

A Successful Transition to Work and Independence:

Former SSI/DI Beneficiaries that Achieved Self-Sustaining Employment

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This study is dedicated in loving memory of Susan Daniels

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ABSTRACT

This study investigates the factors that increase the likelihood that a Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) beneficiary will obtain and maintain self-sustaining employment. This study used qualitative methods to interview 22 former SSI/DI beneficiaries that were no longer receiving cash payments from the Social Security Administration (SSA) due to earnings from employment. These interviews occurred in focus groups and individually. The data was analyzed using grounded theory techniques. The findings indicate that family, significant others and peers were essential in providing influence and motivation to these former beneficiaries as they transitioned to work. The support and encouragement provided to beneficiaries, and the challenge of high expectations were cited as important types of help. Benefits planning, postsecondary education, assistive technology (AT) and work experience were all important elements to a successful transition off of benefits to work. This study examines each of these elements and identifies several implications for practice. A guide for rehabilitation counselors that work with SSI/DI beneficiaries is also provided to assist in the process of helping them become self-sufficient through work.

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There are more than 14 million Americans who receive SSDI or SSI due to a disability that prevents them from working. The total cost of these claims in 2011 exceeded 141 billion dollars annually to American taxpayers (Social Security Administration [SSA], 2012). The total number of beneficiaries includes more than one million people 30 years of age or younger who have almost their entire working lives ahead of them. Unfortunately, many young SSI/DI recipients will never obtain employment at a level that removes them from dependence on their Social Security benefits (Stapleton et al., 2008). Relegated to a lifetime of subsistence on Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), less than one-percent of the recipients ever leave the Social Security rolls because of gainful employment (Livermore, 2008). Although recent studies indicate that the return to work rate for SSDI-only beneficiaries may be as high as three percent, this success rate is very low and does not include SSI-only beneficiaries, many of who are young people (Liu & Stapleton, 2011). The low return-to-work rate of Social Security beneficiaries takes a staggering human and economic toll, especially for young beneficiaries, who have the potential for a lifetime of gainful and meaningful employment.

There have been several studies that identify some of the reasons why SSA beneficiaries do not go to work or return to work at a level that removes them from dependence on benefits (Compton, 2010; Kennedy et al., 2004; Livermore, 2008; Marini, 2003; Marini & Reid, 2001; Olney, 2011). However, there have not been any qualitative studies that examine the factors that

increase the likelihood that an SSI/DI beneficiary will return to work at a level that removes them from dependence on Social Security. This study investigates what worked in the lives of former SSI/DI beneficiaries that helped them not only go to work, but go to work at a level that resulted in self-sufficiency.

Research Design

This study was conducted using qualitative research methods as this type of research is particularly well suited to studies of the disability experience (O'Day and Killen, 2002). An exploration of the factors that led to a successful transition from SSI/DI to self-sustaining employment can be captured and expressed through the voices of the people who made that transition using qualitative research (Niesz, Koch & Rumrill, 23008).

This study was conducted using the grounded theory method of qualitative research. Grounded theory studies lives from the perspective of the actors involved (Hanley-Maxwell, et al., 2002). Grounded theory is a strategy of inquiry in which the researcher gathers data from the views of participants, engages in constant comparison of that data, and allows theory to emerge. The result is a theoretical and practical understanding of the studied experience (Charmaz, 2006; Creswell, 2009). Several common themes emerged from the analysis of the data gathered during this study. These themes will be discussed in detail in the Findings section.

Research Questions

The following research questions were investigated in this study:

- What fears did the participants have about going to work and getting off of benefits?
- What or who influenced and/or motivated former SSI/DI beneficiaries to seek and obtain self-sustaining employment?

- What individuals or organizations were instrumental in helping former beneficiaries obtain and maintain self-sustaining employment?
- What type of help was the most beneficial in assisting the participants to obtain and maintain self-sustaining employment?
- What personality traits or individual characteristics were the most instrumental in helping former beneficiaries to transition to self-sustaining employment?
- Did the participants utilize work incentives available through SSA and how helpful were these incentives?
- What difficulties, if any, did the participants experience with SSA during their transition to self-sustaining employment?
- What is the value of work to participants since they transitioned off of benefits?

Methodology

This study investigated the research questions through the use of focus groups and individual interviews of 22 former SSI/DI beneficiaries. In order to qualify for the study, the participants had to have been a recipient of SSI or SSDI or both, and must have obtained and maintained employment at a level that removed them from eligibility for cash payments from SSA. The participants were recruited through an ad hoc report from the San Diego District of the California Department of Rehabilitation, and through an e-mail recruitment request sent out through listserves generated by the California Health Incentives Improvement Project (CHIIP). A stipend of \$50.00 was paid to each participant that was provided in part by Daniels & Associates through the GRADS project, and in part by CHIIP. There were four focus groups conducted in this study comprised of twelve total former beneficiaries. In addition to the focus groups, there were ten individual interviews. All of the focus groups and individual interviews

were audio recorded. The participants were assured that all of their personal information would be confidential and that only the content of their responses to the research questions would be shared, without any identifying information. A signed consent form was obtained from all participants. The interviews were transcribed, coded and analyzed using grounded theory techniques. The same questions were asked in the focus groups and the individual interviews.

Participant Information

Table 1 identifies some characteristics of the participants in this study.

Table 1

<i>Participant Characteristics</i>				
		M	F	Total
Gender				
		11	11	22
Age				
	18-25		1	1
	26-35	3	4	7
	36-45	1	3	4
	46-55	6	1	7
	56+	1	2	3
Ethnicity				
	White	10	9	19
	Hispanic	1	1	2
	African-American		1	1
	Asian/Pacific Islander			0
	Other			0
Disability				
	Blindness	4	3	7
	SCI	5	1	6
	CP		1	1
	TBI	2	1	3
	Psychiatric		3	3
	Neuro-Muscular		1	1
	Muscular Dystrophy		1	1
Type of Interview				
	Focus Group	8	4	12
	Individual	3	7	10

Type of Benefit			
SSDI	3	3	6
SSI	3	4	7
Both	5	4	9

The participants in this study were evenly split in terms of gender. There was a wide variety of ages, with the majority of participants falling between the ages of 26-55. The vast majority of the participants were Caucasian, with only two Hispanics and one African-American participant included in the interviews. The relative homogeneity of the group's ethnicity was not considered in the recruitment process, and an increase in the diversity of participants should be strongly considered in future studies. Thirteen of the participants were individuals with either blindness or a spinal cord injury. The large number of people with blindness was due in part to a widespread recruitment process in the blind community, which included an advertisement in the Lighthouse for the Blind publication, that was provided free of charge. Several of the individuals with spinal cord injuries participated as a result of a "word of mouth" advertising through an informal network of person-to-person referral. For instance, one individual with quadriplegia sent an e-mail to three friends he knew with quadriplegia that were former beneficiaries, and they agreed to participate.

The former beneficiaries in this study were fairly evenly split in terms of the type of benefit they received from SSA prior to obtaining self-sustaining employment. There were six participants that received only SSI, seven that received only SSDI, and nine that received both SSI and SSDI simultaneously. The higher numbers in the SSDI and Both categories highlights the fact that many of the participants in this study had worked prior to obtaining the job that paid them enough to finally remove them from dependence on SSA benefits.

Many of the participants in this study made several attempts at work before finally obtaining and maintaining employment at a level that removed them from eligibility for cash

benefits from SSA. For individuals receiving SSDI, this level would be nine months of work above the substantial gainful activity level in a 60 month period. For SSI recipients, the level is that point where they earn enough money that the Earned Income Exclusion reduces their monthly cash payment to 0. The participants in this study achieved independence from SSA through a variety of jobs. Table 2 identifies the educational and employment information of the participants in this study.

Table 2

Education and Work Information

	M	F	Total
Highest Level of Education			
High School			0
Vocational Certificate		2	2
Associates	2		2
Bachelors	6	3	9
Masters	2	6	8
JD/Doctorate	1		1
Type of work			
Assistive Technology	1		1
Employment Specialist		1	1
Contract Manager	1		1
Esthetician		1	1
IT Support	1		1
Disability Advocate		2	2
Donor Relations Coordinator		1	1
IL Coordinator		1	1
Customer Service Rep		1	1
EEO Specialist		1	1
Veteran's Outreach Coordinator	1		1
Rehabilitation Supervisor	1		1
Rehabilitation Counselor		1	1
Vocational Specialist	1		1
Executive Director	1		1
Program Manager		2	2
Massage Therapist	1		1
Design Engineer	1		1

Missions Support-US Customs	1	1	
Software Developer	1		1
How Long Employed in Current Job			
0-5 years	5	7	12
6-10 years	2	4	6
11 - 20 years	1		1
21+ years	3		3
Medical Benefits from Work			
Yes	10	8	18
No	1	3	4
Prior Work History			
Yes	9	9	18
No	2	2	4

All of the former beneficiaries in this study had some level of postsecondary education, with 82% of them having a Bachelor's degree or higher. The importance of postsecondary education to the eventual independence of the participants in this study will be articulated by them in the Findings section of this study. It is important to note that the relatively high educational levels supports the previous study funded by Daniels & Associates through the GRADS project that identifies the completion of postsecondary education as an essential element in the pursuit of independence through employment by people with the most significant disabilities (Compton, 2010).

The types of employment that resulted in independence from SSA by the participants in this study were varied, though common themes could be identified. Many of the jobs involve working with people with disabilities (68%), and all but three of the jobs involve working with other people in some helping capacity. More than half of the participants had been working five years or less in their jobs at the time of this study, with 82% working ten years or less. Most of the jobs provided medical insurance. Although freedom from dependence on Medicare and/or Medicaid from SSA was not a prerequisite for participation in this study, most of the participants

had medical benefits through their jobs and were no longer receiving this help from SSA. Their employment resulted in complete self-sufficiency in all but four cases. This independence was a matter of pride for the participants, and they articulated this feeling in depth in the Findings Section.

It is interesting to note that 82% of the participants had worked prior to obtaining the employment that resulted in them no longer being eligible for cash support through SSA. The participants expressed that their work history was an important motivator and influence and that once they tasted the satisfaction and fulfillment that came from work, they would not be satisfied with less. This information supports a previous study by Pluta (2006) that identifies prior work history as an important predictor of return-to-work behavior. These thoughts and feelings will be explored fully in the Findings section below.

Findings

The participants in this study answered the research questions with great depth and, in many cases, passion. The focus group and individual interviews resulted in a significant amount of data that illustrates a potential path to success for working age SSI/DI beneficiaries that are interested in obtaining independence from SSA and achieving self-sufficiency. The findings of this study are broken down into the following themes and broad categories:

- Fears and concerns about going to work
- Influences and motivators
- Personality traits and the type of help that helps
- The importance of postsecondary education
- Work experience
- Work incentives and the trouble with SSA

- Benefits planning, self-advocacy and succeeding despite the system
- The value of work

Each of the above areas will be explored and discussed in this section using the words of the participants.

