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Marjorie F. Olney and Cindy Lyle

*Rehabil Couns Bull* 2011 54: 197 originally published online 18 March 2011
DOI: 10.1177/0034355211400209

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What is This?
The Benefits Trap: Barriers to Employment Experienced by SSA Beneficiaries

Marjorie F. Olney¹ and Cindy Lyle¹

Abstract
In the first of two rounds of interviews, 12 Social Security Administration (SSA) beneficiaries, all of whom professed a desire to work, discussed their perspectives on barriers to employment. Two years later, 8 of the 12 engaged in a second round of interviews. Only 1 of the 8 participants had succeeded in becoming self-supporting. After a review of the literature concerning the effects of SSA procedures in discouraging beneficiaries from seeking full-time work, the authors tell the stories of these participants and then analyze the findings using a phenomenological framework. They conclude by positing suggestions for how to improve outcomes for SSA beneficiaries in the future.

Keywords
employment, psychosocial aspects of, qualitative

Working-age adults with disabilities constitute a small but growing portion of those who benefit from Social Security Administration (SSA) entitlement programs. In 2004, of the 41.7 million recipients of SSA support, only 6.4 million were younger than age 65 (McCarthy et al., 2007). This working-age group differs in important ways from senior citizens. For example, various studies indicate that between 30% and 90% of working-age beneficiaries express an interest in working (Kennedy & Olney, 2006; Kornfield & Rupp, 2000; Marini & Reid, 2001). Yet, less than 1% leaves the SSA rolls once found eligible for benefits (U.S. General Accounting Office, 2001), whereas enrollment in disability programs has continued to expand at a substantial rate. The number of people receiving Social Security Disability Income (SSDI) benefits has grown from 500,000 in 1960 to 7.3 million in 2008, whereas recipients of Supplemental Security Income (SSI) have doubled from 3.6 million in 1974 to 7.1 million in 2008 (SSA, 2008). It is clear that there is a discrepancy between the stated desire of beneficiaries to return to employment and the story the numbers tell: Swelling SSDI and SSI rolls paired with nearly imperceptible movement into the workforce fail to meet the objectives of any of the stakeholders—policy makers, vocational rehabilitation (VR) providers, or beneficiaries.

In a Double Bind
The economic status of Americans with disabilities over the past three decades has steadily declined since the 1980s following the passage of the ADA, even during the prosperous 1990s (Kennedy & Olney, 2001; McAlpine & Warner, 2002). An exception has been part-time work. Working-age Americans with disabilities appear to prefer part-time, entry-level jobs, compared with nondisabled workers, according to Hotchkiss (2004), who concluded that this trend toward voluntary part-time work has resulted from policies—in particular the financial disincentives introduced in the 1990s—that have persuaded Americans with disabilities to voluntarily abandon prospects for full-time work. Workers with disabilities want to hang on to their hard-won benefits and their government health insurance by keeping their earnings low enough to continue to qualify for SSDI/SSI. By

¹San Diego State University, CA, USA

Corresponding Author:
Marjorie F. Olney, San Diego State University, 3590 Camino Del Rio North, San Diego, CA 92108, USA
Email: molney@mail.sdsu.edu
likely shows that a large percentage wish to work—and most onto the rolls of the SSA (Kennedy et al., 2004). Research benefits, which means that he or she frequently opts not to benefits usually leaves a person with a fear of losing those (Stapleton et al., 2005). Ironically, the challenge of winning sharply reduce benefits as a beneficiary’s earnings increase SSDI), they must demonstrate that they cannot work by not apply for social security disability benefits (either SSI or critical component of the poverty trap is that when people “poverty trap” for many people with disabilities. An initial that people with particular disabilities cannot work and therefore must rely on others for support (Stapleton, O’Day, Livermore, & Imparato, 2005). These policies create a “poverty trap” for many people with disabilities. An initial critical component of the poverty trap is that when people apply for social security disability benefits (either SSI or SSDI), they must demonstrate that they cannot work by not working. A second component involves the rules that sharply reduce benefits as a beneficiary’s earnings increase (Stapleton et al., 2005). Ironically, the challenge of winning benefits usually leaves a person with a fear of losing those benefits, which means that he or she frequently opts not to work or to work and earn a minimal amount, once going onto the rolls of the SSA (Kennedy et al., 2004). Research shows that a large percentage wish to work—and most likely could work successfully if given appropriate services, accommodations, and supportive policies (Kennedy et al., 2003; O’Day, 1999; Stapleton, 2007).

It is easy to see why the return-to-work rate remains static. Rather than improve the quality of his or her life, the double bind of receiving disability benefits can leave the beneficiary in a vulnerable position, psychologically, medically, and economically. Stapleton and colleagues (2005) identify this fragile state as a poverty trap: “the self-fulfilling expectation, ingrained in the support system, that people with disabilities cannot support themselves, or perhaps worse, may come to believe that they cannot contribute to their own support through working” (Stapleton, 2007, p. 2). In fact, there is ample evidence that policies that inadvertently punish people with disabilities for attempting to work may actually be shaping their behavior to avoid work: Long-term trends show that more working-age people are not working because of self-reported work limitations, and a larger share are relying on SSDI for support. This statement applies to both sexes and all age groups (Stapleton, 2007).

The U.S. public disability system poses an interesting conundrum for beneficiaries: People must be unable to work to qualify for benefits, and they must stay poor to keep their monthly cash payments and health insurance. In an attempt to reverse this trend, the SSA has offered an array of work incentive programs designed to provide enticements to encourage a return to work.

