

REPORT

Employment Experiences of Young Adults and High Earners Who Receive Social Security Disability Benefits: Findings from Semistructured Interviews

March 17, 2016

Bonnie O'Day
Hannah Burak
Kathleen Feeney
Elizabeth Kelley

Frank Martin
Gina Freeman
Grace Lim
Katie Morrison

Submitted to:
Social Security Administration
Office of Research, Demonstrations, and Employment Support
500 E Street SW, 9th Floor
Washington, DC 20024
Project Officer: Elaine Gilby
Contract Number: SS00-12-60094

Submitted by:
Mathematica Policy Research
1100 1st Street, NE
12th Floor
Washington, DC 20002-4221
Telephone: (202) 484-9220
Facsimile: (202) 863-1763
Project Director: Debra Wright
Reference Number: 40160

This page has been left blank for double-sided copying.

ACKNOWLEDGMENTS

The authors gratefully acknowledge the efforts of many individuals in developing this report. First, we wish to thank the Social Security disability beneficiaries, who generously shared their experiences and perspectives during the interviews. At Mathematica, we wish to recognize Debra Wright, Gina Livermore, and Kirsten Barrett, who developed the protocols and Paperwork Reduction Act approval materials; Dawn Phelps, who developed the beneficiary samples, and Brendan Kirwan and Maura Bardos who processed the administrative and survey data; Stephanie Boras, who led the recruiting effort and Maura Bardos, Daisy Gonzalez, and Brianna Sullivan, who recruited interviewees; Gina Livermore and Craig Thornton, who reviewed and provided input on the report; Sharon Peters, who edited the report, and Kimberly Ruffin, who led the production effort.

This page has been left blank for double-sided copying.

CONTENTS

ACKNOWLEDGMENTS..... iii

LIST OF ACRONYMS..... ix

EXECUTIVE SUMMARY xi

I INTRODUCTION..... 1

 A. Employment of Social Security disability beneficiaries 1

 B. Barriers and facilitators to employment of SSI and SSDI beneficiaries 2

 C. Methodology for the semistructured interviews 4

 D. Contribution of this report 5

II EMPLOYMENT AND BENEFIT EXPERIENCES: YOUNG ADULTS..... 7

 A. Descriptive characteristics 7

 B. Experiences in school..... 9

 C. Initial work experiences 12

 D. Staying at work 14

 E. Future plans regarding work and benefits 17

 F. Experiences with SSA benefits and overpayments..... 19

 G. Suggestions to help other beneficiaries 20

 H. Differences between young adults and high-earning young adults..... 21

III EMPLOYMENT AND BENEFIT EXPERIENCES OF HIGH EARNERS WHO HAD STABLE AND UNSTABLE EARNINGS..... 25

 A. Characteristics of high earners..... 25

 B. Initial work experiences 27

 C. Staying at work 31

 D. Why earnings were unstable or ceased for some high earners 35

 E. Future plans regarding work and benefits 37

 F. Experiences with SSA benefits and overpayments..... 39

 G. Suggestions for SSA 44

IV SUMMARY AND IMPLICATIONS OF THE FINDINGS 47

 A. Beneficiaries’ experiences finding and keeping work..... 47

 B. Beneficiary interactions with SSA..... 50

 C. Study limitations and concluding remarks 52

REFERENCES.....	53
APPENDIX A: RECRUITMENT AND INTERVIEW PROTOCOLS.....	A.1
APPENDIX B: INTERVIEWEE VIGNETTES	B.1

TABLES

II.1	Characteristics of young adult interviewees, young adult beneficiaries earning more than \$500 per month, and all young adult beneficiaries	9
II.2	Individual characteristics of young adult sample compared with young adult high earners	22
III.1	Characteristics of high-earning interviewees, all beneficiaries earning above SGA, and all beneficiaries.....	26

This page has been left blank for double-sided copying.

LIST OF ACRONYMS

DAC	Disabled Adult Child
GED	General Education Diploma
NBS	National Beneficiary Survey
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SGA	Substantial Gainful Activity
SSI	Supplemental Security Income
TANF	Temporary Assistance for Needy Families
TTW	Ticket to Work
TWP	Trial Work Period
VR	Vocational Rehabilitation

This page has been left blank for double-sided copying.

EXECUTIVE SUMMARY

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are an essential lifeline for millions of Americans. SSDI cash benefits are available—after a five-month waiting period—to people with established work histories who have a medically verified work disability expected to last at least one year or to result in death. Other people with qualifying medical conditions can receive SSDI if they have a parent who receives retirement or survivor status. SSI is a means-tested program for working-age people with limited income who meet the same disability definition SSDI uses. SSI is also available to poor individuals over age 65; likewise, low-income SSDI beneficiaries may be eligible for SSI.

The Social Security Administration (SSA), which runs both SSDI and SSI, offers beneficiaries several work incentive programs designed to provide a safety net for initiating work, expanding employment services, and encouraging beneficiaries to return to work. Work incentives such as the Ticket to Work program are also designed to address policy concerns regarding the rapid growth in expenditures and the rising number of people who enter or return to the benefit rolls.

SSA regularly monitors and evaluates its work incentive programs through tools such as the National Beneficiary Survey (NBS), a representative survey on the experiences of a cross section of Social Security disability beneficiaries. Analyses of the NBS data have shown the many factors that can help or hinder a beneficiary's efforts to find work.

To complement the NBS, we used SSA administrative data to identify and recruit 91 SSI and SSDI beneficiaries for in-depth qualitative interviews about their benefit experiences and their attempts to find and keep a job. We selected beneficiaries whose patterns of earning suggested they had the best odds of reducing their dependence on benefits or leaving the benefit rolls because they were currently working or had recently worked. The interviewees included 30 recently employed young adult beneficiaries (younger than age 30) and 61 “high earners”—beneficiaries of any age whose earnings surpassed a certain threshold, known as the nonblind substantial gainful activity (SGA) level, for three consecutive months. Thirty of these beneficiaries had earnings that had remained stable or increased during the past six months, whereas 31 of them had earnings that had fluctuated, decreased, or ceased. Although annual earnings of just under \$13,000 would not generally be considered high, we defined these beneficiaries as high earners because SGA is an important earnings amount for determining ongoing benefit eligibility. Sustained earnings above SGA will eventually result in termination of benefits. It's important to note that, at any point, less than 3 percent of all beneficiaries are earning above SGA (Livermore and Bardos 2015), so we are focusing on a select group of beneficiaries who are especially likely to reduce their dependence on benefits or to leave the rolls entirely.

Below, we describe the key findings from the study.

Finding and keeping work

Motivation

- Beneficiaries were motivated to return to work for monetary and nonmonetary reasons. For some, the SSA cash benefits were insufficient, and they wanted to earn more for themselves

and their families. Others said they were motivated by pride, self-esteem, a desire to be a productive citizen, or a wish to return to the kind of life they had before entering the benefits program.

- Young adults were also motivated by a desire to gain independence, earn their own money, have spending money, or live a “normal” life. However, the majority were not working in or preparing for a chosen field, which some attributed to a lack of education or insufficient financial or emotional support.

Employment barriers and strategies for overcoming them

- Workers with disabilities face numerous obstacles to finding and maintaining a job, and they use a variety of strategies to overcome them. There is no one-size-fits-all solution; each beneficiary has unique challenges and must devise his or her own strategies.
- During high school, many young adults experienced hardships and bullying related to their disability that affected their work aspirations. Interviewees said they often lacked the support to survive and thrive academically and socially. Many were not using vocational rehabilitation, job coaching, or other programs to prepare them for employment. Young adults with stable or high earnings were an exception: they often reported positive high school experiences.
- Health was a major factor in respondents’ decisions to return to work, pursue new careers, or use work incentives. People with poor health were less willing to return to work full time or to seek benefit cessation as a goal. Many beneficiaries with unstable earnings said the episodic nature of their disability, such as flare-ups of back pain or fatigue, required them to rest or take time off of work. Variation in the number of hours they could work each week because of these issues accounted for their fluctuating earnings.
- Beneficiaries reported that networking with teachers, friends, and family; job training programs; and workplace accommodations helped with their initial job efforts. Finding a job that was suited to their unique situation and connecting with supportive co-workers and supervisors were essential to staying at work.
- Only a few young adults and high earners used the Internet to search for jobs. A few interviewees said they wished they had access to a class in basic computer skills. In particular, older respondents felt unfamiliar with computers and current technology and believed that limited the types of jobs for which they could apply.
- Several young adults were offered job coaching and other services while in school that helped prepare them for work, but older workers were not. Relative to the high earners, young adults expressed a greater need for more services.
- Young adults and high earners said employers who were willing to meet their disability-related needs with flexible work schedules or other accommodations were vital. Several discussed how flexible schedules, including advanced notice on scheduled shifts, the ability to choose their own work hours, or the ability to take time off or take paid sick leave, was critical to sustaining work. Some employers also supported interviewees’ desires to work limited hours so they could keep their Social Security benefits.

- Across all age groups, transportation was a major concern and a barrier to finding and keeping a job. For many beneficiaries, transportation is unreliable and affects whether they can accept job offers or, in some cases, continue post-secondary school. A few beneficiaries addressed their transportation issues by finding jobs close to where they lived, and one found a job where she could work from home.

Future plans regarding work and benefits

- Young adults and high earners said the unpredictability of their health is the greatest barrier to future work.
- Beneficiaries with stable earnings mentioned future plans with their job, such as becoming a partner at their firm or being eligible for new programs at work. Many of the high earners with unstable earnings were uncertain about their careers and lacked the opportunity to move up at their current job.
- Young adults and high earners varied greatly in terms of their goals and desire to leave the SSA benefit rolls. Some had a strong desire to stop receiving benefits and were actively working toward that goal. Others saw receiving benefits as necessary but temporary; they wanted to leave the rolls, but it depends on their future health status. Many others rejected the prospect of leaving the rolls because they feared losing benefits or believed their work capacity is low.
- Health and concerns about insurance were consistently mentioned as a factor in employment decisions. Many interviewees were uncertain about their future health. Although able to work at present, they were not sure their health would allow employment in the future. They were nervous about what would happen if they needed to re-apply for benefits if their health worsened and they could no longer work.

Experiences with SSA benefits and overpayments

- Many beneficiaries acknowledged having a limited understanding of their benefits, options for retaining public health insurance, SSA regulations and guidelines, and incentives that could support employment.
- Many asserted that SSA program information about return-to-work policies and reducing or stopping benefits is confusing, burdensome, misleading, or inconsistently applied by SSA staff.
- Overpayments are a major challenge for many awardees, particularly high earners with unstable earnings. Several beneficiaries expressed great frustration when they had reported their earnings to SSA, or been told by SSA they were due a payment, only later to receive an overpayment notice. Overpayments were often caused by delays in SSA processing of earnings information.
- A few young adult high earners were paid biweekly and explained that they routinely receive overpayments when they receive three paychecks in a month, which occurs about twice a year.

- Many interviewees said they were doubly concerned with trying to return to work while paying back debt arising from benefit overpayments. Many expressed a need to continue receiving SSA cash benefits in order to repay SSA for past overpayments. The inability to repay debts or save money was a frequently mentioned concern, especially among SSI beneficiaries.

Suggestions for SSA

Besides describing their experiences, beneficiaries suggested many things SSA could do to help other beneficiaries find work, such as offering case managers or community liaisons to coordinate paperwork or to provide information on return-to-work incentives. However, most of what they suggested already exists in some form, indicating a general unawareness of available supports. SSA might want to conduct marketing research and campaigns to tailor messages toward certain beneficiary groups about work incentives, overpayments, and health insurance policies. The messages could help allay fears of losing health insurance and provide clear examples of how insurance can be maintained while working.

Conclusions

In this study, we illustrated and compared the diverse experiences of young adults and high earners with stable and unstable earnings. We examined many topics not covered in prior literature, including the use of informal networks to find a job, barriers to keeping a job, and experiences with receiving overpayments from SSA.

Our sample is relatively small and was not selected in a manner to ensure national representation of beneficiaries who are working young adults or high earners. Thus, the findings may not reflect the experiences of all beneficiaries with those characteristics. However, the study provides a glimpse into the experiences of 91 beneficiaries and includes a focus on younger workers, who are statistically more likely to be working, compared with their older peers (Wright et al. 2012). Many of the themes described are consistent with previous research findings; however, the qualitative findings presented here illustrate the substantial diversity in beneficiaries' paths toward success and their understanding of SSA's program rules.

I. INTRODUCTION

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are an essential lifeline for millions of Americans. SSDI cash benefits are available—after a five-month waiting period—to people with established work histories who have a medically determinable work disability expected to last at least one year or to result in death. Others with qualifying medical conditions can receive SSDI through a parent who receives retirement, survivor, or disability benefits. SSI is a means-tested program administered by the Social Security Administration (SSA) for working-age individuals with limited means who meet the same disability definition used by SSDI. SSI is also available to poor individuals over age 65. Low-income beneficiaries with very low SSDI benefits may also be eligible for SSI.

Eligibility for SSI and SSDI requires that the individual be unable to work at a substantial level. Still, many SSA beneficiaries (41 percent) have goals relating to work and express an interest in returning to work in the future (Wright et al. 2012). This report describes a sample of working beneficiaries and elucidates their experiences with employment and benefits.

To build on the existing literature about barriers and facilitators to work, we used SSA administrative data to methodically select 91 beneficiaries whose patterns of earning have among the best odds of reducing their dependence on benefits or leaving the benefit rolls because they are currently working or had recently worked. Through our in-depth qualitative interviews, we have found that beneficiaries face significant barriers in their lives, including their health and other issues related to their impairment, poverty, and, in some cases, family instability. We conclude that each interviewee faced some barriers to working and benefited from some facilitators specific to their disability and personal situation. Interviewees took quite different paths to employment. Many succeeded in working over a sustained period; others have only a tenuous attachment to employment or did not stay employed. In addition to delving into the common themes that emerged from our interviews, this report reflects the richness and diversity of beneficiaries' experiences and the routes each navigated toward employment. A deeper understanding of the barriers beneficiaries face and overcome can suggest to policymakers steps that will promote and sustain employment for Social Security beneficiaries.

A. Employment of Social Security disability beneficiaries

To help facilitate return to work, SSA offers a number of work supports, such as the Ticket to Work (TTW) program and payments to state vocational rehabilitation (VR) agencies, which are designed to help beneficiaries obtain job-related services and gradually transition from benefits to work. SSA also offers work supports that allow beneficiaries to maintain their eligibility for public income assistance and health insurance—important concerns for many beneficiaries interested in returning to work. SSA supports the transition from benefits to work by offering a safety net as beneficiaries begin working. For example, under the SSDI program, beneficiaries are allowed a trial work period (TWP) of nine months, along with a grace period of three additional months, in which they can earn any amount and still receive benefits.¹ After that, if a beneficiary's earnings reach substantial gainful activity (SGA), meaning that the beneficiary

¹ Earnings over \$780 in one month count as a TWP month.

earned \$1,090 per month or more in 2015,² benefits are suspended, and then eventually terminated. SSDI beneficiaries may retain their Medicare benefits for an additional eight and one-half years.³ Termination of SSDI benefits is sometimes called the “cash cliff” because the entire cash benefit is lost after the TWP is completed and earnings reach the SGA level. In contrast, SSI monthly benefits are reduced \$1 for every \$2 of earnings (after \$65 of earnings and a \$20-per-month general income exclusion), so SSI recipients lose cash benefits gradually as earnings rise. Participants whose earnings make them ineligible for cash benefits may remain eligible for Medicaid benefits even after SSI cash payments are suspended due to earnings under Section 1619(b) of the Social Security Act. Individuals remain eligible for SSI and Medicaid until their earnings exceed a “threshold amount,” which varies by state.

National Beneficiary Survey (NBS) data show that 9 to 12 percent of all working-age SSI and SSDI beneficiaries are employed at any point in time, with slightly higher rates of employment for SSDI and concurrent beneficiaries than for SSI beneficiaries (Wright et al. 2012). Longitudinal studies that examined the cumulative outcomes of beneficiaries over time suggest slightly better employment outcomes. For example, among those who received an SSDI award in 1996, 28 percent worked for pay, 6.5 percent had benefits suspended for work in at least one month, and 3.7 percent had benefits terminated for work during the subsequent 10 years (Liu and Stapleton 2011). Among those who returned to work, exit rates were higher for beneficiaries younger than age 40. A substantial proportion of beneficiaries who exit the rolls returns to the rolls in the future.

B. Barriers and facilitators to employment of SSI and SSDI beneficiaries

Policymakers face many challenges in promoting employment for Social Security beneficiaries. There are several barriers to work, as reported in the literature, including poor or deteriorating health, inability to find work that is appropriately aligned with the person’s capabilities, inaccessibility or lack of workplace accommodations, being discouraged because of previous negative experiences, and lack of transportation (Livermore et al. 2009). Moreover, many beneficiaries lack education or the job-search or interview skills they require to secure employment. Other beneficiaries mention concerns about losing publicly funded health care when they lose SSI or SSDI benefits because of work and being unable to find an employer who offers health insurance. Beneficiaries have also cited as barriers lack of adequate housing or in-home assistance (National Council on Disability 2005; U.S. Bureau of Labor Statistics 2012).

Beneficiaries have suggested that the SSA requirements for reporting earnings and the risk of overpayments are serious disincentives to work (National Council on Disability 2005). Overpayments occur when a beneficiary receives an SSDI or SSI benefit, or a portion of the benefit in the case of SSI, to which he or she is not entitled. Both SSI and SSDI beneficiaries must report their earned income to SSA each month so that the benefits levels can be calculated. Because it takes several months for SSA to complete the calculations, beneficiaries are often

² The SGA amount for blind individuals was \$1,890 in 2015.

³ The eight and one-half years of extended period of Medicare eligibility includes the TWP months.

overpaid and the overpayment amount is deducted from future checks.⁴ Sometimes SSA is still collecting the overpayment well after the beneficiary has stopped working.

Policymakers who wish to improve employment outcomes for SSA beneficiaries can draw from beneficiaries' reports of the factors that serve as facilitators to employment, such as education and skills training, personal motivation, and good health status. Previous employment is also associated with positive employment outcomes for persons with disabilities who seek to stay at work or return to work (Livermore et al. 2007). Other contributors to employment are knowledge of work incentive programs, such as TTW, or such resources as financial planning or benefits counseling so beneficiaries understand how work will impact their benefits. Employer-related factors, such as adequate wages and health benefits, accommodations to the employee's disability, and employer understanding of worker capabilities, are also often facilitators for employment. Social supports, such as family and friends, home adaptations, and community-based programs, such as VR, and job-placement services, are also often regarded as facilitators (National Council on Disability 2005).