The Fear of Going to Work

Although this study is primarily about what worked for former SSI/DI beneficiaries regarding their transition to self-sustaining employment, it is important to note that they had the same fears as many current beneficiaries regarding employment. The fear for almost all of the participants in this study prior to going to work was that they would not be able to get back on benefits if they lost their job. As minimal as the monthly cash support is, it is still better than nothing, and for all, the loss of medical benefits was terrifying. In addition, the process of becoming eligible for SSA benefits was so long and difficult for many of them, that the thought of going through that process again should they fail in their employment was daunting. Prior to entering employment, most of the participants in this study were not well-versed in their understanding of work incentives or employment supports available through SSA, and that lack of knowledge or confusion magnified their fears. Elaine, an individual with Cerebral Palsy, expressed her fear about losing her safety net of benefits if she went to work,

The fear that I had was whether I was able to maintain my benefits as a safety net... I've always told people that even though I was very grateful to receive benefits it always left me feeling guilty because I've always felt like I could do more. If I wasn't working and I was just collecting benefits that I was lazy and unproductive. But there was a fear of what would happen to my benefits if working didn't work out. Unfortunately, I had to learn the hard way that I had to be responsible for reporting my earnings and things. I fell into a

situation where there was an overpayment issue because I failed to report my earnings, but thankfully I got that situated, but I think that was the biggest fear, was knowing that I couldn't rely on those monthly benefits anymore.

Dawn, a participant with a Traumatic Brain Injury (TBI), spoke about her fear of getting back on benefits if she lost her job. This fear was magnified based on stories she had heard from other beneficiaries.

I think my fear was what was going to happen financially if I failed at my job, and was I just going to be able to get back on, because the horror stories you hear about just getting benefits in the beginning. It wasn't that difficult for me to get on the first time, but I was afraid that if something happened, was I going to be able to get back on, even though they tell you there is a period of time that you can get back on. That was my fear.

Aine, an individual that was receiving SSI due to a repetitive motion disability and a mental health impairment, went through the appeals process to ultimately receive benefits. The process was so stressful for her that she had a great fear of failing at work, losing her benefits, and having to go through the process again. She said,

Oh it was everybody's fear that I'm not going to be able to get back on. It was hard enough to get on the first time. I had to appeal the decision, I had to get help, I had to get legal help, and even though I couldn't drive my car or ride my bike anymore because of my injury, even at that I couldn't qualify. So then you think, ok I have to do all of this work including going to your psychiatrist, getting records from them ... you're running around getting all of these records from people trying to become eligible, so it was really a traumatic experience getting on benefits because it makes you relive the loss you experienced having to quit work and everything that comes with being injured, trying to

get your daily needs met when you have a disability. So, you're going, I have a precarious health condition that responds to stress and work is a stressful environment and all of the deadlines that come with it, so when you think about going back to work, I have to put myself in a stressful environment. I know my body responds badly to stress so what if I have to come off of work again and then I won't have any income. Then to think about jumping through all of those hoops to get back on SSI, I mean why would you do it?

Aine's question, although rhetorical, does capture one of the main research questions of this study. Why did these former beneficiaries do it? Why did they take the risks they had to take to obtain employment, and not just any employment, but work at a level that removed them from support by SSA? What made this group different from the millions of other working-age SSI/DI recipients that, statistically at least, almost never obtain or return to self-sustaining employment? This study will examine these questions in depth and identify several answers to these questions.

Influences and Motivators

The former beneficiaries in this study identified several common people and factors that influenced and motivated them to move from dependence on SSA to self-sustaining employment. The family was the most commonly cited influence for the participants, but professionals, such as rehabilitation counselors or college professors, were also commonly cited. The participants were motivated to obtain self-sustaining employment primarily to achieve financial and system independence. Other motivators included the desire for personal fulfillment and the ability to give back to the community. The major influences and motivators will be discussed in this section.

The Family

The participants in this study were influenced to obtain and maintain self-sustaining employment by many people in their lives. One of the strongest influences came from their parents and family members. The families of the participants were described as role models and as a support system that was instrumental in their future success. The impact of parental and family influence was expressed in several ways, but has been grouped together in the two categories below.

The family as a model that develops self-efficacy. Many of the participants in this study expressed that growing up in an environment with hard working parents that supported and encouraged them influenced them to work, and built up their expectations for success in employment. Peter, an individual with blindness acquired through a motor vehicle accident, stated:

My father was very hard-working and my six brothers followed in his footsteps and my mother's father's footsteps. But my family was all professionals and I wanted to be like them, and they helped me and encouraged me all the way through. They gave me so much emotional support and counseling during the transition to this new life. They encouraged me to do whatever I wanted to do [...] They believed more than anyone else that if I wanted to do something I could do it no matter what; time-wise, energy-wise, whatever it took.

Gabe, an individual with blindness spoke about the work ethic he witnessed in his parents and how that work ethic affected his expectation of future employment. "I grew up in a family with a strong work ethic, so I knew I wanted to be employed and do my part to contribute to society."

Scott, another participant with blindness, echoed these thoughts. He stated:

I've always looked up to my parents and they are both really dedicated in what they did in work so everything they did was a huge influence on me. Neither one of them are visually impaired so when I was born with a disability it was certainly a new thing for them, but they never allowed me to be treated differently because of it. They supported me in anything I wanted to do. They provided a lot of direction for me [...]. They didn't make excuses and they didn't let me make excuses and so I grew after a while to not want to make excuses. I didn't want to just sit around and do nothing. I wanted to live within society like most people want.

The support and encouragement of parents and family members, combined with the modeling of a dedicated and strong work ethic, increased the expectation of future success in employment.

Dawn, an individual with a traumatic brain injury (TBI), stated:

I was always brought up that I could do whatever I put my head to, and I knew I was going to have some challenges and maybe I would have to do things differently, but I wasn't going to let this "thing" get in the way or blame "it." I worked around it, I wasn't using my head injury as a reason I wasn't able to do something; instead I used it as a way for me to do it and I think I learned that from my parents. They always said I could do whatever I wanted to I just had to find new ways.

Many of the participants in this study expected to be successfully employed, even when on SSI or SSDI, because the encouragement and support of their parents and family from an early age, developed that expectation. The power of expectations, from an individual and societal level, will be a recurring theme throughout this study, and has powerful implications for practice that will be discussed later in this report.

Family, the employment assumption and the power of a push. One of the byproducts of a family with a strong work ethic is that all members of the family are expected to work. Many of the participants that saw their parents as role models when it came to work also discussed the fact that their families were not going to allow them to receive public support for the rest of their lives. They were expected to work, and that expectation was often expressed by their parents quite demonstratively. Bud, an individual with quadriplegia, stated:

We had what I called an “employment assumption” in my family which was basically - you work. We grew in a blue collar neighborhood so we were thinking about going to work after high school as opposed to college. There was always an expectation that I was going to work. (My parents) didn’t have a full array of expectations as far as relationships are concerned, but as far as work that was always kind of there. I didn’t really know a whole bunch of people with disabilities, I’m kind of glad I didn’t know a lot of fellow people who didn’t work because I might have given into fear and not pursued employment. I’m happy that those expectations were there and that I took a different path and got more education than I had planned and worked with the Department of Rehabilitation, which actually helped me go through school. ... Those motivators and the environment that I grew up in, everyone just worked. That’s just how it was.

Rusty, an individual with quadriplegia, explained how his mother pushed him to move forward in his life. He said,

A year out of high school my mom came to me and said you have two choices, either get a job or go to college. To me, it was the bravest most remarkable thing she did. She wasn’t just going to let me be. I was really forced to grow up and move forward.

Art, another participant with quadriplegia, conveyed how his parents pushed him to work and expected that he would be employed and not dependent on SSA. He said,

I got hurt right after high school so my biggest influence was probably my mom and dad. I couldn't move anything when I first got hurt. I first got Social Security through my dad and then I got SSI when I turned 18. When I first got SSI they (SSA employee) said, "We need to tell you this is how it works; if anybody gives him any cash gifts or he gets money from anyone you need to keep it a secret because he's going to be on SSI the rest of his life." My parents said, "No, he's not going to be a welfare recipient all his life. Even if he can't walk he's going to do something." My mom pushed me through high school. They just harped on me, they just said, "You're not going to sit on your ass all day." They just pushed me to make something of my life. That was the biggest influence I had.

The expectations of Art's parents stand in stark contrast to the expectations he heard from the employee at the Social Security office. His parent's driving force influenced him to eventually go to work at a level that removed him from dependence on SSI. The force of a parent's push can be felt from a long distance. In a follow-up to Art, Chris, another individual with quadriplegia said,

I'll second that. My father pushed me. He said the same thing, "You're not sitting at home anymore." I lived in San Diego and my family lived in Fresno and that did not deter him at all from pushing and pushing and pushing for about a year until I got back to that first job. It was my father.

It is clear from the perspective of the participants in this study that their parents and families were very influential in their decision to seek and obtain self-sustaining employment. Whether it

was through modeling of a strong work ethic, support and encouragement, high expectations, or a forceful push, the family influence cannot be overstated. That influence on the participants in this study manifested in the development of self-confidence, and the expectation of success in the pursuit of meaningful and rewarding employment.

Rehabilitation Professionals

Several of the participants in this study were influenced by rehabilitation professionals that acted as mentors and inspirational figures in their lives. Rehabilitation counselors and medical rehabilitation professionals were often cited as people that were encouraging and motivating for the participants. Dawn spoke about the influence of her counselor in the brain injury program where she received treatment and a professor she had in graduate school,

The counselor over there was a great influence in my life, and then over at the university, (a professor); the simple stuff that they did, they both believed in me and both made me aware of the different resources that are available, and if I needed to use them they were there [...] I belonged to several different organizations that gave me moral support.

In many ways, the rehabilitation professionals provided the same support and encouragement as the parents cited above. Scott conveyed how the Director of the blind program he attended pushed him to succeed.

The director of the youth program there wasn't visually impaired, but he helped me see that even though I was a person who happened to be blind, I wasn't a blind person. His name was John and he helped me see that being blind wasn't a defining characteristic. He pushed people to find adventure and to find themselves and to try things. Try and stand up on that surfboard and if you don't do it it's no worse than anyone else who tries it and doesn't do it.

The professional staff also acted as role models for the participants, especially when these professional staff had the same disability as they did. Sandra spoke about how seeing other people with visual impairments succeed at work influenced her. She said,

Being able to go to the Center for the Blind, most of the staff is completely blind, and just seeing how they work and that they were able to work and that they were excellent in their jobs was a real incentive for me. It was like if they can do it, surely, I can do it. That was everything for me. That was where I really feel like I got my start, knowing that everyone around me had disabilities, and that they were doing it.

The rehabilitation professionals were, in many ways, mentors for the successful former beneficiaries in this study. The power of the mentoring relationship, and its impact on the return-to-work behavior of the participants in this study was significant. The importance of mentors and their impact on SSA beneficiaries that obtain and maintain self-sustaining employment will be discussed in detail in the Mentors section of this report.

Financial and System Independence

One of the most powerful motivators for the participants in this study was to be self-sufficient and independent. They were driven to get off of SSA benefits, make more money and be free of the SSA bureaucracy. Self-sustaining employment was the path to financial independence and freedom from what was often described as humiliating and demeaning system. The meager existence provided by the cash payment from SSA (especially the monthly SSI amount), was enough to motivate many of these participants to seek a better life through work. Gabe described why he was motivated to work and get completely off of benefits. He said,

The fact is, especially in California, SSI is barely enough to survive on, and if you are going to survive, you almost have to be dishonest. It's very difficult to survive on what

you get for a monthly payment. Looking at people who are still receiving benefits in this current economic climate it's getting even more difficult to survive. As far as my life, it's completely different (now that I am working). On SSI you have to constantly figure out how to pay the rent, buy some groceries and maybe do a little bit extra at the end of the month, and you can't have any kind of a savings, you have to be careful about that. Going to work I've been able to save up and go on vacation, I've been able to get married and buy a house. A lot of things while on SSI are next to impossible to be able to save up and do. Financially, the independence of having the opportunity to save up or do something beyond the scope of SSI, not having to worry about telling anyone about it or record it, I have a lot more freedom. It's completely liberating.