We propose that beneficiaries of SSA disability programs are receiving two distinct and mutually incompatible messages: You cannot work; however, you should work. The policy makers at the SSA seemingly understand the contradictory messages inherent in the disability programs because they have, for several decades, offered an increasing array of incentives to help beneficiaries return to work and thereby reduce or eliminate their dependence on the SSA system. In large part, our study grew out of a desire to understand whether these incentives are having the desired effects by motivating beneficiaries to build satisfying careers and to make it easier for them to return to work and become economically independent.

Research Questions

In qualitative research, a set of research questions is developed, and data collection proceeds flexibly, making it a powerful tool for exploring new intellectual territory. The researcher can obtain a deep knowledge and understanding of a given phenomenon using a semi-structured interview format (Bogdan & Biklen, 1998). In our study, rather than establishing hypotheses to test before research was initiated, the researchers began research with a partial understanding of the relationship between social security benefits and employment based on previous research and literature review. We began with one overarching question: How do the allocation processes related to SSA cash and medical benefits affect thoughts, experiences, and behaviors related to employment? The following specific questions arose: (1) How do working-age beneficiaries view the effects of the SSA? (2) How do work incentive programs affect their desire to work? (3) How do benefits and employment interact to affect the everyday lives or future plans of beneficiaries? and (4) Between the first and second interviews, what major life changes did participants experience in income, employment, life satisfaction, services, and benefits?
Method

A Phenomenological Perspective

The choice of a phenomenological framework for this study was intentional, as people behave and make choices that can be said by constructionists and other postmodern thinkers to be based on their beliefs about reality, not on objective reality per se (Charmaz, 2007). By honoring the subjective perspectives of the study participants, we were able to develop a rich analytical framework that exposed a number of possible gaps in services as well as policy barriers to employment.

Phenomenology is a school of thought that attends to people’s subjective experiences and interpretations of the world. Phenomenologists recognize that people do not respond to situations, other people, or events (i.e., phenomena) but to the meanings they ascribe to these things (Taylor & Bogdan, 1998). Rather than comparing participants’ responses to norms, standards, or objective facts, the phenomenologist seeks to understand how phenomena appear to participants, and how those phenomena affect the person’s behaviors and choices. Our research probes the socially constructed meanings of being on benefits and seeking employment.

Research Design

Statistical reports provide detailed information about beneficiaries’ work behavior and use of work incentives, but they do not provide direct insight into the motivations and concerns of beneficiaries. We embarked on the current study with a deep curiosity about the perspectives of beneficiaries concerning their employment plans and options. Our goals were to (a) more fully understand the experience of individuals as they negotiate SSA benefits and rules, (b) examine the various factors that interfere with a beneficiary’s goal of becoming employed, and (c) determine how these factors change over time. Thus, a phenomenological study was devised.

Using 16 in-depth, semi-structured interview transcripts with eight participants over a 2-year period, we constructed eight individual stories that illustrate the relationships between the beneficiary and “the system” as well as between the individual and the world of work.

Participants

Working-age adults who received SSDI and/or SSI, and who also expressed a desire to work, were recruited to participate in an interview study. The study was designed to explore the effect of receiving SSA cash and medical benefits on beneficiaries’ thoughts, experiences, and behaviors related to employment. During the first round of interviews, five women and seven men participated in a total of 12 60- to 90-minute interviews. Two years later, the principal investigator (PI) attempted to contact all 12 of the original participants for the second round of the study. Four of the original seven men and four of the five women responded that they wished to participate, whereas two individuals did not return the investigator’s calls, and two were not located. At the time of the second round of interviews, participants ranged in age from 31 to 53 and reported having physical, visual, cognitive, and/or psychiatric disabilities. Two participants were from minority backgrounds (one a Pacific Islander and the other Latina). Two people lived alone, three lived with family members, and three were married or living with a partner. Most reported adequate social support from partners, spouses, family members, and friends.

Data Collection

The Institutional Review Board (IRB) of the PI’s university reviewed and approved both phases of the research. The initial interviews were conducted as follows: All local department of rehabilitation counselors were contacted through a Southern California local district administrator. Counselors then contacted consumers on their case loads to notify them of an opportunity to participate in the study. To protect the anonymity of potential recruits, the PI did not obtain the names of all of those who were contacted but did receive a list of names and telephone numbers of 22 interested participants who appeared to meet the standards of the study. The PI or her research assistant contacted participants and shared pertinent information about the purpose and process of the study and asked the following screening questions: (1) Do you currently receive monthly benefit checks through the SSI or SSDI program? (2) Are you between 21 and 55? (3) Are you interested in working or in returning to work? The fourth eligibility standard, to be able to express ideas through the use of the English language, was assessed indirectly based on telephone conversations. Participants were included who answered affirmatively to these three questions and had basic command of spoken, conversational English. During a subsequent telephone contact, the study was further described to potential participants and the selection completed. An interview was scheduled at this time.

Protocol development. Semi-structured interviewing was used, permitting the researchers to be thorough in their exploration of predetermined interview questions while also giving them the reflexivity to allow the emergence of new ideas, directions, and concepts that they may not have considered previously. Care was taken not to “lead” participants but to create a climate for full exploration of the interview questions. All interviews were 60 to 90 minutes long. They were held in the homes of participants.
or in a public location, as desired by the participant. The prepared, open-ended questions and prompts included the following:

- Talk to me about your work activity.
- Let’s discuss your SSA and medical benefits.
- Would you please explain how you became a recipient of SSA benefits?
- Will you tell me about the effect that employment might have or has had on you and your family?
- What do you know about the return-to-work programs associated with social security?