In this report, we expand on the quantitative statistics and other literature described above by documenting the experiences of 91 beneficiaries as they described their attempts to become employed and stay at work. The interviewees included 30 recently employed young adult beneficiaries (younger than age 30) and 61 "high earners"—beneficiaries of any age whose earnings surpassed a certain threshold, known as the nonblind substantial gainful activity (SGA) level, for three consecutive months. Through the in-depth interviews, we learned of the employment outcomes and benefits experiences of 30 recently employed young adult beneficiaries, including their motivation to work, experiences in school and with employers, and their future aspirations for work (Chapter II). In Chapter III, we describe the employment and benefits experiences of the 61 high earners. Thirty of these beneficiaries had earnings that had remained stable or had increased during the past six months, while 31 of them had earnings that had fluctuated, decreased, or ceased. Although earnings of just under \$13,000 would not generally be considered high earnings, we define these beneficiaries as high earners because SGA is an important earnings amount for determining ongoing benefit eligibility. Sustained earnings above SGA will eventually result in termination of benefits. Fewer than 3 percent of all beneficiaries earn above SGA (Livermore and Bardos 2015), so we are focusing on a select group of beneficiaries with a strong likelihood of reducing dependence on benefits or leaving the benefit rolls entirely. In Chapters II and III, we also describe beneficiaries' experiences with overpayments and their concerns about SSA reporting requirements. We conclude in Chapter IV with a summary of findings. In the appendices, we provide the interview protocol used to gather data, and vignettes of nine study participants. The vignettes summarize individuals' specific and complex situations related to employment and SSA benefits.

⁴ SSDI overpayments tend to be higher than SSI overpayments because an SSDI beneficiary who has completed the TWP and grace period will be paid the entire benefit check in any month in which their gross countable earnings exceed the monthly SGA. An SSI beneficiary will have the monthly SSI benefit reduced based on the amount of gross countable earnings in a particular month and may lose only part of the SSI cash benefit.

C. Methodology for the semistructured interviews

The study plan called for interviewing a total of 90 individuals, including 30 in each of three groups: 1) employed SSI and SSDI beneficiaries under age 30 with recent monthly earnings of at least \$500; 2) SSI and SSDI beneficiaries who had recent earnings above the SGA level for at least three consecutive months and who had sustained those earnings as of the time they were contacted for interview; and 3) SSI and SSDI beneficiaries who had recent earnings above the SGA level for at least three consecutive months and who had not sustained those earnings as of the time they were contacted for interview. The design focused on young adult beneficiaries because they are an important target group for employment supports. They have a strong interest in employment, relatively high employment rates compared with other beneficiaries, and, in the absence of employment, the potential to remain on the disability rolls decades. We hoped to gain a better understanding of the experiences of those who had achieved some employment success. The design focused on high earners because these beneficiaries have the greatest potential to work and earn enough to eventually leave the disability rolls. By including both high earners who did and did not sustain their earnings we hoped to gain a better understanding of the factors that facilitate employment above the SGA level, and why the initially successful work attempts of some high earners fail.

We used SSA administrative data to identify and recruit 91 SSI and SSDI beneficiaries to participate in the semistructured interviews.⁵ From March 2 through June 3, 2015, we contacted 818 beneficiaries, with an average of about two attempts per person. Of these, we interviewed 91 individuals, for a yield rate of about 11 percent. We received 90 refusals; the remainder of the incomplete interview attempts resulted from wrong or disconnected numbers, or we received no answer. Our interviews include:

- **Employed young adults.** Thirty employed young adults, defined as beneficiaries younger than age 30 who earned \$500 or more during January 2015 and who were still employed at the time we contacted them beginning in March 2015.
- **High earners who did and did not sustain their earnings.** Sixty-one high earners, defined as beneficiaries of any age whose earnings surpassed the nonblind SGA level for three consecutive months (from September through November 2014).⁶ These individuals were screened when we contacted them beginning in March 2015, to determine whether they had sustained their earnings over the previous six months, which would include the period between identification and interview of these beneficiaries. We asked beneficiaries if their income had increased, decreased or remained the same over the past six months. We categorized those whose earnings had remained the same or increased as high earning beneficiaries with stable earnings; we categorized those who said their earnings had fluctuated, decreased or ceased as high earning beneficiaries with unstable earnings. Our goal was to interview 30 high earners who had sustained their earnings and 30 who had not. Thirty of the 61 beneficiaries we interviewed said their earnings had been stable or

⁵ Recruitment and interviews were conducted simultaneously by a number of staff. Although our overall target was 90 completed interviews, one additional interview was completed before staff realized the targets for each of the three groups had been met.

⁶ In 2014, the monthly nonblind SGA level was \$1,070.

increased over the past six months. Thirty-one beneficiaries said their earnings had declined, fluctuated, or decreased over the past six months.

For both of the groups above, we utilized targeted recruitment efforts to obtain about half of the interviewees from the SSI program and half from SSDI. Employed young adults who met the criteria for the high earner sample were classified as high earners. We provide in Chapter II a separate analysis of the 13 individuals who qualified for both the young adult and high earner interviews.

We developed semistructured interview questions with topic areas that focus on the pre-employment, work, and benefit experiences of young adults and high earners. (Appendix A contains the recruitment and interview protocols.) For interviewees younger than age 30, an additional set of questions focused on school experiences. The open-ended questions enabled respondents to describe their feelings and experiences with employment and benefits, including the barriers they encountered and how they overcame them, what experiences or factors facilitated their employment, and their plans for the future. Interviewers used probes to draw out respondents' observations and elucidate their experiences. We conducted the interviews at beneficiaries' convenience, including evenings and weekends. Interviews lasted an average of 30 minutes. In a few cases, a parent assisted a young adult with an intellectual disability with the interview by clarifying questions and providing more detailed answers.

We conducted two rounds of training for seven experienced interviewers before the interviews, most of whom had some familiarity with SSA benefits and employment programs for individuals with disabilities. The first round of training reviewed the purpose of the study, SSA programs and work incentives, employment programs beneficiaries might use, and barriers and facilitators to work that have been documented in the literature. The second training session covered using Atlas ti to code the interviews.

Each interview was recorded and transcribed. The transcripts were analyzed, coded with key themes, and sorted using Atlas.ti qualitative analysis software. Lead investigators listened to the first two interviews conducted by each interviewer, critiqued interview style, and suggested subjects for further probes. They also reviewed the first two coded interviews to ensure consistency. Interviewers and research staff then summarized the key themes and described findings across subgroups of interest based on age, employment, and program participation status. We also analyzed the interviews of the high earning beneficiaries to ascertain differences between those with and without stable earnings.

D. Contribution of this report

This report contributes in several ways to the literature about barriers and facilitators to employment. First, it summarizes the experiences of SSA beneficiaries with established work histories and earnings—those who have the strongest possibility to decrease their dependence on public benefits. Second, the in-depth interviews provide a fuller understanding of the lived experiences of these beneficiaries, who described in their own words the barriers they faced, how they overcame these barriers to find employment, and the barriers they may face in continuing to work. The study also includes topics not covered in prior literature, including the use of informal networks to find employment, barriers to sustaining employment, and experiences with receiving

overpayments from SSA. The study focuses on younger workers, who are statistically more likely to return to work, compared to their older peers (Wright et al. 2012). Many of the themes described in this report are consistent with previous research findings; however, there is substantial diversity in beneficiaries' paths toward success and their understanding of SSA program rules. We draw out these diverse experiences by contrasting young adults with high earners, and by contrasting high earners with stable and unstable earnings.

II. EMPLOYMENT AND BENEFIT EXPERIENCES: YOUNG ADULTS

In this chapter, we describe key themes from the interviews we conducted with 30 employed young adults regarding school, employment, and SSA program experiences. We first describe the characteristics of the young adults we interviewed. We then consider the barriers they encountered and the facilitators that helped them to find work and stay employed, as well as their future plans regarding employment and SSA benefits receipt. There were an additional 13 young adults with earnings over the nonblind SGA level. We analyzed these interviews as part of the high earning beneficiary sample. However, in the final section of this chapter we describe key differences between these high earners and the 30 young adults who had recently worked at lower earnings levels.

Many of the young adults we interviewed found creative ways to overcome barriers to employment. Some of the barriers they faced are common to all low-income young people seeking their first job but others are unique to having a disability. Interviewees said they experienced difficulties in school related to their disability, but all graduated from high school or obtained a General Education Diploma (GED) and went on to find employment. About half had a long-term goal to leave the benefit rolls, although they feared loss of health insurance (and were unaware of work incentives that enable them to retain Medicare or Medicaid as their earnings rise). They succeeded in finding jobs by relying on family and friends to help identify promising prospects; some volunteered with employers to prove they could do the job. Several with intellectual disabilities benefited from job coaching to find and keep work. The young adults spoke of employers who accommodated their disability and the solutions they came up with to overcome other barriers, such as those caused by their health condition or lack of reliable transportation.

A. Descriptive characteristics

As described previously, we interviewed 30 employed young adult beneficiaries, defined as SSI or SSDI beneficiaries who were younger than age 30, recently had monthly earnings of \$500 or more, and were still working at the time of the interview (Table II.1). We hereafter refer to this group as “young adult interviewees.” In a few cases, a parent helped beneficiaries with intellectual disabilities complete the interviews.

The median age of the interviewees was 26, so most were at an age at which their peers without disabilities would very likely have completed their education or training and have begun a career or steady employment. Seventy percent reported that the onset of their disability occurred before age 18, indicating they had substantial impairments and might have faced disability-related barriers during at least some of their schooling and transition to adulthood. Most (93 percent) reported that they were receiving cash disability benefits, but nearly 70 percent reported stable or increased earnings during the six months before their interview. Many will have their benefits reduced if they continue working.

Consistent with the manner in which we drew the sample for the semistructured interviews, the interviewees differed in many respects from the subset of beneficiaries from which they were selected: all beneficiaries under age 30 and earning more than \$500 per month, based on national survey data (Table II.1). As noted previously, our goal was for the interview sample to consist of

one-half SSDI beneficiaries and one-half SSI recipients so that the perspectives of both groups could be captured equally well. However, SSDI-only beneficiaries constitute an estimated 15 percent of all young adult beneficiaries earning more than \$500 per month, compared with 50 percent of the interviewees.

We also found some smaller differences between the interviewees and all young adult beneficiaries earning more than \$500 per month. Compared with the latter group, the interviewees were slightly older, somewhat more likely to have had a psychiatric condition, and somewhat less likely to have had disability onset during childhood. Some differences are substantial, however; interviewees were less likely to have intellectual disabilities, more likely to have musculoskeletal and circulatory impairments, more likely to have been on the rolls for less than 10 years, more likely to be female, and more likely to be receiving cash disability benefits.

Many of the differences between the interviewees and the larger group of young adult beneficiaries earning more than \$500 per month might be expected given the greater share of SSDI-only beneficiaries in the interview sample. For example, intellectual disabilities are much less common among SSDI-only beneficiaries than among SSI recipients (Bardos et al. 2016). When we reweighted the interviewee sample using the proportions of SSDI-only, concurrent, and SSI-only beneficiaries in the national sample of young adult beneficiaries earning \$500 or more per month, many of the differences became smaller (statistics not shown). Median age became identical, and the distributions for sex and impairment became more similar. However, time on the rolls and the likelihood of benefit receipt remained substantially different between the two groups—a much greater share of interviewees received cash benefits and a much smaller share had been on the rolls for 10 or more years. These differences might, in part, be related to the relatively small share of people with intellectual disabilities in the interviewee sample. Relative to other beneficiaries, those with intellectual disabilities have been on the rolls for a significantly longer period and are less likely to be receiving cash benefits (Bardos et al. 2016). Those with intellectual disabilities may be under-represented in the interviewee sample because they might be more difficult to reach or unable to participate in a phone interview.⁷ Those on the rolls for shorter periods might also be easier to locate for an interview because their contact information in the SSA administrative data is more current. In addition, high levels of sampling error in a sample of just 30 people, and the difference in time periods (2015 for the interviewees versus 2004 through 2010 for the survey samples), likely contribute to the differences.

To provide some additional context, we also show statistics on all young adult beneficiaries in Table II.1. Based on the national survey data, young adult beneficiaries earning more than \$500 per month differ from all young adult beneficiaries in many ways. They are more likely to be SSDI-only beneficiaries, to be male, and to have been on the disability rolls for 5 to 10 years. They are less likely to have intellectual disabilities and to have been on the rolls for less than 5 years. They are also much less likely to be receiving cash disability benefits. Other, smaller differences between the two groups are also apparent.

⁷ Although a parent or family member provided assistance to a few interviewees, we did not conduct any proxy interviews for people who were completely unable to participate in an interview.

Table II.1. Characteristics of young adult interviewees, young adult beneficiaries earning more than \$500 per month, and all young adult beneficiaries

	Young adult interviewees ^a	Nationally representative sample of young adult beneficiaries ^b	
		Earning more than \$500/month	All
Unweighted number	30	265	4,145
Weighted number	NA	59,118	897,320
Weighted percentage of full sample	NA	1	9
Program (%)			
SSDI only	50	15	10
Concurrent	23	25	22
SSI only	27	60	68
Median age (years)	26	25	24
Sex (%)			
Male	47	64	50
Female	53	36	50
Primary impairment (%)			
Psychiatric condition	37	31	33
Musculoskeletal condition	13	3	2
Circulatory condition	17	1	1
Injury	10	4	3
Intellectual disability	3	33	38
Vision or hearing impairment	3	6	4
Other	17	21	19
Unknown	0	1	0
Childhood disability onset (%)	70	77	81
Time since most recent SSI/SSDI eligibility			
Fewer than 5 years (%)	43	26	36
5 to 10 years (%)	47	40	29
More than 10 years (%)	10	35	35
Receiving SSA cash disability benefits (%)	93	58	90
Employed (%)	100	100	26
Earnings over past six months (%)			
Stable/improved	70	NA	NA
Unstable/declined	30	NA	NA

^aData on program, age, sex, primary impairment, and time since most recent SSDI/SSI eligibility are from SSA administrative files and the 2013 Disability Analysis File. Data on childhood disability onset, SSA benefit receipt, employment, and earnings over the past six months are from interviewee self-reports.

^bData are from the pooled 2004, 2005, 2006, and 2010 NBS.

NA = not applicable.

B. Experiences in school

We asked the interviewees about their experiences in school, including whether the disability made it difficult to go to or finish school, what types of services or supports they received or needed, and their career expectations upon graduation.

1. Many interviewees had difficulties in school related to academics and social interactions

Inasmuch as 70 percent of the respondents reported that their disability started before they were 18 years old, a majority described challenges related to academics or socialization, which led to a high degree of frustration with school. The interviewees overcame these obstacles, graduated from high school or obtained a GED, and went on to find employment. Their employment experiences are described in the following sections.

Interviewees said they experienced difficulty with keeping up with the curriculum; remembering class materials; and comprehending the coursework, particularly in math and reading. One said, “If they tell me something during the week, the week before that’s a test or something, I forget the answers and stuff to the questions.” Another said, “Well, I got made fun of a lot. A lot of people would call me names and stuff. I got into a lot of fights because of that. It was hard for me to learn things and to comprehend things and stuff in school, so... I got kicked out of school and they sent me to [a special school]. That’s the only reason why I graduated. If it wasn’t for me getting in a bunch of trouble I wouldn’t even have a high school diploma. I got in trouble a lot because of my disability.” Other respondents made mention of verbal bullying and difficult social interactions at school.

2. Some were enrolled in special education classes or received assistance in the classroom

Interviewees reported participating in special education classes or receiving assistance in a regular class with subjects they found difficult. Some had special classes in math, reading, or science, or received tutoring or note-taking help. A young man with cerebral palsy said, “I spent half my time in regular classes and half in special ed classes. I had a ‘helper’ who took notes and wrote for me because I have difficulty writing. Sometimes I have difficulty understanding what I read, but someone at school helped me to understand.” A young woman with kidney disease said, “I would say I got help from my parents and teachers. And me being disabled, I knew that I needed to get this education, so that I could have a job with insurance in the future for my disability to pay for my medicine and all that.” Others mentioned they got special assistance from teachers; a deaf interviewee used an interpreter in school. The mother of a man with intellectual disabilities who had participated in some regular classes said, “You know, that inclusion in elementary school and middle school really carried him far in terms of just normal social interactions with his typical peers.”

3. Several participated in vocational programs that helped them prepare for or find employment

Several interviewees with intellectual disabilities received school-based vocational programming designed to prepare individuals with disabilities for employment. The programs provided classroom training and employment in the community prior to graduation. Students who received these services generally reported they found employment after high school graduation. Most interviewees who had used these services reported a positive experience. The mother of a man with intellectual disabilities explained, “It gets them out to do some job experiences. It’s the best way to do it. They teach them in the classroom what a construction crew does and what a garbage crew does and then they take them out in the field to see if that is a job that they would like to do once they graduate from their program.”

4. Some lacked sufficient social and academic support or accommodation in school

Some young adults said they did not receive the academic assistance or accommodation to their disability or medical condition they needed while they were in school. Some interviewees expressed doubts about the legitimacy of their high school degree. One said his school allowed him to skip a year because of his disability simply so he could graduate. He interpreted that as: “Just graduate so you can have a high school diploma...you’re going to be a failure anyway, so just go.” Another noted, “...they didn’t try to help me accomplish anything in my life. That’s why I’m...I can’t read, I can barely do math....I look for jobs that don’t have a lot of reading in them.”

5. Those who described career goals did not view disability as a barrier, but few were employed in their chosen fields

A small number of beneficiaries described specific career goals—such as becoming a social worker, a zoologist, a sports journalist, a home interior designer, and a geologist. Most interviewees were not working in their chosen field, but a few were pursuing an education or taking steps to reach their goal. The man who wants to be a geologist is working part-time as a janitor and completing school to achieve his goal. A woman with cancer and other disabilities has used a note taker, a tutor, and some extra time on tests in college to earn a human services degree.

However, the majority were not working in or preparing for a chosen field, which some attributed to a lack of education or insufficient financial or emotional support. One beneficiary who worked as a home health aide said, “I discovered I really liked home interior design. I thought that it was more of like my passion, like I would wake up, go to work, and be happy. And my family didn’t support it, so it just really took a toll on me... thinking my family is not going to support me if I change my major from medical to interior design. Like I said before, I was doing bad in school. I really didn’t care that much about it. And I think if I had changed my major, I would’ve actually gained an interest and actually followed through and graduated...[Now] I’m like, I’m 27 working at a gas station. It’s hard.” Another said, “Yes, I would like to be a zoologist because I like to work with animals but I probably won’t because I think it would be hard for me to learn because of my attention deficit hyperactivity disorder. I don’t think there would be any support to help me.” The beneficiary with cerebral palsy said, “I want to be a social worker or a physical therapist. I want to show people that I can do even though I am in a wheelchair.” But he did not go to college because his mother, who also has a disability, needs his help.

6. Most had not worked before they acquired their disability because that occurred in childhood

A couple of respondents said they changed career goals after acquiring a disability. One woman, who received a head injury and other disabilities from a car crash when she was in college, enrolled in a vocational program to become a dental assistant because she could no longer handle college courses. Others said they could no longer perform labor-intensive jobs. One former factory worker is working for a human resources department. Another man said, “Well, I got a prosthetic leg. I got my leg cut off. I can’t do labor-intensive jobs anymore. The job I have right now, I’m still having trouble doing, and it’s just stocking shelves in a grocery

store. I used to do welding or carry heavy stuff around... I was working my way up in the company when I had the accident.”

C. Initial work experiences

After exploring their experiences in school, we asked about their first experiences with employment, including their motivation to work, whether the goal was to leave the SSA benefit rolls, the steps they took to find the job, barriers and facilitators to work, and the services used to obtain the first job.

