out I'm like "Okay. They're here to do a job and that's to intimidate us." So I developed mind over matter and that mind over matter literally has carried me to this point now. Whatever your situation is, it is literally mind over matter.*

### **Relationships**

- *I was just doing my job ...We were just doing our job like 500,000 other guys over there at the time. So your friends had a way from making you think you were special. But it was good camaraderie. I mean, we were tight. ...The six of us, we were very tight.*

### **Respect**

- *But that was just because that was who they were, but I think I got out of – more out of what anybody gets out of a job in the sense that you have respect for other people you work with and understand the significance of the job that you have and you do it to the best of your abilities.*

### **Responsibility**

- *Yeah, it teaches me how to – you know, my grandfather already taught me how to take care of myself and to be a man, let's say. Responsibility, he just instilled responsibility. It just instilled everything that my family had already told me about responsibility, cleanliness, and how to take care of yourself. I had already learned about weapons because I hunted and everything. They just instilled the things that my family had already taught me. ...That's why I say I was able to deal with*

*boot camp and everything that people say they can't deal with. People telling you what to do or when to go. I had been raised like that – organized. How you go to sleep at a certain time, you take care of your room, your area, and things like that in general.*

### **Survival**

- *Oh, yes! Oh, yes, definitely. It played a big role. Because I been through a lot of obstacle courses, and being in this wheelchair is one obstacle course. It's like an obstacle course. You either pass or you fail. Because it's like going to basic training. Or you goin' Ranger School or Special Forces or, you know, Commando, whatever, Navy Seal, whatever. ...You got to survive.*

## **Feelings and Thoughts Immediately after SCI**

We were interested in what participants felt and thought immediately after their SCI. Since it is sometimes difficult to accurately recall that type of information – especially given the range of years that has passed – the information below can probably be best thought of as current recollections about thoughts (cognitions) and feelings (emotions) after the SCI.

### **Feelings Immediately Following Injury**

#### **Depression / Sadness**

- *Post-injury for like the first year, year and a half, I was pretty down in the dumps. I feel like I didn't know what to do, really confused, just worried about where I was going to go in life.*

#### **Suicidal**

- *This sucks. I had contemplated suicide. I thought maybe it's better if I died. Your mind runs through the whole thing: "What if I'm stuck like this forever? I don't want to live like this." But I think for me it was just part of the thought process and then you obviously reject that.*

## **Anger**

- *I was always angry. It's an adjustment you have to go through. Being depressed is one of them. You have to take your time. You have to go through a cycle, and then eventually accept it.*
- *I was really angry – I mean, really angry. That's why I said I scared the pastor ... I think because I didn't have nothing good to say to God or anybody else as far as that matter went.*

## **Worry / Anxiety**

- *I guess a little anxious about how – maybe worried about how it was going to affect everything.*

## **Uncertainty**

- *I guess there's a lot of fear of the unknown and that's – you don't know what to expect. You don't know what you can do.... And so I think initially you have that fear that you don't have that independence or freedom. It was taken from you....*

## **Broken / Helplessness**

- *I felt just broken down. I know that I went into a – I was worried about my fiancée at the time. I remember being worried about that, like that was – really worried me, but I remember having those same feelings when I had that wound and I went to Chicago and I had to lay in an air mattress, air bed for an extended period of time until it healed. I remember having those same feelings, but they're more feelings of helplessness. And so maybe at a time when I felt broken, I just felt helpless because I didn't have a wheelchair at that time. I didn't have a brace. I wasn't able to get up. So I guess, for me, I wasn't able. You're someone who's independent, doing everything for yourself and everything in life, and then all of a sudden you can't do that. You just kind of feel pretty helpless.*
- *I was sad, you know, I cried a lot. It was kind of like, well, we're in a whole process. I mean when you just – it was sad as much as anything else. It's like god, I mean I can't – just a basic thing, I want to go down, walk down the driveway maybe. You can't do it, and then all of a sudden you're in a world that's not set up for wheelchairs....*



### **Determined to walk**

- *I never let it bother me. I knew I was going to walk. I was going to get around...*
- *Well, I can't tell you exactly what all I was thinking. At that time I was in a lot of pain and stuff so I was more thinking probably about the daily things and my daily routine and what I had to do and get strapped up with that turtle shell and trying to get some of my bounce back and then I pushed it hard for a year in therapy there. I was determined to walk. I did, but like I said, it wasn't functional.*

### **Determined not to give up**

- *I didn't give up. Didn't give up. And I had – one of my biggest inspirations was my daughter. I mean, I wasn't going to be down because – I just got to stay strong because of her. That was probably my biggest inspiration right there, and, I didn't give up. I kept on doing stuff... I did stupid things that I shouldn't have done with that back brace on, like picking stuff up. I was only supposed to pick up the newspaper but I was determined that I was still gonna do it, so I'm lucky I didn't get hurt again. But no, just – strong-minded, kept on going. That's what I did.*

### **Discouragement**

- *Oh, there's times I get discouraged but never for long. Sometimes you get to a project that you just can't get your body in the right spot and I'll just have to go off and I'll say, "Yeah, let it set a little bit," and I'll try something else, and then next thing you know, I'll think of some other way to do it....*

### **Feeling bad / feeling sorry for family members / feeling like a burden**

- *Listen to your doctors. It's not over. There's everything that runs through your head that moment: "What's going to happen to me?" I just keep a positive attitude and hang around positive people. It's best – it's all their personal experience, that's what happened to me. It seems to work; it's not the end. I thought it was. I thought I would be a – laying in there the snow and the first thing is I'm going to be a burden to my family. Someone is going to have to wipe me, feed me, and all that crap and I don't want that. I don't want my family to – I think it's not all about me. It's about a greater purpose and I'm just a small part of a big whole. If I can be a part of it then I'll take it. Just don't quit.*

## **Acceptance**

- *Immediate ability to accept being paralyzed and accept the fact that you're never going to walk. I wasted no time, just, "Oh, I want to walk, I want to walk, I want to walk." I didn't really care about that all that much. Just teach me how to get around and be disabled and I'll be just fine.*
- *Well, probably a positive attitude. I mean even though I was hurt I still could do a lot of things. I mean it was not that, you know, life was ending. There were a lot of things I could still do. There were a lot of challenges going forth and, you know, I knew that, I accepted that. Being young, being physical enough – I mean there were just a lot of things I could overcome; but probably the biggest part sometimes is to accept what you couldn't do, the failures, you know, that things were locked out just because of that. Over the years, things frustrated me like places with steps. I mean, that automatically says "Nope, you're not going there," so that bothers me.*

## **Thoughts / Cognitions Immediately Following Injury**

### **Negative / stunned**

- *Man, I really did one over.*
- *I thought that I was screwed for sure*

### **Caught up in what you cannot do**

- *So that was one of my thoughts just that I wasn't going to be able to do that anymore. A lot of the post-injury stuff was focused – especially depression stuff – on what I wasn't going to be able to do anymore. I was dwelling on that. I couldn't walk. That was when I was just negative and just in a shit mood basically. After I stopped dwelling on that and then I started realizing all the stuff I could do, that's when it picked back up.*

### **Unsure / unfocused**

- *What in the hell does the future hold for me? How do you get about your life? How am I going to get a job? I mean, everything I ever did before I broke my neck was physical. My jobs were physical, and I was a physical person. It was physical, physical, physical, you know, and then that changed immediately.... So now how*

*are you gonna go about your life? What are you gonna do? How do you do relationships? Are you gonna meet anybody? Can somebody love you? It's just a whirlwind of problems, you know, that seemed like they're huge problems and insurmountable at that time... and you worry about it....*

### **Worried about others**

- *I was concerned about my youngest son and my grandkids because it was going to change everything so much – how it's going to change my relationship with the ones I love. I guess that basically was my concern on how it was going to – I was more worried about other people and how it was going to change our relationship.*
- *Oh God, my wife didn't sign up to be married to some gimp in a wheelchair.*

### **Confident that they will figure it out**

- *You know, I was just always confident and trusted in God immensely. A lot of coping skills I learned as a life coach I was able to apply to myself and that helped tremendously.*
- *But yeah, at first it was – I think at the very first, "Well, I can adapt. I can adapt pretty good. I can fight in the jungle. I can fight in the desert and I can fight in the mountains or I can fight in the ocean. So yeah.... Sometimes I get frustrated... but I kind of adapt and try and not take on more than I can do anymore.*

### **Focused on what needs to be done**

- *And I can remember going back to [the rehab center] and probably wasn't as social as I normally was and just telling them, "What do I have to do today?" I remember my wife at the time saying, "What's your deal? Like why are you just – you go out there and you do this and then you're done?" I'm like, "It isn't that. I just want to get out of here. I want to go home and I want to just get back to life." She's like, "Life has changed." I'm like, "Yeah, but it doesn't have to be. It's a chair and we know what to expect. Let's keep moving."*
- *My thoughts after I got injured. Well, when I woke up and they said – and I think my wife told me I was – somebody told me I was paralyzed. I don't know who. And then I just said, "Okay, what do I do next?"*

## **Determined**

- *I just didn't know what I was going to do in life, that's all. I was kind of in awe, but I was determined that I wasn't going to lay down and give up. I knew I was going to get up and do something and make the best of the bad situation. And I have.*
- *Suck it up. You got a family. They don't like you, but suck it up. You've got to deal with it. Worse you are, the worse you're going to be with them. Maybe we can fix it, maybe we can't, but you've got to do something.*
- *Oh yeah, so you know immediately after I'm thinking holy crying out loud, what's happened here, you know? I mean I can remember falling. I can remember I never lost consciousness, so I can remember the episode. I can remember everything.... I know how fragile life is. I didn't have to crash in a blaze of glory to know how fragile life is. I knew that. But now it's actually happening to me. It's not happening to somebody else.... So I thought that was a rather strange experience to kind of go through, and then as far as the being in the hospital, it was always then a mental fight to move, to know that this was not going to happen to me. I was going to walk out of this place, I wasn't going to roll myself out of this place.*
- *Thought it happened for a reason. I know not many people could deal with this, but I understand that this is something I can deal with and I'm able to understand this. Better me than someone else I guess.*

## **Detached**

- *It was kind of freaky. Well, I'm just fascinated with how the human body works. It's just a freaking machine to me. Not that I'm irreverent of it, like somebody who, like, abuses a machine, like hurt their cars or something and drive it. No. I mean I'm in awe of the machine. I think it's really cool. So I think I approached the injury from that standpoint. I just was kind of like, "Oh, that is really weird. I cannot move my foot now." ...So that kind of outlook has definitely helped me. Not that my injury hasn't been a downer, but that kind of viewpoint in life has kind of helped me deal with it. It's just a machine. Your body is a machine. Take care of it or do maintenance on it. It breaks down, you know. It's hard to upgrade it. We're working on it.*

## **Positive**

- *I didn't really fret too much about anything. I guess I just thought, "Well, it's another hurdle I got to tackle." I didn't really – don't really recall having any negative thoughts about it all when it happened. ...You don't have focus on the negative stuff and that's kind of how I dealt with it. Just tried to look at the positive points in how things were going to change. And some didn't work out so well and others did. I mean, I wasn't scared. I guess a little anxious about how – maybe worried about how it was going to affect everything.*

## **Path to Current Life and Sense of Flourishing**

Participants described various pathways to their current sense of satisfaction with life. While some individuals talked about a graduate process, others mentioned specific realizations or events that served as turning points for them. In addition, for a portion of participants, family members were key in providing the support and motivation to continue to move forward.

### **Steady / no real changes**

- *I think it's been pretty steady. As time went on I've learned different ways to do things and I do most of the things I did before but it takes me longer now.*
- *I think it's been a pretty straight path.*

### **Gradual process**

- *I don't know if there were any turning points. I think it was more just a gradual – you know, it was different than all of a sudden if you get hurt in an accident you know, you go from boom one moment. In my case it was kind of like a gradual down, then gradually maybe up a little bit, and then stop. So I guess I had time to adjust, but no, there wasn't. I don't think there was a turning point just – you know a little victory is when I realize, okay, I can drive, or I can get a house that's set up, or I can still do the business. There's a lot of things I can't do, but once I realize there's a ton of things I can do then it helps. But I can't speak for one particular moment.*

### **A series of choices**

- *Everything leads to a point where you are in your life. What can I say? It's just a series of choices with me, even on a daily basis or every little thing changes your direction in life. So yeah, I can look back on some major choices and things, things that I didn't make very well since my injury. It's pretty much focused on my wife, because she – I was just in so much denial because she was an alcoholic.*

### **A process of hard work and determination**

- *Hard work and perseverance, I suppose. ...Anything worth having or being involved in in life you've got to work at it. I'm the same as everybody else. I'm just on wheels, you know.*

### **Turning Points**

#### **Recognition of my ability and strengths**

- *I guess it was when I would finally do something and not be stubborn and say "I can't do it." And realizing that just do it and realizing that you can do it. That would be a turning point.*

#### **Changes in perspectives and approaches**

During the interview, we specifically asked participants about decision points – if there were times that their thoughts or attitudes changed dramatically. While many participants said they hadn't experienced these, others recalled specific events or realizations that shifted their perspectives.