The first set of interview questions was designed based on findings from the literature on work incentives. The protocol for the second interviews was developed based on findings from the first set of interviews (Olney, 2007). From the first to second set of interviews, the protocol remained roughly the same but follow-up questions became much more specific as the PI probed to gain a deeper understanding of the meanings that participants were making of their experiences.

**Interviews.** For the first round of interviews, each of the participants was interviewed individually, in the location of his or her choice, such as a public location, the department of rehabilitation offices, the participant’s home, or the PI’s office. During the second interviews, the eight participants were interviewed in their homes. During the second set of interviews, questions were similar but focused more specifically on changes over the 2-year period. At the beginning of both the first and second interviews, an informed consent document was read to participants, and the PI asked questions to assure that they fully understood the nature of their participation. None of the participants was paid to participate; all willingly volunteered.

**Data Analysis**

The data were collected, sorted, and categorized based on the participant’s subjective perceptions of phenomena related to benefits and employment (Bogdan & Biklen, 1998). The 16 transcripts totaled approximately 200 single-spaced pages of text. Stories were developed in a four-step process. First, the PI and her graduate assistant (not the second author) read and coded the transcripts independently. Second, each wrote analytic memos to preserve their evolving hunches about the data. Third, the two researchers came together to compare their findings. Finally, the two researchers jointly coded and sorted the transcripts using HyperRESEARCH software (Dupuis, 2003). These methods were followed carefully to assure the authenticity and credibility of the findings. Care was taken to stay close to the data and to thoroughly discuss areas of disagreement.

Three broad themes emerged from the data and were used to shape the individual stories of our participants. The themes were (a) barriers to employment, which included such codes as transportation, fear of the SSA, health, job discrimination, and caregiving; (b) coping strategies, which included the codes working the system, knowledge about benefits, the SSA as a safety net, and humor; and (c) engagement in work, which encompassed codes including hours of work, type of job, job seeking, reasons for working/not working, and paid/ unpaid work. These themes and their associated codes are explored in the eight stories that follow.

**Researchers as instrument.** The principal investigator conducted all of the interviews and remained acutely aware of potential filters or biases that might influence her conduct during the gathering and analysis of the data. The PI has been researching the SSA work incentive programs for approximately 8 years and is deeply interested in the effects of policy on recipients, specifically work behaviors and how beneficiaries make decisions about employment. She believes that people who wish to work should have that opportunity and that people with disabilities are too often discouraged from pursuing careers. The PI has had extensive training in grounded theory and symbolic interactionism and has completed several studies using a phenomenological framework.

The second author contributed to the data analysis, conceptual development, and writing of the article. She did not meet the participants. The second author reviewed transcripts and written analyses independently and discussed them with the PI, creating a second opportunity to analyze the transcripts and to create the stories that constitute the Findings section of this article. As described earlier, a different graduate assistant was present for the interviews and assisted in transcribing, coding, sorting, and qualitative analysis.

**Limitations**

Qualitative research methods are excellent for developing theory and provide an opportunity for deep insights into a problem or phenomenon. Several specific limitations are noted, however. First, because this is a qualitative study based on the self-reports of eight SSA beneficiaries, all willing to dedicate time and thought to this project, the findings are not generalizable to the broad population of working-age beneficiaries. Participants were able to self-select into the study. It is not possible to know from this study whether our participants differed significantly from their peers in values, attitudes, and behaviors. Second, qualitative studies are designed to detect participants’ subjective, personal meanings of various phenomena to participants. As a result, what participants felt and believed was given greater emphasis than what they actually did. Participant behavior may not have matched their words in every case.
Third, the purpose of this study was to explore the issues surrounding a puzzling phenomenon. Our findings cannot be tested against a hypothesis, as they would be in a quantitative study. However, our qualitative findings provide the reader with a way to make sense of the complexities of returning to work for beneficiaries. Fourth, although we had equal participation of men and women in our study, we had only two participants from underrepresented groups. These weaknesses are offset, in part, by the rich, in-depth information that the qualitative study design permitted. Last, more women than men opted to complete the second interviews—four out of seven men but four of five women were included in the second round of interviews.

Findings
Analysis for this study required that we deconstruct and then reconstruct the stories of the eight participants who engaged in both interviews. The result is a series of stories that provide insight into the experience of having a disability, wanting to work, and being on SSA benefits. To protect the identities of the participants, names and details have been changed.

Wendy: Need for Appropriate Placement Services
“I don’t really have any marketable skills.”

Wendy was 47 years old at her second interview, was single, lived with her mother in a small town, was a Pacific Islander, and had a visual impairment. She had a 20-year career in California prior to losing her vision, mostly as a driver and landscaper. Wendy experienced moderate job success between the first and second interviews; she became employed, part-time, at a large retail store in her community, but not in the computer field, an area in which she had been trained: “Since the interview, I have a part-time job. I finished school. The state was sending me to computer work station with ergonomic chair and other adaptations as well as speech-to-text software. When we visited him in his apartment and were surprised to see a full computer work station with ergonomic chair and other adaptations as well as speech-to-text software. When we asked about it, Cameron confirmed that he had gotten all of this equipment through the department of rehabilitation. However, not long into the second interview, Cameron indicated that, due to his chronic illnesses and need for close medical supervision, he had little intention of working after he finished his education:

Paid work that you make money off of is not feasible. To make myself feel okay inside, I say to myself, “You’ve worked almost 30 years . . . You’ve paid into the system with really good wages. You live well below your means!” So I paid my dues—and I’m giving back in volunteer work . . . . So that’s how I make it in my mind okay.
When asked about whether he was aware of the Ticket to Work program, Cameron responded, “Why would I want to do that? It’s the same thing, you know. If I go into that, that’s going to take my benefits away.”