1. Young adults were motivated to work for monetary and non-monetary reasons

Most of the employed young adults we interviewed experienced disability onset during childhood, so they made a transition from school into work rather than a return to work after disability onset. For many, the motivation to work was connected to their transition to adulthood. Interviewees mentioned gaining independence, earning their own money, or having spending money as key motivators for working, similar to the motivations of nearly all in this age group.

Several interviewees said they worked to supplement their benefits and to afford necessities. One reflected: “I can’t like just live off my parents or family. I just have to have money to buy what I need to survive. And Social Security, it helps, but...I can’t just live on Social Security.” Another said: “I pay child support. I get like \$600 a month for my disability... That’s the reason why I work. I mean, it’s hard to live off of \$600 a month, it really is.” Others also noted that their benefits were not sufficient to live on.

Many young adults were also motivated by non-pecuniary factors, such as the desire to prove something, live a “normal” life, or fit in with others. One interviewee said, “I wanted to prove that I could get back to being as normal as possible. That was my motive.” Another said, “I want to prove to myself and the family members that said I wasn’t worth anything that I am, in fact, worth something and that I can be a productive member of society.” Other respondents said they were motivated to work because they were bored without a job and wanted to keep busy. One said, “I don’t want to sit around all day. So I’ve got to keep busy. Keep myself productive.”

2. At least half hoped to eventually leave the benefit rolls; others expressed concerns about losing disability benefits

Many interviewees said they wanted to get off of SSA benefits when they started working, but it was a long-term not immediate goal. They wanted to “live a normal life,” “be independent,” and “make my own way.” One beneficiary said, “I would like to [get off benefits] because I want a better life. I want a wife, I want children and I guess you can’t have a life that you really want and have Social Security. You can, but you can only work part-time. I want a career so that’s the reason why I want to work.” Another said, “I just needed them [benefits] as, kind of like a stepping stone, to get me to the next phase in my life, which is where I’m supporting myself.” Other interviewees wanted to retain benefits so they could work part-time and finish school, but believed that when they finished school, they would find a good job and earn enough to no longer be eligible for benefits.

Interviewees who did not want to lose benefits understood they would be limited in how much they could earn. One was content to lose cash benefits, but expressed the need to keep the medical insurance. Another said, “I do not want to get off benefits. I do not want to work too much so I won’t lose my benefits. I like to work part-time so I can keep my benefits. I only work 12 hours a week. My job coach takes all my pay stubs and makes sure I don’t make too much.” Another noted, “If I just drop disability and try to find a better job, I’m afraid I won’t be able to do the job good, you know—I’m afraid I won’t make it.”

3. Social networks, volunteer opportunities, disability services, and supportive employers helped them secure the first job

The young interviewees went about securing a job in a variety of ways. They most commonly said they received referrals to jobs or assistance from family, friends, and teachers. Several cited this kind of assistance as important to their job search and most received a direct referral to a job.⁸ As one beneficiary put it “...that’s the only way you can really find jobs is, I think, to know people.” They also said they received other supports from their family and friends, such as help with transportation, child care, job search, job referrals, and encouragement throughout the job-search process.

Interviewees used various disability and vocational services to find employment, such as the state VR agency, Goodwill, Job Corps, and other programs aimed at helping people with disabilities gain employment; one interviewee mentioned using TTW. In some cases, school programs helped them transition to employment by steering them toward internships and volunteer opportunities that provided valuable work experience or connections that led to a job. Others took advantage of vocational services or job-training services. These training programs offered work experience and job skills, which interviewees said made them more comfortable seeking out jobs and keeping them. In general, interviewees said they found these experiences valuable, even when they did not directly lead to employment. The mother of one interviewee described one program positively, although it did not help her son find a job: “Old Dominion University had a residential program for people with intellectual disabilities and [he] went to that [... and] had a great experience there because it certainly provided him a lot of opportunities to be independent.”

Many young adults had worked with a job coach to help with the job search and orientation to the workplace, and described both positive and negative experiences with them. Those who found the job coach helpful appreciated his or her assistance in communicating with employers, setting up and conducting interviews, and the individual’s presence at the job site. One respondent said, “[VR] provided me with a job coach and a job developer. The job developer helped me get the job and [met with] the owner of the business. The job coach helps me when I’m on the job. If I don’t understand something he will explain it in a way that I can understand.” Those with negative experiences with their job coaches pointed to issues communicating with

⁸ Findings from the qualitative interviews are not generalizable to all beneficiaries, or all working beneficiaries. For example, young adults who find jobs through personal networks may be more likely to remain employed. Because we chose for our interviews young adults who are currently employed, this finding may be biased.

the coach or said the coach did not understand their employment goals or preferences or did not help them find employment.

A few interviewees mentioned volunteering as a first step toward securing a job. They found the volunteer opportunities through their school, nonprofit programs, or on their own. Volunteering led to a job because it provided work experience that was attractive to employers, or allowed employers to assess their capabilities before they were hired. One interviewee who volunteered with a school district said, “I was doing volunteer work for them and they had a job open up. They knew me from the volunteer stuff that I had been doing and were willing to let me try.” Others found a job by searching online; through an employment agency; or through programs geared toward helping people with disabilities find employment, such as a VR agency or Goodwill.

4. Beneficiaries faced obstacles similar to those confronting other young adults seeking their first job, but the disability exacerbated them

Interviewees said one problem was poor job-search or interviewing skills (and that might be common among all young adults seeking a first job). Some interviewees specifically identified difficulty interviewing as a barrier, others made mention of such things as lack of job experience, lack of understanding about which jobs they were qualified for, or living in an area with few job openings. One interviewee could not find child care when she wanted to schedule interviews. Although she was eligible for Temporary Assistance to Needy Families (TANF), which would provide child care after she found a job, it would not provide child care while she was looking for work.

Although many non-disabled young adults face these issues when seeking their first job, the problems were heightened for these interviewees by the presence of a disability. Some said it was difficult to find employers willing to accommodate their disability. One mentioned that employers would get annoyed because she frequently took a long time to process information and answer questions. Others had trouble making it through the interview process. One interviewee with a sensitivity to sounds said he had to cover his ears on one occasion when filling out an application. The employer’s representative said, “Don’t bother filling out an application. We don’t want you people here.” On another occasion, he said the employer’s representative “pulled out a bible and started saying some kind of exorcist chant and splashing bottled water at me thinking it was holy water. I guess that would be considered a barrier at some point.” Another said his disability made it difficult for him to interview, because, “I don’t make eye contact very well because that’s another symptom of autism, so I guess because I didn’t look them in the eye, I feel that might have deterred them a little bit from giving me a callback.” In many cases, beneficiaries overcame these barriers by finding a job through personal networks, or finding an employer who was more accepting of their disability.

D. Staying at work

We asked young adults about the barriers and facilitators to staying at work and what services they used or needed to stay on the job.

1. Work flexibility, individualized training, workplace accommodations, supportive employers and co-workers, and jobs suited to them facilitated employment

The majority of young adult interviewees said employers who were willing to meet their disability-related needs with flexible work schedules or other accommodations were vital. Several—mostly SSDI and concurrent beneficiaries—discussed how flexible work schedules, including the ability to take time off or take paid sick leave, positively affected their ability to work. Interviewees noted that the flexibility of their working hours, advance notice on scheduled shifts, or ability to choose their own work hours was critical to sustaining work. Some employers also supported interviewees’ desires to work limited hours so they could keep Social Security benefits.

The types of accommodations respondents reported indicate that accommodations were low-cost and tailored to the individual’s disability and personal situation. Flexible or reduced work hours, advance notice of work schedules, occasional assistance from other employees, and changes in job duties or modifications to the work station can be low-cost accommodations for some employers. It appears that many of these youth were able to find jobs with employers who were willing and able to make these low-cost accommodations. For example, a nurse whose immune system was weak from chemotherapy was allowed to perform desk work instead of patient care until her treatments were finished. Another interviewee received assistance from another employee with tasks that required occasional lifting. “That accommodation for the heavy lifting, that is definitely the main reason why I’m still at this job because if they would not give me that accommodation, I’d either be one of the patients at that hospital for messing up my back so often or I would not have been able to keep the job anymore,” he said. A couple of interviewees noted that it helped them to have a structured job with familiar tasks. Another said being assigned to a small work area helped her to manage anxiety. One beneficiary who worked as a dental assistant said her job provided a good balance of sitting and standing, as she was unable to do either for too long.

Several interviewees noted that individualized job training helped them to continue to work. A parent of one beneficiary said, “[The grocery store] had an individual from their organization who came in and trained with him on several of his shifts....It was basically side-by-side training to make sure that he met all the requirements.”

A less tangible, but frequently discussed facilitator was a friendly, positive work environment with supportive bosses and colleagues. Interviewees described the importance of feeling appreciated or understood by colleagues and bosses. One said he appreciated the honest feedback of his supervisor: “With the autism, I didn’t get a lot of the social stuff. I think me sitting down and them being mature enough to be able to explain something to me using different words if need be, I think that was another thing why I was able to keep this job as well as I have.” One interviewee noted a huge contrast between two jobs with similar job duties because of his boss and co-workers: “The folks at the [Coliseum] are great. They have been easy to work for and they like me. The folks at [the fast-food place] did not seem to think I could do the job and they let me go after four days.” Another interviewee reflected on his positive experience: “[My supervisor] is trying to give me different experiences at work ... and that’s pretty terrific too, to know that people have enough confidence in me that they’re trying to grow my skills.” Another interviewee said his colleagues “are always willing to help.” Still another said his work

environment helped him gain more confidence and comfort interacting with people. “It’s really helped with me working there...getting over my fears of talking to people.” Interviewees also appreciated receiving awards and recognition.

A few interviewees noted that working toward raises or being rewarded for their efforts helped them stick with their jobs. One said that receiving full employer-sponsored benefits, including a 401k, kept him motivated to work.

2. Lack of transportation, hostile work environments, and poor job fit are barriers

Several interviewees mentioned lack of transportation as detrimental to continuing employment. Some interviewees could not drive or did not have access to a car, and for others, public transportation was limited or unreliable. Lack of reliable transportation limited the jobs they could accept, made them late for work, forced them to rely more on family and friends, or made it hard to work assigned hours. One interviewee said she had to call ahead to have a special bus pick her up, and because her work schedule varies from day to day, this is time-consuming. She said, “I wish I was able to drive in a vehicle to make it easier for me to get to work and back instead of relying on other transportation like the bus or my parents.” In addition to relying on family members or friends for transportation, some interviewees sought employment that was close to their home, pursued travel or mobility training that enabled them to navigate the commute, borrowed cars, or carpooled with co-workers.

A couple of interviewees said they faced hostile or negative work environments or had difficulty getting along with their colleagues. One said he was targeted by his shift supervisor and called inappropriate names. Several said their work duties made it difficult for someone with their disability to do their particular job. For example, some mentioned difficulty focusing, trouble communicating with others, learning new tasks, handling physically demanding tasks, and physical pain on the job that made it difficult to carry out their duties. One mentioned an immune-deficiency condition that made working around others unsafe for her. One beneficiary who is deaf said, “Communication is the hardest thing...because I can’t talk to people, and people can’t hear me. They’ll make announcements and stuff that make it difficult, so mainly the communication.” Interviewees said they either struggled to overcome these on-the-job obstacles or left their jobs to find more suitable employment.

3. Respondents used job coaches and job-related training to help them stay at work

Several interviewees discussed ongoing use of job coaches, often provided through the state VR agency, to help orient them to the workplace, learn new tasks, and monitor their progress. Overall, interviewees praised their job coaches. One individual said, “My job coach checks in on me once in a while. He used to come more often but I know more what to do now. I use my job coach to help me learn new things.”

Other services interviewees used included job counseling through a regional service provider, local social service agencies that provide child care, and one beneficiary mentioned a TTW provider. Few interviewees identified needed services that they lacked to keep their jobs. One individual had difficulty finding child care near work; another identified the need for a sign language interpreter at work.

4. Interviewees feared losing health insurance and were careful not to endanger eligibility for health insurance by earning too much

Many interviewees expressed a desire to remain on the benefit rolls to ensure continued health insurance. Only a few mentioned initiatives to retain their Medicare or Medicaid benefits while working. Some said they “would get rid of” the benefit checks, if there were a way “to get health insurance.” Many noted that health insurance through work typically requires full-time employment, which can be difficult to find. One SSI beneficiary with cystic fibrosis said she must “tread the really fine line to be able to keep Medicaid while working.” She keeps her earnings low enough to retain Medicaid coverage under section 1619b because her medical condition is so serious losing that health insurance would be “pretty much a death sentence.”

Moreover, many of the respondents said they fear losing the cash benefits because their wages are not enough to live. Several suggested that working just under the earnings limit to maintain eligibility for their monthly cash benefits made the most sense. For example, an SSI beneficiary indicated she would work more if she “got paid enough and got insurance;” another concurrent beneficiary remarked, “I just want to work a little and not lose my benefits and Medicaid.” Several parents who assisted with their children’s interviews suggested that beneficiaries with cognitive disabilities could not generate sufficient earnings to exit the rolls. Hence, their children work part-time and under the earnings limit to remain eligible for the cash benefits.

Interviewees also expressed concerns about losing their eligibility for non-cash benefits for earning too much. Many said they were better off overall by maintaining “dual income” (benefits and wages) and remaining eligible for the non-cash “fringe” benefits associated with receiving SSA disability benefits. Several mentioned the need to maintain eligibility for food stamps and Medicaid coverage. One concurrent beneficiary lamented the fact that her current work had already made her ineligible for food stamps and TANF; she especially misses the child care supplement that TANF offered. The loss of child care meant that her “benefit” from working was reduced by the cost of paying for the child care. Another SSDI beneficiary described a financial drawback to working. He said, “The help and benefits that I had before are getting cut to the point where I’m earning the same amount I got before I started working.”

E. Future plans regarding work and benefits

We asked beneficiaries about their future employment plans and whether they thought they would eventually leave the disability benefit rolls.

1. Most young adults wanted to increase or maintain their work efforts; some perceived barriers to sustaining employment

In general, working was a positive experience for the young adults we interviewed, and the majority said they want to increase or maintain their current level of work. Many said that work added meaning to their lives, giving them something to do with their time, helping them to pursue their personal goals, and allowing them to achieve financial independence. One interviewee said, “I do hope to continue to work. I don’t plan on stopping. As long as I can physically keep up, I plan to [continue].” Another interviewee said, “I’ve had this desire ever since I was a little kid to work in the sports industry, and I want to have a better job and make

more money.” Another said, “I plan on getting a job where I don’t need benefits once I graduate college in [the field of] geology.” One interviewee mentioned plans to reduce his work effort temporarily while he returns to school. “I’ll probably work a little bit less when I do go back [to school], but until then it’s probably just going to be the same amount of hours.” Another beneficiary who wants to return to school said, “School is kind of hindering [my ability to work] more, I guess. My main goal is...to get a degree first and then I would [like to] start really working, whether it’s one job or two jobs or whatever.”

Some respondents were cautious about predicting their future work activity. They said they would like to continue working and earn more money, but they believe there are challenges. For example, some mentioned that they work part-time due to health limitations or a lack of full-time opportunities, and that limits their earnings. Others said lack of promotions made earnings growth difficult. As one beneficiary explained, “I want to make more money [but] I’d have to have a different job. [There is] not much room for promotion [in my current job].”

2. Few expressed intention of leaving the disability benefit rolls in the short term

Even though continuing to work and earn more was a goal for the majority of young adult interviewees and many said that leaving the benefit rolls was a long-term goal, only a few, consisting primarily of SSDI or concurrent beneficiaries, indicated that getting off benefits was a short-term goal. The desire to give up benefits appeared to be tempered by the experience of working, paying bills, and managing their disability. Reasons interviewees gave for wanting to get off benefits included a desire for independence and career success. As one interviewee declared, “I’m going to take off and I’m going to excel and I’m going to become a store manager someday! And I’m not going to be on benefits anymore because I don’t want the government holding my hand.” Another SSI beneficiary with an MBA stated, “You can run the math and know you’re going to be better off [working].” Another SSDI beneficiary wanted to work enough to get off benefits and “be completely on my own,” as long as she could ensure that working would provide a better standard of living. Respondents also noted the importance of making a contribution to society. One interviewee said, “I don’t want those benefits for the rest of my life . . . I want to become a better, bigger, more productive member of society. I do not want the American people paying my bills.”

Other interviewees who planned to continue working said that leaving the benefit rolls was not a goal. A parent of an SSDI beneficiary said, “I don’t foresee that in the near future. His mind [and] skill set’s not there [and] some motor skills aren’t there.” Another SSDI beneficiary expressed concern over losing benefits and not being able to earn enough from working to make up the difference, explaining, “I think they told me I can earn up to \$780 a month without ever losing my benefits. If I make more than that, I want to make a whole lot more than that, enough so that when they do take my benefits I’ll be financially stable . . . I’d work more if I didn’t lose my benefits.” Another SSDI beneficiary was concerned about the prospects of finding a job that would pay enough to replace the cash and non-cash benefits.

3. Young adults said health status is the biggest barrier to future work; for many, the episodic nature of disability symptoms was a key determinant of work expectations

The most frequently stated concern for future work was related to ongoing health status. As one explained, “If I get sick again...then I have to stop working but other than that...I don’t

think there's anything that would make me want to stop working." Interviewees also mentioned difficulty being able to work enough hours each week, or working a consistent number of hours week to week, due to their health or due to their specific jobs. Many beneficiaries talked about fluctuating disability symptoms that determined how many hours they could work each week and which often varied from week to week. The episodic nature of disability symptoms and the uncertainty of health status greatly affected their decisions to work and expectations for leaving the disability rolls. Other barriers to future work were lack of transportation or difficulty finding an employer who would accommodate the disability.

Respondents described several things that would help them continue or increase their earnings. Some mentioned that it would be helpful if their employers better understood their impairments. One suggested that his employer should "keep being understanding and friendly [and] If I don't understand, then [show] me." Another said that additional training would be helpful so that he could get "more skills at what I am doing and able to handle it easier [and] focus on other things." Others said that skill building, such as reading or math classes, or other training opportunities would help to increase their earnings. Few mentioned services they needed, such as from a VR agency, family issues such as the desire to have children, or other issues outside of work that might affect their future work plans.

F. Experiences with SSA benefits and overpayments

We asked these interviewees about their experiences with Social Security benefits, including whether they feared loss of benefits or overpayments while working and whether the fears impacted current work efforts or future plans. We also asked whether they had experienced an overpayment and how it was resolved.

1. Many said SSA's program information was hard to obtain and understand, especially relating to return-to-work policies and reducing or stopping benefits; a few said their benefits were reduced because they lacked information about how much they could work

Many interviewees expressed frustration with the complexity of SSA's work incentives and the volume of paperwork required for reporting wages. One parent said his son's benefits were temporarily suspended because some paperwork was not submitted in a timely fashion. Others described the challenge of obtaining information about reporting requirements, work incentives, and maintaining Medicaid eligibility under the 1619b program. One interviewee said she finally obtained the information from a local university professor who was well-versed in SSA policy.

A few interviewees said their lack of knowledge about SSA rules led to benefit reductions or overpayments. One SSDI beneficiary said the rules were not sufficiently explained and he thought it was unfair to be penalized "for working a half hour too much one month." He did not understand until after it happened that, after completing his TWP, earning even slightly more than the SGA amount would mean he was not eligible for any SSDI that month. "Sometimes," he said, "there's a lot of miscommunications.... [and] I was never aware of that."