- *No, just deciding that I can't sit around and be a little crybaby about stuff. Just get back to living life and do what you want. I don't know – I don't really have a motivational sentence to say that. Just making the decision that I'm not going to sit around and feel bad for myself, that I'm going to get back to living and having fun and enjoying every day like I did throughout the rest of my life.*
- *Consciously thinking that I would not allow the wheelchair to limit what I did with my family / my opportunities.*

- *The biggest thing for me about going anywhere was that I didn't want anybody to see me in a wheelchair. I felt pretty much inferior, so I didn't for a while. I just wanted to kind of stay here and try to figure it out. That wasn't the right way to go on. Once I decided that, hey, I'm alive just like everybody else. Only everything I've got to do has got to be totally different than the way I used to. Once I come to that realization and I wanted to get back into what I used to, then I had to start back and say "Okay, how are you going to fish?"*

## **Sports**

- *Well yeah. I mean, I used to love to kayak. I decided to go try that. So, I made that decision to go try it. I know that I need more help than me and an aide. There has to be people there. I went for a glider – just things I'd never done before. And I'm going to try to make the decision to stay active and do what I want to do – go figure it out. ...I just made a decision that ... I'm not going to die five years into my injury. I'm going to carry on. There's a lot of life left to live and that's the decision I made I guess.*
- *Oh, a turning point is when I decided to go back to hand cycling. That was a turning point.*

## **Independence / moving out on my own**

- *Turning points? Maybe one thing was moving out on my own. And I'm real grateful for that because many people with spinal cord injuries cannot do that. But I'd grown up – grown up – stop. No. You know I'm lucky enough I'm able to have the ability to do that. I don't have to somebody stay with me 24/7 because I can do a great deal on my own. Not everything, but a lot of stuff on my own. So I think that was a turning point for me.*

## **Injury / disability itself**

- *I guess I would say the biggest turning point was the instant I hit the ground and became disabled because at that point, I said, "All right, just teach me what I need to know. There's no way I'm going to walk again." I wasn't one of those people that for years and years and years all they want to do is walk. I mean, I see so many people, "All I want to do is walk. I don't care about doing anything. I just want to be able to walk." Well, 99% of those people are going to walk. They need to figure out what they're going to do in life to make them happy. And if you continue down that path of "I'm not going to do anything besides wanting to*

*walk again,” you’re going to be hugely disappointed because there’s no cure for paralysis, at least not now and probably not in my lifetime.*

### **Employment**

- *The first day – I was off work for three months – so the first day back to work, that was a turning point because I didn’t go away and I had to face the same people – the same guy – that didn’t want me. So that kind of turned a little bit. But the biggest turning point between the crash and today, without doubt, was like five minutes after I crashed and decided to move forward.*

### **Desire to prove others wrong**

- *Yep. My junior year in high school. I remember later, towards the end of the year, they brought me in to talk about what classes I was going to go to my senior year and about what colleges I was going to apply to. And all of them were sub – just below my standards of colleges [laughter], and I made it a mission of mine for the next year to get all As and to get accepted to [preferred university]. So then that next year, I took a full schedule and I took the AP classes and did what I would have been doing before my accident.*

### **Increased social comfort**

- *I think that it took me a few years to get adjusted to where I was really comfortable, and hanging out and being a lot more social and stuff like that. Once I got out of high school I kind of became a lot, you know, talked a lot more, because I was kind of a quiet person back then. I still had a lot of friends I hung out with, but kind of just expanded my friend base. I really, I think I just, what I don't know, changed everything, in just hanging out with different people and different perspectives on everything. It just got me to where I am.*

### **Wanting to make a difference for others / impact**

- *Yeah, it was coaching. It was at this school coaching in the early 2000s that – life was good and all that kind of stuff, but for where I am now, had a kid cry and tell me what an inspiration and all those kinds of things. And I, just at that moment, knew that I needed to get out of the job I was in and go back to school, so I could teach and coach, and try to have that kind of impact.*



## **Spirituality**

- *I was raised a Catholic and I always struggled with my religion, because I really oppose some of the things that the church stood for. And I think spiritually that's very important to someone who goes through something as traumatic as a spinal cord injury or, you know, any other serious disease.... I guess I found a different form of spirituality as I went through this. And I think that was really important in finding peace with what happened.*

## **Motivated by others / importance of family and friends**

- *Just like I say, family. It takes time, over time. Like they say, time cures all and you deal with things, become better with things.*
- *So because of my speaking up for this situation I feel like I have to kind of lead the way or set a path for others to follow.*

## **Motivated by opportunities**

- *For me the turning point was the opportunities to work, to just work, and basically being able to say that I have accomplished being able to go to work from my wheelchair. When I was working a temporary job I never missed a day. I always shoot for goals for myself, something that I feel reachable within this situation, and I do my best to try to make sure that I tackle and bring out all barriers. Any barrier that is set before me I try to find routes around them from knocking on doors or trying to figure out what is the next alternative. There has to be a way.*

## **Adjustment Process / How Those Thoughts Change Over Time**

### **Need to learn patience**

- *But I was used to mowing my lawn or doing things. I needed help getting things done now so I'd call people. Well, they have lives and they're busy too. "But hey, yeah, I'll get over there, but it'll probably be on Wednesday." And this is Sunday and you're like, "Damn, I don't want to wait until Wednesday. I want to do it right now." And so that was probably one of the biggest things where I said, "Okay. That doesn't have to be done today. What else can I do?" and then move on. That was a big adjustment for me because when you get something in your mind and you want to get it done and you're fixed on that and all of a sudden you can't*

*do it because you just can't physically do it. You have to wait for someone else. That's like, "Okay, we'll get it done, but it's just not meant to be done now. We'll get it when we get it."*

### **One day at a time**

- *Just take one day at a time. You know I think my thing is just one day at a time because as soon as you're injured you tend to think, you know, "How bad is it going to be? How am I going to do this?" And all they need to do is like everyone else, just one day at a time and then you find it gets easier, it gets easier. Whether they get better or not, physically, it does get easier. You figure out new tricks and it can be very rewarding. But it's hard. I mean, I've tried to help people who've been injured. I remember the feeling when I got hurt. I didn't want to be in that wheelchair because I wasn't going to be that way. And so it's doing that time, and so just do it one day at a time. I also forced people around them, keep telling these people, the people around them, keep telling that person how loved they are, how valued they are.*

### **Finding a sense of acceptance**

- *You have to take your time. You have to go through a cycle, and then eventually accept it.*
- *Oh, I think just acceptance. Accept what you got and do the best you can with what you got 'cause there are other people that depend upon you.*
- *This is something that you were dealt with this. Move on now. Make the best of it.*

### **Learning what was possible**

- *I guess kind of regaining like a normal life, so to speak, and not letting the wheelchair affect me whatsoever when I think about going out and doing stuff. Just going out and doing it and figuring out.*

### **Find a sense of purpose and meaning**

- *Whatever you can possibly do to add substance to your life and help others, do that to give you—so that your life in your own mind is meaningful. And that you feel good about yourself once you're doing it. You're not going to be depressed if you do something to contribute. If you don't—if you don't feel you are*

*contributing, you have to sometimes work it, doing something extra as much as you can because there's so much you can't do. Focus on what you can do, not on what you can't.*

### **Identifying a meaning / purpose for the injury**

- *But the big realization that turned me around was the good Lord slowed me down. I was working fast and loose, and he got my attention. So I got my hands back; was not supposed to. It's a real blessing, so I'm going to use it to its fullest.*
- *But I realize it's all got to happen for a reason.... I got to make peace. I don't let myself get all worked up.*

### **Disconnecting from people who don't understand**

- *And finally you got to let things go, you know. It's like playing poker. You got to know how to hold 'em, know how to fold 'em. That's how life is. Sometimes you thinkin' you got friends you know 20, 30 years or whatever. Sometimes you have to let—I had to let a lotta people go to get to where I am. I mean, ...they just don't understand. I ain't got to 'splain that. I got to look out for [myself]. I want to live too.*

### **Taking responsibility**

- *Well, it was my fault that I did the drinking and I bought the booze and then I [had the accident]. I mean, I just took responsibility for what I've done, and there's nothing I could change about it. It's just something you have to learn, that it is what it is.*

### **Allow yourself to grieve**

- *Try to be positive, but it – going through their grieving process. You have to go through the grieving process and eventually accept it.*
- *I've adjusted with the wheelchair, I've gone through probably all the stages of denial and sadness and all that, but then you start figuring out different ways of doing things and you do something [a long time] and pretty soon it's the new normal. You adjust to it and go from there.*

- *You know, it's a lot of "I can't, I can't, I can't." You know it's a tough adjustment at first for anybody, and I think there is really just kind of a grieving period there where you feel sorry for yourself then you're pissed off, and eventually you've just got to decide to get on with it.*

### **Reconnect with who you are and pre-injury identity**

- *There's a book – and I didn't read it but there's a great title, Christopher Reeve's book – it's called "Still Me." You know, the double meaning of still me, but also still. So if you really enjoy the person – now that's sometimes easier said than done – sometimes because if you're buddies with people because you all like to do rock climbing, well, then it's like "Okay, we can't do this much together." But you find other things that, hey, maybe you like doing because ultimately you like spending time together. So you just try to figure out certain things, and there's a lot of activities – generally there's different ways of doing it. And most – you can do it somehow in a chair.*

### **Stay active**

- *So, still do what I like to do. It just takes me longer. Little more frustrating at times, but – and I tell you, you got to stay active. I notice if I have a bad day, I sit on my butt, I eat, and drink a lot of soda, whatever, and the next day I'm feeling it. So, when I get bad day or a bad couple of days, it takes me a couple days to get back in the groove. So, that's why I try and keep going. Try and keep going.*

### **Reading, learning and keeping your mind active**

- *But I think like in terms of – and this isn't spirituality, but, in terms of helping me like cope with, like a mental sort of thing to cope with my disability, it's really been my reading and my learning. I have a – I'm very passionate about that...And that, honestly, I know it sounds kind of odd, but that's actually been a real coping tool for me because it's – I just find it so fascinating to study about other centuries. I just find it so fascinating. And it, it keeps me so that my mind isn't constantly on my disability because it can be on your – I mean, if you want it to be, your mind can be on your disability 24/7 if you wanted, if you let it. Some people who are injured they find that they deal with it best by going into some sort of advocacy work, and that's great if that's how they deal with it. That's too much for me. I need to know that I'm more than just my disability.*

## **Avoid negative thoughts**

- *I guess a big point would be is to spend your time thinking about what you can do, instead of what you can't do. Because if you just sat there all day and thought about the things you used to do, you can't do now, that would destroy you.*
- *If you get them into the attitude that everything happens for a reason and get them dwelling on the things they can do, rather than the things they can't do, they probably have a better chance of coming out of it.*

## **Need to move forward and get things done**

- *The thing that helped me cope with it is just what you say is, "Who's going to do it if you don't? You've got to do it yourself." If you're going to wait around for everybody, it's bad. Let's just get out there and do it and be done with it. It frustrated me to see this barn that we're sitting in here. I would have built this myself, but I broke my neck and I can't do this no more. Same thing, I got a shingle roof and I'd go up there and do it my – let's get this job done. It has to be done. But I can't do that no more. So you've got to go get somebody to do it. That's the physical capabilities that you can't do that anymore. Know your limitations.*

## **High Points**

Most of our participants reported experiencing full and meaningful lives. The high points they described reflected the importance they placed on family, relationships, activity, recognition, and making a difference in people's lives. This was so well articulated in the following two statements.

- *High points? ...Faith, family, friends. ...The ability to do things, the ability to do work I love. I love having my own little business. I love being involved in my kids' lives. I love coaching, I love being able to contribute. ...And love for the memories I have of great parents and siblings.*
- *The friendships I've developed, the achievements I did and made both as a professional and a personal individual, the lives I've touched and influenced both positively and negatively, writing my memoirs down about doing things like that, and what a good life I've had. It's been good, paralyzed or not. I've been cut down to 2% of the man I was before, just muscular ability and then cut that in half again 30 years later and taken away and fighting back and getting some of it*

*back each time. Still maintaining what I call independence and running my own life and making my own decisions and living alone independent, proud of that.*

Additional high points are reflected below. Family, including spouses, children, and grandchildren, were mentioned most frequently as being the best part of life after SCI.

- *Really fortunate to have a family of friends in good health.*
- *My prayers were answered when I got to see my kids grow up. She got to grow up to 16.*
- *Well, I guess the wife's the biggest high point. Then the grandkids. I try and take care of them and get them squared away.*

Friendships and romantic relationships were also important.