**Ana: Punished by “the System”**

“Work is worth more than a paycheck.”

At the time of the second interview, Ana was single and 33 years old, Latina, and a wheelchair user. She lived with her family of origin and used the door-to-door accessible transit system, MTS, to get around the city. At the time of her second interview, Ana had worked part-time for 3 years at a human services agency where she had been promoted to an outreach position. She seemed to be challenged by the job and to truly enjoy working in Latino communities. However, Ana had been using MTS, and transportation had become a central issue, as she discovered that she now needed a car to access various meeting places throughout the city. “Just yesterday, my supervisor and I went to the Hispanic Chamber of Commerce breakfast. It’s small business owners. It was at 7:30 in the morning, so we were there until like 9:00, and that’s why MTS doesn’t work anymore because I can’t set my schedule to when they want me to. Things will come up at the spur of the moment.” Ana had begun saving money using a PASS to purchase and adapt a vehicle.

During her first interview, Ana expressed frustration with the system. She stated that she felt punished because she loses one dollar of her SSI benefit amount for every two dollars of earnings and because she had gotten into an overpayment situation. Overpayments occur when a working beneficiary does not appropriately notify SSA that he or she is working, resulting in later deductions to the monthly SSI benefit amount. Ana said that she had notified the SSA about returning to work but had not been told that she needed to submit her paystubs each month. This resulted in a hefty reduction in Ana’s check for a period of several months. She talked at length about her mistrust of the system: “They don’t seem to care if they are right or wrong. They still slam you.” At the same time, her PASS was potentially going to allow Ana to be fully employed by funding her to purchase a vehicle: “I’m hoping that things change to the better, and hopefully the program will allow me to become a full-time employee. My goal right now is to get a set of wheels because without it, I can’t go anywhere.”

**Barbara: The Intersection of Gender and Disability**

“They don’t think women can be engineers. It’s still a man’s field.”

Barbara, a European American, was 42 years old at the time of our second interview. She had a psychiatric disability and chronic pain. “I’m living with my mother. She’s 83 . . . and she doesn’t have her driver’s license anymore and so I have to take her all of the places she wants to go.” Despite a degree in mechanical engineering, Barbara was still attempting to reenter a career as an engineer. Barbara believed that gender had been a barrier to employment for her and that there were very few women in this line of work. “It’s still a man’s field . . . and pay discrimination too.”

Despite having actively looked for work for many years, Barbara had worked very little, and mostly in temporary jobs. “I worked at [a local community college] in the bookstore during rush hours, helping students out, twice this year . . . . My jobs have been few and far between, so the [department of rehabilitation] just called me up once and said, ‘Your case is still open. Let us know if you get a job that you have for 3 months,’ and then they’ll close it out.”

In addition to having difficulty getting hired in a male-dominated field, Barbara functioned in a caregiver role for her mother. In fact, Barbara’s responsibilities as the sole caregiver and as a job seeker appeared to conflict. When describing her trips to a job club, Barbara recalled,

My mom wasn’t really fond of it . . . . My mom gets upset sometimes when I apply and she has something planned. . . . I got a cell phone so I can call her often when I’m out or she can reach me. She’s pretty healthy. She’s just slowing down and taking more naps and stuff . . . . I’m getting annoyed because my brothers, they come over once a week maybe, to see her, and maybe one will take her out. Then I have to do all the taking her to the grocery store, taking her to the doctor, taking her to get her prescriptions. She kind of wants things run her way. But I just don’t get angry and just kind of suck it in. . . . I have my bedroom, and she wants me to keep the door open, and that’s my hiding space. I don’t say it that way, but I have my computer in there, my sewing machine in there, music and everything, and I just feel so comfortable to be in there because it’s my territory. . . . I feel like I’ve been in Alice’s hole or whatever and not being able to go out because I have to tell my mom wherever I am going and you can’t meet people that way . . . . I have met a couple of guys, but I had to lie to my mom because she wouldn’t think it’s right.

Barbara’s relationship with her family members seemed not to be compatible with becoming completely self-supporting. Two brothers lived nearby, and a third brother lived about an hour’s drive away:
So he comes down every 2 weeks for 3 hours and reads my mom’s financial documents, has dinner, and goes back. . . . She likes to go out to dinner now. She’s tired of cooking and stuff. My brothers come in and she feels like she should cook them a meal because they don’t have home cooking. And so it gets her tired, but they don’t understand.

The brothers also criticize Barbara for not having a job: “They just can’t understand why I don’t have a job now.”

By the second round of interviews, Barbara had attended a job club and learned how to use the Internet to search for jobs. “Now I’m an expert on the computer finding jobs. . . . I’m so good at finding places to apply, my psychologist, he wants my list of job sites for his patients because I found so many.” However, she did not have an adequate computer at home to complete a job search and applications. “A new computer would help because mine is slowing down and I would be able to do that much more. It’s 5 years old and the chances of me making enough money to buy a new one is. . . . All I need would be the CPU because I have the 19-inch screen.”