Financial freedom was directly related to the ability to make choices in their lives, and work was the vehicle that allowed them to make those choices. Lisa Marie said,

My motivator really was to be financially independent, to have a quality of life that allowed me to be happy in whatever it was that I did. ... I think the financial independence was big for me, to do what I want when I want, live where I want, buy what I want. I was not satisfied by any means with the amount of money I was receiving, especially in the bay area.

Lauren's work earnings allowed her to move out on her own, away from her family for the first time. She spoke about how financial freedom was a motivator for her to work.

I think my main motivator was just to be self-sufficient. I knew that SSI is only so much money realistically and it's not enough to live on long term. I wanted to move out of my parent's house and live on my own. For me, it's knowing that I'm self-sufficient, but

also the financial flexibility in creating my own earnings and not having to report anything has opened up housing options, all kinds of options, just more flexibility overall. The lack of flexibility in the Social Security system alluded to by Lauren, its controlling, confounding and onerous rules and reporting procedures, motivated many of the participants in this study to be free of the system. Obtaining freedom from involvement with SSA was enough to drive Peter to find self-sustaining employment as soon as he graduated from college. He said,

Once I was in the program for a couple years I could not wait to get off it. I did everything in my power to get off it as fast as possible because it was driving me crazy. Going to the meetings, and the offices that seemed to be run down and full of chaos, and all the paper work that kept asking you questions; it was kind of humiliating to me, I didn't want to be monitored. There was a lot of bureaucracy I didn't like.

Several of the participants in this study expressed a desire to be free of the control of SSA. They felt restricted and unhappy with the invasion of their privacy that resulted from the constant reporting to SSA. Sandra said,

When you're in the system, you can only have so much money. You are controlled by the system. I did not want to be controlled by the system I wanted to save as much money as I could and spend the way I wanted to spend, so that was my motivator. I didn't want to be controlled.

Carla echoed this thought when she said,

I thought there was kind of a stigma that comes with being on SSI and I always wanted to get off because I wasn't comfortable collecting a check from the government. Also there's this rude awakening with SSI wanting to know everything in your life. There's no privacy and you're financially restricted.

There was no true fulfillment in the lives of these participants until they were free from the dependence on SSI or SSDI. The restricted and austere life they described while dependent on benefits was starkly contrasted to their expressions of the satisfaction they experienced through self-sustaining employment.

The Progressive Growth of Independence

The drive to achieve financial freedom and independence from the Social Security system was, at least partially, fueled by the empowering and efficacy-building process that the participants experienced through gains in independent living and functioning. Many of the participants in this study expressed that the confidence they built from living on their own, using technology, completing college, or other challenging activities directly affected their return-to-work motivation and behavior, and their work retention. Scott, an individual with blindness, spoke about how important independence was to his pursuit and retention of employment and his overall mental health. He said,

Living independently gave me a taste for what it really feels like to be an adult, to have to pay your own bills, and that's an example of something that's not the glamorous side of work, but also you can buy your own food and buy what you want, when you want. If you want to go out and get a coffee at nine at night then you can do it. So absolutely the experience of living independently definitely galvanized me to want to continue that feeling and if I wasn't working there would be much less a chance of that happening. One of the first benefits is gaining that self-esteem. It can provide an outlet for your energy. It makes your brain have to work. You interact with people so you maintain that connection. So if you're fortunate enough to be doing something you enjoy, that is a priceless thing to have. Mentally, you can't pin down how much that helps. Then of

course, it comes back to living independently and living within your own means not anyone else's. A lot of the decisions I make from the moment I wake up are because I have the financial stability to do so.

The acquisition and use of assistive technology for independent living played an important role in developing confidence and the expectation of future success at work for many participants. Every gain in independence at home and in the community developed a belief that they could do more, and this belief resulted in an increase in return-to-work behavior and success. Lisa Marie explained how the use of technology increased her confidence. She said,

I work with clients in the blindness field, so it's your ability to be a blind person who has the skills to succeed, you know brail, adaptive technology etc. When you have those skills under your belt you're able to be on the right track to be successful. It doesn't matter where a job is or what it is, if you know you can use your skills and get around town, you can do that job. If you don't have computer or adaptive tech skills then it gets tougher to be employable because no one wants to hire you, so you don't think that you have the skills to be successful.

It is clear from the results of this study that activities and experiences that increase a beneficiary's confidence and expectation of success in activities like independent living and functioning, positively affect their drive to achieve self-sustaining employment and their desire to be free of dependence on benefits. The participants in this study were also driven to be self-sufficient through the influence, motivation and modeling of mentors.

The Power of Mentors

The influence of peer mentors was cited as a powerful force in helping the participants of this study transition to self-sustaining employment. The peer mentoring

relationship took many forms, from one of general exposure to people with similar disabilities, to a support group, to a close individual friendship. Regardless of the form of mentoring, the effect on the participants of this study was cited as a major factor in their successful transition to work. Sometimes, simple exposure to people with the most significant disabilities engaged in meaningful employment acts as an encouragement and motivator to people. The working individuals don't need to necessarily act as mentors, they simply need to demonstrate by their actions that self-sustaining employment is possible. The exposure to working peers acts as an encourager and motivator to beneficiaries and showed them a life beyond dependency on SSA.

The exposure to peers that were working often resulted in the establishment of a mentoring relationship that was instrumental for many of the participants in this study when it came to preparing for, acquiring and maintaining self-sustaining employment. The peer mentoring relationship did not have to be a complicated one in order for the participants of this study to make the transition to work. Oftentimes the mentor simply provided support and encouragement to the individual. Cheryl spoke of the encouragement provider by her Benefits Coordinator at her local Independent Living Center,

One of my great motivators, besides the fact that I never intended to stay on benefits, because I just didn't want to stay at home, was meeting the Benefits Coordinator here at (the local Independent Living Center). She was a great influence on me because she was an individual with a disability and I felt like a person with a significant disability wasn't going to steer me wrong. So, she was my great influence in going back to work. She kept encouraging me to just give it a try and I did a bit of volunteering and things like that. It just makes me wonder if having another person with a disability to light the way makes you believe that you can go ahead and do what you want to do with your life. You know,

when you have your life a certain way and it's completely flipped over, and an able-bodied person tells you that they understand you just know that they don't because there is no way to. So I want someone I know has my back and someone with a disability I know will have my back. I really feel like having a mentor is important. I think a big reason a lot of people don't go back to work is because they don't have any one to show them the way.

Peer mentors provided inspiration and support in numerous ways to the participants of this study. Support was demonstrated through encouragement and modeling, but it also came in the form of being challenged. Mentors were not just cheerleaders. They pushed and challenged these former beneficiaries to dream big and to strive for self-sufficiency. Bud spoke very passionately about his mentor and how he challenged him and his family to work and be successful.

I was blessed to know people who started working even before the work incentives [...] I just had those mentors. He actually came to my house when I lived in Sacramento in whatever van he had and ticked off my parents because he challenged them. He eventually apologized, but I think he needed to challenge them. They expected me to go to work eventually, but they were protecting me. Joel said, "Kick him out. He needs to move out." Seeing that others can do it and say, oh I can do that! As opposed to saying, all I can do is... and not thinking oh they're smarter and blessed with good health and that they're better. So somehow for people, hopefully, they can get stirred up enough to (go to work).

Rachel, who recently completed her Master's degree in Rehabilitation Counseling, was mentored by a professor with a significant disability when she was in college. In addition to the support

and encouragement he gave her, he challenged and pushed her to succeed beyond her expectations. She said,

I had a really strong mentor who was really influential in helping encourage me to go to work and take all of these steps that led me on the path I'm on now; doing a lot of volunteer work as a mentor for other college students, with disabilities and doing a research study, which was a really big resume builder. He was one of my professors that was doing a fellowship at UC Berkeley. He helped guide me through continuing my education and my studies, and just acted as very supportive and encouraging person. He was so encouraging! I don't think I would be where I am if it wasn't for him pushing me to go above and beyond getting good grades and do an honors thesis. Get this work experience, ya know, go above and beyond... For me, my relationship with my mentor was key in building me up and making me feel like I was capable and bright and able to contribute and give back to the field in some way-the disability field.

Many of the participants in this study attributed their drive and success to the mentors they had in their lives. In some cases, peer mentoring occurred in the form of a support group of individuals with similar disabilities. Aine discussed how important mentors were, whether in the form of a support group or an individual, as she transitioned off of benefits through work.

Actually support and mentoring is absolutely necessary. .. You need emotional support when you're making the transition because you're afraid. Some people need practical support like writing a resume, but for my own experience, I had a group that I went to that was women with disabilities, and we met once a week and shared resources and all like that. I have a very good friend that was sort of like a mentor relationship with this one guy, and you know, he kind of mentored me through this. I would say, here's my

plan of action for today and talk about it with him and then check in with him and let him know I got these items squared away but not these two... And I did that constantly over the time period.

The support, encouragement, and push provided by peer mentors were consistently cited as essential elements in the transition to work. The peer mentors challenged the participants of this study to strive for independence, excellence and self-sufficiency. Mentors helped them envision a life beyond dependence on SSI/DI. The mentors had high expectations for these participants, and helped the participants have high expectations for themselves.

The Loving Gift of High Expectations

A recurring theme in this study involves the concept of expectations and their effect on the return-to-work behavior of people with the most significant disabilities. On the one hand, the participants in this study spoke about the low expectations that society has regarding work for SSI/DI beneficiaries and how these low expectations negatively affected their confidence in their ability to obtain and maintain self-sustaining employment. The low expectations of society were especially challenging when they came from organizations that serve people with disabilities such as State Vocational Rehabilitation Agencies (SVRAs) or the Social Security Administration. On the other hand, the participants spoke of the high expectations that their parents or mentors had of them and how this inspired them to expect more from themselves than living a life dependent on SSI/DI. In effect, these former beneficiaries indicated that people lived up or down to the expectations of those that surrounded them.

Elaine is an individual with Cerebral Palsy that works as an Employment Specialist for a large corporation in California's Bay Area. She spoke of the low expectations that she sees

young people with disabilities have about their futures and how important it is to get past those mental barriers in order to be successful at work.

A lot of students I work with don't have as much experience as their able-bodied counterparts, and those able-bodied students don't have to deal with those self-inflictions that people with disabilities have to deal with. I often find that it's more mental barriers that we place on ourselves than our own physical barriers that keep us from promoting ourselves in life and in work, so if people can overcome that, then yea I think the sky is the limit.

The struggle to overcome the low expectations of society regarding work was a major challenge for many of these participants. It was their experience that society simply did not expect them to work. As a wheelchair user, Albert spoke about how he viewed society's expectations of him.

It's society at large. Once you're a special group and this group is receiving benefits they put you in this lump sum group; that's the group that doesn't work. They say, "Don't you guys get benefits? You don't have to work then." I wish society would be a little more accepting that us working is the norm, but it's not.

Rachel echoed the thoughts of Albert. She said,

The expectations were so low and I had to fight for high expectations and just also I had in me I had a self-optimism, even though things kept pushing me down I really deep down felt like I would reach my goal of getting out of the house and reaching full-time employment because I knew that sitting in front of the TV was just going to kill me in the end. I think you do have to take some risks.