- *Um, high points are seeing the friends that you know are your good friends, seeing them stay and ...and knowing you have some incredible people in your life.*
- *Having a new girlfriend is one. ...And, I don't know, I'm always happy. I'm just a happy guy. ...I don't get down that much. It's not worth it. Stress isn't good.... I've always been that way. I'm just the most easiest, go-lucky guy you'll ever meet.*

Many participants mentioned sports and recreational activities as high points in their lives. These included competitive sports as well as activities that allowed them to just relax and enjoy life.

- *High points for me have been racing stock cars. People just don't see the wheelchair. Lately, it's been the [outreach group] thing where we take on some pretty good challenges. Engage people into the outdoors, trying to get them to see, "Hey, there is a life beyond whatever problems you have, but you just got to look forward, and you got to learn. You got to know that there is something there," and that's what we try to provide.*
- *This is my first year playing on the wheelchair basketball team. So this is another high point in my life.*

For some participants, continuing or completing their education brought with it the opportunity to connect with people as well a sense of self-worth and accomplishment.

- *College, for sure. ...It was the most – I made some best friends that I'll have for the rest of my life that are just tons of fun.*
- *The high points? My schooling. It was something I'm proud of. It took a long, long time to get through. I felt like I was in school forever doing that, and finally finished up two years ago. I couldn't go back. I just don't – I love, love to learn, but I just – I couldn't go back to doing homework again, any of that kind of stuff. I just don't have the stamina for it anymore. But I'm proud of that.*

One high point that was both explicitly stated as well as implied by many was how our participants valued making a positive impact of others.

- *I think it was really neat because they definitely don't have the same opportunities that I have had. ...For example, I went to their school and they all were asleep on the floor with just little mattresses next to each other, and so I think it was neat for them to see there's a couple of us there that were in wheelchairs, like they're able – they're often seen as less in their society, so I think it was neat for them to see us as leaders going over there, that they can do pretty much whatever they want to do. So for sure I think it was highly positive.*

Other notable highlights included returning to work and career, traveling, and building a home.

### **Employment**

- *But getting back to work at [my job] that was very important. That was a highlight of my life.*
- *In my career, here at [auto manufacturer], I've been here a little over 30 years. I've had numerous jobs. But a couple of the high points are when I was in public relations, I was the manager of a child safety program. ...But I get most of my satisfaction giving back. That's just the way I was raised. Give back to the community.*

### **Travel**

- *I think really though, besides that, the highest points of my life have been my – and I have to credit my parents a lot for this too because they worked really hard to do it – is my being able to travel.*

- *I think some of the trips that I've taken have been really fun. I did a cruise one time and other times just road trips to Florida. I went to New York and the Adirondack Mountains. Yeah, there have been some fun trips and things that I've done that have been good.*
- *As I said we have the lakeshore which is Lake Michigan. My favorite pastime is to go to Muskegon to that lake. It is breathtaking to go there. My peace is there, especially in the spring and the summer when the ice melts and you can go out there. It's beautiful. It's just breathtaking. I get a peace when I'm out there and that's what I can do. Writing my poetry and I don't know I just feel like I'm closer to God for some reason when I'm out there.*

### **Home / building a house**

- *Building a house is probably one of the better highlights of my life. We designed the house after going through a bunch of different people's homes that were accessible, taking bits and pieces of each home that we liked and kind of incorporating it into this house. I have a – again it comes back to family and friends. I've got a brother that – or I've got a brother and a brother-in-law that are builders. Another builder that's an excavator. We have friends that donated material and time to help build the house. I mean, if it weren't for friends and family, I have no idea where I'd be at right now.*

### **Low Points**

Participants in this study discussed the various low points they had experienced since their SCI. While some were directly related to their injury, others appeared related to losses, hassles, and frustrations that are common in the general population.

As mentioned, the spinal cord injury itself was mentioned as a low point by some, but not all (or even the majority) of participants.

- *Breaking my back. That's definitely the biggest disappointment.*
- *Obviously getting injured was a low point, but after I got over it, which I think I did pretty quick – probably about three months. That was pretty quick, I would say, for that kind of thing.*



Other participants articulated specific factors associated with their SCI that they struggled with.

### ***Not knowing what to do or what to expect***

- *The only time I felt low post-injury was just that first year or so. After my injury I just felt like the world was spinning around me. And I didn't know what to do until I started to get kind of a game plan together and realized I guess I could live again and didn't really feel low anymore.*
- *Well, the lowest I ever was, was when I broke my back, not knowing what to expect, and not from me. More from my wife because she didn't – she was not into that bike and she would say every day, "You're going to get hurt. You're going to get killed on that thing." "Oh, no. It'll be fine." And it happened, so that was probably the lowest point that I felt, but it was for her really because, at the time, I was like she didn't sign up to be married to some dude in a wheelchair, nor did I know anything about disabilities or chairs or anything like that.*

Participants mentioned difficulty with mobility associated both with the original injury as well as aging with SCI as one of the specific losses associated with the injury.

### ***Decreased functioning / aging with SCI***

- *Yeah. Aches and pain and little things. ...It takes me 20 minutes to get my shoes on and that's frustrating as heck but, you know, I got to do that. And when I can't – I'd like to do things sometimes, but I'm not capable – I can't do what I used to and that gets frustrating.*
- *I remember after being in the hospital for three and half, four months – I came home and I went from this end of the house to that end of the house and I came back to the door, and I realized I'd lost my purpose. I couldn't clean the house or cook meals or take care of my family anymore. And I really sat there at the door thinking, "Can I go back? Just let me go back to the hospital where there's more room and people." Just something to do besides – really, I was lost.*
- *Now there's frustration with aging and the injury where they combine together because the injury was incomplete. And so over the last couple of years, I've lost a lot of the feeling that I had in my lower extremities and stuff like that. It's a combination of the injury and then age compounding it.*

Secondary conditions, as well as injuries and other illnesses that occurred after the SCI also were low points in people's lives.

### ***Hospitalization / illness/ surgeries***

- *I'd say low points are probably just not taking care of my body like I know I'm supposed to. Like I stated earlier, I just had a flap surgery at the beginning of August. And I knew what caused it. I just didn't take the time to take care of my body. So, it really wasn't a low point. Then I did have a pressure sore like two years after that, so that was a , but it was costing me time –being up and around and possibly being able to do things. So I had to pick and choose events I wanted to go to or if I wanted to see a friend or go somewhere. I guess the low point, too, because I had to lay in bed for like three months would be just not listening to my body and taking care of it the way it should be.*
- *Um, being hospitalized, nursing home, sickness. Little stuff like that.*
- *Some of the low points, when I have a lot of pain.*

Sometimes the low points were factors associated with living with SCI and the lack of awareness, assistance, or accommodations of others. These included hassles with red tape, problems with aides, and disability-related employment issues.

### ***Healthcare providers***

- *Once we knew what was going on and once the doctors, I will just say had their heads up each other's ass. I'm not exactly thrilled with a majority of the doctors on that particular team.*

### ***Feeling isolated***

- *Not having anybody to talk to, or not feeling like you want to discuss anything or see anybody.*
- *Well, some of the low points are thinking about the things I want to do and can't do and sometimes not having enough people around. Not having enough people around makes me reflect back on things that I don't want to think about. Other than that I'm okay.*

## **Red tape**

- *The state – the very first thing Social Security does when you get hurt [is to] deny your claim. Paralyzed from the neck down, they denied it. Submitted an appeal thing, whatever.... The federal government says the money that's being paid to my father for taking care of me is called a "difficulty of care" payment and that is tax-exempt income. The State of Michigan says it's not tax-exempt income and they give you a 1099. If you don't report that state nontaxable income, then your 1099 does not get entered into your 1040 and then your 1040 doesn't match what the IRS says you earned.... But last year the IRS changed the instructions, so now you enter that into your tax form and attach a note and you get tax-exempt because most states and the IRS realize that the "difficulty of care" payment is about one-third what it's going to cost to keep [someone] in a nursing home.*

## **Frustrations associated with impaired physical functioning and needing the assistance of others**

- *The low points inevitably surround the aide situation. New aides that don't show up – that's my biggest frustration. Aides that will not be flexible enough to cover each other and yet want to be covered when they need it. The struggle was dealing with aides. Scheduling more so than anything is a bummer for me.*

## **Disability-related employment issues**

- *When I broke my back, I'd been with the company almost five years and the director of our group held a meeting and I'll quote what he said. "[Name] no longer fits the image of a young professional [in this field]. I hope he goes away." So that really pissed me off a little bit. It hurt my feelings hugely, but it really pissed me off because he doesn't know me. He never took the time to know me as an able-bodied person, let alone as a disabled person, and he went out of his way to make it a little tougher.*

## **Missed opportunities**

- *When I wasn't able to go on our senior trip in high school ...because that would have been just too difficult and I was too tired.*

### **Lack of accessibility**

- *The only thing that caused problems was the actual physical limitations. Some places are less accessible, and some places are just not accessible by the wheelchair.*
- *When you go to a party or something like that, or house parties. I don't like going to house parties because you have to ask somebody to get you up inside the house. You always got to think when you go in these houses, "I have to go to the bathroom. Where am I going to the bathroom?" Sometimes you can't get into the house.*

Finally, for some participants, low points were factors that did not appear to be directly associated with the SCI – things like problem bosses, bad marriages, financial hardships, and the poor health or death of family members.

### **Employment issues – not disability related**

- *I lost a job once. That was a low point. That wasn't due to the injury or anything like that. Just typical life frustrations like everybody has.*
- *My low point, actually, was my last six months at my job.... I had a new boss who was just a tyrant. There's been a lot of turnover under her. She was just a miserable individual. I hated going into my job every day. I was just – I hated it. Just terrible. So really, it wasn't a reflection of my disability. At that time, it was just dealing with my boss.*

### **Bad marriages**

- *I got married probably late, 34 maybe, and then I had a baby and then I went through a bad marriage, and so that was tough. And then I remarried and went through another bad marriage so I've gone through two – and those were tough.*

### **Financial issues**

- *Low points, I think they're every day, I mean still to this day fighting, you know, since [my wife] was the major breadwinner in the family... and now it's gone. So our salary, the salary coming in, the income coming in this house has dropped by 75 percent. And nothing else has changed. ....So I'm trying to figure out how to rob Peter to pay Paul.*

## **Grief / loss of family through death or divorce**

- *The low points were definitely the loss of my grandfather and my divorce and obviously becoming paralyzed. The divorce was probably one of the hardest situations to deal with, primarily because you feel like you were the one responsible for that, which I know isn't the whole truth. But you know it takes two, and I wasn't perfect and I accept my faults in that.*

## **Current Thoughts about Life / Attitude / Outlook**

While we selected participants based on a general sense of well-being and feeling as if they lived a purposeful life, we also felt that it was important to learn a little more about that specific attitude or outlook. The responses below summarize what we heard.

### **Positive / good / life is good**

- *Very upbeat. I have a positive outlook. Play the hand you're dealt. I do the best I can.*
- *I think I'm super positive. I think if you ask anybody, I'm positive and optimistic about everything in the future. I know we have highs and lows in life, but it's life. I really enjoy living and having a good time. Yeah, I'd say overall I'm optimistic about everything.*
- *So there's a song by the Pretenders that Chrissy Hynde sings. One part of the lyrics is "I've got a smile for everyone I meet." That's what I try to do. My outlook on life is really good, hugely positive. Maybe in four, five, or six years I'll retire, but I love what I do now, so I'm not in any hurry to get out of here. There aren't many nights when I just sit home and do very little. If I'm not out riding my bike or playing hockey, I might be up at mic night at [a local pub], having a couple beers or something. But my outlook on life right now is good. It would be great if I could fix my neck and get my hand to stop falling asleep all the time, but the rest of it is quite good really.*
- *As we talk, I think life is good. Sometimes I had to swallow some bitter pills. I swallowed it, see, and God ain't gonna put no more [on my back].*

- *My general outlook on life? I live the day the best I can for the Lord. I look back and see what I've done for him, and look forward to what he's got in store for me. You only can live that way. I guess it's positive most of the time. You got to deal with the things that come your way in a positive way and not get down about it.*

***Desire for a family and a good life – do what you need to get there / SCI as a speed bump***

- *I want to have the same life I had growing up and give that to someone else and just be loving and caring. I guess my outlook in life is just get a job, fall in love and have a family and be happy. And deal with everything that comes in between. That really hadn't change. That never changed with the spinal cord injury. It just kind of put a speed bump in it....*