Frank: Subsisting on Benefits

“It’s just disappointing to me because I feel that at 51, I haven’t gotten hired in order to retire. A lot of my friends are getting ready to retire and I’m thinking, ‘Yeah, I could feel like retiring too.’”

Frank was Caucasian, had quadriplegia and chronic illness, used a power wheelchair, and lived independently with the help of a personal assistant. Two years earlier, Frank had been a graduate student. He needed to take a hiatus to assist his father, who had developed dementia. He was the primary caregiver for his father, who lived in a facility near Frank’s city. Frank stated that managing his father’s care, as well as his father’s numerous rental properties and personal finances, took most of his free time. “I realized how draining it could be to have a room floored and painted.” In spite of these weighty responsibilities and his own precarious health, Frank was involved in a variety of work activities.

Due to a need for adaptive equipment and his intensive medical requirements, Frank had been a heavy user of government-funded health benefits. He stated that he truly could not survive without them. Frank was an educated, skilled, and capable person who gained a great deal of his positive sense of self from his work. However, rather than establish a regular career, he had opted to volunteer his time at churches and for youth groups, or to provide his services in exchange for stipends and travel reimbursement, in order not to threaten his health insurance. He relayed a story about a minister’s response to a parishioner who suggested that the minister hire Frank: “Oh, I like him. I could use him to help me at my church. Too bad I really can’t afford him.” Frank replied to the parishioner, “Did you tell him that I can work for really cheap, like nothing, because I am on SSI and I don’t dare lose it?” As a result of this interaction, Frank and the minister worked out an arrangement whereby Frank could work in exchange for travel reimbursements.

When I was little, I used to worry about how I was able to be useful. I was not able to do a lot of physical, hard labor things. . . . Now it turns out that somebody who is willing to listen and be patient is in high demand. Payment? Uh, it’s under the table. . . . But no more than $150, and that’s a combination of stipend and remuneration. . . . [I’m trying] to start a disabilities ministry. . . . We’ve been having a bible study here on Thursday evenings. . . . I’m. . . . just going out with my friends and different people who are disabled and want contact. They’re not feeling good about their church not contacting them, or not meeting their needs.

However, the church network had not filled Frank’s deepest needs for a support system. “But yeah, support systems are hard. I’m beginning to realize when you’re a [leader], you can’t just be friends with the people at a church because you have to have a certain professional relationship because you’re the one in charge, you’re the expert. So I very much value those friends [outside of the church family].”

Frank described his experience with the SSA and the department of rehabilitation this way:

When I first went through rehab, they insisted that I get a job right away. So I wrote up a plan of self-support and I had all these things in there, especially paying for my van, parking spaces downtown, and basically I did the whole plan of self-support. And I was able to justify enough expenses to meet the amount I was making, or half the salary. So I was able to keep my whole salary and my SSI as well. . . . Then I was cut down to half-time because they were concerned about having somebody have a job helping me in the restroom and that kind of altered things a bit. . . . The [CETA] jobs ended. I couldn’t find any new jobs, so I wound up in the cycle of applying for unemployment, trying to apply for jobs, and being told, “Sorry, you’re nice, but it won’t work.” And going on and on until I was no longer required to apply for unemployment and pretty much then went back straight on SSI and Medi-Cal.
Thus, Frank was very dependent on the health care and cash benefits he received through SSI. Because he feared losing his health benefits, he had not pursued a career.

I did a little bit of work, again under the table . . . but it never really panned out and I could never go to a place where I could get another plan of self-support or say, “Okay, I’m going to make X number of dollars per month and then let’s work it out.” I was trying to go through that plan. The caseworkers at social security [said], “It’s going to be rough out there.” I had the best of motives. I was saying . . . “How about if I start putting away $10 in a savings account now for later.” They said, “Well, you’re not allowed to do that. You have to put that in a burial fund.” So I just had all these disincentives being thrown at me. You know, [a caseworker] said, “If you have $10 at the end of the month to put into a savings account, go to the movies, go out to eat, treat yourself.” This system was not made for people with integrity and creativity . . . . This system was designed for people who are abusing the system, but it’s what is available to help you get by. This is not to help you get ahead. This is to help you just barely get by. Month to month. And so . . . when something like . . . a really bad flu season hits, I can be ill with practically pneumonia, and now I don’t have any transportation or have to rely on friends . . . on their vans to drive me some place. That has become much more of an issue.

Mike: Working All the Angles

“There those who have, get.”

At the time of our second interview, Mike was a 45-year-old European American man who had worked in a well-paying job and incurred a spinal injury mid-career requiring use of a wheelchair. His situation was quite unusual for a person with a disability in that he received an ample monthly income from multiple sources: “I was in the union. I get a pension from them and I get social security, and I get an annuity.” Mike had medical coverage from his previous job in addition to Medicare. He lived on a large property with his wife and young stepchild. Two of his grown children also lived in his home, creating a supportive family atmosphere.

During the first interview, Mike had an open case with the department of rehabilitation with the goal of becoming self-employed as the operator of a small business. During the second interview, Mike said that he was continuing to work toward getting the business opened: “We’ve got a plan, a good plan. I did pass my administrator’s license, so I got that through the state [VR].” The department of rehabilitation had purchased some items and paid licensing fees to help him launch his business. However, Mike mentioned that he felt ambivalent about accepting help from vocational rehabilitation as he was not positive that he would ultimately become self-employed: “I would feel guilty if they did all that and then I didn’t [start the business]. I’d rather they didn’t and then I did it on my own.” He wondered which of his benefits might be affected if he began to earn an income: “I don’t think they could take my disability retirement away. I don’t think so.”