The low expectations of work for people with significant disabilities was not just conveyed to the participants of this study by society in general, but often by organizations serving people with

disabilities. These organizations, which in many cases are tasked with helping people with disabilities get back to work, conveyed a message counter to independence and self-sufficiency at times. The Social Security Administration was one of these organizations. Karla was a former beneficiary that became independent from SSI through work as a Benefits Counselor for SSA. She discussed the message she received from SSA when she reported her wages to them.

Finally after I had been working for over a year, I finally had an appointment with a Claims Representative (at SSA). She put in all my info and I said to her, “Are you going to terminate me now?” And she just looked at me funny. I said, “I know I’m over the threshold.” She said, “Well Karla, we don’t do that.” I said, “Well the rules say you’re supposed so explain to me what that means.” She said, “People like you.” And I said, “Stop. Explain to me what that means.” She said, “People on SSI usually don’t stay employed, so it’s too much of a pain of an ass to take you off and put you back on.”

Karla conveyed how these low expectations made her feel diminished as a person and how she had to fight to finally get off of benefits and be independent. It is difficult to reconcile these low expectations with organizations charged with helping people with the most significant disabilities become independent through work. Many of the participants of this study understood that the expectations of others can often become a key motivator or discourager to return-to-work behavior. Bud directed an Independent Living Center as part of his work history, and he spoke about how important it is for organizations that serve people with disabilities to have high expectations for the people they serve.

We have talked about all of these assumptions that we grew up with, that lit a fire under us that other people haven’t been blessed with. That’s why I’ve said this multiple times, but at the Independent Living Center, there was a phrase; *The loving gift of high*

expectations. I always give the consumer that. I want to ask them more questions, what are your plans to get off these programs? [...] Do something. Don't just come in here [...] I want to light a fire of high expectations for people with disabilities because I know what a gift employment has been for me.

The loving gift of high expectations is essential to those individuals who did not have the benefit of growing up with parents and family members that instilled a strong work ethic in them. The participants in this study spoke repeatedly about how the challenge and push they received from others was an essential component in their initial motivation to go to work, and in their desire to become fully independent through work.

Personality Traits and the Type of Help that Helps

What is it about this group that is different from other beneficiaries that have not obtained self-sustaining employment? It is clear based on the statistics that this group is a rare exception to the rule that once you are on benefits, you stay on for life. The participants in this study were aware of how rare it is for an SSI/DI beneficiary to leave achieve complete independence from SSA based on work. Several of them pondered the question of low return-to-work behavior. In one of the focus groups, Bud and Albert had the following exchange in response to the question about why some beneficiaries go to work and others never try:

Bud: Unfortunately it seems like there's this an internal thing that some of us have that others don't. I thought that the more the incentives played out the more people would get to work, but that hasn't really played out at the level that I expected. That's where we are today in 2011. Work incentives have been there for a really long time, but it hasn't all of a sudden caused a rush of people wanting to get to work.

Albert: I have friends that have died because they are so hopeless and they drank themselves to death. I always try and figure out. Why, why didn't they just get it? Why didn't the light bulb go on? I don't know why.

The answer to that question of "Why" the light bulb goes on for some and not for others is the central question of this study. We know that these participants shared the same fears as other beneficiaries when contemplating going back to work. They were influenced and motivated by parents and mentors that developed positive efficacy expectations that encouraged risk-taking and return-to-work behavior. They were challenged and pushed to do as much for themselves as possible, and their increase in independence also worked to increase their expectations for meaningful work. The people and organizations that mentored and supported them in their transition to work had high expectations for them, and these expectations challenged these individuals to not just work, but to obtain self-sustaining employment that contributed to giving their lives meaning.

The participants in this study identified several personality traits that were essential in helping them to become one of the rare people that broke free of dependence on SSA through work. One of the most important traits that was cited repeatedly was tenacity. Rachel felt that her tenacity was one of the most important traits that led to her work success. She said,

Tenacity was the word that came to mind. You have to keep fighting. I found the way that I achieved success was to fight for what I thought was possible for me, and if somebody said no to creatively find ways around it or persuade them otherwise. I felt like I had to fight a lot to get the services and support I needed to go to work.

Chris was in the same focus group as Rachel, and he reinforced her words of advice. His advice to beneficiaries was to,

Try. Keep Trying. You can't give up. Get some education. Get out there and engage in the world and the working world. That's what's going to give you some courage. I mean just keep trying.

The ability to persevere and remain tenacious was rooted, at least partially, in the ongoing support of parents, peer mentors, and helping organizations. Tenacity is also partially rooted in self-confidence and feelings of empowerment. The participants of this study were able to deal with the challenges of returning to work, in part, because they believed in themselves and had others that believed in them. Rachel followed up her comments on tenacity cited above when she gave advice on what it takes for beneficiaries to go to work.

I think it's just empowering people wherever they're at, especially in working with people with disabilities and helping them take charge of their own lives and live up to their fullest potential and not just their satisfactory potential. I think it's important to teach them to be proud of who they are, disability or not. For me, recognizing the strength of my disability and being a part of a larger community was huge for me. I think employers might fear the disability, so I put it out there right up front. So I'll say, "You know I have a disability," but I look at it as having a strength. I look at it as having a strength and being able to think outside of the box because I am proud of having a disability. I do see it as a strength, and yeah it comes with its own inherent challenges, but it's made me who I am and I wouldn't change it. I sell it because I really believe it.

It is not difficult to see why Rachel was one of the few that went to work and is now free of dependence on SSA benefits. She had a tremendous belief in her ability and felt empowered to advocate for herself and become independent. These traits were cultivated by supportive people in her life.

Support, encouragement, and belief in the ability and worth of each participant in this study were the types of help that helped the most. Emotional and moral support was instrumental as they faced losing the certainty of a monthly check from SSA, no matter how meager, to the uncertainty of a pay check and the loss of their safety net. Bud referred to the support needed as “cheerleading,” and tied the support he received back to the concept of expectations.

For me, it was about having people believe in me, and having expectations of me. If we don't shift people's expectations of themselves, then we get stuck in this vicious cycle. So we really do need cheerleaders that say, “I believe in you.” It really helps when people say, “Oh you do that so well,” or, “It was really great talking to you,” just things to really build you up. A lot of us at different times in our lives struggle with self-esteem, with the way people look at you or approach you. Sometimes you feel like, oh I'm different, so maybe you think you're inferior, so having the other side. It's nice to hear, oh you can do these things and that's normal. Life is so much about our attitude. If you believe you can do things, then for the most part you can. I think in my mind it's critical that folks that are considering moving down this path somehow need to shine their spotlight on their abilities not their disabilities. It is so important to shine on their abilities. Yes, you have this disability. I try that on everyone that comes in my office. Let's look at your abilities, your capabilities, your interests, your goals, your dreams in life. What do you want to do in life? What have you always dreamed of doing? You can do it.

Bud articulated the most important element of the support the participants received from others; the resulting increase in their belief in themselves. This increased self-confidence helped sustain

them through lengthy educational endeavors, multiple job attempts, discrimination, overpayments from SSA, and the general low expectations of society.

The support of others often took the form of encouragement, cheerleading and counseling. The participants in this study identified several organizations that were helpful to them in transitioning to employment. Professors in college, staff at community rehabilitation programs, healthcare providers and other service providers were frequently cited as essential in providing them with numerous types of support as they prepared for, and sustained employment. It is important to note that the support the individuals in this study received frequently came through their rehabilitation counselors in the public Vocational Rehabilitation program in California. All of the participants in this study were clients of the Department of Rehabilitation (DOR) at some point in their past. Although a couple of them described some difficulties with their rehabilitation counselors at DOR, the participants in this study overwhelmingly expressed gratitude for the emotional and financial support they received from DOR and spoke about how essential this help was in their transition to independence through employment. Peter described the different experiences he had with two rehabilitation counselors, and how meaningful his good relationship was. He had such a good experience that he became a rehabilitation counselor, and promoted to rehabilitation supervisor at the time of this study.

Now my first counselor was lousy and then he retired, and then I got this new counselor who I'm still friends with to this day, Patrick. Patrick really listened and really just allowed me to try even if I failed. They sent me to college and then law school and helped me transition to being a lawyer at a big private law firm. When that didn't work out four years later, they allowed me to come back, which I didn't think they would. But they helped me write a business plan to start my own business and then in fact, the DOR

helped me (which again I didn't think they would do), the DOR down here helped me get in and get my Masters. So at all three phases, they helped jump start my career again, so they've been the biggest help throughout my whole life. They helped me start my life from scratch and they spent the most time of all trying to work that out. Patrick came and visited me at college just to check on me, in the good ole days when you could spend quality time counseling your people. I still remember that vividly. I wish some of my counselors could do that today. In terms of government agencies, they were number one. Sandra also spoke about how helpful the financial support of DOR was in her transition to self-sustaining employment. She said,

The DOR gave me everything I needed to get a job. Everything. They gave me the education the training. Without them I wouldn't be where I am today. My parents didn't have any money. So without the DOR there was no shot of me getting any education. Sandra identified one of the most essential qualities that separate the participants of this study from other SSI/DI beneficiaries that have not obtained and maintained self-sustaining employment – their educational level.

The Importance of Postsecondary Education

It is very clear from the history and feedback of the participants in this study that completing postsecondary education at any level was one of the most important reasons that they were able to acquire employment that paid them enough money to get off of benefits. Table 1 indicates that all of the participants in this study were high school graduates and all had completed some level of postsecondary education. Most had completed at least a Bachelor's Degree, and 41% had completed a graduate degree. Sandra spoke about how important her Master's degree was in achieving employment at a high enough level that she could independent.

I knew the only way for me to come off of the system was through education. That's when I started down that path. I literally made education my job [...] You have to have that education [...] Even with a Bachelor's I couldn't find a job. I had to get a Masters. The employment opportunities for many of the participants in this study were limited due to the significance of their physical disabilities. Postsecondary education was the main way that they could acquire the knowledge and skills to obtain career-level employment. Lauren, an individual with post-polio syndrome said, "Because of my disability I couldn't go into any field that was manual labor, so it was definitely important for me to get an education."

In addition to providing the participants of this study with the necessary education credentials to obtain self-sustaining employment, the success they experienced in the educational arena worked to develop their expectations for success in employment. The increased self-efficacy developed through progressively passing challenging courses and mastering educational content encouraged their return-to-work behavior, which translated to an increase in their persistence in looking for work. The participants in this study were not easily discouraged by the subtle discrimination or rejection they experienced as they engaged in their job search. They did not give up, and they recognized the importance of this persistence and tenacity to their success. Another process that worked to develop their expectations for success at work was the participation in internships or work experiences, and it is this efficacy-building process that will be discussed in the next section.

Work Experience

The process and experience of participating in real work, whether it be through volunteering, paid or unpaid internships, temporary or part-time work, or any other kind of work experience was one of the most important elements in the transition to self-sustaining

employment for the participants of this study. Work experience in any form taught them valuable hard and soft skills, and developed a sense of confidence in their ability to succeed on the job. Elaine was one of the participants in this study that was only receiving SSI when she went to work. She currently works as an Internship and Work Experience Specialist for a program that provides job placement opportunities for people with disabilities. Elaine perfectly described how her efficacy expectations were built through a series of internships, and she gives sound advice to any rehabilitation professionals on how to approach the process of work experience.