2. Many beneficiaries indicated that the fear of being overpaid (and losing benefits) affects employment decisions

Many interviewees said fear of receiving an overpayment affected the type of work and the amount of hours they are willing to work. For example, one said, “I’ve got to keep my hours down because of Social Security.” Another said, “I need less hours, I think I’m getting too much money.” Another, who had previously been terminated and received an overpayment because of earnings but had returned to benefits, said she was very careful not to earn too much to get overpaid again now that she had returned to work.

3. Some beneficiaries rely on cash benefits to repay their debts to SSA

A few interviewees said they could not give up their SSA benefits until the overpayment they owed had been repaid. They said their wages from working were not sufficient to repay the overpayment. For example, one SSI beneficiary indicated he is putting his future on hold while he repays an overpayment from 1998. He plans to postpone seeking a “high-paying” job until the overpayment is repaid. SSA is currently reducing his monthly SSI check by 10 percent to recoup the overpayment. “I have to have Social Security to help me pay off my debts, but at the same time, I can’t wait to start making more money,” he said. He has been told that if he earns enough to lose his benefits, the overpayment will be deducted from his mother’s check and he does not want to burden her.

G. Suggestions to help other beneficiaries

Interviewees offered suggestions for SSA program improvement related to early contact, job-related services, allowable SSI savings, and information dissemination. Although many of these suggestions are outside of SSA’s mandate under current law, they point to the problems beneficiaries face in developing expectations for employment while still in school, learning about resources to find and keep work, accessing job training, or saving for education or future emergencies. Beneficiaries also asked for resources to help them obtain complete and accurate information about SSA work incentives.

Regarding early contact, several interviewees suggested that SSA conduct webinars that are targeted to parents of middle school and high school students so as to educate parents and representative payees about the disability service system and vocational resources. These webinars could also help new beneficiaries and their families better understand SSA rules and procedures. As one parent said, “If you want your child to be successful you need to figure out early on the steps [needed] to help them achieve success.”

Respondents also suggested that job-related services, such as skills assessment, job referrals, or job coaches, could facilitate employment success. One parent said SSA should encourage customized and tailored employment for people with intellectual disabilities. Another suggested SSA place an emphasis on educating employers about the capabilities of people with disabilities to help reduce stigma and stereotypes.

Many interviewees suggested SSA appoint a liaison or case manager to give ongoing social support and assistance to find a job or stay at work and negotiate the SSA system. Others suggested SSA improve the quality and consistency of program information disseminated to

beneficiaries, particularly information about returning to work, allowable earnings, and changes in SGA levels.

Several SSI beneficiaries said SSA should alter its rules regarding allowable savings to help promote economic stability. As one noted, “There’s no way for someone to save up, to get ahead in order to truly get off of the benefits. If you have no savings or safety net or anything, how would you jump [off benefits]?”

H. Differences between young adults and high-earning young adults

As noted previously, we classified young adults who had earned over the SGA level for at least three consecutive months as “high earners.” All beneficiaries who earned above this level were included in the high earners group, irrespective of age. As noted in Chapter I, earnings above the SGA level would not generally be considered to be high; however, sustained earnings at this level is a determinant of future benefits receipt. We include the 13 high-earning under-30 individuals in our analysis of the 61 high earning beneficiaries and describe findings from these interviews in Chapter III. In this section, we examine those 13 young adults and describe differences between them and the other 30 young adults who had not reached this level of earnings.

Table II.2 shows characteristics of the 30 employed young adults compared with the 13 young adults classified as high earners. The two samples are relatively similar, but they differ in the type of benefits they receive, which may impact their work efforts. Fewer of them are still receiving Social Security benefits, due to their higher level of earnings. There were no high-earning young adults with an intellectual or circulatory disability, and they were less likely to be childhood SSI recipients. High earners were less likely to have stable earnings over the past six months, compared with other young adults.

Based on our analysis of the 13 interviews of high-earning young adults, we note the following differences from the other young adults we interviewed:

1. More positive school experiences

Overall, high-earning young adults tended to have better experiences in school than the other young adults in our sample. Few indicated they had been frustrated with the academic curricula; many described various accommodations and supports they received, such as participation in special classes, career-oriented activities, and classroom modifications to address a physical disability. Although some high earners mentioned difficulties in school related to their impairments, barriers to education were mentioned less frequently by this group.

2. Advanced education or training

High-earning young adults appeared to be more strongly motivated to complete high school and pursue a college education or advanced training. Their educational outcomes ranged from completing a GED to college or post-high-school training, and several linked their education to their ability to obtain jobs. A few high-earning young adults took out student loans to obtain a college education. Some of the few who had worked prior to acquiring their disability said they obtained a college degree to transition to a more suitable occupation, as they could no longer

work in their predisability vocation. One interviewee said, “I needed a job that I could do where I can sit down if I need to and stand up if I need to... I needed a job that I could be in control of. Being a teacher does that.”

3. Strong motivation to work and eventually leave the benefit rolls

Young adult high earners tended to set career and life goals, which often included a desire to leave the benefit rolls, although it is not clear from this small sample of beneficiaries whether strong motivation leads to high earnings. Some high-earning beneficiaries said they worked over longer periods of time, ranging from months to years, to reach a specific career benchmark, including obtaining a promotion from part-time to full-time work and reaching a management position. One interviewee, who obtained her GED and found a job as a property manager for an apartment building said: “It’s been a process but it was...well worth it.”

Table II.2. Individual characteristics of young adult sample compared with young adult high earners

Characteristic	Young adults (n = 30) ^a	Young adult high earners (n = 13) ^a
Type of Benefit (%)		
SSI only	27	23
SSDI only	50	15
Concurrent	23	62
Median age (years)	26	27
Sex (%)		
Male	47	31
Female	53	69
Primary impairment (%)		
Psychiatric condition	37	46
Musculoskeletal condition	13	15
Circulatory condition	17	0
Injury	10	8
Intellectual disability	3	0
Vision or hearing impairment	3	8
Other	17	15
Unknown	0	8
Childhood Disability Onset (%)	70	77
Time since most recent SSI/SSDI eligibility		
Fewer than 5 years (%)	43	54
5 to 10 years (%)	47	46
More than 10 years (%)	10	0
Receiving SSA cash disability benefits (%)	93	77
Employed (%)	100	92
Earnings over past six months (%)*		
Stable/improved	70	46
Unstable/declined	30	54

^aData on program, age, sex, primary impairment, and time since most recent SSDI/SSI eligibility are from SSA administrative files and the 2013 Disability Analysis File. Data on childhood disability onset, SSA benefit receipt, employment, and earnings over the past six months are from interviewee self-reports.

Being a parent seemed to be a strong motivator to work. One interviewee who wants to leave the benefit rolls said, “I want to have a better tomorrow for my kids.” One woman was motivated to earn more so she could support her children after she separated from her husband. Another beneficiary said, “I have two daughters and the Social Security income was just not enough money for me. So that’s why I decided to go back to work because then I could pay my bills and also help support my children.”

Some interviewees said they wanted to stay with their current employer because they were treated well and the employment was stable. They had an expectation to “continue along the natural path” and progress in their careers. These beneficiaries also said they valued independence and the chance to “work and learn to do different things” on their own.

4. Overpayments tended to be small and beneficiaries did not alter their earnings to avoid them

Eight of the 13 high-earning young adults were concurrent beneficiaries. Concurrent beneficiaries who continue to work will likely have their SSI benefits gradually decrease and will experience the “cash cliff” only for their small SSDI benefit. They may be less likely to view benefit loss as a work disincentive. They will receive an SSI overpayment before an SSDI overpayment because of the way the benefits are calculated. If overpayments occur, they are likely to be against the low SSI check and likely to be minimal. The high-earning young adults reported overpayments that ranged from \$200 to \$500. Only a few of the 30 young adults had overpayments and they were unsure of the amounts because a parent or guardian managed their benefits. Most young adult high earners said they did not modify their work schedule to avoid overpayments, while those in the young adult group tended to limit their work hours to retain benefits.

A few of the young adult high earners were paid biweekly and explained they receive overpayments about twice a year, during the months they receive three pay checks. A mother of a beneficiary described the situation: “[We receive an overpayment] usually on the two months out of the year that she gets paid three times a month. There’s no way to get around that, because they get paid biweekly. So two months out of the year, you get three paychecks, and that tends to put her over. So she just doesn’t get benefits that month.” Two of the three beneficiaries did not change their behavior as a result of the overpayment and one beneficiary took time off during the months he expected to be overpaid.

This page has been left blank for double-sided copying.

III. EMPLOYMENT AND BENEFIT EXPERIENCES OF HIGH EARNERS WHO HAD STABLE AND UNSTABLE EARNINGS

As described previously, we interviewed 61 high earners, defined as SSI and SSDI beneficiaries of any age whose earnings surpassed the nonblind SGA level for three consecutive months (from September through November 2014). We screened these individuals when we contacted them beginning in March 2015 to determine whether they had stable or increased earnings over the previous six months. We interviewed 30 high earners who had stable or increased earnings and 31 whose earnings were unstable (that is, they had fluctuated or decreased).

We asked them about their initial experiences finding work, the barriers to and facilitators of keeping a job, their future plans regarding work, and their experiences with SSA benefits. High earners were motivated to work to increase their income, support their families, and be productive citizens. The barriers to finding and keeping work and the solutions devised by high earners were similar to those of the young adults we interviewed, but most high earners said they need fewer services than young adults to stay at work.

We also compared beneficiaries who had stable versus unstable earnings in the six months before the interview. We noted some differences: a few high earners with stable earnings had returned to a previous employer, whereas those with unstable earnings did not. Beneficiaries with unstable earnings also reported having to take time off without pay to attend to medical issues because they did not have sick leave. Both groups of high earners had to overcome many obstacles to stay employed, but those with stable earnings appeared to have more workplace supports and helpful co-workers who helped them stay employed.

High earners with unstable earnings cited a number of reasons for their earnings instability: health or other reasons related to their disability, reducing their hours due to fear of benefit loss, burnout, and layoffs. Some of these issues might have been addressed by identifying a job that was a better fit for the employee's impairment or by providing more complete information about SSA work incentives. Many interviewees wanted to stop receiving cash benefits in the future, but they also feared losing health insurance, especially if their health condition worsened. As was the case with the young adults we interviewed, many high earners appeared to lack information about SSA work incentives or ways they could retain health insurance with increased earnings.

A. Characteristics of high earners

Table III.1 presents the characteristics of the high-earning interviewees and compares them with all SSI and SSDI beneficiaries with monthly earnings above the SGA level, based on data from the 2004–2010 NBS.⁹ The high-earning interviewees were roughly similar to all beneficiaries with high earnings on nearly all characteristics shown in Table III.1. As with the young adult interviewees, we attempted to achieve a 50/50 division between SSI and SSDI-only beneficiaries among the high-earner interviewees. This division happens to correspond to the

⁹ NBS respondents were categorized as earning above the SGA level if the sum of their monthly earnings from all jobs held at the time of the NBS interview exceeded the nonblind SGA amount established by SSA for the respondents' respective survey years.

program distribution of high earners in the general population, which helps explain why the two groups are so similar in many other respects.

Table III.1. Characteristics of high-earning interviewees, all beneficiaries earning above SGA, and all beneficiaries

	High-earning interviewees ^a			Nationally representative sample of beneficiaries ^b	
	All	Stable/ increased earnings	Unstable/ decreased earnings	All	Earning above SGA
Unweighted number	61	30	31	16,190	526
Weighted number	NA	NA	NA	9,718,618	189,678
Weighted percentage of full sample	NA	NA	NA	100	2
Program (%)					
SSDI only	51	53	48	52	49
Concurrent	18	17	19	17	12
SSI only	31	30	32	30	39
Median age (years)	44	44	43	51	40
Under age 30 (%)	21	20	23	9	20
30–54 (%)	61	60	61	49	64
55 and over (%)	18	20	16	42	15
Sex (%)					
Male	34	29	40	50	56
Female	66	71	60	50	45
Primary impairment (%)					
Psychiatric condition	30	23	37	29	32
Musculoskeletal condition	21	26	17	18	9
Circulatory condition	5	7	3	8	3
Injury	10	10	10	4	6
Intellectual disability	5	3	7	13	12
Vision or hearing impairment	5	7	3	3	14
Other	18	23	13	25	24
Unknown	7	3	10	1	0
Childhood disability onset (%)	36	40	32	23	32
Time since most recent SSI/SSDI eligibility					
Less than 5 years (%)	46	49	43	29	25
5–10 years (%)	53	52	53	29	35
More than 10 years (%)	2	0	3	43	40
Receiving SSA cash disability benefits (%)	64	60	68	95	63
Employed (%)	77	100	55	8	100
Earnings over past six months (%)					
Stable/increased	49	100	NA	NA	NA
Unstable/decreased	51	NA	100	NA	NA

^aData are from the pooled 2004, 2005, 2006, and 2010 NBS.

^bData on program, age, sex, primary impairment, and time since most recent SSDI/SSI eligibility are from SSA administrative files and the 2013 Disability Analysis File. Data on childhood disability onset, SSA benefit receipt, employment, and earnings over the past six months are from self-reports from high-earning interviewees.

NA = not applicable.

However, interviewees differed from the general population of high earners in a few respects. They were more likely to be female and to have musculoskeletal conditions, and they were less likely to have sensory or intellectual disabilities and to have been on the disability rolls for more than 10 years. Some of these differences might be associated with how easily people could be contacted by phone to participate in an interview; those with intellectual disabilities or hearing impairments might have been more difficult to reach. As with the young adult interviewees, the contact information in the SSA administrative files might have been more up to date for beneficiaries who had entered the rolls more recently, and so those individuals were more likely to be contacted for an interview. Interviewees were also less likely to be employed, but this is because of differences in the manner in which high earners were identified in the two samples. In the NBS, we identified them based on earnings from work at the time of the interview, so all were employed by definition. For the high-earning interviewees, we selected them based on their earnings in the recent past, regardless of their current employment status.

Among the high-earning interviewees, there were few differences in characteristics between those whose earnings over the prior six months were stable or had increased and those whose earnings were unstable or had declined. Those with stable/increased earnings were more likely to be female, more likely to have musculoskeletal conditions, and less likely to have psychiatric conditions than those with unstable or decreased earnings. Not unexpectedly, those with unstable/decreased earnings were less likely to be employed (55 percent); by definition, all members of the stable/increased earnings group were employed.

To provide additional context, Table III.1 shows statistics on the characteristics of all beneficiaries. Based on the national survey data, beneficiaries earning above SGA differ in many respects from all beneficiaries. Those earning above SGA are younger and are less likely to be female, receive SSI only, and have musculoskeletal conditions. They are more likely to have hearing or vision impairments, to have had disability onset during childhood, and to have been on the rolls for 5 to 10 years. They are also much less likely to be receiving disability benefits, presumably because of their relatively high earnings.

B. Initial work experiences

We asked the high-earning beneficiaries about their initial work experiences after they most recently began receiving disability benefits. They described their reasons for seeking work, their goals regarding continuation of SSA and other benefits, barriers and facilitators to work, the steps they took, and services used to find a job.

1. Beneficiaries noted many reasons for wanting to return to work, most frequently citing a desire to increase income, be a productive citizen, and stay active; reasons for seeking work did not differ between those who had stable earnings and those who did not

Most beneficiaries indicated that they wanted to return to work because they needed a higher or more stable income. Many said they wanted to work to be able to pay their bills. One respondent said, “Because I was going to school, and rent and going to school ain’t going to make it. My money just wasn’t enough for me to do both. I had to make a choice. Either go to school or go to work. Because when I get through paying my rent, I wouldn’t really have nothing left over.” The need for more money meant different things to different respondents. For some, it meant being able to afford basic necessities, like food and housing, and for others it meant being

able to save money for an emergency fund or for larger purchases, such as buying a house. Being a parent appeared to be a strong work motivator. One interviewee's response was typical: "Well, because I have two daughters and the Social Security income was just not enough money for us. So that's why I decided to go back to work because then I could pay my bills and also help support my children."

Another very common reason for returning to work was the desire for a sense of purpose and independence. Especially among those whose disability occurred later in life, the desire to prove that they were still productive and contributing members of society was strong. One interviewee said, "I want more than disability, I want to be the same person I was before I was disabled... Responsible, to be able to do the same things I did before I got sick." These respondents often noted that they liked working and did not want to "burden" the system if they were well enough to return to work, to ensure that others who are in worse situations could receive disability payments. "I just felt if I was capable, then I shouldn't take somebody else's spot on benefits that was less capable," one beneficiary commented. Another noted that getting off benefits was a goal "because that means I'm doing well enough on my own."

Interviewees mentioned staying active as another reason to seek employment. Some described how easy it was to get stuck at home, and many said that depression would follow bouts of inactivity. One respondent said she wanted to return to work because, "I just think you have to do something. It is terrible sitting at home and there's nothing to do. I just think it doesn't work. Being at home, if you're a depressed person and you're at home all the time you're going to become more depressed. People need to be out around other people and that's all there is to it." Another respondent said, "[I wanted to return to work] because I wanted to show people that just because I'm handicapped doesn't mean that I can't do anything. And I got tired of just sitting at home." Beneficiaries with severe or chronic pain had to be selective in the kinds of work they accepted, but were nonetheless grateful for the chance to be productive.

2. Many high earners, including those with stable and unstable earnings, wanted to work enough to go off of cash benefits, but maintaining health insurance coverage was a concern for many

A large share of the high earners we interviewed said that their long-term goal was to stop receiving disability benefits. However, a few of the interviewees clarified that this became their goal only once their pay was actually high enough to sustain a desirable lifestyle. One interviewee said he would give up benefits "eventually, but I want a job that's going to pay me at least like \$14 an hour or something like that."

Other interviewees did not want to lose their benefits when they started to work. A few said they purposefully entered the workforce as a part-time worker to keep benefits. One interviewee noted that his goal changed as he became more comfortable at work, but another said, "No, I didn't have a goal of wanting to get off benefits, but I know it's going to happen because I'm earning money now."

Of those who did not want to go off benefits, about half said the need for health insurance was a primary motivation for keeping them. Interviewees did not mention options for retaining public health insurance with increased earnings, such as Section 1619(b), or state Medicaid buy-in options. "No, I just kept my benefits because... I go to specialists I wouldn't be able to afford,

and they didn't offer [health] benefits where I worked,” one interviewee said. Only one interviewee mentioned extended Medicare eligibility, but wondered what would happen when the extended period of Medicare eligibility ended.

Many interviewees were uncertain about their future health status. Although able to work at present, they were not sure their health would allow employment in the future. They were nervous about what would happen if they needed to re-apply for benefits if their health worsened and they could no longer work. As one beneficiary who had stopped working commented, “...health care is definitely a plus. I mean, I don't think I'd be able to afford health care on my income now. And I knew once I started working again, they were going to cut me off, although I would prefer to work than be on benefits.” One beneficiary said that although leaving benefits was not a current goal because of his health, if his health status were to change his goal might change.