It was surprising to see how well the system seemed to work for Mike. He was able to keep cash flowing into his home, to maintain his medical coverage, and also to have his stepchild covered by the SSA as a nondisabled dependent, resulting in yet another monthly check.

Jerry: Employer Biases

“’m 31! Why don’t I have this yet??”

Jerry was European American and had a degenerative disease that had resulted in impairments in mobility and speech. He used a power wheelchair, drove an adapted vehicle, and was very independent. Jerry had a work history in another state and had completed an advanced degree. In our first meeting, Jerry consistently averred that he wanted to work and to get entirely off benefits. During the second interview, Jerry said that he was no longer sure about full-time work, as he was beginning to feel discouraged:

“I want stability. I don’t feel like I have it. I almost feel like I am underemployed. I’m not living up to my potential.” With a strong work ethic, an advanced degree, some job experience in his field, and a great attitude, it seems to us that Jerry should have had an easy time finding work, but this was not the case.

In the 2 years between our first and second interviews, Jerry was employed full-time for 9 months. “Well, I think when I did have that full-time position, in the beginning, my self-esteem, my happiness went pretty high up. Then it became more stressful and more of a not fun place to be anymore.” He left this job after a management shakeup: “So then . . . we got a new executive director and she basically rubbed almost everyone the wrong way and everyone left.” Since then, he had worked part-time. Jerry noted that employers routinely limited him to basic tasks and hesitated to allow him to learn new things or to grow on the job. He wondered aloud about whether employers thought that because he talked more slowly, his cognition was also slow. During both of our interviews, Jerry relayed stories about what appeared to be discriminatory treatment by employers. At one point, he said, “I hate phone interviews . . . I hate them. I hate them
because of my voice—people think I’m drunk. . . So I’m trying to figure out a way to sort of broach the subject without blatantly saying, ‘Hey, I’m in a wheelchair!’” At one point, a national, nonprofit service organization had agreed to hire him but reneged on the offer after they learned that they would have to make the bathroom accessible for him. He also attempted legal redress for hiring discrimination at a large hospital but was not able to get a lawyer to take the case. Like Mike, Cameron, and Barbara, Jerry still had an open case with the department of rehabilitation.

Linda: The Importance of Personal Resources in Getting Off the System

“Control is an illusion anyways, really.”

Of European American origin and with a visual impairment that is due to a degenerative eye condition, Linda was 47 and newly married at the time of our second interview. “Met on the Internet. . . . Since I don’t drive, it’s hard to meet people, and the computer’s right there. So it starts on the Internet and there’s all the different single websites to meet people. You get free trials, so I tried a bunch of different ones and picked two or three out.”

Linda had a master’s degree in marriage and family counseling, held an out-of-state license, and was an experienced counselor. Two years previously, she had been working full-time, with full benefits, as a counselor and had been able to completely discontinue her SSDI benefits. During our second interview, Linda told me that her hours at work had been cut from 40 to 32 and that her benefits had thus been eliminated. Nevertheless, she was in the process of severing ties with the Social Security Administration, Medicare, and the department of rehabilitation and was feeling very good about this. She had gone onto her spouse’s health insurance and so had not needed to attempt to get back onto Medicare. Linda felt good about the fact that she had put her life together and was totally independent of the system. She stated that she never wanted to go back to dependency on government benefits. Getting off the system was not without its difficulties, however:

After I’ve gone through a 9-month trial work period and collected the money, they’d come to me and said, “Oh, you were never supposed to get that money.” . . . So I had to pay it back. Even though in the end it was their fault . . . almost four thousand dollars . . . fifty dollars a month . . . At least there’s no interest.

Despite the difficulty arising from the overpayment, Linda was the sole participant in our study who had successfully left the SSA system.

I know that my state department of rehab worker is happy. My case worker says, “You made me look really good. Here’s all the equipment. What do you need?” You know . . . before I start up a job . . . I got a computer and different things.

At the time of her second interview, Linda was regularly using magnifying glasses, a lighted magnifying glass, CCTV, and Zoomtext, which enlarges the computer screen.

Linda’s remaining career obstacle was transportation: “Been actually looking for other employment as well. From here to there it’s a long commute. Five and a half hours roundtrip on the train and bus . . . sometimes six.” Linda was thus looking for a new job. She described applying for a case management job with a government agency:

I went for an interview and they just came up . . . which wasn’t in any of the postings that you need to drive. I think I could’ve really done well with that position, but they said, “Oh! You can’t drive, and 60% of the work involves driving all of the different places where clients are [to] visit their homes.” And they [just looked] at each other: “Oh we should’ve put that on the description, shouldn’t we?” So many positions require the ability to drive. . . . It seems like vision just . . . again . . . goes back to the transportation. That already by that definition cuts off your world. You can’t drive. That’s the number one thing that all of my students will say . . . that losing the ability to drive is the hardest thing. That represents freedom, represents the ability to be in control of one’s life.