After I graduated (from college) I got an internship as a Public Relationships intern [...] Then after that, I wasn't working for little while because it was at the time of the economic collapse so I was just unemployed for about 6 months, so I reenrolled at a community college to be able to secure another internship with a small web design firm. That was unpaid, and I did that for about a year, and then this job came along so I transitioned from the web design intern job and I worked part time, I think no more than 30 hours a week [...] It was a perfect job for me because I developed confidence and an interest in working with people and helping people. So, for me every job I've had has been a build-up of skills that I've utilized in the next job [...] If you're a person who has to take things slowly I would suggest finding an internship or part-time job where you can figure out how you are as an employee and how it's going to feel working when you haven't done that before. So go slow, and figure it out and see how it feels and how it might feel in a full-time position. So for me, incremental growth is the best way to describe it. You don't want to push yourself into a full-time job if you've never had any

experience, so build on your strengths incrementally and wean yourself off of SSI because that will create the most successful path.

The internships and part-time work experience helped Elaine develop confidence in her abilities and sparked her desire for full-time, self-sustaining employment. This pattern revealed itself in several of the participants of this study, especially as they sought to transition from their postsecondary education into career-level employment. Lauren said,

So when I first graduated I started doing some volunteering to get my feet wet and then this job opened up, I thought it was the first opportunity I saw and I just took it. I wanted to get some work experience. It seemed like the natural progression, you finish school, you get a job [...] (The internship) really just helped me develop a professional environment rather than an academic one. Also it helped me develop some office skills and just learn the lay out of the office and get to know the staff, so that it wasn't such a huge adjustment when I started working full time, and I was able to focus more on what my new responsibilities and my work load rather than everything at once.

The gain in self-confidence that the participants of this study experienced as a result of engaging in work experience of any kind was one of the key elements in their future success. In hindsight, they recognized how meaningful work experience was in their professional development, and they encourage other beneficiaries to experience the same. Albert spoke emotionally about how his internship as part of this Master's degree program changed his outlook on his life and his future.

It was during that internship that I really found that I had some self-worth, and that there are things I can do. Matter of fact, I could excel at some things better than other people and some things I needed help in, but the real key is to help people get into a position

where they can get that confidence and that drive to succeed; to get a taste of nectar. I never had any nectar during my life. I was stuck on benefits and I thought that was my life and I wasn't real happy and I wasn't in the business of making other people happy because I wasn't happy. The reality of it was that my life didn't really turn around until then.

Work experience provided the participants of this study with numerous benefits in addition to gains in self-confidence. Through work experience, these former beneficiaries were able to engage in job exploration, asking themselves if the work they were doing was the kind they would be happy to do for the rest of their careers. They were able to utilize and experiment with assistive technology and identify any reasonable accommodations they would need when transitioning to full-time employment. The internships helped the participants of this study build their work stamina, so that full-time employment could become a reality for them at some point. Work experiences also gave them a taste of purchasing power and this taste often blossomed into a full-blown craving for independence and self-sufficiency. Another benefit of work experiences was that they prepared the former beneficiaries for the difficulties that they were going to face with SSA once they began earning money.

Work Incentives and the trouble with SSA

The level of awareness and utilization of work incentives available to provide employment support through SSA varied among the participants in this study. Several of the participants in this study were very knowledgeable about the work incentives available through SSA to help them go to work, but many were not aware of what types of work incentives were available to them or the benefit of using the different incentives. Table 3 provides information

on the work incentives used, the knowledge of work incentives, benefits planning provided, and the overpayments experienced by individuals in this study.

Table 3

<i>Work Incentive Information</i>				
	M	F	Total	
Used Work Incentives				
yes	7	8	15	
no	4	3	7	
Work Incentive Used				
Blind Work Expense	1	1	2	
PASS	3	1	4	
Trial Work Experience	2	1	3	
TTW		4	4	
1619A		2	2	
1619B	1	3	4	
Earned Income Exclusion		1	1	
IRWE	3		3	
250% Working Disabled	1		1	
Benefits Counseling				
yes	10	9	19	
no	1	2	3	
Who Provided Benefits Counseling				
ILC	3	3	6	
CWIC		2	2	
VR	7	4	11	
Overpayment				
yes	11	11	22	
no			0	

There were 15 of the 22 participants that were aware that they had used any work incentives through SSA as they transitioned to work. There were 19 participants that received some level of benefits counseling, but of that number, about half got the counseling after they started working and ran into trouble with SSA through overpayments. It is important to remember that all 22 of the participants in this study were consumers of the DOR at some point in their transition to work, yet only four people knew they had used the TTW program. When

one examines the time in their current job identified in Table 1, eighteen of the participants in this study would have assigned their TTW to the DOR during the transition to employment. The participants in this study, even the ones that were very well informed about work incentives, found them to be confusing, complex, and punitive. These problems were compounded by inconsistent information provided by SSA employees and an inconsistent level of knowledge of their own system. A few of the participants found the work incentives to be helpful, especially those that had been on SSI and retained their eligibility for Medicaid through 1619B. However, the difficulties these former beneficiaries had experienced with SSA overshadowed the benefit they might have felt from using work incentives. The difficulty with the SSA system manifested for every one of the participants in this study in the form of overpayments.

One of the most shocking results of this study was that 100% of the participants had experienced an overpayment from SSA as they transitioned to self-sustaining employment. These overpayments ranged from \$2,000 to almost \$40,000. The financial and psychological cost of these overpayments cannot be overstated. The burden of owing so much money to SSA was a heavy weight for many of these former beneficiaries, and several of them were still paying their overpayments back at the time of this study. Gabe is one of those still paying SSA back for an overpayment. He spoke about how his overpayment happened,

When I went to work for this company, I ended up with an overpayment that I'm still paying back now. I didn't have any of the transition benefits, so I was trying to get all of the information on my own, which is part of the reason that I ended up with an overpayment because I didn't have, and didn't know where to get, all of the correct information. I didn't know how to properly relay my employment information to SSA, so that's what happened I guess. They really don't make the process easy. The only way to

get off it is to get a job where you can completely get off of it. They say you can get work part time and work it down, but it doesn't really work out like that at all. Since I'm visually impaired, the process is even more confusing and the situation inevitably ended in an overpayment [...] I really wasn't even aware of any benefits counseling or any place to go to try and get information, so it was basically trying to get a hold of someone at my local SSA office and it took a lot of going back and forth to get a hold of them, and then when I took the receipts that they asked for in to them, they just said, "Ok, you'll hear from someone," and I didn't, so I called back a couple months later. They said they didn't have any record of that stuff every getting turned in, so there was an overpayment there. So I went back in and turned in receipts for work expenses etc., and they said, "Ok, you can have a credit for these and continue receiving SSI," and then a little while later I was hit with a larger overpayment, so I ended up having two separate overpayments that I'll end up paying off. I'm still working off paying off the first one and then the second one I'll start after this one is done.

The confusion and frustration expressed by Gabe was repeated by many of the participants of this study. The fear of being punished by SSA for their earnings remains palpable for many of these individuals, even years after they have transitioned off of cash benefits because of their previous experiences. Art, an individual with quadriplegia, spoke about his frustration with inconsistent communication by SSA employees and how his current progression at work is affected by his concerns.

So even though you're not getting a check from (SSA) they're still watching you. They're supposed to call you in every year and they don't. I write them a letter every year and notify them here's my new salary, is there a cap? And I still can't get an answer from

anybody. So I get to the point where I'm like, I'm just going to go until they call me in and then we'll deal with it then. I'm afraid to advance in my job because I'm afraid of losing my caretaker to get me to work. Who's going to get me up at all? Or let me earn enough to where I can pay for own nurse? [...] I can never get an answer every year. Every single person tells you something different. You guys tell me two completely different stories. It's like, do you work for the same agency?

The confusion and frustration associated with overpayments is more than just an inconvenience for the participants of this study. In many cases, it is extremely stressful. Owing thousands of dollars to a government agency that can garnish your wages if they wish, can elevate anxiety and stress levels in the mildest of people. Teresa spoke about how stressful her large overpayment with SSA is,

What happened with SSA is, in December of 2010 I received a letter from SSA that they overpaid me over \$38,000. I was just in shock when I saw it. I don't have that kind of money. I was living month to month already, even now that I've cut back hours, I'm still living month to month. It was so stressful that I owe SSA that much money and I had no idea that this kind of thing could happen because like I said, their process was very confusing to me. I was assuming that they were keeping track and that they would know what to do and everything, so the more that I talked about it, the more that I found out that this was a very common thing for SSA. In fact, they sent me to a branch which was all that they do is deal with overpayments. I felt like it was a really great waste of money and time if they have a system that monitored the system, to know not to let it get up to 38,000 dollars. When I first saw it I thought I would have to file for bankruptcy so that's actually when I found Disability Rights to see what I could do, and they were of really

great assistance and let me know that I could set up a monthly payment plan and there's also filing for a waiver that I could do. It's a huge amount of money and I'm kind of just going through my finances because right now I'm just paying them back right now a little bit each month, just with getting over my illness and getting back in the work force, and getting myself under control is a huge burden and very stressful.

It is unfortunate that the work incentives offered through SSA frequently end up acting as disincentives to beneficiaries that attempt to return to work and eliminate their need for SSI/DI benefits. Although the work incentives by themselves, when understood by beneficiaries, do provide several incentives to return to employment, the inability of SSA to manage reduced cash payments, track reporting, and provide consistent information to beneficiaries has the cumulative effect of discouraging return-to-work behavior. Many of the participants in this study discovered a very important activity that helped them rise above the discouragement of the overpayments and confusion of SSA's system; they became educated and strong self-advocates.

Benefits Planning, Self-Advocacy and Succeeding Despite the System

The participants in this study consistently told similar stories of their interactions with SSA. They all expressed that the work incentive system is confusing and complex. The wage reporting process is arcane and fraught with mistakes. In many ways, the participants in this study succeeded in obtaining and maintaining self-sustaining employment despite the system, not because of any support it provided. In the attempt to continue to answer the question of why this group succeeded where others have not, one of the answers rests in benefits planning and the power of self-advocacy.

Many of the participants in this study indicated that benefits planning is one of the most important elements of a successful transition to independence through work. The power of

benefits planning to influence return-to-work behavior is magnified when provided by a peer that has made the transition. Ryan spoke about how important benefits planning was for him in the transition to work. He said,

I didn't get any benefits counseling when I started out with VR. I think that really held me back and kept me from work many years longer than it should have. It kind of all came together with, well, I had been floundering around and I was connected with a workability program and they had an excellent intern working there that put together a summer job club and had speakers come in and had peer support. That's the first time I heard a speaker from the Benefits Planning Assistance and Outreach program talk about work incentives. I finally at that point got that I didn't have to worry so much if something happened and I had to get back on, that there were ways I could do that, so that really pushed me forward to say let's go, let's do it.

Even with benefits planning support, which was not readily available for many, almost all of the participants in this study experienced a tremendous amount of frustration with SSA during the transition to work. Several of the participants in this study found themselves responding to the frustration caused by reporting and overpayments by becoming strong self-advocates. Albert spoke about how difficult the transition off of benefits can be, and how important it is to be psychologically strong. He likened the difficulties with SSA such as overpayments to blows received by a boxer. He said,

(The transition off of benefits) is just psychological and it can really take some tolls. If someone says, "Why are you scared?" I say, "How would you feel if the IRS was auditing you every year?" It makes you feel *less than*. At that time, I felt like I was doing something wrong even when I was doing something right [...] It's just you have to go

down there and do what we've done all our lives; advocate for yourself. It takes a sophisticated person. Some people get hit on the chin and they're down for life. I've gotten hit but I've always gotten back up.