***Feel thankful, lucky, and grateful***

- *It's always been a good outlook. I'm a little more humbled. I call it a rebirth, actually. You know, we have a tendency to take life for granted. Even though I was pretty sad about a fresh divorce, I still was pretty much in a good place. Then the accident came along and it was one of those "wow." I was around people that had these complete spinal cord injuries, and it still makes me just so grateful for how lucky I am. I guess I'm somewhat humbled by how fortunate I am and so grateful. I think about that constantly. I have a lot of time alone because I am alone and a lot of that time is spent being grateful for what I have. Trying to figure out how to make it a little bit better.*
- *Be thankful every day. Not a lot of people in my condition are living in a home. Most of them are living in a nursing home. I'm thankful every day when I wake up, just to wake up and open my eyes. People die every day, and I'm still living. I'm terrified of the nursing homes. And I have my wife and son too. They're the ones that keep me going.*
- *I'd say good. I get along good. I can do a lot of things that other people can't. I feel lucky about that because other guys are worse. I've seen guys doing this with a wheelchair, and I don't have to worry about that. My upper half's good. I can get around.*

### **Optimistic, hopeful**

- *I was always optimistic. It hasn't changed. I go exercise when I can, three days a week, and just keep living. Living life.*
- *You know, life is good. Again, not being in pain contributes to being able to feel that way. I mean, I see a future for myself, being a productive member of society, having good relationships, the potential for a marriage. I'd like to experience that again. And I see potential for it, so my outlook is definitely hopeful and good.*

### **Things are the same – may take a little longer**

- *Like I said, I do everything normal like anybody else would do. It might take me a couple of more minutes.*

### **Realistic/ day by day**

- *I wouldn't say it's way positive, but I wouldn't say it's way negative either. It's pretty realistic, I think. But I don't think that it's really negative or anything like that. I think it's pretty positive. There's certain things that I would like to be doing now that I'm not doing and that is in part because of the disability. Not all, but in part because of it. And because the disability limits your choices on things. Sometimes that's frustrating, so it's kind of hard for me to say, "Oh wow, it's super positive." But it's not negative either. It's just kind of day by day.*

### **Pessimistic / cynical**

- *Good for the most part. My general outlook is usually good. Do I always see the best in people? Probably not. I'm probably more of a pessimist as far as people go. I generally think most people are scum when given the chance, but my personal outlook is good.*

### **Life is not fair but you deal with it**

- *No, life's never fair. When you expect – what you expect life to be – it'll turn on you. It'll turn on you in a heartbeat. I'm a living, breathing [example] of that. It slapped me down more times than – but I keep getting back up.*
- *No, life's not always fair.... It's probably pretty much what you make it.*

### ***If you want something, work for it and earn it***

- *My outlook is: if you want something, work for it and earn it and go get it. I mean, I think that's just kind of the life I live. I know for a fact that my wheelchair has hindered some things in life. There's no doubt in my mind. But I also feel that's my responsibility to tear those barriers down for people.*

### ***Don't take anything for granted***

- *My outlook on life is real positive. I take nothing for granted. I did before all the time. Never in my life would I wake up and be like, "Hey, this is going to be a great day." But now, after the crash, I don't take anything for granted. Life is pretty good, and I know so many people here that hate what they do all day long and they just bitch and complain and bring everybody down. It's like it's just not a good thing.*

### ***Everyone has their struggles***

- *[Life is] not fair, but I think that's kind of given. But I'm also a strong believer that no one person's situation is worse or easier than the next. We all have our struggles, and we all have things we deal with....*

### ***Happy / enjoy life***

- *I enjoy doing what I 'm doing. I enjoy going to work all the time, and now I have a lot of hobbies. I am very happy. Got a good wife, family, all the kids. Everybody is doing well, so I'm very pleased.*

### ***Taking it as it goes***

- *I describe it as taking it as it goes, I guess.*
- *My outlook on life is just go with the flow.*

### ***Experience regrets but not letting them consume me***

- *Oh, the longer time goes on, it gets better, I guess. I'm still disgusted whenever I start thinking about it. It's like, "Why did I dive off that dock," you know? If I just had that ten seconds back, things would've been a lot different.... Oh there's regret, yeah – can't deny it. I really wish I could get up but I also don't plan on*



*sitting like this the rest of my life because I know they're working on it. I just wish they would hurry up faster.*

- *Well, I wish my spinal cord never would've happened. I think it probably would have been own my own business by now. But overall I wish it was a lot better – wish it would've turned out differently, but, gotta be happy with what you've got, so I'm gonna put it at that – that's it.*

### **Life is life**

- *I don't know. Life is life. You just get up and do it, I guess. Yeah, I mean there is no -- I can't -- I don't know if it is from the injury or just getting older, but you kind of go from "I'm going to do this," to "I need to do this because tomorrows are getting less and less." It's not anything terrible or grievous; it is just I guess I'm starting to realize that I need to start -- instead of planning for one day, you start doing so....*

## **Behaviors Associated with Successful Adjustment to SCI**

In general, participants identified three overlapping categories of behaviors that seemed to be associated with being able to do well or flourish after SCI. These included behaviors associated with maintaining physical health, behaviors associated with maintaining emotional health, and behaviors associated with changing the environment.

### **Working to Maintain Physical Health**

#### **Being proactive**

- *So, on the other side of the house there's like a little gym area. I work out almost every day. Diet – very, very important. I definitely like to eat so it's very important that I do try to maintain a healthy diet most of the time. Especially, in the wheelchair, I've noticed having a bowel and bladder routine, it's – I know I still drink alcohol and hang out with the guys, go fishing, do those things – still do those same things so I have to be more cautious, I think, sometimes where I don't think other people understand. Friends do, now. I mean, it's been – I've been in the wheelchair probably 12 years. But those things that I guess you take for granted, I can't take them for granted, if that makes sense. I have to be aware of what I'm doing.*

- *I do my annual physicals. I do go to my doctor appointments. So I do preventative maintenance of my health. Very blessed. No high blood pressure, no diabetes, no high cholesterol. All of that is intact and I think that is what allows me to have a healthier lifestyle and that's why I don't consider myself sick and that I am malfunctioning because my mechanics don't work as well.*
- *Constant maintenance and preventative care.... So take charge of your life and don't smoke, exercise, eat healthy, and you will be healthy, strong, productive.... Take control of your own health and learn about it and how to treat. Communicate with your doctor and nurse or aide and make your needs known. Remember you're number one because you've got to have your health to be a good partner.*

### **Listening to medical advice**

- *Doing what the doctors told me. Keep my physical activity to a minimum, stretching. I go to a chiropractor, which relieves the stress because I'm always in pain, so my muscles in my neck are always getting tense and all that shit, so he helps me with that. Went to a – what are they called? “massage” – a friend of ours took massage therapy school to become a therapist, so I was a guinea pig for the first two years after my surgery. That really helped relax me, tension wise.*

### **Develop a routine or structure**

- *Well, the only thing I can think of is I'm structured. So like the cathing and taking care of my bladder and the bowel program, and taking my meds.... And I wash myself. I was really worried the first while about skin conditions so I wash my clothes, and I have had no issues on skin conditions. ...UTIs one every two years or so, as far as a urinary tract infection or something like that. I just don't have many day-to-day problems.*

### **Exercise**

- *I exercise. Over the past four months I have not been as avid at it as I usually am. I will do at least six or seven miles on a track, pushing. However, because I am not able to get on the – well, during this time now because it is dark when I get out of work – I have a tabletop bike that I get on and ride for about an hour. I try to do it at least three days a week for my health. I know it is very important, especially in this particular situation, that I have to try to remain as healthy as possible.*

- *I go exercise when I can, three days a week and just keep living. Living life.*

### **Diet**

- *To manage my health? Try to eat right the best I can. I set patterns for my – I still have problems with my bladder and bowel incontinence. So, each and every day I have a pattern, when I have to go the bathroom, whether – cause I can't feel if I have to go or not – so I have to use a pattern and go every particular time each day.*

### **Skin care – monitoring and prevention**

- *I'm really cognizant about avoiding skin issues, like on your bottom, that a lot of people in wheelchairs get. I always sit on an air cushion. About the only time I'm out of my chair is in bed or in a car. But I never sit on anything hard, or if I do get in my recliner, I'm good about doing pressure releases because I understand that once that stuff starts, that's pretty much the beginning of the end. You're never getting rid of it because you're always sitting on your bottom.*

### **Bowel and bladder management**

- *You know, that thought is never far from your mind, because you're – it's almost subconscious – but you're always aware of your situation. Partly because even like bladder or whatever, I keep track of when the last time I went to the bathroom, when I probably need to go to the bathroom again, how much fluid am I drinking. Bowel movement, when did I last have – you know. It's all that but then also where am I going, like I'm going to Dallas this weekend, so you've got to – I know I'm flying, I know I need to be there at a certain time because I'm the first one on the plane. So I think it's a daily thing of in your mind, you're planning all these things, of what you need to do differently that I wouldn't have done before. You know, I never kept track of the last time I went to the bathroom, you just go with it... But when you know you can't control it as much, you just plan these things. So it's constant. If I'm going someplace I haven't been then you have to plan it more, but then you also have to let it go, like it may not go as planned but it'll be okay. No matter what happens, I'll be okay. If I can't get in the bathroom, it's fine. If I have an accident, I'll live. If I can't get handicapped seating at the sporting event, I'll live. So it's all – it's kind of like you do the planning but then if it doesn't happen, it doesn't happen.*

### **Pain management**

- *I do pain management where I meditate and close the gate on pain....*
- *I think if you have the pain, investigate everything you can as far as medication, if it's therapy, physical therapy, or mindset or a counselor – if you're having a hard time, get a professional... that knows something about what you're dealing with.*

### **Fatigue management**

- *Fatigue – I tend to take naps every afternoon for 45 minutes to an hour, which helps tremendously. They're pretty important. I don't always take them, but about three to four times a week, I do take them, take naps.*

### **Range of motion**

- *The biggest thing that I do is the range of motion, stretching exercises, morning and night.*

### **Weight management**

- *I think that managing my weight is important.*
- *You know, I try to eat right and I was heavy. I weighed almost 400 pounds and I had bariatric surgery because the doctor told me you won't live to see 60 if you don't do something, so I went and had the bariatric surgery and lost about 250 pounds because I want to stick around awhile.*

### **Medication management**

- *I try to keep on top of my medication.*
- *Oh, I weaned myself off of all my medication, so I'm two years now without a drug. So I don't take anything. I don't take Tylenol. I don't take glucose, and even for my workouts, spinal cord medications, I weaned myself off of those. It's been two years. It took me about four or five months to do it, but I'm pretty happy about that. I'm real happy that I'm not on any meds.*
- *That's what I do, you know, take my handful of medication. It's real important for me to try to keep my pain from getting too high.*

## **Blood pressure management**

- *This blood pressure issue is because of the spinal cord injury and it fluctuates so much and it is dangerous when it is terribly low or terribly high because my heart is just working too strong and does damage to the heart. So for the last two years it's just been fluctuating all over. When it's really high I have to stay in bed. When it's really low I have to stay in bed because it's just not safe for me to be running around when my blood pressure is really high or really low. So that's been a bit of a struggle.*

## **Working to Maintain Emotional Health**

### **Learning how (and who) to ask for help**

- *I want to be independent and I want to do it myself and then I'm frustrated because I have [to ask for help].... It was back in rehab when I [learned that I] had to ask for help... realizing that, yes, I have to ask for help when I have to go to the bathroom. And realizing that I needed to ask for help when I couldn't turn on a TV or things like that. So it was early on in rehab, learning—but I still have trouble with it.... I think people who are more willing to say, "He's disabled and so I have to do this," and so they'd go yes, so I would ask them. And then there are other people who say, "No, you can do it so you need to learn how to do it on your own." So I definitely know that game of who to ask and who not to ask.*

### **Problem-solving / figuring out what can be adapted and do it**

- *A lot of things – a lot of things are, for me – they were just figuring things out on my own.*
- *I don't know. As far as a new situation or whatever I always go back to my engineering-type things and try to figure it out. Like I say, my mind works very mechanical. So I think our kids today – the very simple things, just simple levers and pry bars and things like that that you can do to get something done – they don't learn any of that. Just simple little things. It's simple to me that you see somebody else struggle with it.... But I was fortunate enough to be doing stuff when I was probably too young to be doing it.*

## **Setting goals**

- *I think they need to keep setting goals and targets. That is something I would do. I would set goals, you know, I'm going to lift my foot this far, I want to take three steps, I want to take ten steps, 20 steps. ...It was real important. I kept setting goals and I would have usually a goal beyond the goal, you know, two goals in mind. You know this one and I would already know what the next one might be and I kept rolling with that.*

## **Relationships / social networks**

- *And go out and be social. Still be friends with your friends and keep in contact with them.... That's one good thing about social media. Now you can do that with Facebook. Three guys I played football with and I email probably every day about something, during the football season anyway. And we use our football numbers instead of our names when we sign. ...We email about every day because we talk about the Iowa game and I tell them about the Michigan game. Just, you know, keepin' in contact and having lots of friends.*