Discussion

Our research confirmed that participants were leery of the SSA and afraid to lose the safety net of benefits. They carefully calculated how much they could afford to earn and felt that they could not save other than perhaps through a PASS. We found that participants were not very familiar with the work incentive programs and, because of this, they were cautious about using them. They preferred to be safe rather than sorry. We also found that five of the eight participants kept their earnings low in order to maintain monthly checks and medical benefits. As a result, they did not pursue careers with opportunities for advancement. Instead, they sought out jobs that were low paying and lacked growth potential. This was not true for all participants. Both Jerry and Linda were pursuing full-time work.

Between the first and second interviews, our participants experienced several changes. Linda’s hours were cut and her benefits reduced, but due to her spouse’s health insurance, she succeeded in getting completely off benefits.
Jerry had worked full-time for a period with apparent disregard for any danger of losing benefits. In contrast, Ana had gotten a promotion but worked little enough to keep her benefits. Wendy chose to work only part-time to maintain her benefits. Cameron continued to barter and do some work under the table to maintain his benefits and qualify for low income housing. Frank volunteered to protect his benefits, and Barbara took temporary work assignments but seemed to be seeking more lucrative employment regardless of the risk. Mike had passed his license exam to start his own business but was cautious about competitive employment.

In spite of the advances that the SSA has made to create a more flexible system for beneficiaries who want to work, some of the people in this study viewed the SSA as restrictive and punitive (e.g., Ana, Cameron). Some participants knew about and used some of the work incentives such as PASS (Ana, Frank) and the 9-month trial work period (Wendy, Jerry, Linda), and some had developed skill in navigating the SSA system to protect their benefits (Mike, Ana). Participants who were working or had worked during the 2-year period derived a great deal of satisfaction as well as financial improvements in their lives. This may be the most important outcome of the study: People benefit from working in many ways; work can specifically provide meaningful structure, added income, and opportunities to interact with people.

All of our participants engaged in a cost-benefit analysis that governed their decision making with regard to whether, how much, or how to work. This analytical process was described in Olney (2007). If participants had financial support and/or health care coverage through a family member, this usually reduced or eliminated their reliance on SSA benefits. In these cases, employers, beneficiaries, spouses, or other family members functioned as the primary facilitators, freeing each individual to use benefits as a stop-gap measure until he or she could become self-supporting.

SSI and SSDI beneficiaries are especially dependent on health care coverage because they have disabilities. Thus, it is no surprise that the only one of our eight participants who had willingly given up her benefits, Linda, was the one participant who had begun receiving health care coverage through her spouse’s employer. If beneficiaries are to be motivated to work and progress in their careers, it appears that medical insurance will need not be contingent on keeping earnings unnecessarily low.

Hotchkiss (2004) asserts that SSA beneficiaries choose part-time employment. The findings of this study suggest that such a choice is a forced one, often selected to preserve cash benefits and, more important, health insurance. Beneficiaries need to feel safe, and getting off benefits is often seen as a risky move. Most of the participants in this study were deeply affected by policies that restrict work activity.

A Culture of Disablement

The system of double messages and disincentives has been termed a “culture of disablement” by Rose and Gustafson (2005). A number of researchers have urged policy makers to create, in its place, a “culture of enablement” that treats beneficiaries as capable and skilled adults who may need continuing health benefits, a temporary period of assistance, counseling, and perhaps retraining or accommodations to get them “back on track” (Growick & Babson, 2005; Rose & Gustafson, 2005; Wittenburg & Loprest, 2005).

Disability systems other than the SSA can provide bases for comparison in the search for effective alternatives. Both foreign and U.S. private insurers tend to favor an employment-enabling approach that would support, rather than discourage, the work efforts of the individual with a disability. Under an employment-enabling system, the SSA’s adjudicators evaluate a disability as an interaction of abilities and disabilities within a given environment, rather than looking only for information confirming a long-term, severe work disability. An employment-enabling approach would support the efforts of the individual with a disability. It would take into account the supports and accommodations that might ameliorate impairments and functional limitations in the workplace. This concept is not new; enablement is embedded to varying degrees in the procedures of both private insurers within the United States and the government-run or -regulated disability programs of many other countries. For example, Wittenburg and Loprest (2005) reviewed information available about the disability systems in England, Germany, Sweden, and the Netherlands, as well as those used by U.S. private insurers, especially the workers’ compensation (WC) program. No two systems are exactly alike in policies and procedures, but Wittenburg and Loprest found that all of these systems emphasized return to work more than do the SSA disability systems. Among the features supportive of return to work in at least some, if not all, of these systems are (a) definitions of disability that are less rigid and suggest a continuum of impairment; (b) definitions of work limitations based on capacity rather than incapacities or income; (c) initial and ongoing assessment that channels applicants into “tracks” that determine services according to rehabilitation potential; (d) periodic reassessments that trigger changing rules and cash benefits levels; (e) more complex categories of impairment that allow for temporary or permanent benefits, as well as partial living subsidies; (f) mandatory temporary programs funded by employers; (g) early intervention in timing of return-to-work services and benefits; (h) triaged rehabilitation services, recognizing that people have different needs; (i) mandatory rehabilitation, requiring a claimant to begin a VR program before qualifying for cash and other benefits; (j) integration of programs within a country, creating public–private
partnerships and providing incentives and enforcement for employers and providers; and (k) integration that links temporary to permanent disability programs. Although the best European service systems can cost two to six times as much per person as in the United States, higher return-to-work rates can cut costs and provide greater tax revenue in the long run (Wittenburg & Loprest, 2005).