Self-advocacy often consisted of educating Social Security employees about their own systems and how work incentives applied in their specific case. Rachel described how she had, and still has to educate SSA employees regarding her benefits. Rachel uses the continued Medicaid coverage, or 1619B work incentive for SSI recipients with earnings too high to receive cash payments. This incentive allows Rachel to continue to use her Medicaid for in-home support services for her attendant care. She said,

I still have the 1619B that connects me to medical and the in-home support services. It's a pain in the butt, it really is. It's time sheets, and it's not only that, its dealing with Social Security still and having to educate them every time I have to go into the office and tell them what program I need to be in. Luckily I've built up the self-advocacy skills and I know what to tell them what I need to do to be in the right programs. I can just imagine how hard it would be for someone who is not well connected-to be able to advocate. A lot of times people will take what Social Security says at their word because oh, they know because it's their program, but I've found time and time again that they don't know.

In Carla's case, she educated herself to such an extent on work incentives and what she could earn for work that she became a Benefits Planner, which is the job that earned her enough money to become free of dependency on SSA. Carla knew, based on numerous stories from other beneficiaries, that she would experience an overpayment from SSA. She set her SSI checks aside after she started earning money through work so that she could pay the overpayment back

when it inevitably happened. This process of anticipating the overpayment and setting the continued cash payments aside for payback was used by three of the participants in this study that were particularly well educated about the difficulties associated with transitioning off of benefits due to work. Carla said,

I used 1619b and ticket to work and when my first job that got me on the path to being able to terminate my SSI was a benefits planner and that was partly due to the personal frustrations having and the frustrations I saw other people having and the fears I saw holding people back. It was one of those Ah-ha moments! I could go out and learn the rules and use it to help other people, be able to affectively work with Social Security to be able to go to work, so it was like my optimism was that I would be able to help other become employed. Part of it was in learning the rules [...] I experienced the Social Security reps giving you complete misinformation. I went in right away. I wanted them to take me off then and there, and told the service rep how much I was going to earn. I knew I was going to have an overpayment and that there was a lag time between the time to report and your check. The representative said, "Oh no you can keep those checks. You can spend them." She's like, "Oh no, you get to keep that free and clear," and I'm sitting there arguing with her saying, "No I don't!" In my learning curve, I thought once I reported immediately it went to zero payment for SSI that they would terminate me, but it doesn't work like that. They don't technically terminate you until you accrue earnings and have achieved over that threshold. In my excitement I didn't realize that, so with reporting it was horrible. I was always on the ball about mailing in my pay stubs every month... I knew that (an overpayment) was going to happen, but that's ridiculous because I did all that work and then it was like I didn't do anything. So I had

overpayments of over \$3,000 and I had just put my checks aside because I knew. So I just paid it back, but that's not really the case for most people. They didn't officially terminate until last year. So it was years that I had been over the threshold.

Carla finished her focus group interview with some excellent advice for beneficiaries and the rehabilitation professionals that will work with them. She said, "Empower yourself with knowledge." Knowledge of how benefits will be affected by work and the development of strategies to deal with the inevitability of overpayments can be the difference between a successful and unsuccessful transition to independence through work.

The Value of Work

The participants in this study travelled a long and often difficult road to achieve freedom from dependence on SSA benefits through self-sustaining employment. The original motivators to pursue employment rather than live a life reliant on SSI/DI were fully realized once they were earning enough money to be independent. The power to purchase the things they wanted, the satisfaction of supporting a family, and the ability to give back to society through meaningful work were articulated as important values of work. Dawn painted a beautiful portrait of the American dream that she was able to attain because of work. She said,

It's great that we're independent. We have a house and a beautiful daughter. We get to travel, I get good health care, we can create a (trust) for our daughter and think about her future and her life and that in itself is just a very warm feeling, to not have to worry like these people on the news who are suffering and struggling on the streets, not just here but all around the world. We have a good life, that's the benefit.

Albert expressed how gratifying earning and income is compared to living on SSI. He became choked up with emotion as he spoke about receiving his first paycheck.

When I got my first pay check, I wanted to hang it above my desk. When I looked at the taxes, it was the same amount of money that I used to get (on SSI) and I felt so much better giving that money than taking it. I can't say enough about the real world, about my life.

Many of the participants in this study had been helped by others along their way to freedom from SSI/DI. The help they received developed in them a sense of gratitude and indebtedness that they felt compelled to respond to through employment. Their work was seen as a way to give back to the community, a way to help others as they had been helped. Rachel and Ryan were in the same focus group for this study. One exchange they shared expressed this theme well.

Rachel: I think it's important to give back to the community. What I do relates very closely to my personal experience with having a disability, so helping other people with disabilities make the transition to work and giving back is what's important to me.

Ryan: I feel the same. Being a service to others and assisting, that's what brings me such gratitude for still being alive. Just being able to help others and seeing the smile on their faces and knowing what goes around comes around just feels really good. I want to continue to help as many people as I can. That's my main drive in life.

All of the participants in this study found self-sustaining employment to be exponentially more gratifying than receiving SSI/DI. Nobody questioned whether or not work was worth the effort. On the contrary, they were all motivated to help other beneficiaries achieve the same level of independence that they were experiencing. That help is at least partially to be found in identifying the implications for practice resulting from the findings of this study.

Implications for Practice

Rehabilitation counselors and other professionals dedicated to assisting SSI/DI beneficiaries to obtain and maintain self-sustaining employment can utilize the findings of this study to inform their practice and, in partnership with their consumers, maximize the possibility of success. The implications for practice that result from the findings of this study are presented in two major sections. The first section deals with acknowledging, addressing and overcoming the fears and challenges that beneficiaries face when returning to work. The second section contains implications for practice that develop the self-efficacy of SSI/DI beneficiaries and prepare them to obtain and maintain self-sustaining employment. This section concludes with a brief guide for rehabilitation counselors to use when working in partnership with SSI/DI beneficiaries interested in achieving independence from SSA's system through work.

The Fears and Very Real Challenges of Returning to Work

SSI/DI beneficiaries have significant fears and concerns about going back to work, or entering the workforce for the first time. As this study has shown, these fears are based primarily on the fear of losing medical insurance and financial support should they not succeed at work. Although there are many work incentives offered through SSA to help beneficiaries return to work and retain eligibility for benefits in case of a job loss, these work incentives are not well known, are not frequently utilized, and are complex and confusing. It is important for any rehabilitation professional to acknowledge that beneficiaries have fear of losing the safety net, however small it may be, when they return to work. Practitioners must also be aware of the myriad of problems with wage reporting, communication and overpayments that beneficiaries experience with SSA and plan accordingly.

The planning process for a return to work effort by an SSI/DI beneficiary must include educating the beneficiary about how work will affect the receipt of benefits. Commonly referred to as “benefits planning,” this process is an essential step in helping beneficiaries to address their fears. Rehabilitation counselors have several options to choose from when considering how best to provide benefits planning for consumers. The results of this study indicate that the two best ways are through self-education of the beneficiary and peer mentoring.

It is clear from this study that every beneficiary that returns to work will have difficulties with SSA. There will be problems with reporting and tracking wages and with overpayments. The more informed the beneficiary is about what should happen to his/her cash payments once they start working, the better they will be able to advocate for themselves with SSA. Rehabilitation counselors must expect that there will be problems and help prepare the beneficiary to deal with those problems through education and advocacy. Rehabilitation counselors should ensure that all of the beneficiaries they are working with have as many opportunities as possible to be educated about the work incentive system, and that these beneficiaries have the chance to become experts in this area if they choose to. The opportunities for educating beneficiaries about work incentives are available through local SVRA offices, Community Rehabilitation Programs (CRPs) that provide benefits planning on a fee-for-service basis, and through self-directed study. One of the most powerful and impactful forms of education and advocacy occurs through peer mentoring.

It is clear from this study that information presented to beneficiaries by their peers has a significant impact on their ability to understand, accept and prepare for the challenges they will face when dealing with SSA as they return to work. Peer mentoring comes from those who have “been there” and have experienced overpayments and other problems first-hand. Ideally, SSA

should fund for a wide network of peer mentors that would work to educate beneficiaries about available work incentives and encourage return-to-work behavior. In addition to that however, rehabilitation counselors and other professionals should recruit successful beneficiaries to act as peer mentors for others, and connect them with other beneficiaries that are considering going to work. Peer mentoring need not occur on an individual basis only. Peer mentoring groups, gathered for the purpose of addressing concerns about benefits and other work-related issues, can be equally as effective. Rehabilitation counselors play an important recruiting role in establishing such a group, can facilitate communication between members, and can provide meeting space as needed. Individual peer mentors and group peer mentors provide more than just education about work incentives, they provide support and encouragement for beneficiaries and can be a major motivating factor in helping people determine to obtain and maintain self-sufficiency.

Education and awareness of work incentives and benefits planning should not be limited to beneficiaries alone, but should include family members and significant others as agreed to by the individual. Because of the complexity and confusion surrounding work incentives and the associated reporting problems with SSA, enlisting the support of family and friends can be critical in the long-term success of the individual. A family or significant other's awareness of the common problems with return-to-work efforts can provide another layer of assistance and advocacy for the individual. Rehabilitation counselors should, with the agreement of the beneficiary, recruit committed family members and significant others early in the process of working with the individual, and give them every opportunity to become as educated as they can about how benefits will be affected by work. This information and support can be very useful

when the beneficiary faces inconsistent or incorrect information from SSA, or when they are faced with an overpayment.

Rehabilitation counselors must expect that every beneficiary they help go to work is going to experience an overpayment from SSA, and they must plan accordingly. Planning for an overpayment begins with each beneficiary keeping close track of their income, reporting that income to SSA in a timely manner, and ensuring that they are clear about what should happen to their cash payment from SSA as a result of their earnings. If an SSI recipient's cash payment should have been reduced by \$300 one month due to earnings, but the person receives a full check the next month, the beneficiary must know enough about what should have happened to put the \$300.00 in a separate account to pay it back when the overpayment comes due. If an SSDI recipient earns above Substantial Gainful Activity (SGA) for a tenth month or more during a 60 month period, but receives a full check from SSA, he/she must put that check aside in a separate account for payback to SSA. Rehabilitation counselors must ensure that beneficiaries and/or their family members or significant others, are fully capable of calculating what should happen to their cash benefits due to earnings, and then set the money aside in a separate account in order pay SSA back at a later date. This was the only process identified by the participants in this study that resulted in them being able to effectively deal with the overpayment problem.

Another strategy that was helpful, though not foolproof, was establishing a single point of contact at SSA. The former beneficiaries in this study expressed great frustration when they dealt with different SSA employees through the toll free number or when they went in to different offices. They found the most benefit when they were able to establish one person that they communicated with on a regular basis. In many ways, these former beneficiaries created their own case managers, and to SSA's credit, they encouraged this behavior to ensure

consistency of information. Rehabilitation counselors can help ensure there is a single point of contact at SSA for each of the beneficiaries they work with by informing their consumers of this strategy and engaging in the process with the individual as needed. This will help minimize confusion and frustration for the beneficiary when they deal with SSA in the future.