## **Talk to / work with mental health professionals**

- *And over the years if I've been struggling mentally or if I've been stressed out, I will go see some kind of mental health professional if I need to.*
- *That's why psychiatrists and psychologists have their jobs, as you know, to help if people do need help adjusting to a new situation. There is no shame in that. Because it is a traumatic event, and it's not just the person that it happens to. While the person that it happens to is the kind of object of, and suffers kind of the brunt of the accident, it very much does impact the family as well. It's going to change the dynamic, but if you work at it, you can get things to a new normal. Not the old normal, but a new one.*

## **Support groups**

- *Well, some of those focus groups and stuff would help them. I don't think it would help me much, unless you have a focus group where I was getting information about various things other people had done that I would like to do. Once you got their attitude fixed, I think the rest will pretty much take care of itself. And I think sometimes the focus group helps people's attitude. Some people have to expose your soul as such and talk about things in order to get somebody to build them up.*

- *You come to realize that everything is going to be all right as long as you've got a support group. If you've got a support group and it's the right group, everything will work out.*

### **Meditate**

- *I'll meditate and I'll calm my thoughts or my pain levels. Mostly I learned to meditate to control my pain.*

### **Be aware of / in touch with your feelings**

- *I think the most important thing is being in touch with yourself and your feelings.... I would advise a lot of people to just realize those things. If you don't settle with yourself first, you won't be able to settle with anybody else. I found that out the hard way. If it's not sitting right with me, it's not going to sit right regardless of what anything else would come into the picture.*

### **Prayer**

- *Pray, because prayer does work. A lot of people don't believe that, but prayer does work. God will put you with the right people for the right things. That's been my biggest support.*

### **Return to work / school**

- *I guess for help to transition into a career, maybe help a person to find a career that's going to interest them that they're able to do and then to get them – because I think the easiest thing to do after post-injury is to not think that you can make good money and get a real good job and stuff like that, and to keep them, I guess, from going – not that greeters at like Wal-Mart are bad – but just to keep them out of that mindset that they have to go to that job, that they can still achieve anything and maybe pursue education. ...So one of the biggest things, I guess, is to help maybe get them to achieve their educational goal too.*

### **Adaptive sports**

- *I'm partial to sports, still very involved in sports and I really enjoy them, but I think that even if you aren't a sport person, getting involved in those will lead you to avenues of whatever activities you do like and I really think being active makes you healthier, which makes you happier, and so that's kind of my advice.*

## **Keep your brain working**

- *Being able to learn. My intellectual curiosity has helped me a lot and had given me a lot of happiness, I think, in dealing with it too.*
- *Well, going back to working, physically working, has helped my brain work, or getting off the drugs helped my brain a lot. My brain was just not functioning. So, going to work, practicing working, that helped. Reading – well, I can't turn pages – the reading keeps my brain working a little bit.*

## **Focus on the positive / avoid the negative**

- *You know, my family, my wife, my family, the environment, my ability to work, to be productive, to pretty much do as I please within my constraints. I mean, I can go on for two hours about things that are positive and happy things. I mean, sitting here looking out this window right now and leaves are changing and winter is coming, and we have a nice home. It's made for us, you know, we have no needs.... Have never got a hungry day in my life. I have worries about the future, about retirement, but they're not any different than anybody else's, I guess, when you get to that stage. And we have books, we have a coffeemaker, a dog laying here. I mean, there's just a ton.*
- *Oh, just look for as many things as you can do, and do them and feel as good about them as you can. You know, continue. Whatever you can possibly do to add substance to your life and help others, do that to give you—so that you, your life in your own mind is meaningful. And that you feel good about yourself once you're doing it. You're not going to be depressed if you do something to contribute. If you don't feel you are contributing, you have to sometimes work at it, doing something extra as much as you can because there's so much you can't do. Focus on what you can do, not on what you can't.*

## **Changing the Environment**

### **Adapting house, car**

- *It started out from moving in here. I didn't even have a ramp on the deck or even the front porch, or any of that kind of stuff. So I started out with building ramps... To help out with my shoulders, I widened my bedroom doorways. I opened up my bathroom and did like a roll-in shower and added a Jacuzzi tub and stuff just to make it really [nice] and easy to get around. I moved the washer and dryer to a*



*place where I could easily access it. Just basically making everything wide and open, and easy to get around in a wheelchair, I guess.*

- *I had hand controls put in the car so you can drive.... I made my car drive-able, I made the house accessible, I got standing frames here at home. You know, I got hand cycles. I got things that made my life easier where I could, one, have enjoyment, but two, take care of myself.*

### **Creating tools**

- *I've made so many different little contraptions just to be able to do certain stuff. Every day I feel like I'm faced with some kind of a weird challenge or something to figure out.*

### **Do-it-yourself projects**

- *Well, I made a lift for my tractor... Very early after my injury, we've got a walk-out basement here and it's a pretty steep hill to go down in the back and not – I could make it with a wheelchair but really difficult, so I took an old lawnmower and whacked it in two and took the front wheels and put them on the back wheels and put a platform on it so I could ride up and down the hill on it.*

## **Things that Contribute to Your Feelings of Happiness**

When asked about things that contributed to feelings of happiness, most of our participants mentioned people in some way – people in general, family members, or friends. Activities and other personal factors also play an important role. Finally, the attitude or approach to life that people adopted was mentioned by many respondents.

### **People**

#### **People in general**

- *I love people, care about people. I want to be there for my friends too. I'm real sensitive to some things. I love my family and I enjoy watching them grow and move forward. I love people and a strong faith that give me real certainty in life. Kind of simple.*

### **Family, particularly children, including adult children and grandchildren**

- *God and my wife. I guess the way I take to things. If it hadn't have been for them two, I wouldn't have been as positive as I was. The grandkids kept me level, kept me busy doing something. I was always occupied. I have five kids ranging from 31 to 39, and all of them were there.*
- *What contributes to it? I'll tell you what the number one thing is that contributes to me staying strong. It's that girl that you've seen just grow up to college. That's my number one thing that kept me strong, I'm going to tell you that right now. That goes all the way back to the beginning of my injury. It's to make sure I raised her – that was the first step. Now it's just me saying "Hey, good to see you grow up and can't wait 'til I get some grandkids."*

### **Networks of friends**

- *What contribute the most? My friends. And I wish I could say my family but they're kind of missing.... So it's mostly my friends. Those are the people in my life to keep me going. And I'm so respectful of them.*

### **A good support system / siblings who are willing to help**

- *I think having a good support system. I'm very lucky I have a really good family support system. I know that a lot of kids who, or parents, who end up having a disabled child – at least in the time that I was a kid, and things might be better now because there's more education now, I don't know – but at least in the 70s, in the early 80s when you born or if you had a disabled child, the divorce rate was so high. And it was usually – no offense, but it was usually the men leaving the wives because they didn't want to deal with this imperfect child. Luckily my dad's not like that at all. And so my parents stayed together, not that things weren't rough. I'm sure they were, and they had a marriage like everybody else where there was good and there was bad to it, but overall they've got a good solid marriage. And I think what helps a lot is having a good support system. Having siblings that are willing to help you too. That's really important.*

## **Others with SCI**

- *You know, I think everybody needs to be allowed their grieving period and their time to be pissed off, but pretty quick somebody has got to kind of say, "Hey we got to get on with it." I think meeting someone in a similar position is very helpful because it really helped me meeting a guy... who was in a similar position. A little worse of an injury, but still doing well. I think it really helps to talk to other people that are in the same position and have got through that initial hard period. I think that really helps. You know, at first I thought, "Oh, I don't want to go to that support group meeting. I'm not like them; I'm not a cripple," although I was. And I had to kind of come to the realization of it, and it helps to meet other people and talk with other people in a similar position.*

## **Activities**

### **Keeping busy**

- *My wife, family. Part of it is that I'm a geek. I like tinkering with stuff. I've got an office area set up where I've picked up the hobby of making some jewelry. I got myself a laser so I can monkey around with creating some patterns and different materials or marking stuff to make this or that or whatever. I've got enough to keep me busy. It's nothing that is going to be like a Tom Swift type of environment, but it's close enough where I'm not going to get bored and I won't let myself get bored. I will always find something to keep myself occupied with, or I'm sure I will come up with some decorating ideas that will require some thought into it. So we keep ourselves busy.*

### **Volunteering / helping others**

- *Volunteering is important to me, to give back.*
- *I work, actually, down at the medical center as a volunteer employee, going to the floors, talking to the patients, letting them know that it's not the end of the world.*
- *At the local level here I volunteer at the fair. It gives me something to do, to be a part of, and you're included. You're not forgotten.*

## **Wheelchair sports**

- *I'd definitely say that sports had a big impact. It made me want to do more. I ended up playing in college, so it was motivation and I got scholarships. That was nice, paid for some of my schooling. I definitely feel like that was a huge part, and I feel like it connects you with other people that do have disabilities.*
- *And I'm very active. I play wheelchair tennis, not so much anymore just because of the time it takes. Our team, we practice twice a week, but it's at night during the time that I work so I can't make the practices. In the wintertime they do have a one-time day practice that I can usually make it to.*

## **Doing what you enjoy**

- *I just think doing what you like, finding what, like anybody, I don't know, finding something that you're really passionate about and it's like doing that and just like you can do whatever you like regardless. I've never really thought much about being in a chair, like making me happier. I'm happy, I've done a lot of these studies and stuff. I don't know, I feel like the biggest thing is – especially for people that are injured later is just introducing them to normal – what they did before. You can adapt most things – it might not be exactly what you did before but you can adapt most things and they'll probably be reluctant to do it because it won't be exactly the same but once they realize that there's so many things they can do once they've been injured...*

## **Returning to pre-injury activities such as hunting and fishing**

- *Being able to just get back the little things that I always did pre-injury, like hunting, fishing, and stuff like that. The further post-injury I get, just regaining more of that stuff back. I guess kind of regaining like a normal life, so to speak, and not letting the wheelchair affect me whatsoever when I think about going out and doing stuff. Just going out and doing it and figuring out.*

## **Being able to get up and around and do most things that need to be done**

- *Simply being able to get up and get around and do most things that I want to do or need to be done. In terms of getting around, I may be a little sore at the end of the day, but if I want to close the pool, I can close the pool. If I want to take the Jet Ski out, I can take the Jet Ski out. If I want to go for a walk or a bike ride, I can go for a walk or a bike ride. Otherwise I probably wouldn't be doing very many*

*other things, other than just maybe like waterskiing or snow skiing and that might be two or three times a year even if I was doing it. So that part is not much of a loss.*

### **Work you enjoy/ employment / being productive**

- *I think the most important thing was to be able to continue to work and be productive. You can't sit around and dwell on what isn't there. You get dealt a deck of cards, you got to play on. And I think you just have to accept that, that this is the hand I got dealt and I have to make the best of it. And I think being able to work and be active physically, find other enjoyable things like kayaking, that I could do physically for enjoyment to replace some of the things that I lost. You just have to get on with your life. And I think being able to go back to work as I said, go back to work and contribute was important.*
- *Part of what keeps me happy every day is I've got a great career to go to.*

### **Other Personal Factors**

#### **Good disposition / personality**

- *I think the personality I was born with has helped a lot. Who I am and the way I look at things helped a bunch. My family foundation, but with the injury and stuff like that, my wife – it was a support kind of thing like that. I had my best friend and confidant, and all of those things all in one, always with me and always supportive and stuff like that. She could see and somewhat understand my frustrations when I had them. And then just going on and having a family, that was a positive thing.*

#### **Pets**

- *The top thing, I think it would be my dog, honestly. I feel like that would be the one thing that makes me the happiest, or has made me the happiest.*
- *Well, the dog is definitely a big help.*

## **“My land”**

- *I do it with happiness because I look back on my land and my cabin and my pond and the wild life and all the good stuff. It's kind of cool, but I go up in the morning, I sit down there, I face the west, sun sets over there, rock parlor every night and you know, sun comes up over there and I get to see all that.... The land is my happiness.*

## **Spirituality / faith / religion**

- *It's definitely my faith and my perspective that this is just a journey. It's not the destination. It's just a journey that I'm on.*
- *I think my faith. I'm real certain and like beyond believing. It's more knowing to me that God is real and alive and I've seen way to many things to question that. So my faith number one.*
- *My spirituality. Knowing that I can do good for others and just being the person that I am. I'm always looking for the positive in anything and everything and everybody. When I hear something that's negative, I have to look at whatever positive is in that and change it around.*
- *Well, of course the Lord being there for my guide, and my help, and my provider. The wife that he's given me to live a life that's an honor and glorifying to him. I guess that's the biggest thing that contributes to my happiness, and I hope to the happiness of my wife. We kind of just pray that we be the best husband and wife for each other that the Lord will have us to be.*

## **Family foundation / how I was raised / parents**

- *Well, probably starting with the foundation that I had. Good, better, or indifferent, I had a good foundation in family, and still basically do. I think everything's based on a foundation. Whether it's your family, your home, or whatever, building your house or your marriage, your life is based first on a foundation, so I was given a good foundation for that. Again, that's not something I had control over. So I think all those types of things come from that beginning, having parents that loved and cared. They weren't the best but they certainly weren't anywhere near worst or bad, they just are who they are, but again, they had an obligation and they stuck with it, which made us in a sense sort of stick with it and understand that.*