**Recommendations**

In this study, we join many other researchers in sounding a clarion call for the SSA to revise the policies that keep working-age beneficiaries underemployed and poverty stricken (Bjelland, Burkhauser, & Houtenville, 2008; Growick & Babson, 2005; O’Day, 1999; Stapleton, 2007; Wittenburg & Loprest, 2005). Revised policies that encourage engagement in the workforce would likely be more practical, cost-effective, and compassionate. Moreover, such policies would allow individuals to attempt work and to strive to go beyond marginal employment to real career growth. Specifically, we offer four recommendations to the state-federal VR disability systems to improve services to working-age SSDI/SSI beneficiaries.

**Appropriate Vocational Goals and a Triage Process**

Problems facing the SSDI/SSI beneficiary and his or her VR counselor are numerous and complex. We found evidence of a perplexing mix of problems, such as minimal contact between the rehabilitation counselor and beneficiary; an apparent eagerness to close VR cases regardless of the appropriateness of the job or its relation to the Individualized Plan for Employment; and both over- and under-allocation of resources. With just eight participants, we noted several situations that may not have served the VR client well. In Wendy’s case, the vocational goal was changed and the case closed; in Cameron’s case, the client told us that he was not sure that he would return to work but nevertheless received funding to complete a graduate degree. In Wendy’s case, the beneficiary was relegated to a life on benefits, as she will most likely never be able to afford health insurance without government assistance. In some cases, like Frank’s and Barbara’s, it appeared that stronger advocacy and/or counseling would have helped these individuals achieve a vocation. In Barbara’s case, an up-to-date computer might have made the difference. In her case and Wendy’s, proactive job placement activities may have helped. VR counselors may get better results if they carefully assess a client’s intentions and calibrate the appropriate level of support accordingly. For the client who has a burning desire to work and does not express a great deal of ambivalence, immediate services are in order. However, for the client who expresses quite a bit of ambivalence, counseling (and not services) is probably a prudent first step.

Our study suggests that the state-federal VR system might need a triage mechanism such as that used in some European countries and by private U.S. insurers, whereby counselors can calibrate types and levels of support to match abilities and recalibrate these types and levels by conducting periodic assessments of consumers’ abilities, needs, and motivations. Moreover, for those who are prepared to move into work and off benefits, there needs to be more emphasis on proactive job placement. The efficacy of job placement in assuring that vocational success has been supported through research (Rogers, Crystal, & Bishop, 2005). In our study, several participants (such as Wendy, Barbara, Frank, and Jerry) were determined to work but may have needed more help in negotiating with employers, dealing with employer concerns, and “closing the deal” with employers.

**An Emphasis on Building Careers**

Rehabilitation counselors may encourage individuals to settle for jobs that are easier to find rather than develop career plans that will benefit their clients in the long term. Based on our study, it appears that counselors may be tempted to close cases as successful even when easy-to-find jobs should perhaps be thought of as temporary (Wendy). Rehabilitation counselors could also be more proactive in the job placement process, thus facilitating career development. For example, Barbara, Frank, Jerry, and Wendy would all have benefited from more career development.

**A Better System of Health Care Delivery**

One cannot help but note that the biggest barrier shared by most of our participants was a fear of losing health benefits. It is no coincidence that the only beneficiary who was in a position to terminate her benefits did so, not because she was well prepared or her counselor especially proactive, but because she became covered by her spouse’s health insurance. It is our hope that the U.S. disability system will be improved as our national health care system continues to be transformed. Our findings lead us to believe that if people with disabilities were guaranteed health care, many more would very likely choose to work competitively.

**A Less Punitive Social Security System**

Based on our study, we surmise that many working-age adults who receive benefits would like to work and could be successful if not for their concerns about losing medical or cash benefits. Social security personnel would do well to encourage SSA beneficiaries to attempt work and to eliminate the threats that seem to paralyze many recipients.
In conclusion, the U.S. public disability system seemed to operate as a “benefits trap” for most of our participants, regardless of their personal differences or of variations in the state-by-state delivery of social services. All but one participant seemed destined to remain dependent on disability benefits indefinitely. This was true across individual characteristics like gender, race, educational attainment, job experience, family situation, work attitude, sense of self-efficacy, degree of hopefulness and resilience, and adaptation to disabilities. The disability system also seemed to spring its trap regardless of systemic conditions, such as those arising from employment environment or variations in experience with the SSA and other gatekeepers. We conclude that the U.S. disability system will become more functional and efficient when (a) standards for an early and thorough triage process are developed; (b) careers are emphasized over rapid placement; (c) the U.S. health care delivery system is dramatically reformed; and (d) social security’s rules and procedures are reformed to reduce disincentives and to create true employment incentives.

**Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interests with respect to the authorship and/or publication of this article.

**Funding**

This article was partially funded under a Medicaid Infrastructure Grant from the Centers for Medicare and Medicaid Services of the U.S. Department of Health and Human Services, grant number 1QACMS030313/01.

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### About the Authors

**Marjorie F. Olney**, PhD, is an associate professor of rehabilitation counseling within the Department of Administration, Rehabilitation, and Postsecondary Education at San Diego State University where she directs the psychiatric rehabilitation specialization. Her areas of expertise include employment strategies for people with disabilities, disability and identity, and psychiatric rehabilitation.

**Cindy Lyle** is a graduate student in the Rehabilitation Counseling Program at San Diego State University and is a graduate student assistant at the California Department of Rehabilitation, San Diego District Office. She is a seasoned writer and editor.