3. Some beneficiaries used personal networks to find employment; others volunteered or used other job-seeking methods to find their first job after they experienced disability. A few workers with stable earnings returned to a previous employer when they were ready to return to work; workers with unstable earnings did not

High earners entered or reentered the workforce by many different avenues. Both those with stable and unstable earnings commonly used family members or friends to hire them or refer them to a job. Some of those with stable earnings returned to jobs they had held prior to acquiring a disability, but interviewees with unstable earnings did not.

In most cases, the respondents had spent a fair amount of time—sometimes months—searching for positions by such methods as online resources or newspaper listings. High earners appeared to use the Internet as frequently as young adults, but for both groups, personal connections finally got them into the workforce. One interviewee explained, “I found it through this guy that I met at the church, he actually knew about the place so he told me about it and then I called and I set up an appointment and then I went in... I think I did ok at the interview. So they hired me.” Another interviewee, who has bipolar disorder and unstable earnings, said, “I went to work for my mother because she understands my disability.”

For others, applying through online and newspaper listings, or visiting local businesses to hand in resumes secured the job. One interviewee said, “I filled in a bunch of applications online and never heard anything, but when I showed up with a reference in my hand, that worked.” Another respondent started as a volunteer to “prove” herself to her employer, who eventually hired her. She explained, “I wanted to work for a specific company... so I volunteered for a couple of months to show I could do the job, then they hired me.” Others entered as either part-time or under a trial period to see how they would handle working. Others had job coaches who referred them to positions or to relevant jobs. One started through a temporary employment agency and was eventually hired.

4. Respondents cited a variety of barriers to finding employment, which did not differ between those with and without stable earnings; job accommodations and supportive family and friends facilitated employment

Interviewees noted many hurdles to finding a job, or finding one that met their needs. Some required specific accommodations. For example, one respondent who is blind had difficulty finding an employer who would hire him. He finally accepted a job with a sheltered workshop and is paid what he characterized as “very low wages.” For others with physical disabilities, finding positions that were not strenuous or did not require much standing, sitting, or lifting was difficult. Respondents frequently mentioned the difficulty of managing pain on the job and often requested such accommodations as a special chair or a reduced work schedule to address pain. One respondent summarized the situation for many: “So the thing is, it’s not hard for people with disabilities to find jobs. It’s hard to find jobs you can handle.”

For some respondents, lacking access to reliable transportation made it difficult to find or keep a job. Many interviewees said transportation issues limited where they could look for work. One interviewee who moved to a new city to take a job said, “My mom gave me her old car, and that’s the only reason why I was able to move down to New Orleans in the first place.”

Some respondents noted that the job market is filled with qualified individuals who need jobs, and they were frustrated by the few job opportunities available in their locale. One interviewee explained, “Well, the way the job market is nowadays, it’s just the employers have the upper hand, to pick and choose all kinds of different people. There was once a place I went to look for a job, and the guy, he says he’s got applications from biotechnology engineers.” A few interviewees pointed out it is disadvantageous to have a disability-related employment gap on a resume. One said, “...there was a big gap and that’s a big thing. I would imagine with a lot of people that become disabled and then are rehabilitated and want to get back to work, they have a big gap, and it’s probably one of the biggest problems in getting back to work.”

A beneficiary who uses a wheelchair and who had fluctuating earnings due to frequent absences due to medical issues summarized several obstacles to employment: “Well, I break it down into two categories. The main one is just the functional—that I need certain accommodations and a lot of private companies they don’t want to or know how to do that. I’ll need specifically a headset to use the phone. I’d need a custom keyboard that is made for me. I need a trackball mouse. Then, of course, there’s limitations like actual type of jobs I could go for. I obviously can’t go into construction. There are physical barriers which, you can’t really work on them. Stuff like I can’t really retrieve the printouts. There are lots of physical things... Another one is just perception. I think especially private companies. I’ll roll into the interview, and you can see that they’re a little bit uncomfortable or unsure. I don’t think it’s really always intentional, but there’s negative perception.”

Respondents said that low-cost, informal accommodations, including flexible work hours, working conditions that fit their disability, and supportive co-workers and supervisors, were most helpful to starting a new job. One interviewee employed as a technician and whose earnings fluctuated explained, “So far they’ve given me all my accommodations, like when I have to step out for a doctor’s appointment due to my low back pain I call in and let them know that I’m trying to go to the doctor to get my back looked at and they’ve been really patient with it. They accommodate everything so I’m really happy that I was able to have this job.” Another said,

“Being that I got the job right after having open heart surgery, the lady who interviewed me had a couple questions like if I would need to have any more time off work, which I did, because I had to have physical therapy. And she was lenient with that and hired me.”

5. Only a few interviewees said they used or needed services when they started work; this did not differ between beneficiaries who had stable and unstable earnings

In contrast to the young adult group, few beneficiaries in the high earners group mentioned any services used or needed when they returned to work. The few who did mentioned Goodwill, the state VR agency, and TTW as providing help with job training and resume preparation, as well as counselors who helped them prepare for job interviews. A number of respondents, mostly those with intellectual disabilities, said that job coaches helped them find a job. One respondent’s comment was typical: “My job coach had seen this job come available toward the beginning of last year and this is what led me to the job.” A couple of respondents noted that physical therapy was very important to their return to work. Another respondent went through a prison-sponsored re-entry program that helped incarcerated individuals prepare for job searches when they were released.

Interviewees offered mixed reviews of the services they received. A couple of interviewees noted that they sought services at the state VR agency or through a TTW provider, but were told that they could not be helped because they already had job experience or advanced degrees. One interviewee said, “[SSA] sent me this Ticket to Work thing and I attempted to use that. I met with a couple of people who said they couldn’t help me. They said I had already done everything that they would have recommended me to do, which was to educate myself so I could find a job that could fit within my ailment. I had already done that so they said they couldn’t really help me. It was like, ‘Well, we’re not really job placement, we’re just here to help you educate yourself and give you tools where you can go back into the workforce.’ So pretty much no assistance, just me doing what I felt I needed to do just to survive.” One said her job coach did not listen to her and had an “agenda” that did not align with her goals or desires; another noted that the program she attended was not helpful in her job search.

A few interviewees said they wished they had access to a class in basic computer skills. In particular, older respondents felt unfamiliar with computers and current technology and felt that hampered their job search. Another respondent who had used a TTW service provider mentioned that he wished the program had given him more information about what would happen to his disability benefits after he was hired instead of focusing solely on job preparation. Another respondent noted that lack of information about what would happen to her benefits and how to report income was very stressful.

C. Staying at work

We asked interviewees about the barriers and facilitators to staying at work and what services they used or needed to stay on the job. We asked those whose earnings had dropped or ceased why they did not sustain their higher level of earnings.

1. Both groups of high earners had to overcome many obstacles to keep their job; however, beneficiaries with stable earnings reported more workplace supports and helpful co-workers, which enabled them to stay employed

For jobs that require manual labor, respondents noted that they often needed special chairs or assistance from co-workers for such tasks as lifting objects, or they needed breaks from their tasks. One beneficiary said, “The chair that I sit in has to be above knee level or higher... because my low back surgery starts bothering me a lot. So, they gave me a proper chair. If I need materials to work, I ask somebody to bring the material over and they do.” One beneficiary with stable earnings said, “I went and bought me a nice, ergonomic chair, that if I’m hurting I can sit down on it and I’ll teach from my chair if I’ve got to.”

Many of the high earners with stable earnings said they had returned to work with their previous employers and colleagues; whereas many with unstable earnings indicated that their new jobs differed from previous work due in part to their disability. Interviewees also said that adjusting to working after a period of unemployment was difficult due to the long hours, learning curve, or high internal and external expectations or pressures. A school teacher described stress on her job, primarily with keeping up with grading and communicating with students and colleagues. She said, “I was really nervous about taking a school job because it’s a lot of pressure, but you know I did decide to give it a try and it worked out. I received a lot of support from my colleagues... They are always there for me.” Others, particularly those with unstable earnings, said that even after the initial adjustment, the job itself was stressful, overwhelming, or fast-paced. One customer service employee said, “That job was so stressful that it got to the point where it just – I didn’t even want to go to work.” One beneficiary expressed frustration that there is no room for growth at her current job, and she and other respondents noted the difficulty of working where supervisors do not provide much encouragement or incentives for employees to perform well.

Whereas many with stable earnings described professional development opportunities that helped them to stay at work, interviewees with unstable earnings did not. One beneficiary with stable earnings said, “[my employer] also offers opportunities...they’ll pay and help you to get your CPA. They have different opportunities so you can pursue different certifications that will help you advance yourself within the industry”. In contrast, a beneficiary with unstable earnings said, “Retail is a real hard job. And if you don’t know, a lot of these jobs just throw you out there. They don’t really give you no training.”

Interviewees frequently mentioned supportive supervisors and co-workers as facilitators to staying employed. Despite difficulties on the job, having helpful, thoughtful people to work with often made it all bearable. Supportive supervisors often ensured that workers had flexible schedules to attend doctor’s appointments or were given flexibility to get their work done in the best way they could. One respondent said, “They’re very lenient. They understand with my health issues that I ...can only work a certain amount of hours every week. And I don’t have any trouble getting those hours... like they understand.” For a number of interviewees, having to sit or stand for long hours caused pain, and the ability to take breaks or move about when needed allowed them to perform their tasks without pain.

While both groups mentioned supportive employment environments; beneficiaries with stable earnings shared more stories about flexible work schedules, supportive employers,

friendly or helpful co-workers, and related support systems than those with unstable earnings. One with stable earnings said, “I’m a salaried employee, so as long as I put my time in for the week or for the two weeks, nobody cares if I come in at 7:00 or at 10:00. Put in the time, give my work, and that’s it.” One beneficiary with unstable earnings said, “No, not a flexible schedule, though that really would’ve helped. [They] were understanding [of my medical situation], because they had no choice, but otherwise, they weren’t very flexible.” Another with unstable earnings said, “The doctors they put me out of work for a while. Then they gave me a note saying that I could go back to work, but I got to do work sitting down. My boss, he looked at [the note] and he laughed and he goes, ‘We don’t have nothing like this. You need to go home until you are 100 percent and then you can come back to work.’”

Interviewees said low pay was another barrier to staying employed. Low wages and no overtime pay were mentioned as sources of frustration, especially for respondents living in areas with high rental rates or generally high costs of living. Not having sick leave or being paid hourly were also cited as problems: even though these kinds of positions often offered flexible work hours, the interviewees could not rely on a stable income if their health fluctuated and they had to take time off. One interviewee solved the problem by working two part-time jobs. “Yeah, to get the money that I needed, no, it wouldn’t work at that one job because they wouldn’t give me enough breaks if I worked full-time... I had to have two part-time jobs in order to make it work,” he said. Other interviewees compensated for the low pay and lack of health insurance by making sure they kept their incomes low enough to continue to receive cash and medical benefits.

Factors outside of the job were also seen as barriers to staying employed. For beneficiaries with and without stable earnings, getting to and from work was a problem due to the lack of reliable or affordable transportation. Individuals in rural areas cited as barriers lack of public transportation, vehicles that are unreliable and high fuel costs. An interviewee explained, “Absolutely, [transportation is] always one of my biggest concerns. I feel like I have a lot of potential. I’m very smart. However, I either have to live somewhere that has very good public transportation or I have to live somewhere very near where I work. So if I work in an office, I have to be somewhere in a more metropolitan area that I can have a short walk to work. So yeah, that’s definitely the biggest concern that I’ve always had.” This interviewee found a job where she could work at home, but felt that lack of transportation limited her employment potential. Other beneficiaries mentioned similar transportation concerns. For other interviewees, family and friends helped beneficiaries work by providing transportation or helping with daily chores, such as meal preparation and child care. One beneficiary with stable earnings said, “My son helps me a lot. If I need to, he’ll come right up there to the school and fix something for me. If I needed him to drive me to work he’d do that every day too.”

Similarly, individuals who had previously traveled a lot for work felt constricted in the amount of traveling they could do because of their health, and that limited training and other opportunities. “...I probably need more training than I get, but because of the disability it kind of limits me from traveling and going places to get more training... I have to work a lot harder and stay on top of more things than normal people because they get to go to training for a week... I have to be reading, researching online stuff, and it’s just training myself instead of somebody teaching me,” one said.

Both groups of respondents noted that they enjoyed their line of work and/or the sense of purpose and confidence working gave them. For example, one beneficiary who had stopped working said, “I felt independent. I felt good about being able to bring home a paycheck, where I was able to take care of my family...So it felt kind of good. If I wanted to take my grandson to the zoo, I could.” Entering the workforce helped beneficiaries get out of the house and interact with others, and it boosted their self-esteem and mood. Having a routine was also mentioned as a huge motivator for those with depression. As one respondent said, “Working has been great because it makes me happy and everything... It’s been a good success and I’m still continuing to do what I love to do best.” Similarly, having a more reliable source of income helped interviewees with paying their bills and gave them a sense of accomplishment and pride. One respondent appreciated that he was not treated any differently because of his disability: “They were willing to give me a job even though I was disabled and they didn’t treat me no different. They treated me as an equal employee and I appreciate that. I don’t want you to feel that because I got a disability that I can’t do my job. Because a person has a disability doesn’t mean they can’t perform at a job. They didn’t treat me like that and I was grateful ...I learned a lot.”

2. Health related issues often drove decisions about when and how much to work and this often varied from week to week

Both high earners with stable and unstable earnings said that health-related issues often determined the types of jobs they pursued and the number of hours they worked from week to week. For example, one beneficiary pursued a security position that enabled him to sit down, as it was difficult for him to stand for long periods. Another, formerly employed as a nurse, asked for a change in job duties to avoid strenuous activities, such as lifting or moving patients. Additionally, some beneficiaries said that health or disability issues, such as the need to attend doctor appointments and physical therapy, often limited the number of hours they could work each week. Many beneficiaries with unstable earnings said that the episodic nature of their disability, such as flare-ups of back pain or fatigue, made it necessary for them to rest. The variation in the number of hours they could work each week accounted for their fluctuating earnings.

Both groups of high earners said health-related problems could limit their ability to stay at work; however, beneficiaries with stable earnings were more likely to cite personal motivation or coping strategies that allowed them to remain employed. For example, one said, “Over the last month or two, I was in the emergency room twice, but I still made it to work.”

3. In general, high earners did not use employment or other services to sustain employment; some beneficiaries with unstable earnings wished for a counselor or case manager to help in various ways

Few high earners mentioned using or needing services after they were working. As noted previously, a few young adults had used services such as supported employment or VR, to maintain employment, but high earners did not mention a need for these supports. A small number of high earners indicated that they continued to use physical therapy or mental health services after they began working; others mentioned attending continuing education classes in reading or math, or training programs (on-the-job offerings or community options). A few

continued to work with job coaches from various assistance programs, and one noted that her place of work provides a mentor for all new employees. One respondent continued to need assistance from an in-home care worker; another used a free transportation service to get to work. A couple of respondents said they bought equipment with their own funds to help with their work or manage daily pain.

A few respondents with unstable earnings noted that having an assigned case worker to assist with Social Security paperwork after hiring would be extremely beneficial. Beneficiaries noted that completing paperwork was difficult and they were not certain how the reporting system works, so having an assigned person to help would alleviate stress and anxiety. Similarly, a couple of respondents with unstable earnings talked about the benefits of having a case manager who could also provide emotional support or encouragement. One interviewee said he needed “a support system and maybe some other options, like some help from Social Security or some people that would talk to me about going back to work. And the challenges I had been going through. And possibly helping me find ways of figuring out what job would be suitable. If I knew this job would be suitable earlier maybe I could have found someone that I related with and I could have went back to work earlier. I was never given the choice.” Others thought that having more computer training even after being hired would be useful. Another said she would like to have an ergonomic chair, as that would probably help ease her pain during the work day.

D. Why earnings were unstable or ceased for some high earners

We asked interviewees whose earnings had been unstable or stopped during the last six months about the reasons their income had declined. Interviewees said their earnings were not sustained for a variety of reasons: health and disability-related issues, transportation problems, fear of benefit loss, and other job-related issues including low pay, stress, and discrimination.

1. Health and disability-related issues determined whether beneficiaries could stay employed and how many hours per week they could work

The most common threat to remaining employed among high earners with unstable income was their health issues, including limited stamina, chronic or work-induced pain, or mental health issues. One woman we interviewed, who has multiple sclerosis, left her job as a home health nurse. “Just it’s basically maintaining my balance,” she said. “Just kind of like my left arm and my left leg just feels like dead, like they don’t exist. So I always look like I’m walking sideways, or it made me basically look like I’m drunk all the time. Also, I have to be able to move a patient, and it just got to be overwhelming. And you’re there by yourself. So it’s not like you can call on a co-worker at the next station and ask for help.”

Some said their earnings fluctuated in the last six months because they frequently could not work because of health. These beneficiaries did not have sick leave, so they took time off without pay to attend to their medical issues. “There are times that I can’t make it in to work due to my low back surgery,” one explained. “I get paid by the hour like when I come and clock in, my pay starts but if I’m not going to be able to make it the whole day it’s like eight hours that I’m not getting paid for. There have been times that I’ve only worked 60 hours in two weeks.” His supervisor is often understanding about his need to miss work for a doctor’s appointment, but the position offered no sick leave and he was not paid for any missed time, resulting in fluctuating earnings.

Respondents with mental health issues noted such challenges as getting along with co-workers or supervisors or being able to communicate effectively and productively. When introduced into stressful work environments, respondents with anxiety or bipolar disorder had to be mindful of the amount of stress they were under and their reactions to it, and had to be very diligent to take their medication, they said. One interviewee enjoyed her job working with children, but stopped working because she could not take breaks. She was always responsible for the children, and that was difficult. “When it got overwhelming,” she said, “there was no out, because I was the only one with my kids.” There was an additional problem: “My medication makes it hard for me to get up in the morning and I have to take it. I had to be there early so that was hard.” Others said it was hard for them to focus for long periods of time, or that they had difficulty setting priorities. An unemployed beneficiary with a history of poor workplace relationships said she probably would not seek employment in the future because “I had trouble getting along with people at work. People used to get mad at me... I don’t feel like people really like me.”

2. Some beneficiaries stopped working because they could not solve transportation problems

Transportation problems, including long commutes, sometimes caused beneficiaries to leave their jobs. For example, an unemployed beneficiary said, “Then I found a job again, with [a government agency]. I worked for them for three months, but the job was so far away. It was like a three-hour commute, and I couldn’t deal with the commute anymore.” Another respondent’s license had expired and he did not have enough money to renew it, so could not drive to interviews and was not working.

3. Fear of benefit loss caused some beneficiaries to limit their hours or stop working

One interviewee said he stopped working because he was making too much money to keep his benefits, and he wanted to make sure to keep health insurance coverage. He said, “I didn’t want to lose the insurance so I can take my meds. It’s important.” He did not appear to know about options for retaining health insurance while working.

4. Other job-related issues

Low pay was another reason some beneficiaries left their jobs. One respondent who had worked for \$10 an hour said, “Not making any money. That was horrible. Every time I’d get that paycheck, it was, oh my God, you worked two weeks and you barely get \$600? That’s hard; to see that really affected me severely every two weeks.”