## **Financial resources**

- *I'm not rich, but I'm not financially strapped either. I can kind of do whatever I want to do, go where I want. That money can't buy you happiness. Without a doubt it cannot, but it doesn't hurt sometimes, being disabled. They told me this in the rehab too. They said, "Being disabled is expensive." And it is. I mean, there's some stuff that insurance doesn't pay for. So, I mean, there's lot of things.*

## **Approach to Life / Attitude**

### **Quest to be as independent as possible**

- *Like even me being in my situation, me being in a chair. I still drive. Still cook. Still clean, mop – you name it. Move stuff around. I lift weights, attached to my wheelchair to be exact.*
- *I guess my independence makes me happy. I mean, just knowing what I can do on my own and doing it on my own. Being my own adult, I guess.*

### **Accomplishing things / getting things done**

- *To be able to achieve things. That's one question they asked me when I was in therapy. They said, "Well, what do you do for fun, recreation?" I said I work! "What do you mean – that's what you do for fun?" I said yeah. I feel better when I can look back at something I accomplished and not just sitting around. So that's what I do, I try to accomplish things.*
- *For me probably having goals and having something to work towards.*
- *Well, doing chores and getting them done. I like that accomplishment where I plan to do something, or me and the wife get together to plan and do something, and completing in a respectful amount of time and without breaking too many things.*

### **Taking on challenges and being able to overcome / pushing yourself**

- *Taking on challenges and being able to overcome. Doing some things that I never thought I'd be able to do. I hate talking in front of people, but that pushes me out of my comfort zone. I still don't like it. It's just people are leaning on me from all angles in our group to get things done, where the people who walk around don't*

want to accept the responsibility. So I don't mind that challenge. I hope we're doing it for the right reasons, and as long as it's for the right reasons, we're going to be blessed as we have been.

### **Sense of purpose**

- *Family, friends, sense of purpose, having someplace to go, keeping busy, feeling a sense of self-worth, being able to just get in and out of your house.*

### **Having goals and something to work toward**

- *So, if you think you're going to walk again, that's a good positive goal. Chances are you're not going to walk again. If they found a cure for paralysis today, I wouldn't be able to walk. I've been in a chair for 25 years. My legs are so atrophied, there's zero muscle left in my legs. So, anybody that's been in a chair for five or six years wouldn't be able to walk anyway because they don't have any leg muscles. So the quicker you get over that and move on to "All right, I'm disabled, I'm cool with that. I get great parking spots now. What can I do?"*

### **Recognize the impact you can have on your own life and its outcome, even with SCI**

- *I guess my outlook on life that I've had all along. Yeah, I mean I've known people that have passed away due to drug and alcohol abuse, being unhappy in their lives. I guess one of the things I've always felt like is we don't control other people. We can control ourselves, and we can choose who we want to be around. And having other people that are living normal, good lives around you I think is a good thing. I think it's good for me.... And again, being around people that are also of the mindset that you can improve your circumstances, whether it's economically, physically, mentally, spiritually, relationships, you know. Being around people like that is important too.*

### **Not dwelling on paralysis / accepting impairment and moving on**

- *You have to accept what happened to you. I can't go back and say, "Feel all sorry for me, I got hurt. Oh, poor me, I got hurt. I can't do what I used to do." You can't let this define you. You got to find some other way to do what you got to do.*



## **Positive attitude**

- *Well, probably a positive attitude. Even though I was hurt, I still could do a lot of things. I mean, it was not that, you know, life was ending. There were a lot of things I could still do. There were a lot of challenges going forth and I knew that, I accepted that. Being young, being physical enough, there were just a lot of things I could overcome. But probably the biggest part sometimes is to accept what you couldn't do. You know, the failures, that things were locked out just because of that. Over the years, things frustrated me, like places with steps. I mean, that automatically says "Nope, you're not going there," so that bothers me.*

## **The drive to prove people wrong, to work, to contribute / determination / persistence**

- *My drive now was to just prove people wrong who had the idea that people with disabilities can't contribute to society. So what drives me is working – just being able to say to people who don't know somebody with a disability that despite the physical differences, I can be just like everybody else. Work, pay taxes, have a girlfriend, family, participate in society, as opposed to just collecting disability and sitting at home. So that's what drives me.*

## **You are responsible for your own happiness**

- *You're responsible for your own happiness. You can choose to be happy, you can choose to be appreciative of the things you have, or you can choose to wallow in your own self-pity, I guess, too, sometimes you got to go there. You'll go there sometimes. We all go there. I mean, it's part of being human. If you've never been there, I don't think you're being truthful. Everyone's been there. I've been there and I'll probably be there again. ...But what makes me happy is I don't dwell there, or I don't end up having to stay there very long. It's usually a reason or something that brings you out of it. You realize or recognize or you just take action.*

## Things that Detract from Your Feelings of Satisfaction or Happiness

Possibly because of the way we selected participants for this study, most people were not focused on the negative things in life nor dwelled on what detracted from their happiness. Responses tended to fall in three general categories: (a) internal factors associated with their impairment and health, including psychological factors; (b) interpersonal factors, such as the attitudes of others; and (c) environmental factors, including policies and physical accessibility.

### **Nothing really**

- *I'm not sad. I'm not sad, I'm not angry. In general, I'm happy to be alive. I'm happy to be here. I have no major complaints on nobody, with nobody, with life.*
- *No, I can't think of anything.*
- *Take away from my happiness? A lot of homework, I guess. I don't really know. That's about all really. I don't really have anything that takes away from my happiness, I guess. I feel like I'm super fortunate. I don't really have anything to complain about.*

### **Normal stuff – not associated with SCI**

- *Probably my own pettiness or my own frustration – you know, I get frustrated with kids – not really wheelchair related. I mean, I'm so used to that, but you know, if I got a daughter that's acting like a knucklehead, that gets frustrating.... Just the normal stuff.*
- *Right now, I think it's just getting committed. I've got to set priorities and I'm a good one for not being able to say no if somebody asks for something.... That's my biggest problem – I got too much on my plate.*
- *Usually, it's outside sources. I get annoyed on Facebook when people post a lot of political and social stuff. I just want to see how my friends are doing. I don't want to know what you think of a political candidate. When people aren't nice, that's what brings me down. Everybody just try to get along and be nice to each other. So those are the things that bother me.*

## Internal Factors Associated with Health and Impairment

### **Impairment-related factors**

- *Take away most from my happiness? Definitely my condition. I really feel held back. And that's a struggle for me, because it's like a dragging anchor on my life. And it doesn't matter how positive I am, or like how much steam I pour on, it's still there every second of every day of my life. So definitely that, because I feel like I can do anything in life, but you really can't.*

### **Pain**

- *My pain. My pain. I put my pain way above being a paraplegic. Even if I couldn't move anything, the pain is far worse of a disability.*
- *Pain – actually, I would say pain is the number one thing. I take medicine for my pain. I could take a lot more, but I don't want to because then it just knocks me out, or it doesn't knock me out, but I don't want to take any more medicine because of the effects of it. So, pain is the number one thing.*

### **Self-image**

- *And self-image, body image, I think that's kind of hard too. I'm getting over it more so now that I'm getting older and realize that I'm not really as cool and as handsome as I think I am or ever was, but – and my kids tell me, "Dad, you're fine. You're fine. You're fine, Dad. Don't – you're not fat. You don't look like a slob." But I've seen people in wheelchairs and think, "Gross! You smell like piss and you're filthy." And I think that's one of the big factors why I take so long with my bowel program because I don't want to be that guy.*

### **Limitations on mobility**

- *Mobility is definitely an issue. I know they're making leaps and bounds they say. When I got hurt, they said, "Oh, Christopher Reeve, they're putting so much time and money into this program that he's developed, and you'll be walking in ten years." Now it's been 15 and I don't. I still can't feel anything. And maybe one day I will walk. I don't really – I don't look at it that way. I don't anticipate ever doing that. Maybe somebody with a damaged spinal cord. Maybe someday they will. I'm sure someday they will. But probably not in my lifetime. But I don't have just a*

*damaged spinal cord. Mine is completely severed. So, there's a lot more work to be done before that, or before that happens to me.*

### **Poor health**

- *My health, my health....*
- *Illness. I mean, that was a big thing for us though. We didn't have to worry about one thing, but we had to worry about PET scans and sleeping the day before those. I mean, it was nothing like you ever experienced in your life when you're waiting for the results of a PET scan. I mean, that's just pure torture.*

### **Increasing functional limitations – things are getting harder**

- *Some of the things that are more difficult for me to do now than they were before, and my quality probably isn't as good. I do quite a bit of welding, in the winter especially, and it's a lot harder for me to get my body in position to do the welding, so when you're reaching, and with bifocals, it doesn't help. My quality isn't quite as good as it once was, so that bothers me. To see my quality slip a little bit.*

### **Frustration with the lack of independence / dependence on everyone**

- *The dependence. I have to depend on everyone for everything. I have to have aides in the morning to get me up, to get me dressed. The basic things. Just the dependency. I have learned not to mind asking people for help, but you still are dependent on them coming through.*
- *The occasional frustration with the lack of independence. Usually I can find somebody to do stuff with me, whether it's family or a friend. But as I've gotten older, just that drive to be independent, to be able to do things on my own. It gets on my nerves a little more when I want to be able to go do something and I can't. That's gotten to me more.*

### **Nuisance of needing to carry around supplies**

- *I'd say very little. Just the nuisance of having to carry around a bunch of catheters when we go away for three weeks. That's a suitcase full of catheters, basically, and diapers. I think the nuisance associated with that is probably the biggest thing, and just the idea of having to use the catheter, not having a normal bowel*

*and bladder. And that also means having the erectile dysfunction, which is probably one of the strangest of the lingering effects. And so I'm still working on that part.*

### **Neurogenic bowel and bladder**

- *My bowel program. When that's not going right, stuff isn't going right.*
- *The whole bowel/bladder routine is a pain in the ass. I hate to say this because every time I do say something like this, I jinx myself, but I don't have bowel or bladder accidents. Very rarely I do. I do if I'm sick or I'm stressed or I eat something bad. That tends to screw things up. But for the most part I've got it under control. But it's just so time consuming. That's the worst part. It's a good two, two and a half hours a day, every day, out of my day going through that.*

### **Erectile dysfunction**

- *I think if I could have some of the intimacy I could have had with my wife as beforehand would have resolved some of the tension at times. We've since learned to work around stuff like that, but because of the injuries, part of that is no longer – a no-go at this particular point. That human touch is always in the back of your mind because you want the rest a little bit, but you really can't.*

### **Negative thoughts and tendencies**

- *I think holding onto mistakes I've done. That takes away from it. If I make a mistake doing my work, I hold onto that feeling a lot. And I still do that. You could say I struggle with trying to let that go.*
- *I guess if I feel too sorry for myself, only if I let it. I mean, you're in control of your happiness.... It's easy to be unhappy if you let yourself be unhappy. Sometimes I am a little disappointed. I'd like to be a little more of a macho guy that I used to be, but I can't.*

### **Relatively minor nuisances and frustrations associated with physical impairment**

- *Some of the frustration with the – one of the things I think of is when my wife and I got married not being able to dance kind of thing. Things that would've taken away, would be like when the kids grow up could go play catch. But I wasn't like going to go run them down, and do some of the running around and things like*

*that. Did it a different way. Those things would've added frustration. Oh, the frustration, you know. The daily frustration of wanting to do something and not being able to figure out how you can do it. I think that's probably the worst thing.*

- *You just can't walk up to somebody or hug somebody, you know, those kind of things.*
- *Just like doing things that I couldn't do and asking people to help me do things, things that were so simple before. And nowadays, you just got to wait and get somebody to help you and kind of show them how to do it, where you expect them to know it and they don't. And you got to explain every step to them. Things like that are a little irritating sometimes.*

## **Interpersonal Factors**

### **Divorce**

- *And like I said before, the divorce, that's what nearly killed me. I didn't think of suicide or anything like that. It's just that was the most stressful, heartbreaking trial of my life. I look back and I think of the spinal cord injury, thinking, "Wow, that was really bad." But I don't think that really compared to this – to the divorce. So that really kind of sucked.*

### **Lack of partner / relationship**

- *I don't have a girlfriend or a wife, and I enjoyed being married. I was married 11 years. It was the most amicable divorce on the planet. We just really didn't love each other. So we got divorced.*

### **Concerns about children**

- *Watching my son struggle takes away a little bit. He really is trying hard to do something with his life but he's lost. He changed so much after my injury and that worries me some. It takes away from my happiness because I want him to be happy and I watch him just struggle daily. He's lost and I don't know how to guide him. I mean, I can talk, but I never went to college and never really did any of that and I just don't know how to guide him through what he needs.*