The education and strategies articulated above might be beyond the capabilities of some beneficiaries, and some may not have the support of family or friends to act as benefits planners and advocates. It is incumbent on the rehabilitation professional to explore and assess this with the beneficiary and identify some way to ensure that each individual receives the support they need to enter into, and stay in, the workforce. In order for work incentives to truly incentivize people to work, there must be the supports in place to help them understand the work incentives and prepare for likely problems. This education and planning will help alleviate the fears that are keeping beneficiaries from entering the workforce in larger numbers. In addition, the support systems developed for benefits planning can and should act as an encouraging force to help beneficiaries as they develop their expectations for a better future through self-sustaining employment.

Developing Positive Self-Efficacy

One of the recurring and unifying themes that emerged from this study was the importance of positive self-efficacy in the job acquisition and maintenance process. Confidence in one's ability and the expectation of success increased risk-taking behavior in employment and helped the participants in this study to develop tenacity and persistence in the face of significant challenges. Self-efficacy refers to one's belief in one's capability to successfully engage in a specific area of behavior. According to Albert Bandura (1982), people avoid activities that they believe exceed their coping capabilities, but they undertake and perform assuredly those they

judge themselves capable of managing. Judgments of self-efficacy also determine how much effort people will expend and how long they will persist in the face of obstacles or aversive experiences. When beset with difficulties, people who have doubts about their capabilities slacken their efforts or give up altogether, whereas those with a strong sense of efficacy exert greater effort to master the challenges facing them.

In a given situation, an individual with strong self-efficacy will sustain the effort needed for optimal performance, but those with self-doubt will reduce their effort as they expect failure. Persons with strong self-efficacy will give all of their attention and effort to difficult situations and are spurred on to greater effort by obstacles they encounter. On the other hand, those who judge themselves inefficacious in coping with environmental demands dwell on their personal deficiencies and imagine potential difficulties as more formidable than they are. These misgivings create stress and impair performance by diverting attention from how best to proceed with whatever the undertaking is, to concerns over failures and mistakes (Bandura & Locke, 2003).

According to Bandura, performance varies as a function of perceived self-efficacy. Increase in perceived levels of self-efficacy, in groups or individually, gives rise to progressively higher performance accomplishments. In effect, self-efficacy levels can be a self-fulfilling prophecy for people. If they believe they will do well, performance improves. If a person believes he/she will fail, then the possibility of failure increases as effort, persistence and performance suffers.

Bandura identifies a causal link between self-efficacy and action. Individuals will avoid tasks and situations that they do not expect to do well in, but successfully execute tasks that fall within their enhanced range of perceived self-efficacy. They will persist at a level consistent

with their belief in their ability and expected outcome (Bandura, 1982; Bandura & Locke, 2003). There are numerous implications for practice that emerge from the application of Bandura's theory to the return-to-work behavior of SSI/DI beneficiaries. Rehabilitation professionals can engage in many activities with their consumers that directly relate to the positive development of self-efficacy, and will ultimately improve their ability to obtain and maintain employment. These activities are discussed below.

Identifying and Developing a Support System

The participants in this study repeatedly spoke about how important the support of family, friends, peers and professionals were in encouraging them to achieve independence from SSA through work. This support system helped them initially pursue employment, and persist in that pursuit despite significant challenges at times. In many ways, these supportive people were cheerleaders, and were not shy about pushing the beneficiaries when needed. The implications for practice are clear. Rehabilitation professionals must identify the support systems that are available to the beneficiaries they work with, and assess the strength of that support system. Individuals that serve as a support system to the beneficiary should be coached to have high expectations for the individual, if coaching is needed. They should be supportive, but challenge the beneficiary to have high ambitions and greater expectations than a life subsisting on SSA benefits. When further support is needed, rehabilitation counselors should enlist the help of peer mentors that have been through the transition process and can provide information, encouragement and support to beneficiaries.

Rehabilitation counselors should mirror the behavior of the individuals acting as the support system for the beneficiary, in fact, the rehabilitation counselor is an essential component of the support system. As such, the rehabilitation counselor should not expect that they can

effectively serve the beneficiary through minimal contact and referral to external providers. The rehabilitation counselor should be fully engaged as a consistent and regular contributing member of the beneficiary's support team, acting as the loudest cheerleader and encouraging the beneficiary to achieve their maximum potential. In addition, the rehabilitation counselor should act as the convener of the support team when needed, and utilize their expertise to offer creative solutions to problems that arise. The rehabilitation counselor plays a critical role in funding of service delivery, but that funding, while important, takes a backseat to the supportive behavior of that counselor, especially with beneficiaries that do not have supportive family or friends in their lives.

Independent Living and Assistive Technology

Positive efficacy expectations are developed for people with disabilities as they acquire the ability to function and live independently. The confidence gained as a result of increased independence translated to the employment arena. The individuals with blindness in this study articulated this concept especially well. As they learned how to be independently mobile and to cook and live on their own, their expectations for full-time, self-sustaining employment grew as well. Consequently, rehabilitation counselors should establish and nurture relationships with Independent Living Centers (ILCs) and establish a strong referral system with those centers. They should encourage increases in independent living for their consumers, and engage in in-depth assessments with beneficiaries to determine, what, if any, gains can be made in independent living. Rehabilitation counselors should not hesitate to fund IL training, and provide the assistive technology necessary for the beneficiary to make gains in independent function.

Independent living and the use of assistive technology were closely related for the participants of this study. The use of AT increased their ability to function and live on their own, and ultimately, to perform the essential functions of their jobs. Rehabilitation counselors should ensure that every beneficiary they work with has an AT evaluation and that they do not hesitate to purchase AT devices that will increase independence. The acquisition and use of AT will increase the confidence of the beneficiary and this will translate to his/her belief that they will be successful at work.

Maximizing Employment and Earnings Potential through Postsecondary Education

The link between educational attainment and employment and earnings is undisputed. College graduates are more than twice as likely to work as those who do not graduate from high school (Kennedy, Olney & Shiro-Geist, 2006). For people with disabilities, higher education is essential to participating in meaningful work throughout their lives. An individual with a disability who has a college education is 3-5 more times likely to be employed than a person with a disability who never attended college. Specifically, less than 18% of adults with disabilities who have less than a high school diploma are employed. Individuals with some college are employed at 44%, and those with four or more years of college are employed at a rate of 53.4% (Hennessey, 2005). These results are supported in several studies along with the fact that people with disabilities who participate in higher education have greater earning potential, perceived quality of life and greater career success than those who do not participate in higher education (Flannery, Yovanoff, Benz & Kato, 2008).

Participation in higher education is especially important for people with disabilities in that it opens up doors for different types of employment that are consistent with their functional capacity. One study of SVRA consumers with spinal cord injury found that higher education

was a key positive predictor in return-to-work rates, and the earlier in life it is provided the more effective it is. The effect of education on employment for people with spinal cord injury is even more dramatic than most other people with disabilities. People with spinal cord injury who have a college education have a rate of post-injury employment of 70%, while those with less than a high school education are employed at a rate of 6% (Marini, Lee, Chan, Chapin, & Romero, 2008).

A longitudinal study of SSI recipients with severe hearing impairments that attended the National Technical Institute for the Deaf (NTID) within the Rochester Institute of Technology found that graduates from NTID spent less time in the SSI adult program than those who did not graduate. Graduating from NTID had a significantly positive effect on earnings, with graduates earning 51% more than those who withdrew prior to graduation (Weathers et al, 2007). These results are consistent with other studies that have documented the long-term positive effects on earnings for people with disabilities that have completed higher education. A study completed by Swett (2000) established that there is a positive relationship between education and workforce participation for beneficiaries, concluding that the higher the educational level, the more likely the person was to be working above SGA.

In a study completed as a supplement to this report, Tucker (2012) analyzed 2011 Rehabilitation Services Administration (RSA) 911 data for all vocational rehabilitation (VR) programs nationally to determine the impact of postsecondary education degree completion upon positive employment outcomes and wages earned. Chart 1 identifies the results of degree completion on competitive employment outcomes (cases closed successfully rehabilitated) for VR consumers.

Chart 1

Competitive Employment by Education Level at Closure

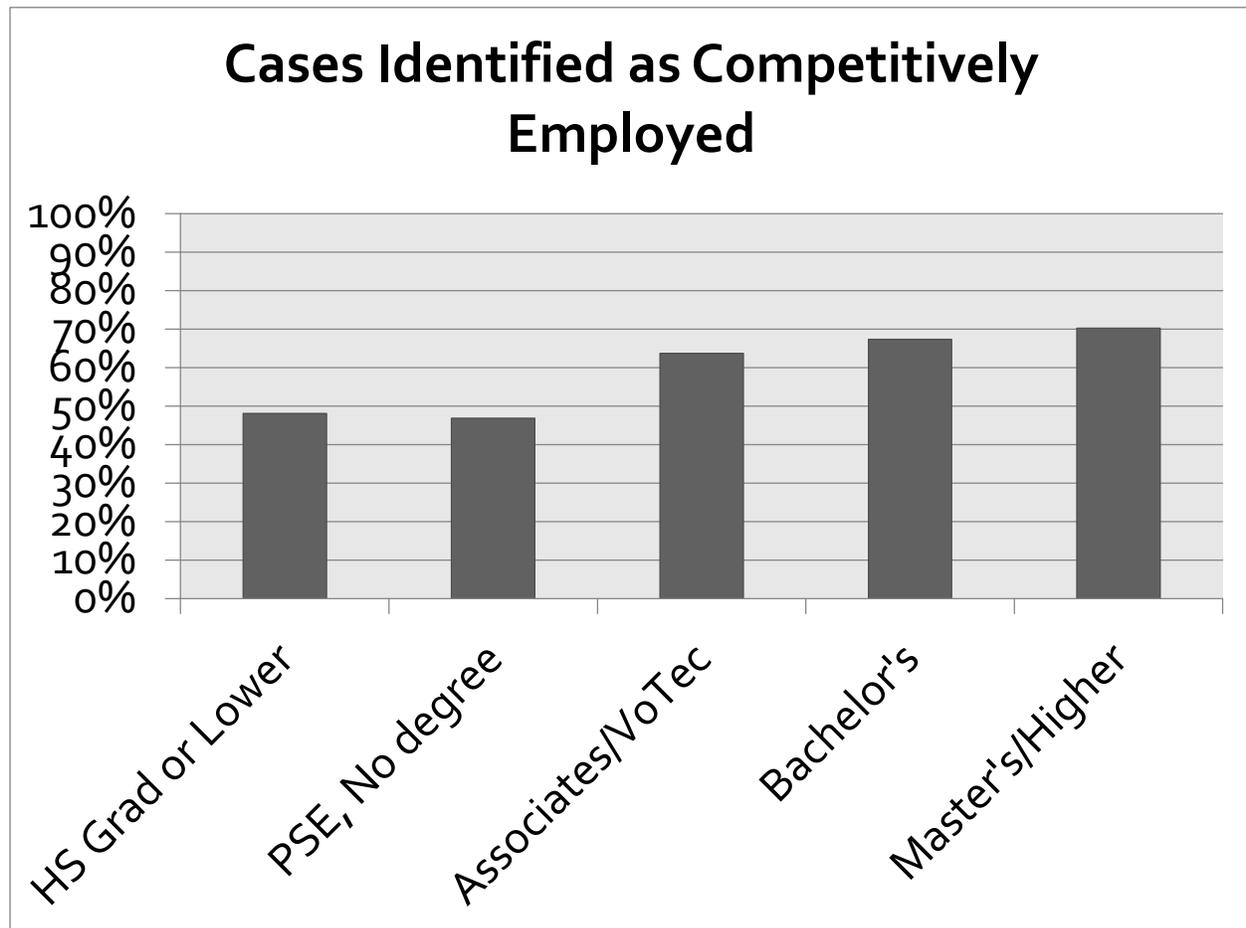


Table 1 indicates that the completion of a college degree at any level significantly positively affects the chances that a VR consumer will achieve competitive employment. If a VR consumer has a high school diploma or lower, the competitive employment rate is 48.1%. If a VR consumer receives some level of college training, but does not complete a degree, there is a slight drop in the competitive employment rate to 46.8%. If they completed an Associates' degree or vocational technical certificate, the competitive employment rate jumps to 63.7%. Completion of a Bachelor's degree increased the employment rate to 67.3%, and completion of a

Master’s degree or higher increased the employment rate to 70.2%. It is clear from this information that VR consumers that complete postsecondary education degrees obtain and maintain competitive employment at much greater rates than those without degrees, and the higher the education level, the higher the employment rate. In addition, degree completion positively affected earnings levels.