A few interviewees mentioned high stress and burnout as reasons for leaving their jobs. For some, feeling overwhelmed by expectations and on-the-job pressures exacerbated health problems, and they decided it would be best to go. One respondent said that he felt very confident in one role in the company, but things changed. “Well, they moved me to another position that I did not know anything about, and my work started going down,” he said. “I got confused. I didn’t know what I was doing, and I didn’t want to mess up... They provided training but I was so slow. I just got tired of it.” He eventually quit. Another interviewee said she left her job because she felt inadequate when she could not perform job tasks as well as she wanted.

One respondent lost her job when the company was sold; another was laid off. The latter indicated that his bipolar disorder might have contributed to his layoff because he had lost his temper with a few supervisors while on the job.

Only a couple of respondents mentioned discrimination, and in both cases, the discrimination was perceived as being subtle. For instance, one said that although he did not feel discriminated against on a day-to-day basis, he did not receive promotions at the rate that he believed his performance warranted. Another respondent who recently left his job said, “Discrimination, I think that’s kind of there a little bit here and there. Well, ‘cause when the person that was my manager, he left, so things changed at the job. So I was more taken advantage of instead of appreciated.”

E. Future plans regarding work and benefits

We asked beneficiaries about their future employment plans and whether they thought they would eventually leave the disability benefit rolls.

1. Most interviewees wanted to increase or maintain their earnings

Most interviewees indicated that they wanted to sustain or increase their earnings in the future. The reasons they cited ranged from wanting to provide for family or children to paying back loans, increasing savings, keeping up with the increased cost of living, and feeling productive or personally fulfilled. One respondent said, “Hopefully down the line I’ll find a job that pays more, and start saving more, so I can get off the benefits and then just be able to try to do it on my own.” However, nearly all also indicated that they foresaw many barriers to working in the future, all related to their previously mentioned problems with finding and keeping work. Both beneficiaries with stable and unstable earnings mentioned the need for less stressful work. One beneficiary with stable earnings said, “I don’t know how long my body can take the constant stress of a full time job like this. I might need to find something that’s a slower pace and pays less, or whatever.”

2. Some beneficiaries wanted to stop receiving benefits in the future; for those that wanted to continue receiving them, health insurance was the biggest factor

Beneficiaries with stable and unstable earnings shared similar sentiments about leaving the benefit rolls. Many expressed a clear motivation to earn enough money to permanently go off benefits in the near future. These beneficiaries expressed the desire to cease reliance on SSA, regain their independence, and return to the “normal” life they had prior to receiving disability benefits. As one stated, “I haven’t always been on Social Security Disability. I did have a flourishing career at one time, and I know what it’s like not to deal with Social Security in your life. And ultimately, I would like to live like that again.” Others hoped to work enough to stop receiving benefits because the benefit amount is not sufficient to live comfortably. As one said, “It’s pretty set that I can make more working than what Social Security would be paying me monthly. It’s simple math.”

Among beneficiaries who wanted to keep receiving benefits, most were concerned about loss of health insurance. Most indicated that they might be amenable to losing their cash benefits in the future, but, given their reliance on expensive medication, in-home care, and other medical

services, could not imagine losing health care benefits. One interviewee explained, “If they at least let me keep my in-home care and my medical benefits, they can keep the cash part, but I have to have the health care 100 percent.”

A few indicated that it made the most financial sense to continue earning below the SGA level so they would receive benefits. One explained, “Ultimately, if [your wages alone] still don’t add up to what you’re going to get on disability and your job is paying you under how much you can make, then it doesn’t make sense [to work enough to stop receiving benefits].” Others indicated that the unpredictability of their health condition made them hesitant to earn enough to stop receiving benefits. One stated, “The thing is with health problems...I never know what the future’s going to bring. If I can’t work anymore, what am I going to have to do—wait six months to get a benefit again?”

3. Both groups of high earners said the unpredictability of their health condition was a potential barrier to future employment

Almost all interviewees cited their health as a major potential barrier to future work efforts. Although the majority did not see their current health status as a barrier to continued or increased employment, they were concerned that their health condition was unpredictable and that if their condition got worse, it could hamper their ability to work. One beneficiary said, “The problem that makes me nervous is one minute you’re okay and working, but what if you’re not okay?” Even beneficiaries who hoped to get off benefits expressed concern that if their health declined, they would have to quit their jobs. A few said that they doubted they could sustain employment, given their current health status. They will probably have to decrease their hours or quit altogether someday.

Several respondents said future work endeavors would depend on whether they could find or keep a job they could do, given their health condition. One interviewee whose job involves manual labor said, “I would like to [work more] at another job, maybe in an office, something sitting down.” Another employed as a front desk security guard said he worries what would happen if he lost his position: “I was lucky. I could have gotten a security job where I had to stand on my feet for eight hours, which I can’t do. This happens to work for my disability. So it isn’t an easy job to replace.”

4. Beneficiaries with stable earnings were more likely to describe career advancement and training opportunities than were those with unstable earnings

Beneficiaries with stable earnings mentioned future plans with their job, such as becoming a partner with their firm or becoming eligible for new programs at work. Many of the high earners with unstable earnings described uncertainty about their careers. For example, one beneficiary who lamented the lack of opportunities for advancement at her current job said, “Maybe I’ll stay, maybe do something on my own, maybe start a business.”

Across both groups, respondents who worked at jobs in which they could increase their wages or hours were more likely to say they planned to earn more in the future than those who had no opportunities for upward mobility. Several noted that they would ideally like to sustain or increase their work level in the future, but doing so would require finding a new job where they could get more hours or earn higher pay. Many beneficiaries with stable earnings mentioned that

furthering their education with an additional degree or formal training program would help them in the future. One said, “I’m going to get my medical interpreter license from the state and as I get that, then I’ll be able to work more, maybe even get paid more and that might be nice.” Another said, “By the time my son has his high school diploma, hopefully I’ll have my bachelor’s degree and can get a better job.” Several beneficiaries with unstable earnings who were dissatisfied with their current job or industry also viewed additional education as a route to greater job satisfaction and possibly greater earnings. One beneficiary with unstable earnings who had recently quit her job as a cook at a restaurant decided to pursue a degree in graphic design because she assumed the graphic design field would be “a lot less high stress,” interesting, and more manageable.

5. Most high earners said they needed no additional services to enhance future employment, but some wanted help with medical or social services or assistance finding work

Most high-earning interviewees could not readily identify specific services and supports that might help them sustain or increase future earnings. Those who did want employment help mentioned assistance finding a job that they could perform with the issues they have (for example, a job requiring minimal movement, offering part-time employment, or one close to home). Employed interviewees said they could use more assistance with the search process to help find a job that was a better match, or with opportunities for advancement.

Additionally, interviewees cited a need for information from Social Security regarding their benefits. One individual tried to hire a Social Security lawyer for help after receiving inadequate information from the local Social Security office, but could locate no one to help navigate the system. One respondent said, “Too bad they don’t assign a caseworker to help guide you and tell you about your resources and what you’re doing right, but just on a check-in basis.” A few interviewees said they could use help identifying social services, including housing assistance, mental health counseling, and transportation, or low-cost medical care. Finally, a small number expressed a desire for additional funding for education and training programs to help them advance in their careers.

F. Experiences with SSA benefits and overpayments

We asked beneficiaries to comment on the benefits they received, whether they feared losing them, and whether they had ever had an overpayment.

1. Most interviewees said they relied on SSI or SSDI benefits while unemployed; beneficiaries whose earnings fluctuated said they relied on SSI or SSDI benefits during times of reduced work activity

Beneficiaries said they relied on SSI or SSDI cash benefits to pay their bills and meet basic needs. For some, the benefits helped them make ends meet when they were not working or had intermittent health crises. For others, the SSI or SSDI payments supplemented their earnings from low-wage jobs. One SSI beneficiary described a week-long hospitalization that led to two weeks of missed work, during which she had no earnings: “The Social Security sent me a little bit of money to help out.” Another said, “It took a long time [to find a job]. But in the meantime,

I was getting Social Security disability payments, and so that was good that I was getting that while I was trying to look for a job that fits my disability, which is hard.”

Most interviewees said they worked part time or intermittently, with wages of \$10 to \$12 an hour. Even those with consistent earnings said they had trouble making ends meet. Many had a tenuous attachment to the labor force. One beneficiary who found it difficult to find a job could not sustain his earnings. After he worked for a while, he was laid off and had to get benefits reinstated. Another who works part time explained, “I’ve had a pressure sore...for 14 years, and the job that I have now, I work two or three times a week, and my board of directors is okay with that, as long as my job specifically is being done.... But even if I wanted to go get another job, I mean it just wouldn’t—the pressure sore and my disability, I just don’t think I would be able to.”

2. Most high earners feared losing medical benefits more than losing cash benefits, but those with unstable earnings also feared losing cash benefits

Medical coverage was a critical issue. Study participants said they needed health care coverage, either through public programs or employment-based fringe benefits, to cover the medical expenses resulting from their impairments. They pointed out that they have had medical procedures, doctor visits, medication, surgery, or therapy they could not afford without coverage. They feared losing SSI or SSDI because they thought this would mean losing their public health insurance coverage. Only a few understood that they could keep their Medicare for several years after they stopped receiving benefits or that they might still be eligible for Medicaid. Many said they would not take the risk of losing health benefits and limited their earnings to ensure continued eligibility. As one stated, “I was going to drop Social Security. I was going to try to make it, but I couldn’t get insurance through [my employer].... I got a letter from Social Security, and it said my trial work period ended. And so now, I guess I need to let Social Security know that I’m working part time and keeping under my gross income so I can keep my insurance and benefits.”

Still, a few participants wanted to work badly enough that they were willing to give up public health insurance for a job, even though the loss of insurance concerned them. One employed beneficiary with stable earnings said, “I would love to still have medical insurance, but when I started getting paid more that also went. So I don’t know what I’m going to do about insurance. I would be super affected to not have insurance, but other than that, I think I’m okay.”

A few beneficiaries said they were not worried about losing cash or medical benefits. These respondents tended to have stable earnings, received SSDI, and had returned to full-time jobs with health insurance and other benefits. Some beneficiaries with unstable earnings feared losing cash benefits due to the fluctuation of their earnings week to week. They wanted to remain eligible for cash and medical benefits and sometimes reduced the hours they worked to do so.

3. Many high earners received overpayments for a number of reasons, including lack of information and problems with reporting earnings to SSA; for those with unstable earnings, delays in processing work reports and the resulting overpayments were a major problem

About half of the high earners we interviewed said they had received an overpayment, which ranged from a few dollars to \$16,000. Those with larger overpayments tended to be SSDI

beneficiaries. Beneficiaries with earnings that fluctuated month to month had more frequent overpayment problems, and it was more difficult for these beneficiaries to repay SSA. Interviewees cited several causes for the overpayments.

Lack of accurate information. Some beneficiaries' believed their lack of information about benefits and work incentives contributed to the overpayments. These beneficiaries said they did not know how much they could earn and still receive benefits, why they received an overpayment notice, or how the overpayment was calculated. This was particularly true for people whose earnings fluctuated from month to month. One beneficiary, whose earnings fluctuated between \$500 and \$1,200 per month and who had received multiple overpayments, said, "I have been told so many times the different pay amounts that you can earn, and I guess evidently, none of them were right.... So I didn't even realize how much I could make. And now Social Security says I owe them something like \$1,000, and I have to pay that back. I tried to explain to [the SSA representative] that I didn't have that kind of money, and she says, 'It doesn't matter. We'll just take your tax [refund].' She was very rude." Another beneficiary who had left his job after receiving an overpayment said, "I know the next time when SSI or any other body wants to give me a job, I will make sure I get the right information. I had to pay the government back money for something that I didn't know I had to do. I didn't feel that was right, but it is what it is. No one told me 'When you get to work, or you make this [many] hours, you are only allowed to make this. You got to pay this back.' They just told me, 'You can go back to work, keep your benefits.'"

Only a couple of interviewees said they received good information from a benefits counselor or SSA staff member about what would happen to their benefits. "The benefits counselor has explained all that to me," one said. "I have Medicare, but apparently, you keep Medicare for eight years after you lose your benefits. There's lots of things that they put in place to help you get back [to work], get you off of benefits." Others said they understood that they had a TWP but did not realize that their benefits would be reduced to zero if they earned just a few dollars over the SGA amount. Others thought that if they lost their SSI payments, they would automatically lose Medicaid. None mentioned the Medicaid Buy-in, the Affordable Care Act, or other options that might permit continued coverage under Medicaid.

Processing delays at SSA. Several beneficiaries expressed great frustration when they had reported their earnings to SSA, or had been told by SSA they were due a payment, only later to receive an overpayment notice. This comment was typical: "And with Social Security, a lot of times, you send your check stubs in, and you never get an answer back from them. That's the biggest problem." Another beneficiary, whose earnings fluctuated, understood that SSA sends the monthly SSI check before processing the pay stubs, which can cause overpayments. He explained, "Instead of [SSA] sending me a check after I turn in my time, they send me a check before [they receive my stubs]. So that causes the overpayments." Another SSI beneficiary with fluctuating earnings said, "So when I started to work...I was told that I had to report my income every month. I was given a way to send my check stubs in, so faithfully, I sent in every check stub. And so they were still putting money into my bank account. Well, I don't know what scale they use or how all of this stuff works, so I'm just assuming I'm not making as much as they thought I was making, so I'm still eligible to receive income. This went on for approximately 10 months. And then all of a sudden I get a letter saying that I owe \$1,800. And so I called and they

apologized, and the person I talked to said that they were shorthanded, and my check stubs were being stacked up on the side and not processed.”

Another beneficiary who received an overpayment said, “They were still paying me, and I was still working and reporting my income and telling them I was still working, and then I think in October, I called and I said, ‘I’m off of the [trial work] period...and you sent me another check.’” And they’re like, ‘No, you’re supposed to have that.’ And then like three months later, I get an overpayment letter. I don’t know what they are saying.... I just sent them a check today. I just can’t afford to pay the lump sum.”

A beneficiary with stable earnings had the same problem. She explained, “I reported everything that I was doing. I reported I was working, I reported my income, I did everything as I was instructed, and then to come back and say, hey, we screwed up, we overpaid you, we didn’t process your information or case as we should have, but you know what, now you owe us \$12,000. Yeah, I ran into that situation....”

In one case, delays in processing pay stubs at SSA combined with a misunderstanding of how earnings should be reported created what a parent of a deaf son called “a nightmare.” She explained:

I can remember being so frustrated when I went in there to the office because I was reporting wrong. I was reporting by the days of the week he worked, instead of the day that the check was issued, which got everything off, and so we ended up owing everything that we received that year, and I kept calling. [The lady at SSA] said, “Nope, nope, they never make a mistake. If you’re reporting, there’s no problem.” So this went on for six months. I took a day off work because the SSI office is only open between the hours of 9 and 2. ... I took all my paperwork.... I have a huge cart with all of his stuff in there, and I just wheel that in. She says, ‘I don’t have time to look at this. I’m telling you. If you’re reporting it, it’s in the system. There’s no mistake, and don’t hoard that money. You need to spend it.’ Within a month, I’m getting all these letters from SSI saying I owe them \$1,000.... The next day, another one came. It was up to \$5,000. I honestly do not know how people do it that have learning disabilities and live on their own.... I don’t understand how they expect people to do this by themselves.

Failure to report wages properly. Only a couple of beneficiaries admitted that they did not always properly report wages. One explained, “It’s hard to turn in my hours, you know? Turn in my check stubs, and I don’t do it every month. I do it like every six weeks or so.” Another said, “Yeah, I think it’s ‘cause I really forgot to report it. That’s really what it seems like. If you don’t report it, then they just cut you off, no matter what.”

Anticipated overpayments. A couple of beneficiaries with stable earnings knew they would receive an overpayment and so developed plans to repay them. One explained, “I don’t think I’m supposed to be getting it, but they sent me a check this month. I’m figuring it this way—that I just stick it in the bank, and if they figure out what they’re doing, they may ask for it back.” Another found the SSA worker in the local field office to be very helpful in explaining the circumstances under which he would receive an overpayment. Based on the information he

received, he expects to get an overpayment notice in the future, but he plans to put money in the bank so he can repay SSA when requested.

4. Repaying overpayments caused significant hardship and inconvenience for many

Repaying overpayments was very difficult for many interviewees. One beneficiary who had received a \$1,000 overpayment said, “[Having to repay SSA] caused me to become homeless. I wasn’t able to pay rent that month, and so I was kicked out. So that started my homelessness. And then...[SSA] kept \$300; something happened with my insurance. There was a lapse, so instead of saying, ‘Hey, can we take this in payments?’ No, they just took the whole thing, the \$300. That’s a lot of money when you’re only making \$1,000 a month and you’re trying to survive.” Another beneficiary described the overpayment process as “a nightmare.” He had to ask for help from his church to pay his monthly bills.

The sudden and unexpected loss of benefits to repay an overpayment caused hardship and frustration for some. One beneficiary with a \$12,000 overpayment, who believed he had faithfully reported his earnings, explained it this way: “Oh, it’s been frustrating, believe me. I was making maybe like \$12 an hour...and out of the blue they just cut my benefits. They didn’t send me a letter, they didn’t call me, they just cut them off. So I had to default on the [school] loan that I was paying every month. I lost that benefit with no notice, and I couldn’t put a plan together to get something done. They don’t realize the situation they put people in when people are actually trying to do something right with their lives. So it has been a frustrating situation.”

People with smaller overpayments said they had resolved them quickly, but most were still repaying them through a payment plan or were appealing the overpayment. Addressing the overpayment notices required many trips or calls to SSA offices, and in some cases, took many years to resolve. One beneficiary was still trying to resolve an overpayment identified in the mid-1990s, and another was attempting to resolve one from 2009.

5. Despite expressing considerable anxiety over the threat or receipt of overpayments, most interviewees said they had not changed their behavior as a result of this anxiety

Most interviewees who had gotten an overpayment said they did not alter their work behavior to retain their benefits. However, a few said they did reduce their earnings to retain benefits. Two of these interviewees were worried about getting back on benefits if their disability worsened, and one worried about losing medical benefits. One beneficiary said, “For the most part, I did enjoy working, and I believe that when I get my medication stable...I’ll probably be able to sustain a job for a longer amount of time. But it’s a little bit scary because if I do get a job, and I go over however many months it is, and I get depressed, now you lose your Social Security. And then if I get an overpayment because I worked too much, I’d need to pay it back, and I wouldn’t even be working.”

For some beneficiaries, the overpayment gave them a greater incentive to work so they could earn enough to pay it back. One said, “I had to change where I worked. What I was making when I first started working, I couldn’t make the payments they were asking me to pay back.... I had to find a way to make more money.... They were asking me to pay almost \$600 a month back. Where do you want me to get that making \$12.50 an hour? So you have to always be proactive and try to grow that income. You have to because if you don’t, then you get

stuck...and it's miserable. I mean, you do just want to give up.... Why did I take on all this responsibility to just be in the same place that I was trying to get out of five years ago? So don't ever get on Social Security, I'll tell you that much!" Another beneficiary who received an overpayment said, "Now I'm terrified to get anything. I got to work, that just makes me more determined to keep working because I'm scared to death to get a check from them.... I mean if I can do it myself, I want to do it myself. I don't ever want to owe them money ever again."

G. Suggestions for SSA

To conclude the interview, we asked interviewees for their suggestions regarding SSA program improvement that might encourage them to return to work, stay at work, or leave benefits. Interviewees suggested ways to encourage employment, including case managers and other supports, better customer service, higher savings and earnings limits, and others.