### **Suffering of others**

- *I don't like seeing other people suffer. [My spouse]'s mom and dad just passed away. I don't think anybody likes seeing that, but that takes away from my happiness.*

### **Perceptions of the public/ media**

- *I think public perception on disabilities. I think media. All of that stuff makes things things very difficult. ...They don't show people in wheelchairs that often at all and I think our society has a long way to go with that kind of stuff with public perception. They don't show them being married, they don't show them as a family, none of that stuff. So, it gives the impression that it doesn't happen. It gives the impression that it can't happen. And I think if they would change the way they do some of that stuff, it would help some of the public perception.*

### **Inconsiderate or negative people**

- *Maybe some of the coworkers I work with. You just deal with people. Dealing with people that aren't happy sometimes. They might get me grumpy, but they don't take away my happiness. It's a choice: You can be happy or you can be sad or you can be grumpy. It's the mindset that you have.*
- *Negativity and laziness. If you're a negative person, get out of my life. And I'll run them out. I have had enough of your negativity.*

## **Environmental Factors, including Policies and Physical Accessibility**

### **Insurance companies**

- *What takes away? Insurance company ... I guess the struggle that you get with things that I need, like a van where I could work, or more money. Definitely more money. Disability does not pay well. Struggle with the bills. I guess that – the struggle trying to get things I need to go farther. Because the more independence I gain, I can't utilize any of it because I hit a roadblock.*

### **Lack of accessibility**

- *So it was hard and you've got all those emotional things. How am I going to do this? My family was in a two-story house, and we're in the second-floor bedroom. And it's like, well, that house doesn't work, and all of a sudden you're there, and you can't fix it yourself, so you feel like you're trapped and you can't help and people are relying on you.*
- *You know the thing that's taken away from me, the thing I miss is walking across the curb. You see people, instead of meeting them on the sidewalk and then got to go to find out a way to get this way. People just – I mean, it's part of nature, 'cause you didn't actually go anywhere 'cause you're walking on curbs, grass, any kind of thing or just any kind of obstacles – you just miss that. Oh, this curb, nonchalantly going up the curb, going up the steps. Like with this wedding. ...So I was going to this bar to hang out for the reception. We went to this local bar and it wasn't accessible at all except for everybody walking up the stairs. You're thinking, "Oh, how in the hell am I going to get up the steps?" Guy says "I'll pick you up." Say, "No, you don't need to pick me up." Then we find out another way to get in. It was these little things....*

### **Transportation problems**

- *Right now, for sure, it's the transportation. I'm working on getting back into the van, driving from the wheelchair. Yeah, that's a big thing. I've been trapped in the house pretty much, since I really threw out my shoulder and I did that when I was getting out of my car and up into the wheelchair, about a year ago or so. ... But yeah, transportation, the freedom of going wherever you want yourself, that's a big thing.*

### **Lack of money**

- *Pain that I have now in different areas and bills and the snow, but otherwise I'm happy all the time usually.*



## Recommendations for Those with New Injuries

Participants were asked to use their experience to provide recommendations for others. We hope that we have accurately captured the wisdom and practical suggestions that were provided.

### Interactions with Healthcare Providers

#### ***Listen to the doctors.***

- *Listen to the doctors. Or psychiatrists. Whatever's available, take it. For your benefit 'cause they know. That's their job – they help people. That's why they're called specialists.*

#### ***Have hope.***

- *The doctors certainly played a role, a pretty big role – the doctors and the rehab people – just in the sense of having hope that I would get to be – to whatever extent I would be functional. ... So I think that there's a lot to the human body that is – the doctors know some of it, but they don't know all of it. So a lot of it just is a function of getting up every day and doing what you're supposed to do. ... I think you have to have hope and you have to, a little bit, be satisfied with what you can do and not the old story of looking at it half-full, not half empty.*

#### ***Stay informed about your own health and the things that are available to you.***

- *Don't be ignorant about – especially with the internet. Find out if there is something out there that can help you do X, Y, or Z. Anything that was something... When I was in the hospital there wer these brainiacs in the basement of the hospital that worked in the orthotics department, and they would help you do anything you wanted to try to do.*

#### ***Experiment. Do things differently.***

- *Experiment. Do things differently. Don't get stuck in the same, you know, "I've done it. We've done it. What the hell are we thinking? What were we thinking? Why didn't we do this 20 years ago?"... Don't be afraid to experiment and do things, you know. And don't be afraid to experiment and do things differently than what the doctor told you to do too. Because if you do what your doctor tells*

*you to do when you leave, you're gonna be pretty limited. They're conservative, you know. Don't be so conservative.*

### **Get your seating proper.**

- *Number one, get your seating proper. Get the lightest chair you possibly can and adventure as much as possible.*

### **Advocate is a number one thing.**

- *Advocate is a number one thing. Do that and, like I say, the cushions are important, don't – if you're – I don't care how active, they got low profile ROHOs, real cool things now you can hold the air side to side. It has a valve in the front. The ROHOs for your butt so you're comfortable on the butt, ain't going to be all sore and then learn how – the most ultralight chair you can get good with a wheelchair.*

### **Actions to Take (as well as ones to avoid)**

#### **Stay active.**

- *Stay active. Get up and get out of bed every day and go do something. Get out in the fresh air. Very important. And not worry about things that you need help. Try to do things on your own. See other people, see what they do, things like that. Driving a car was a big thing for me. Once I started to drive a car again, I just felt independence like nothing.*

#### **Don't give up on yourself.**

- *Don't give up on yourself. .... Don't give up on it. You give up on it, you've already shut down the process. So always keep that brain open up there that says, "Hey, these wires are going to go back together." Just one of these days you're going to wake up and go, "Boy that was bad dream I had there, wasn't it?" But don't give up on it.*

#### **Build networks / make connections with people.**

- *Man, man. I would hope for them that they do have a strong support system. If not, they need good therapists, positive input, can-do attitude from anybody that's around them. I know mine – every one that was around me had a positive*

*attitude. And that's a big part of it. If they can just realize that. I know when I first got there and I could do my hands – I could brush my hair, couldn't do anything. I was like, "Oh my gosh, she's making me try and brush my hair, my teeth." And gradually I saw that her attitude – she showed me you can still do everything, but in a different way. It was just that positive input from, it seemed like, every angle that kept me going. And I was strong-willed anyway, and determined. And I just rolled with that – just the positive instead of the negative. Again, I didn't want to be like my cousin. He was hateful. It's not over. I'm just in a chair. ...So, I guess, that would be it. To surround themselves with as many friends and family. And if they do need counseling, take them up on it. It is a lot to take in when you end up in a chair, and I wonder too with other people that are worse off than me, I guess. I looked at them and thought, "It could be worse." So, I was just happy with – I was just glad that what I got was not like them, I guess. It sounds terrible to say it that way, but I'm glad my level of injury and that I regained a lot of the things that I did. I guess that's just the approach I took. It could have been worse. Make the best of what you got here.*

***Work to be as independent as you can.***

- *So be positive, get over it. Let your friends help. Be as independent as you can. It's good to have all of the help in the beginning, but you need to do things on your own. Classic example of that is I tell all the younger kids on our hockey team, like most people are creatures of habit – and since this is for a university I'll just be as blunt as I can. So most people wipe their butt with the same hand. I always tell our kids on the team. I'm like, "Do things out of the ordinary. Use your other hands for a lot more other things than you normally do because if you're going to be an active paraplegic, without doubt, you're probably going to have an upper body surgery at some point in time." Don't do things the same way all the time. Do things a little bit differently. Lean to the other side. It will feel really weird. The first time I tried it, I fell right off the frigging toilet. Like okay, note to self, "Figure that one out just a little bit better." But there's always to do –whatever you want to do, you can do it. There's always ways to do it. Like I said, I've even skydived and that was a lot of fun.*

***Get involved / take advantage of services and organizations, like PVA.***

- *Involved with, exactly. Absolutely is imperative, with the VA you've got to know what that's all about and get involved with whatever the Veterans of Foreign Wars or those organizations that become your sponsor within the VA and know what the VA – and be patient with it. It's a big system. You know you can't – it's*

*not perfect. You've got to be patient with it. I think it's again one of those things where you get more out of it by being patient and being friendly and not being belligerent and expecting everybody to bend over backwards for you....*

***Find ways to connect with people.***

- *I think just to realize that they are not alone hopefully. I mean I'm thinking that most people have some kind of a network and system. They should be looking for ways to reconnect and to realize that what they're feeling today isn't the way they're going to feel in the future. It may feel impossible now, but impossibilities become possible when you know what your attitude is – more of an "I can do" than an "I can't do."*

***Connect with peers with SCI / disability.***

- *If you can surround yourself with peer groups and with positive people. Somebody told me one time at the Center for Independent Living, you need two of three: You need family, friends, or money. And if you have two of the three, you've got a shot. This is a guy who's been in a wheelchair for 35 years. I took that to heart, and I think that's so very, very true. So if somehow the people can surround themselves with positive energy and positive reinforcement and keep going....*

***Allow yourself to grieve but don't stop living.***

- *So I would say those are the key takeaways for being happy. And it's not – and it's okay to be sad and "why me?" for a while, but it's not okay to have that perpetuate. I couldn't tell you how long. I'm sure for each person that time period might differ, but it's something that shouldn't linger on for a really long time in my opinion. And I'm no doctor, but I see a lot of people that get hurt and the ones that are the happiest, the ones that are the most successful, 100% bar none, are the ones that embrace their disability, have made the best out of it, are outgoing, friendly, and they've tried to minimize the effect it had on their livelihood and the ability for them to have fun and continue to do the thing they enjoy and love.*

***Keep your body healthy.***

- *And even just like, if you don't want to walk again or if you don't think you're going to walk again, look into your health. So many people with spinal cord injuries are so unhealthy. You've got to work out still. Exercise is still good for you. You don't want pressure sores, you don't want heart disease. There's just so many*

*things you've still got to work out, even if you don't want to work on walking, go to the gym, work out.*

## **Things to Understand or Realize**

### **Realize that there's life after this.**

- *I think the first thing you need to realize is that there's life after this. I don't know what their circumstances are, or their level is. I'm very fortunate that I could do so many things. If you're a higher-level spinal cord injured person, there's lots less things you can do. But with the technologies available today, there's a lot of things that are available with computers and things like that, that will allow you to do. But just remember that there is a life after spinal cord injury and that you can accomplish anything you want.*

### **Don't be afraid to ask for help.**

- *There's a lot of people out there that will help you that you aren't even aware. Don't be afraid to ask for help. ... Some people think they can do it even though they can't do it. I can't pick up a little tiny screw and screw it into my glasses if I need to fix them. I need to have somebody do that for me. Don't be afraid to ask for help.*

### **Be realistic.**

- *If you have a new spinal cord injury, don't let people tell you that the harder you work, the better you're gonna be. Sometimes the injury level you're at, that's all you're going to get back as far as your physical abilities, no matter how hard you work. You just have to accept that and do the things that you can do, and not get too frustrated with the things that you cannot do.*

### **Get the most out of life that you can with what you can do.**

- *Get the most out of life that you can with what you can do. For the newly injured person – for me, if somebody told me that all you can do is this, and just accept it, I think I'd be a little bit more open-minded to realize “Yeah, this is it.” You can strengthen the muscles you have. You just can't get back what's not going to come back. You have to accept that. I think some people get their hopes built up on “Oh I'll just work harder and harder and harder, and something will come back.” It won't. There's always hope, they'd say; after a couple years of your*

*injury, you realize your limitations, and that's all that's going to probably come back. You just have to accept it and move on with life. I think that's what I would... In fact that's what I was for Mary Free Bed a little bit, I was like a person where I could go in, and talk to newly injured people. Show them what's going on. Every injury is different. But basically, you still have a mindset. What's what. I guess that's what I would tell somebody.*

## **Perspectives to Adopt / Suggested Approaches to Life**

### **Be proactive – “push, push, push.”**

- *Yeah, I think that's just what independence is. If you're going to be somewhat on your own, you have to take responsibility for the actions you choose to take. I can't blame someone else for being independent. I'm the one who chose to be independent. I didn't choose to have a spinal cord injury but I chose to be the one who did not stop drinking and that's what it led to.*
- *Push, push, push. If people can be encouraged. I don't know the mathematics, and the science of physical medicine and the way your recovery processes are most important, but people's mindset right out of the gate is excellence and doing your best. Somehow that can get communicated. How you tell that to somebody that was in a car accident that eats Cheetos and watches Oprah all day long, and how you get those people to be positive, I don't know the answer. But if there's some way people can find a silver lining out there, I just think that's so important.*

### **Stay positive.**

- *I'm just saying they need to keep a positive attitude. In this day and age, you can do anything with a spinal cord injury. It may not seem like that, you just have to learn how to do it differently.*