In an analysis of the same RSA 911 data for 2011, Tucker (2012) examined how degree completion affected earnings for individuals that were competitively employed for all VR programs nationally. Chart2 includes the results of this analysis.

Chart 2

Average Hourly Wage at Closure by Education Level

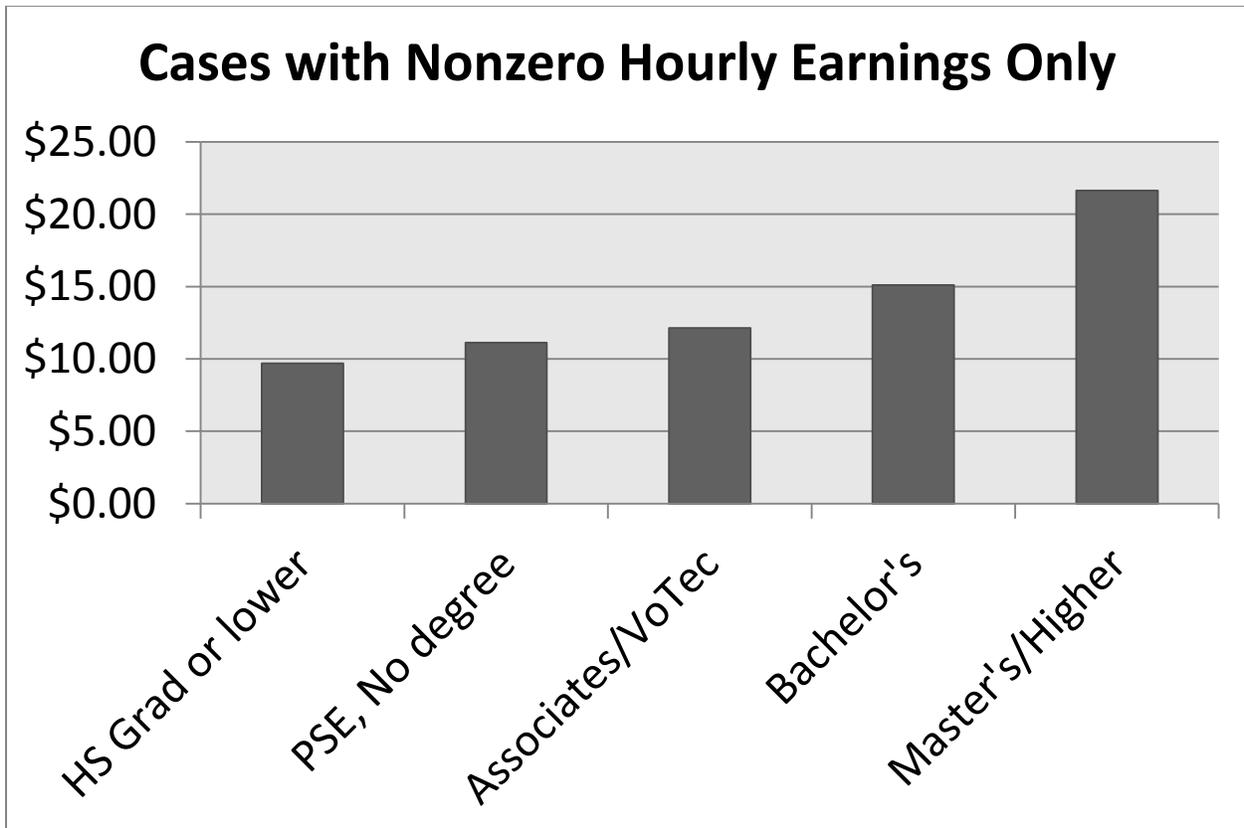


Chart 2 indicates that if an individual’s highest level of education at time of closure from VR is a high school diploma or lower, their average hourly wage is \$9.69 with a standard

deviation of \$4.06. Participation in postsecondary education at any level positively affected earnings levels. If an individual received some college training, but did not complete a degree, the average hourly wage increased to \$11.13 with a standard deviation of \$5.52. Completion of an Associates' degree or vocational/technical certificate increased the average hourly wage to \$12.14 with a standard deviation of \$6.38. Completion of a Bachelor's degree or higher increased the average hourly wage to \$15.10 with a standard deviation of \$8.54, and completion of a Master's degree or higher increased the average hourly wage to \$21.64 with a standard deviation of \$15.71.

The implications for practice resulting from this information are dramatic and clear. In any attempt to help SSI/DI beneficiaries achieve independence through self-sustaining employment, rehabilitation counselors must help their consumers, consistent with informed choice, to pursue the highest level of education possible. Rehabilitation counselors should begin discussions about postsecondary education early in the process and work together with consumers to develop long-term support systems to sustain the individual through a multi-year process of education. Rehabilitation counselors should develop these postsecondary education plans in a manner that respects the fact that some of the beneficiaries they work with have been out of school for several years and may need to begin the process slowly and build to attendance full-time. Many beneficiaries will need AT or other reasonable accommodations to successfully complete school, so VR counselors should ensure that these individuals are connected with the Disabled Student Services Centers at the colleges they attend and that they have the technology they need to complete the required course work.

Postsecondary education plans developed with the proper supports and with small steps that are likely to lead to success for the beneficiary will lead to the development of positive self-

efficacy for the individual and will increase the likelihood of long-term success. Rehabilitation counselors should eliminate the thinking that the VR program should only provide support for education levels that prepare people for entry-level employment. It is clear from Tables 1 and 2 that the higher the degree, the higher the likelihood of employment and the more money the individual will make. If the goal is to help the SSI/DI beneficiary achieve employment at a level that will be self-sustaining, VR counselors must help their consumers achieve their highest potential educationally. This achievement will directly translate to their future employment success and earning potential. The participants in this study were living examples of this truth.

Work Experience

The exposure to work through internships, part-time work, volunteering or any other kind of work experience provides SSI/DI beneficiaries with numerous benefits. The benefits include job exploration, the development of work stamina, acquisition of necessary work skills, the ability to identify and utilize necessary AT, and an increase in confidence and a belief in ability. Rehabilitation counselors should work to ensure that their consumers who receive SSI/DI are exposed to work through volunteering, part-time work, internships, or as appropriate, temporary agencies.

Work experience represents another avenue whereby self-efficacy can be developed through a graded series of small successes in the work place, which can increase the likelihood of future employment success for individuals that receive SSI/DI. When provided in combination with a strong support system, helpful assistive technology that increases independent functioning and living, and postsecondary education degree completion, work experience of any kind represented an important final step in the transition process for the former beneficiaries in this study. Rehabilitation counselors should work diligently, often in partnership

with other organizations or businesses, to ensure that work experiences are available for beneficiaries interested in self-sustaining employment.

Guide for Rehabilitation Counselors

A number of implications for practice have been identified in this study based on the findings. The following guide is offered as a quick reference help for rehabilitation counselors working with SSI/DI beneficiaries.

GUIDE FOR REHABILITATION COUNSELORS

Activities from Intake to Plan Development

- Act as a “cheerleader” and support to the consumer
- Convey high expectations for the consumer
- Assess the existing support system for the beneficiary
- Recruit family, significant others, or other individuals identified by the consumer to act as an ongoing support for the consumer
- Educate the individuals in the support system to understand the importance of being active and consistent cheerleaders that encourage and challenge the consumer
- Assess the consumer’s interest in, and ability to act as, a self-advocate and train accordingly
- Recruit and connect the consumer with a peer mentor and/or support group that can assist and encourage consumer throughout the transition process
- Refer consumer to, or connect consumer with, individuals or agencies that will act as benefits planners and help with an understanding of work incentives
- Assess the consumer’s need for AT
- Assess the individual’s interest in becoming more independent and provide information on available services and organizations to help in that process
- Provide information to consumer and his/her support system on the importance of postsecondary education and identify ways to help the consumer survive and be successful should he/she choose to pursue higher education
- Assign Ticket to Work

Plan Development and In-Plan Activities

- At as a cheerleader and support to the consumer
- Develop plans that will result in high-paying self-sustaining employment consistent with the consumer’s informed choice
- Encourage consumers to strive for their maximum potential in education and work to ensure self-sustaining employment from high-paying jobs
- Identify, purchase, and provide training in needed assistive technology
- Connect consumer with Disabled Student Services programs at their college or university

- Write intermediate objectives that start slowly in school and build towards more rigorous work loads
- Meet regularly with the consumer and their support team to review progress and ensure a consistent message of support.
- Provide internships or other work experience to help the consumer transition to work
- Increase benefits planning for the consumer and support team as paid work occurs
- In partnership with the benefits planner, establish a separate bank account and set aside SSI or SSDI checks that are overpaid to eliminate the impact of overpayments

Closure Activities

- Ensure ongoing supports are in place
 - Ensure consumer is aware of the availability of post-employment services
 - Recruit consumer to act as a peer mentor to other beneficiaries
 - Identify an Employment Network to use the Partnership Plus model and provide ongoing support for the consumer
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Conclusion

The purpose of this study was to identify what factors increase the likelihood that an individual on SSI or SSDI will obtain and maintain self-sustaining employment. The participants in this study identified many factors that were essential in helping them to become employed at a high level. They had strong support systems, with family and peers that encouraged and challenged them throughout their transition to work. They were highly educated and confident in their abilities due to the success they achieved in their lives. They were able to overcome the fears they had about going to work because they had tasted success themselves and saw it in those they loved and admired. Many became experts on how their benefits were affected by work, or they had the help of others that were experts. They participated in work experiences or internships that built their confidence in their ability to successfully perform work, and they utilized assistive technology to help them function independently.

There are several implications for practice identified from the findings of this study. Rehabilitation counselors should act as “cheerleaders,” planners, facilitators and coordinators for their consumers that are receiving SSI/DI and want to achieve self-sustaining employment. It is

clear that establishing and maintaining a strong support system is an essential component of any plan developed in partnership with a beneficiary. Benefits planning, postsecondary education, AT and work experiences are all elements that should be provided to those beneficiaries interested in obtaining self-sustaining employment. Although rehabilitation counselors can provide many services that will assist beneficiaries to transition to work, it may be that the most important thing a counselor can do is to encourage the beneficiary to aim high, dream big, and achieve their highest potential.

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