1. SSA case managers and other supports

Several beneficiaries said it would help if SSA were to appoint a case manager or SSA community liaison to encourage and motivate beneficiaries to work, maintain periodic phone contact, answer technical questions, coordinate necessary paperwork, and serve as an advocate for returning to work. These services are outside of SSA's legislative mandate, but the requests point to the need for more support as beneficiaries seek and maintain employment. One said, "[case managers] that's probably the best way to not just improve, but to continue to improve, because then you have continuous information, current information." Another beneficiary said a SSA community liaison would be especially useful for beneficiaries who live in rural areas who want to return to work or find a new job.

Others suggested SSA provide additional resources, such as funds for education, transportation, or training for independent living to "help people overcome the challenges of having a physical disability" and to encourage a return to work. For example, they suggested training sessions or workshops on disability disclosure during interviews, how to request reasonable accommodations, and legal rights as a worker with a disability. One beneficiary said training could serve as a motivator because "you have to give people a reason to believe that they can do something more with their lives." Another suggested that SSA reimburse beneficiaries for out-of-pocket school expenses when the schooling is intended for or leads to employment.

One beneficiary suggested that early-intervention efforts consisting of supports and services might help some beneficiaries—before they become too depressed and detached from the workforce. "The first year is where all the opportunity is," he said. "If you can provide assistance in the first year, people will not fall deeper into debt, deeper into paperwork, deeper into depression, and deeper into hopelessness while adjusting to disability. Their odds increase of getting a self-sustaining job in the future because they get help early."

2. Improved customer service and staff training

Several interviewees stated they were treated rudely by SSA staff and suggested that SSA improve its customer service. Others suggested SSA improve its staff training, describing experiences in which SSA staff had limited knowledge, including about impairment-related work expenses. SSA staff also often made mistakes, failed to follow up as agreed, provided

inconsistent information, or lost important paperwork, beneficiaries said. For example, one beneficiary said, “I would call one person and ask them something and then I’d call another person and ask and I would be getting two and three different answers to the same question.” Another beneficiary said, “No one really knows a whole lot. You get passed around to a lot of people. It’s frustrating.”

3. Higher savings limits under SSI and higher allowable earnings limits

Many SSI beneficiaries suggested rule changes to increase allowable savings. Most implied that a savings account would give beneficiaries a “cushion” to serve as a safety net for emergencies and a pathway toward stability as they try to leave the SSI rolls. Others suggested the SSI program could be improved if SSA did not reduce SSI payments due to marriage or savings, especially for beneficiaries with a large family, or who are pursuing a goal of independent living.

A substantial proportion of respondents suggested SSA increase the benefit amount and allowable earnings, stating SSA benefits are insufficient for today’s economic conditions. One beneficiary who lives in an expensive area of the country suggested SSA adjust benefit and earning amounts to reflect regional differences in cost of living. Several SSDI beneficiaries with experience working above SGA suggested SSA gradually reduce benefits, in a manner similar to the rules under SSI. One said that a gradual reduction in benefits could serve as an incentive to return to work. Another said a gradual reduction in benefits “would be a transition, a smoother transition, more motivation to actually make more money. As it stands right now, I’m really struggling to get the extra hours I need. It’s like you try and work, and carry on with your life, and then they rip the rug out from under you.”

4. Other suggestions

High earners suggested, as did young adult interviewees, that SSA improve outreach to local employers to improve employers’ understanding of beneficiaries’ capabilities, availability of workers who receive SSDI and SSI, and the benefits of hiring workers with disabilities. A small number of respondents suggested SSA consider offering tax breaks to employers to retain employees. One beneficiary suggested SSA encourage clients to seek government employment because the benefits and accommodations are better.

Several interviewees said it would help the SSA system overall if SSA reduced fraud and tightened disability eligibility rules. One said, “There are people that know how to play the system everywhere and all over the United States, and they’re just getting a free ride and it’s taking from people that really do need it.”

This page has been left blank for double-sided copying.

IV. SUMMARY AND IMPLICATIONS OF THE FINDINGS

The findings of this study underscore the diversity of options that beneficiaries use to overcome barriers to find and retain a job. Beneficiaries face many problems in keeping a job—problems that are similar to those faced by low-wage workers in the general population and many had a tenuous connection to the labor force. Because of their health issues, these beneficiaries faced additional obstacles to working. But a number of factors—including individual motivation, education and job skills, family support, the local job market, needs for accommodation, and the nature of the job—play a role in whether the beneficiary will succeed. For SSI and SSDI beneficiaries, there is no one-size-fits-all solution to employment. Each person faces unique challenges and must devise his or her own solutions. Most of the participants in this study have found supportive employers, co-workers, and family members who made it possible for them to work. Many are able to earn enough to reduce or eliminate their benefits. Their successes suggest that flexible services tailored to the unique needs of each beneficiary might help others to pursue their employment dreams.

Our findings are drawn from 91 telephone interviews with SSI and SSDI beneficiaries selected from SSA administrative data files and interviewed in spring and summer 2015. Each beneficiary was working at the time of his or her interview or had worked recently. Thirty of the interviewees were employed beneficiaries under age 30 who were earning at least \$500 per month. We categorized the other 61 as “high earners” compared with the total SSI and SSDI population. These high earners had recent earnings that exceeded the nonblind SGA level for at least three consecutive months. Thirty of these high earners had stable or increased earnings during the six months before the interview; 31 had reduced their earnings or stopped working during the preceding six months.

A. Beneficiaries’ experiences finding and keeping work

1. Beneficiaries were highly motivated to find and keep a job

Young adults and high earners were highly motivated to find and keep employment. High-earning young adults wanted to pursue advanced education or training and saw this as a way to get a good job and to forgo benefits. Indeed, the motivation to work and leave the benefit rolls appears to be a strong factor in beneficiary behavior, particularly for young adults, those with families to support, or those who had had a career or high-paying job earlier in their lives. Beneficiaries wanted to work for the same reasons that motivate other job seekers—the desire for a better income and the chance to contribute to society and make something of oneself. Young adults and high earners who said they were highly motivated to work—including those with stable and unstable earnings—appeared to have better employment outcomes, a more positive outlook, and a preference for leaving the benefit rolls, although it’s possible that positive employment outcomes made workers more motivated.

The interviews suggest that SSA may want to identify work-motivated beneficiaries early in the application process, as this group might respond to work incentives. Similarly, early intervention to provide education and work supports might help new beneficiaries before their motivation wanes and health declines.

2. Beneficiaries in all groups commonly used social networks to find work

Although a few high-earning and young adult beneficiaries searched for jobs using newspaper ads or the Internet, most used informal contacts, such as friends and family, to find jobs. Some high earners with stable earnings were able to return to their predisability employer, but others had to start a new career. A few young adults said they volunteered to prove to an employer that they could do the job. Strong social networks and family support were important to these interviewees and might be lacking for many beneficiaries who do not pursue employment. Beneficiaries who are isolated by disability and poverty or those with little or no work experience are not likely to be able to use social networks to find a job.

The interviews suggest that SSA might want to further explore the role of social networks in helping beneficiaries find and keep work and how social networks might be leveraged or enhanced by programs that support public employment. Many of the interview responses suggest social networks might facilitate future employment, but it's unclear how social network supports might vary based on the primary disability or SSA benefit type.

3. Some young adults used formal services, such as job coaching or VR, to find and keep work, but few high earners used these services

Some young adult interviewees were connected with school-based employment services and used them to find their first job. Counselors to help with skill building, resume preparation, and interviewing, as well as job coaches to help with job searches and on-the-job support, were most important to them. Some young adults continued to receive job coaching through nonprofit organizations such as Goodwill, but such services became less available as they moved into adulthood. Only a few young adults said they used other services, such as TTW or state VR programs, and their experiences with such services were mixed. Most young adults and nearly all high earners in our sample said they used few or no services to find and keep work.

Many former students, especially those with intellectual, learning, or psychiatric impairments, said their experience in school reinforced their own or others' expectations for failure and underachievement and did very little to prepare them for employment and adult life. Despite this, they all secured jobs. To better prepare students for work, SSA might want to promote flexible services and interagency collaboration between schools, SSA, VR, and other social and employment agencies that can help young adults and their families better understand SSA policies and resources for employment. The Promoting Readiness of Minors in SSI (PROMISE) project, a collaborative effort between SSA and other federal agencies to promote positive outcomes for youth and their families who receive SSI, may provide evidence of unique approaches that can be modified to improve adult employment outcomes.

4. Employers provided accommodations that helped beneficiaries work; many of these supports appeared to be informal and relatively low cost

Beneficiaries frequently mentioned workplace accommodations that enabled them to work. They most often mentioned flexible work hours, ergonomic office equipment, or small changes in their job duties. They often mentioned supportive colleagues and supervisors who understood the need for frequent breaks or absences to manage pain. Several interviewees discussed how flexible schedules, including the ability to take time off or take paid sick leave, enhanced their ability to work. Beneficiaries were able to find jobs where these accommodations could be

tailored to their needs and were not overly expensive or burdensome to the employer. Some employers also supported interviewees' desires to work limited hours to retain their eligibility for Social Security benefits.

5. Beneficiaries said that health issues and the ability to keep their health insurance affected their decisions about whether, where, and how much to work

Beneficiaries most commonly mentioned that a health condition or disability was their primary barrier to work, and medical coverage was very important. They expressed the need for health coverage, either through public programs or employment-based fringe benefits, to pay for the medical expenses associated with their impairments. They spoke about medical care—including doctor visits, medication, surgery, or therapy—that they could not afford without medical coverage. They feared losing SSI or SSDI benefits because they thought this would mean they would also lose their medical coverage. Many said they would not take the risk of losing health benefits to increase their earnings.

People who work part time, as many of these beneficiaries do, rarely have employer health insurance. Moreover, such insurance usually covers only limited outpatient therapy, not the in-home services many beneficiaries need. Participants said they believed they needed to restrict their earnings to remain eligible for medical benefits, and many of them behaved accordingly.

Beneficiaries overwhelmingly mentioned health and disability-related issues as factors in their decisions about whether, where, and how much to work. The episodic nature of disabilities, such as flare-ups of back pain, depression, fatigue, or other chronic issues, affected whether beneficiaries pursued full- or part-time work. These conditions often affected how many hours they could work in any particular week. In addition, beneficiaries mentioned the need to take off work for frequent doctor or therapy appointments or even for hospitalization.

Not surprisingly, almost all beneficiaries were concerned about losing their health insurance when they began working. Some of the young adults and high earners wanted to work enough to leave the benefit rolls, but they were concerned about their future health and the need to maintain insurance. In fact, the most common threat to remaining employed among beneficiaries was their health issues and the need to keep their health insurance. Fear of losing health insurance is still a major disincentive to work, despite the availability of Medicare for 93 months after the TWP ends, the availability of Medicaid through 1619(b) of the Social Security Act, and increased availability of health care coverage through the Affordable Care Act and state Medicaid Buy-in programs.

A few high earners said they were not worried about losing cash or medical benefits. These respondents tended to have stable earnings, received SSDI, and returned to full-time jobs with health coverage and other benefits.

SSA might want to conduct a targeted marketing campaign about retaining health insurance while working to help address this work disincentive. The messages and supports could help allay people's fears of losing health insurance and provide clear examples of how health insurance can be maintained.

6. High-earning beneficiaries with unstable earnings differed from those with stable earnings in a few important respects

Although high earners with stable earnings were similar to those with unstable earnings in many ways, we note a few important differences. In terms of personal characteristics, those with stable earnings were more likely to be female, more likely to have musculoskeletal conditions, and less likely to have psychiatric conditions than those with unstable earnings.

Barriers to finding and keeping work did not appear to differ between workers with stable and unstable earnings. Both groups had to overcome many problems to find and keep a job, but those with stable earnings tended to have more motivation or capacity to solve them. For example, beneficiaries with stable and unstable earnings mentioned finding transportation to work as a barrier, but those with stable earnings tended to have more resources to draw on to solve their problem. Although both groups mentioned workplace supports, beneficiaries with stable earnings mentioned them more often. They described flexible work hours, supportive bosses and co-workers, and other accommodations that helped them stay employed. In addition, both groups talked about health issues and work stress, but those with unstable earnings said that even after the initial adjustment, the job itself was stressful, overwhelming, or fast-paced, which sapped their motivation to work.

A few high earners with stable earnings returned to a previous employer or to the type of job they held before acquiring a disability, whereas those with unstable earnings had to find a new line of work with a different employer. Many with stable earnings also described professional development opportunities that helped them to stay at work, but those with fluctuating or decreased earnings did not.

When asked why their earnings were unstable, beneficiaries with fluctuating earnings said they had to take time off to go to medical appointments. Those with limited stamina, chronic or work-induced pain, or mental health issues sometimes could not keep consistent work hours. They did not have sick leave, and so they took time without pay, resulting in earnings that varied week to week. Beneficiaries with unstable earnings said they feared losing their health insurance more frequently than did beneficiaries with stable earnings. Fear of benefit loss, particularly loss of health insurance, caused some beneficiaries to limit their hours or stop working.

B. Beneficiary interactions with SSA

1. Most beneficiaries have a limited understanding of SSA regulations and guidelines

Most beneficiaries had a poor understanding of SSA rules and policies related to their benefits, health care, and work incentives. Many appeared to lack knowledge specifically about retaining health coverage while working; only a couple mentioned extended Medicare coverage, and no one mentioned Medicaid eligibility under Section 1619(b) of the Social Security Act, the Medicaid Buy-in, or insurance under provisions of the Affordable Care Act, despite policymakers' efforts to inform beneficiaries about these options.

In addition, many beneficiaries lacked knowledge about the type of cash and health benefits they receive, SSA work incentives, and what would happen to their benefits if they continued to work or increased their hours. Many did not know whether they received SSI, SSDI, or both

types of benefits, which is crucial to know given that work incentives differ for each program. Even beneficiaries who did know this seemed to have inaccurate assumptions about work incentives. The complexity of the incentives makes it very difficult to understand and navigate them, and beneficiaries thought that few SSA staff truly comprehend the intricacies of these programs.

2. Beneficiaries expressed extreme frustration about overpayments

Although most interviewees said that they had not modified their work effort to avoid overpayments, many were very fearful of the need to repay them. About half of the high earners had received an overpayment, and most did not understand why they had or how it was calculated. Beneficiaries said they did their best to report their earnings and were extremely frustrated when overpayments occurred. Many of these beneficiaries appeared to have reported their income correctly or had been told by SSA staff that their payments were correct. Processing delays or other issues at SSA seemed to be a major cause of these overpayments.

Repaying overpayments caused some interviewees great hardship, although overpayments did motivate some to work harder and eventually leave the benefit rolls. Beneficiaries said they would appreciate more timely documentation of work reports, better information about how the overpayment was calculated, and advance notice that an overpayment would be collected.

3. Some beneficiaries suggested that SSA create programs that already exist in some form

Interviewees suggested many ways that SSA could help other beneficiaries find jobs. However, most of what they suggested already exists in some form, indicating a general unawareness of available supports. For example, they asked for accurate information on work incentives and help completing paperwork to report earnings, which the Work Incentives Planning and Assistance programs routinely provide. They requested web-based information and training on resume writing and interviewing, which is readily available through a simple Google search. They also requested counselors to help with job searching, although such help is available through TTW, American Job Centers, and state VR agencies. Beneficiaries who requested methods or mechanisms to help them save some of their benefits for an education, a car, or other items that would enhance employment were unaware of Individual Development Accounts or Plans to Achieve Self-Support.

There was substantial variation in beneficiaries' understanding of SSA programs. To address this, SSA might want to conduct market research to find out what messages, channels, and sources work best for getting information about work incentives, overpayments, and health insurance policies to different beneficiary groups. Tailoring information means combining content with what is known about the target population to create customized content and persuasive messages (Kreuter and Wray 2003; National Cancer Institute 2004). Market research might include strategies to identify and educate family members who influence SSA beneficiaries' decisions. SSA might also consider reviewing the consistency and accuracy of information provided to beneficiaries by SSA field office staff.

C. Study limitations and concluding remarks

The nature of the sample of individuals who participated in this study prevents us from drawing conclusions that can be broadly generalized. For example, we only spoke with beneficiaries who had a phone, were willing to take part in a phone interview, and spoke English. Moreover, our sample is relatively small and was not selected in a manner to ensure national representation of beneficiaries who are employed young adults or those who are high earners. Thus, the findings may not fully represent the experiences of all beneficiaries with those characteristics. It's also possible that social desirability effects—beneficiaries' awareness of societal norms about work—affected their answers about their employment efforts or work and benefits goals. However, the study provides a glimpse into the experiences of 91 beneficiaries who have successfully kept a job, at least for a time, and supports findings from other research on the barriers to and facilitators of employment among people with significant disabilities.

REFERENCES

- Bardos, Maura, Karen Katz, and Gina Livermore. "SSI and SSDI Beneficiaries with Intellectual Disabilities." Disability Research Consortium Data Brief. Washington, DC: Mathematica Policy Research, 2016.
- Kreuter, M. W., and R.J. Wray. "Tailored and Targeted Health Communication: Strategies for Enhancing Information Relevance." *American Journal of Health Behavior*, vol. 27, 2003, pp. S227–S232.
- Liu, Su, and David C. Stapleton. "Longitudinal Statistics on Work Activity and Use of Employment Supports for New Social Security Disability Insurance Beneficiaries." *Social Security Bulletin*, vol. 71, no. 3, 2011, pp. 35–60.
- Livermore, Gina, and Maura Bardos. "Characteristics of Disability Beneficiaries with High Earnings." Disability Research Consortium Data Brief. Washington D.C., Mathematica Policy Research, 2015.
- Livermore, Gina A. "Social Security Beneficiaries with Work-Related Goals and Expectations" *Social Security Bulletin*, vol 71, no 3, August 2011, pp. 61-82
- Livermore, Gina A., Nanette J. Goodman, and Debra L. Wright. "Social Security Disability Beneficiaries: Characteristics, Work Activity, and Use of Services." *Journal of Vocational Rehabilitation*, vol. 27, no. 2, 2007, pp. 85-93.
- Livermore, Gina, Allison Roche, and Sarah Prenovitz. "SSI and DI Beneficiaries with Work-Related Goals and Expectations." Report No. 5 in Work Activity and Use of Employment Supports Under the Original Ticket to Work Regulations. Washington, DC: Mathematica Policy Research, 2009.
- National Cancer Institute. "Making Health Communication Programs Work: A Planner's Guide," Rockville, MD: NCI, 2004.
- National Council on Disability. "The Social Security Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems." Washington DC: NCD, 2005. Available at <http://www.ncd.gov/policy/social-security-administrations-efforts-promote-employment-people-disabilities-new-solutions>. Accessed July 15, 2015.
- U.S. Bureau of Labor Statistics. "Persons with a Disability: Barriers to Employment, Types of Assistance and Other Labor Related Issues." Washington, DC: BLS, May 2012. Available at: http://www.bls.gov/news.release/archives/dissup_04242013.pdf. Accessed July 15, 2015.
- Wright, Debra, Gina Livermore, Denise Hoffman, Eric Grau, and Maura Bardos. "2010 National Beneficiary Survey: Methodology and Descriptive Statistics." Washington, DC: Mathematica Policy Research, 2012.