### **Don't let your disability define you.**

- *So I'd say support's the biggest thing, and just don't even quit. Just don't let the wheelchair define you. Just keep pushing it. People are totally able to live a normal life, if not way more of a rewarding life, being in a wheelchair than others that aren't. That's the way I view it.*

### **Accept responsibility for your own life / health/ happiness.**

- *I would just say take responsibility for what you want to do from here on out, maybe. I mean, from here on out, you have a new—you have a choice in everything you want to do. You can choose to be a nice person or you can choose to be the jerk that says, you know, “I told you to be here at this time. You’re five minutes late!” If you’re new to an injury, you can choose to have a different life, I feel. You can choose to have a positive one or you can choose to push people away. That’s not what I chose to do. I chose to be open with everything that’s going on, open and accepting others who are open and accepting in what they do as long as I was.*

### **Be willing to tailor and adapt things.**

- *I started adapting the things I could adapt so I could do the things I used to do. I’ve just been going forward ever since.*

### **One day at a time.**

- *I just – I’m trying to think about myself. I don’t know if I’m any more well-adjusted than the next person. In getting back to thinking about the survey, I don’t know. Every day you have a choice, and I think what comes back to you is you have a choice and you can be happy with your situation and you can move on, but I guess if you even talked to someone before, and you had struggles and you weren’t happy every day before the accident or wheelchair, whatever. So how do you expect that now that this is one more speed bump in the road or one more hurdle that it’s any different? So I don’t know. For me that’s how I view every day: one day at a time. I mean, yeah, that sucks but it’s so accustomed to how I live, I don’t even – that’s not the part that I do a lot. More or less – like using this summer – I’m not thinking about, “Damn it, I’m in a wheelchair and I can’t do this or that.” I’m thinking more of “Man, I’ll get to see my daughter today.” Those types of things. So I don’t know, I wish there was like a perfect answer to help other people, but I don’t think there is. I think it’s case by case, situation by situation, individual by individual.*

### **Focus on what you can do, rather than what you can’t do.**

- *[Go] back to what they can do, rather than what they can’t do. If I was going to give you a one liner that’s the way I’d give it to you.*

- *Yeah. I guess a big point would be is to spend your time thinking about what you can do, instead of what you can't do. Because if you just sat there all day and thought about the things you used to do, you can't do now, that would destroy you.*

## Critical Resources, Programs, and Policies

Participants were asked about the resources, programs, and policies that they felt were important, or that allowed them to do well after their SCI. While this came at the end of what was, for some, a very long interview, the following responses were noted.

### Information

#### ***Information about social services, benefits, attendants, insurance, federal programs, etc.***

- *Well, that's what I wanted with the CILs too, was to – that's the one thing, the entire time that I was there working on was trying to get – call it a “welcome-to-disability” package, whatever you want to call it. These are the things that you must do now because you're going to get burned if you don't. The whole Medicaid thing, they deny your stuff – those, they have to go back on retroactively, but that can be a lot of money, and a lot of people got a lot of strain on them because they haven't received anything back saying that they're going to get it.*
- *Stay up on top of the rules and regulations for the food stamps and the Medicaid. That's a big, big thing.*
- *The biggest thing is Medicaid... Medicaid is there for that reason and they don't cut your pay first thing – first thing they do is cut your Medicaid benefits. So now, it's not, “I need this money to live comfortably,” it's, “I have to have this money to survive.” ...But the instructions are on the Internet and I highly recommend to anybody that needs to get Social Security, food stamps, any of these attendants – any of these assistance programs that you're going to have after disability – that you read the instructions. Because there's one golden rule that the state has – this is what burns most people – is they are not allowed to solicit services. They can't call you and tell you this program is available for you – they're not allowed. If they do that, they're in big trouble. They won't tell you that that's a policy, but that's a policy – they're not allowed to solicit services. That's like the unwritten rule. And here's the other part you're going to really love: a very high percentage of the people that work in the system at the state don't know the rules themselves.*



### **Information about what happens next**

- *Well, just everything. This is completely vague, but everything that I learned in the first three months. If that could have been consolidated into a nice neat pamphlet or handbook right after my accident, that would have been a lot of help. But because every injury is different, they can prepare you in the general sense, but it's not even close to what you're going to encounter at home because right as you start thinking "Okay, it's manageable," that's when you're going to get discharged from the hospital, and a house, an apartment, a condo, whatever you may be living in, isn't a hospital room. It's completely different. I know that when I came back, there was no ramp into my house. So my dad and his friend had to put me into a manual chair to bump me up the steps into the house. Then him and like three other guys had to carry my power chair in so I could get around the house. So you have to understand that things are not even going to be close to the same. You can only try to move forward and take it day by day at first, because anything you try and plan is not going to work out until you start getting the hang of how things have changed.*

### **Information given during inpatient care but also available later on**

- *It needs to be given when you're in the hospital. You need to give them resources. Whether they say you're going walk or not walk, whatever, they need to at least give you the option to look into it, to figure out, see what's going on.*
- *I just think definitely information, and I don't think...I guess, just the way they handle giving, telling you what the odds are and that kind of thing. I think they just need to be like "We don't know." Just "We don't know," because they really don't. The books say this, you really just don't know, so they need to say that....*
- *So, I have body image issues now that I didn't have before and for years I could still eat anything I wanted and I was still fine but now I can't eat spaghetti and meatballs, try not to eat red meat, so my diet is pretty restricted for sure.... I've always looked fit and now I don't look fit anymore. [Laughter] But I've cut down as much as I can.... But you know, a big issue too is, I think right from the start, in rehab they did not talk about weight gain as being something that's going to be inevitable and they should. I was eating full meals all through rehab and stuff. They should teach you to eat very small portions right from the very start and actually get used to that and know the importance of it. That also, I think, affects not only your body weight and then... affects the pressure you're putting on your body.*

## Programs and Policies

### **Personal care attendants and programs that support self-determination**

- *Well, one of the biggest things I'm dealing with right now – like I said it's been 11 years since my injury, and things are getting a little bit harder to do – is getting someone to just come and help out with like daily things, like case in point the VA won't provide any home health aides unless it's medical related. I had Medicaid, which got cut about a month ago, and they were providing someone six hours a week, which was perfect. ...Yeah, the biggest frustration for me right now is how I'm gonna be able to afford an aide to come help me with stuff as things get harder to do.*

### **ADA / accessibility enforcement**

- *I was really surprised about how many places were not really very accessible [for] wheelchairs. Even some of the restrooms in the hospital and hotels and places like that that... So I think that there's still some things they can do as far as making things more accessible for wheelchairs.*
- *It's a lot – let me see – being disabled today is a million times easier than it was October of '89. I mean, you have hotels now that really have wheelchair-accessible rooms and it's just the curb cuts and everything about it. The strides that have been made in the 25 or 26 years have been huge, just huge. People are way more willing to accept disabled people. You see more disabled people out doing their own thing. In the past you really didn't. So all the disabled folks being out in public has helped the public deal with them and I think it helps the disabled community as well dealing with all the able-bodied people. So that might help a little.*

### **Employment / work supports**

- *What pushed me was Michigan Rehab Services. You have Michigan Works even. They help cater to people with disabilities as well. Goodwill Industries. ... I don't know if it is still there since I have been here, but Can-Do helped to promote and push people with disabilities as well to help get out and about. Your situation doesn't define you, you know; let us help you see that you can get beyond this. There are so many networks, 180 that helps people out for disability advocates. ... If they just - the resources of being able to know not only where to go, but have the want to go. Don't just sit and let your disability define you. See what you can do.*

### **Support for PT / OT / recreation therapy**

- *Therapy is the number one thing. ... Physical [ therapy].*
- *I would say they should have more programs to help people adapt to the outdoors and different stuff – or whatever interest they have. I guess I did have some programs, but it was more dealing with sports and stuff like that. I never had anybody like "Yeah you wanna get out in the woods? We'll take ya out there, or something. You wanna get out there fishing?" I know it's not an easy thing. It wouldn't be an easy thing to implement, but I guess that'd be about it. Even just having a place people can get out to and explore and check out different places, besides just being stuck inside, because I think a lot of people are just stuck inside way too much of their lives.*

### **Peer mentoring**

- *[My mentor] was important. He came down to talk to me while I was an inpatient.... Spent a couple of hours with me going over a lot of different things. So that was huge, you know, from talking about what catheters are out there, and how to deal with that, and just the importance of having a routine.*
- *You know, something that I never had was [a mentor]. ... But sometimes when you talk to those people, they always been in the wheelchair for years. They say, "Take that away, take your sideguards away. Take your tippers away. You don't need that." They talk like you've been in chair for years and years and you've only been in the chair for 30 days. You just got a wheelchair. But have somebody that can relate to what you are right now. I think that's what the policy should have: ... a mentor, yeah. Let's have a mentor that's been in a wheelchair for eons and even though they know what to go through, they say "Oh, okay. This is what you need to do. Don't worry about that; you'll learn that down the road."*

### **Rules about durable medical equipment and supplies**

- *Well, I think the electric wheelchair option should be offered, encouraged for everybody with a spinal cord injury because in the long run, the complications, ... it's better to give them an electric wheelchair and encourage them, an electric wheelchair that tilts right away for pressure relief than he gets a regular wheelchair and then the person gets pressure sores and you have surgical complications, ambulance fees.*

- *There's one thing that I think it needs to be – it's stupid. If you use a catheter to urinate, I think the government or the state mandates that you get four per month. Like four. I pee seven or eight times a day. So I get 200 a month just because I fought this thing forever. But I think that's stupid. That rule or however all the healthcare companies – whoever guides that is 50 years ago. That's just ridiculous. So something needs to be done there.*

### ***Inpatient rehabilitation and continued outpatient therapy***

- *You know everybody should have the ability – it's hard to say because of resources. But everybody should have the ability if you get hurt with a spinal cord injury to spend some time in a rehabilitation institute. It's not only for the physical part, but the mental part as well.*

### ***Psychological and vocational counseling***

- *Beneficial to people in chairs, like transitional counseling. Like from the time you're in the hospital – this is my social work background – but from the time you're in the hospital, maybe a social worker gets connected with you, like if they're a mental health therapist and then they just work with you maybe through a transitional period. Maybe this will be a policy, I don't know. But through maybe like a three or four-year transitional period, kind of get somebody from post-injury immediately to maybe where I am today. ... I think that it would be good to have a mental health therapist to kind of keep pushing them and helping them figure things out as they go. ... Yeah, regular contact with somebody who you can always depend on to provide you with some counseling or some help. It doesn't have to be that you're depressed at the time, but just to talk about stuff and to get things out on the table. ... Yeah, and I guess for help to transition into a career, maybe help a person to find a career that's going to interest them that they're able to do and then to get them – because I think the easiest thing to do after post-injury is to not think that you can make good money and get a real good job and stuff like that, and to keep them, I guess, from going – not that greeters at like Wal-Mart are bad – but just to keep them out of that mindset that they have to go to that job, that they can still achieve anything and maybe pursue education. So that's one of the biggest things, I guess, is to help maybe get them to achieve their educational goal too.*

## **Programs to support independent living and participation**

- *Programs. Definitely want to look into all the organizations out there that are willing to help people with disabilities or spinal cord injuries or things like that. I was able to get involved with BVR here in Ohio and they were very helpful in getting my college paid for and things of that nature. I would say programs, you want to get involved with as many or just find as many as you can so that it's not such a burden if you need a vehicle or if you need to go to school or if you need just adaptive equipment in your house. So then possibly get on a government program that will allow you to have an aide if you need one and things like that.*
- *The biggest thing is Medicaid... People on disability should not have co-pays on their Medicaid. People that don't have disabilities on Social Security, they could medicate with no spend-down. That's exactly, ass-backwards, how it should be. Now they got the waiver program, that's one of the best things they've done in a long time – is not starting a waiver program, because they started it quite a while ago. What became better about it is now they have self-determination on the waiver program. So, you can hire who you want instead of having to go through an agency.*

## **Putting It All Together**

Successful adjustment to SCI does not appear to be one thing or one approach; rather it seems that individuals may need, or at least benefit from, having one or more of the following strengths or resources in order to deal with a spinal cord injury:

- Attitude / focus / motivation
- History of confidence and success
- Skills of communication, problem-solving, and adapting
- Resources / access to the right services at the right time
- Support of family and friends (positive people)

Three factors came repeatedly as being very important: a good attitude, health, and social connection and support. Health may not have been directly associated with flourishing, but our participants reported finding it harder to feel good if they were in pain or poor health.

- *Having good health and good family. Those two: health and family. Really, you got to be healthy, you got to be able to take care of yourself if you're going to*

*take care of somebody else. I don't really take care of my family, but they're very much there for me and I'm very much there for them. So, that's huge. And the network of friends and the support group I have.*

Having a support network and people who you can count on in your life was also critical.

Finally, our interviews seemed to make clear that happiness and a sense of meaning in life were different though often connected constructs. Some of our participants were happy; others felt that they made a difference and that their life had meaning. Many, but not all, expressed feeling both.