This page has been left blank for double-sided copying.

APPENDIX A

RECRUITMENT AND INTERVIEW PROTOCOLS

This page has been left blank for double-sided copying.

A. YOUNG ADULT SAMPLE PROTOCOLS

This page has been left blank for double-sided copying.

Employed Young Adults Recruitment Protocol

The script is intended to recruit current and former SSI and SSDI beneficiaries for interviews about barriers and facilitators to employment and benefit independence. The information collected will be used to deepen SSA's understanding of factors that impact employment success, including people, programs, and employers, among other things.

We will obtain a sample of SSI and SSDI beneficiaries from SSA who, based on SSA administrative data, are under age 30 and are likely to be employed at the time we contact them (that is, have recent earnings in the administrative data).

During the initial recruiting phone call we will explain the study goal, gain interest, verify the sampled person's name, address, and phone number, and determine the sample person's employment and benefit status. The verification of current employment, maintenance of earnings levels, and current benefit receipt status will allow us to determine eligibility for interview. This is necessary because SSA administrative data will not contain current information on these characteristics.

We will recruit with the goal of completing interviews with 30 individuals under age 30 who are working at the time we contact them. We will also attempt to achieve approximately one-half of interviewees to be current/former SSI recipients and one-half to be current/former SSDI beneficiaries in each group (status determined based on administrative data).

Note: If beneficiaries attempt to ask questions about their benefits at any point during the discussion: I'm sorry. I am not an expert on [Social Security disability benefits/Medicare/Medicaid]. So I cannot answer questions or give advice about disability benefits or your personal circumstances.

A. Recruitment

Hi, my name is _____, and I work for a company called Mathematica Policy Research. May I please speak with (beneficiary name)?

If not available, arrange callback.

If gatekeeper says not intellectually capable, explain the goals of the interview and that it is designed for people like their household member. Determine from gatekeeper if the beneficiary is currently employed. If yes, determine if he or she could likely handle the interview. Suggest that gatekeeper could help beneficiary answer the questions if that permits he or she to participate. If beneficiary comes onto line, reintroduce and continue. If the beneficiary cannot complete the interview with assistance, thank the gatekeeper for his/her time. Do not accept a proxy interview.

I am contacting you today because we are doing a study for the Social Security Administration. The study is about how people with disabilities find and keep jobs. As a thank-you we will send you your choice of a \$20 gift card from Wal-Mart or Amazon for talking to us. The gift card will not affect your benefits in any way if you are receiving any. We would like to talk for about 30-40 minutes on the phone at a time that is good for you.

What we learn from you will help the Social Security Administration do a better job of serving individuals with disabilities through its benefit programs in the future.

Would you be willing to help us with our study? [*Regardless of answer, continue with next paragraph*].

Your participation in this call will be voluntary. Whether or not you participate will have no effect on your Social Security benefits now or in the future. There is no risk to you participating. You can stop the interview at any time. You also do not have to answer any question you don't feel comfortable answering.

[If reluctant]: We would really appreciate your help with our study. It is only by talking to people that SSA can understand what works and what doesn't work for people who may be trying to work and get off benefits. Would you be willing to talk to us? We want to talk to you whether or not you are currently receiving cash benefits.

[If still reluctant] Is there any information I can provide to relieve any concerns you have? *If yes, provide information or offer to provide SSA contact for more information: Elaine Gilby, 202-358-6449, elaine.gilby@ssa.gov if legitimacy of the study is a concern.*

[If no, terminate call.]

[If agrees to participate] Thank you for helping us with our study. [Go to Section B screening questions]

B. Screening Questions

Before we schedule an interview, I want to confirm some information and ask you a few questions to make sure you are eligible for our study.

INTERVIEWER: Refer to contact sheet and update contact sheet as necessary based on responses below.

1. I have your name as _____. Is this correct?

2. I have your age as _____. Is this correct?

3. Are you currently working for pay or self-employed?

Yes: _____ [Go to 4]

No: _____ [Go to Termination Section D]

4. I understand that in the past you received Social Security disability benefits. Are you currently receiving disability benefits?

Yes: _____ [Continue to Scheduling Section C]

No: _____ Did your benefits end because you were working or because of some other reason?

Off benefits due to earnings: _____ [Continue to Scheduling Section C]

Never on benefits: _____ [Go to Termination Section D]

Off benefits for reason other than work: _____ [Go to Termination Section D]

C. Schedule Eligible Respondent

1. When would be a good time for us to call you? The call would take about 30 to 40 minutes. *(Refer to times available on interview calendar, if none convenient to beneficiary, write down generally convenient times and say that we will call them back to confirm a time)*

2. Is the phone number we are talking on now the best one to use or should we call another number?

This one (note number dialed) _____

Other _____

That's all of the information I need right now. One of my colleagues will call on (appointment time) to speak with you. Thanks again. Have a great day.

INTERVIEWER: Update contact sheet with relevant information from the phone screen.

D. Termination for Ineligible Respondents

Based on the information you have given me, it appears that you are not eligible to participate in our study. Thank you for taking the time to answer my questions. Goodbye.

Employed Young adults Sample Interview Guide

The following protocols are intended to elicit information from working Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries who are under age 30 about facilitators and barriers to employment and benefit independence. The information collected will be used to help SSA better understand the personal, environmental, and employment factors that help or hinder beneficiaries in their effort to find and keep a job.

Beneficiaries will be recruited and screened for the interviews by telephone. We will obtain a sample from SSA of SSI, SSDI, and concurrent beneficiaries under age 30 who are employed. During the initial recruitment call, we will have verified the sampled person's name, age, address, and phone number, and determined whether the sample person is employed. In Module I, we will confirm employment status again at the beginning of the interview and determine other characteristics that are important for question routing.

The following protocols are intended to elicit information from young SSI and SSDI beneficiaries about facilitators and barriers to employment and benefit independence. Module II will be administered to beneficiaries who, although working, indicate that their earnings have recently declined or have been unstable. Module III will be administered to beneficiaries who indicate that their earnings have remained about the same or increased. At the end of each of these modules, screening questions will determine whether respondents should continue to Module IV for questions about benefit suspension or skip to the interview termination Module V.

Note: If beneficiaries attempt to ask questions about their benefits at any point during the discussion: I'm sorry. I am not an expert on [Social Security disability benefits/Medicare/Medicaid], so I cannot answer questions or give advice about disability benefits or your personal circumstances. If you'd like, you can call the Social Security toll-free number. That number is 1-800-772-1213 or TDD 1-800-325-0778.

Introduction

See contact sheet for information from initial screen.

[After scheduled interviewee is on the line] Hello, this is _____ from Mathematica Policy Research. We set an appointment for me to call now. Is this still a good time? I am calling to talk with you to learn more about the things that help people with disabilities find work and continue working. The Social Security Administration wants to learn how well their programs meet the needs of people like you. We know how hard it is to find and keep jobs so we would like to understand how you were able to reach your success. We want to learn about what worked in helping you to succeed and anything that made it hard for you to keep working.

My questions will take about 30 to 40 minutes to answer. As a thank you for talking with me, we will send you a \$20 gift card to your choice of either Amazon or Wal-Mart. The gift card will not affect your benefits in any way if you are receiving any. At the end of our talk, I will make sure I have your right address for mailing the gift card.

You can choose not to answer any questions you don't want to. Your answers will be kept strictly confidential and our reports will not use your name or identify you personally. Further, Social Security will not use this information to decide whether you can stay on disability benefits. We are talking to you only to collect information for research. This call will be recorded so that I can refer to it when writing up my interview report. Is it OK to begin now?

MODULE I. CONFIRM CURRENT EMPLOYMENT AND BENEFIT STATUS

Interviewer: Start recording now.

First, I would like to confirm some information you told us previously.

Interviewer: Correct information on contact sheet if necessary based on responses below.

1. I understand that you are now working at a job for pay or are self-employed. Is that correct?

Yes ____ [Continue to 2]

No ____ [Clarify current employment status. If not currently working terminate interview, respondent is no longer eligible.]

2. Thinking about how much money you made from working over the past six months, did it:

Stay about the same _____ (steady earnings)

Mostly go up _____ (increased earnings)

Mostly go down _____ (earnings declined)

Go up and down _____ (earnings not steady)

INTERVIEWER: Note earnings status on contact sheet for Module II/III skip and question wording in subsequent questions.

3. Are you currently receiving disability benefits from Social Security?

PROBE: This includes either Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI).

INTERVIEWER: Note on contact sheet for Module IV screen:

____ Currently receiving benefits (Go to 4)

____ Not currently receiving benefits (Continue to 3a)

____ Never received benefits (Terminate interview if does not acknowledge ever receiving benefits. Note reason(s) for interview ineligibility on contact sheet.)

3a. When did you last receive disability benefits from Social Security?

PROBE: Your best estimate is fine [approximate timeframe is OK, probe regarding how many months/years ago last received benefits].

Terminate interview if does not acknowledge ever receiving benefits. Note reason(s) for interview ineligibility on contact sheet.

4. How old were you when you first became limited in the kind or amount of work or other daily activities you could do? Your best guess is fine.

INTERVIEWER: If earnings have declined or not been steady, go to Module II. If earnings steady or increasing, go to Module III

MODULE II. EARNINGS DECLINED OR NOT STEADY

Responses to all open-ended items should be followed with standard probes such as: “Please tell me more about that.” “And then what?” “How did that happen?” and “Anything else?”

Use the subquestions and probes following each open-ended question below as needed to elicit more detail from the respondent.

A. School and Early Work Experience

I would like to start by talking about your experiences at school.

1. Did having a disability make it difficult for you to go to school or to finish school? Why or why not?
 - a. Did you graduate from high school?
 - b. (if graduated high school) Did you ever go to college or vocational school after high school? Did you graduate?
 - c. What kinds of things helped you with your disability while you were in high school [or college]?
 - d. (if applicable) Why didn't you graduate from [high school/college]?
2. How old were you when you first started receiving disability benefits?
3. (If appropriate based on age of first benefit receipt) Did you ever have a steady job before you went on benefits?
 - If yes: Were any of the jobs you had in your chosen field or career at the time, or did you consider them just temporary jobs?
 - If worked in chosen field/career: Has your disability caused you to change the types of jobs you can do or to change your career? If so, how and why?

B. Initial Work Attempts/Starting to Work

1. Now, I would like to ask you to think back to the time when you most recently began working. How and why did that happen?

Address the following questions if not covered in answers to questions above:

- a. Why did you want to work? What led you to make that decision?
- b. What steps did you take to start work?
- c. How did you go about finding a job and starting to work? Who helped you?

- d. How did you find your job? Was it difficult to find a job? Why? What barriers did you face?
- e. Did you get any services to help you find a job or get ready for work? How important were these things in helping you get back to work at the beginning?
- f. Was getting off benefits a goal? What led you to make that decision?
- g. Were you worried about overpayments or losing benefits if you worked?
 - If so, did your concern about overpayments or losing benefits affect the type of job you looked for or the amount of time you were willing to work?
2. Why did this job work out for you (willing company, accommodation, transportation, OJT program)?
3. Why did you start working when you did?
 - Did something change? (Health, access to transportation, finished school, needed more money)
4. What was most important in helping you start working?
5. What help or supports did you use or receive, if any?

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

6. Were there any supports you needed to start working but did not have? How could these have helped?
7. Is there anything else that we didn't talk about that you think was important to your being able to start working?

C. While Working

1. Now I would like to ask you about how things went for you after you started working at your current job. How is it going?

Address the following questions if not covered in answers to questions above:

- a. What things went well and helped you work when you first started this job?
- b. What are the most important things that help you work now?
- c. What supports did you use or receive when you first started and what do you use now?

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

- d. What was your biggest work-related challenge? Why? How did you deal with this?
 - e. What other issues did you face with working?
2. Are there any supports or assistance that you don't have but that would make it easier for you to keep working? How would they help you?
 3. Is there anything else that we didn't talk about that you think was important in helping you to keep working?

D. Reduced or Unsteady Earnings

You told me earlier that...*(refer to contact sheet for appropriate status)*

The money you make from working has gone down over the past six months.

OR

The money you make from working has been up and down over the past six months.

1. What were the most important reasons [your earnings went down /your earnings went up and down]? Why?

Probe with a few examples from the following list, if needed.

Personal	Employer or work-related
<ul style="list-style-type: none"> • Child or elder care issues • Transportation issues • Housing issues • Needed assistive equipment or a device • Getting ready took too long • Change in health or functioning • People who were helping stopped 	<ul style="list-style-type: none"> • Needed accommodations • Problems with physical workspace (accessibility) • Schedule was too taxing, too many hours • Job was too stressful, hard, couldn't handle it • Dissatisfied with job • Got fired or laid off

2. What might have helped you to stay working and earning the same amount or more?
 - a. Are there any supports you need that you do not have? How would these help you?
 3. Did you stop working, reduce your hours, or do something else because you were you worried about losing benefits?
 - a. If so, why is it important to you not to lose benefits? What do you worry will happen if you lose them?
 - b. What about other benefits like Medicare/Medicaid, food stamps, welfare/TANF, and housing?
 4. Were you worried about overpayments?
 - a. Have you ever received an overpayment notice from Social Security? If yes, what happened and how was it resolved?
 - b. If worried but never received overpayment: What do you worry will happen if you receive an overpayment notice?
 5. Is there anything we haven't discussed that might make you have to work less or stop working?
 6. Is there anything else that we didn't talk about that you think was important when thinking about why [you started earning less/your earnings have not been steady]?
- E. Future Work Efforts
1. Thinking about the future, do you think you will continue to work or try to earn more? Why or why not?
 - a. What will affect your decision?
 - b. What would have to be different for you to be able to work or earn more?
 - c. What supports do you need that you do not have?

2. Is there anything else we didn't talk about that you think would be important for you to keep working or to work more?

F. Screen for Module IV

1. Earlier you told me...(refer to contact sheet for appropriate status)

You are not currently receiving disability benefits [Go to 2]

OR

You are receiving disability benefits [Go to 3]

2. Did your benefits stop because you were working?

Yes [Skip to Module IV]

No [Continue to 2a]

- 2a. Why did your benefits stop?

INTERVIEWER: If reasons why disability benefits stopped are *unrelated* to work and earnings, go to Section G; otherwise go to Module IV.

3. At any time during the past year, were your benefits stopped because you were working?

Yes [Skip to Module IV]

No [Continue to Section G]

G. Other

1. Before we end, is there anything else you would like to tell me or that you think I should know about what working [and going off disability benefits] has been like for you?
2. Do you have any suggestions about what Social Security could do to help you or other people with disabilities become employed or stay working?

GO TO MODULE V. INTERVIEW TERMINATION

MODULE III. STEADY OR INCREASED EARNINGS

Responses to all open-ended items should be followed with standard probes such as “Please tell me more about that.” “And then what?” “How did that happen?” and “Anything else?”

Use the subquestions and probes following each open-ended question below as needed to elicit more detail from the respondent.

A. School and Early Work Experience

I would like to start by talking about your experiences at school.

1. Did having a disability make it difficult for you to go to school or to finish school? Why or why not?
 - a. Did you graduate from high school?
 - b. (if graduated high school) Did you ever go to college or vocational school after high school? Did you graduate?
 - c. What kinds of things helped you with your disability while you were in high school [or college]?
 - d. (if applicable) Why didn't you graduate from [high school/college]?
2. How old were you when you first started receiving disability benefits?
3. (If appropriate based on age of first benefit receipt) Did you ever have a steady job before you went on benefits?

If yes: Were any of the jobs you had in your chosen field or career at the time, or did you consider them just temporary jobs?

If worked in chosen field/career: Has your disability caused you to change the types of jobs you can do or to change your career? If so, how and why?

B. Initial Work Attempts/Starting to Work

1. Now, I would like to ask you to think back to the time when you started working at your current job. How and why did that happen?

Address the following questions if not covered in answers to questions above:

- a. Why did you want to work? What led you to make that decision?
- b. How did you go about finding a job and starting to work? Who helped you?
- c. How did you find your job? Was it difficult to find one? Why? What barriers did you face?
- d. Did you get any services to help you find a job or get ready for work? How important were these things in helping you get back to work at the beginning?
- e. Was getting off benefits a goal? What led you to make that decision?
- f. Were you worried about overpayments or losing benefits if you worked?

If so, did your concern about overpayments or losing benefits affect the type of job you looked for or the amount of time you were willing to work?

2. Why did this job work out for you (willing company, accommodation, transportation, OJT program)?
3. Why did you start working when you did?
 - a. Did something change (health, access to transportation, finished school, needed more money)?
4. What was most important in helping you start working?
5. What supports did you use or receive, if any?

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

6. Were there any supports you needed to start working but did not have? How could these have helped?

7. Is there anything else that we didn't talk about that you think was important to your being able to start working?

C. While Working

1. Now I would like to ask you about how things went for you after you started working at your current job. How is it going?

Address the following questions if not covered in answers to questions above:

- a. What things went well and helped you to work when you first started?
- b. What are the most important things that help you work now?
- c. What supports did you receive when you first started, and what do you receive now?

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

- d. What has been your biggest work-related challenge? Why? How do/did you deal with this?
 - e. What other issues have you faced with working?
2. Is there anything else that we didn't talk about that you think was important when you first started working or that is important now to make it so you can keep working?

D. Ongoing Work Effort

1. I would like to ask you about things that might make it easier for you to keep working. What will help you to keep working?
- a. Are there any supports you need that you do not have? How would these help you?
2. What kinds of things might make you need or want to work less or stop working?
3. Is there anything else we didn't talk about you think will be important for you to keep working?

If earnings increased over past six months, go to Section E (refer to contact sheet for appropriate status).

Otherwise, skip to Section F.

E. Earnings Increase (If earnings increased in past six months)

1. Earlier you told me that your earnings have gone up over the six months.
 - a. Why did they go up?
 - b. What did you do to increase your earnings?
 - c. Did you use any new supports or assistance to increase your earnings? How did these help you to increase your earnings?

F. Future Work Efforts

1. Thinking about the future, do you think you will continue to work or try to earn more? Why or why not?
 - a. What will affect your decision?
 - b. What would have to be different for you to be able to work or earn more?
 - c. What supports do you need that you do not have?
2. Is there anything else we didn't talk about that you think would be important for you to keep working or to work more?

G. Screen for Module IV

1. Earlier you told me...(refer to contact sheet for appropriate status)

You are not currently receiving disability benefits [Go to 2]

OR

You are receiving disability benefits [Go to 3]

2. Did your benefits stop because you were working?

Yes [Skip to Module IV]

No [Continue to 2a]

- 2a. Why did your benefits stop?

INTERVIEWER: If reasons why disability benefits stopped are unrelated to work and earnings, go to Section G; otherwise go to Module IV.

3. At any time during the past year, were your benefits stopped because you were working?

Yes [Skip to Module IV]

No [Continue to Section G]

H. Other

1. Before we end, is there anything else you would like to tell me or that you think I should know about what working has been like for you?

2. Do you have any suggestions about what Social Security could do to help you or other people with disabilities become employed or stay working?

GO TO MODULE V. INTERVIEW TERMINATION

MODULE IV. BENEFIT SUSPENSE

Refer to contact sheet and note status for skip at question 3 below:

___ *Currently receiving benefits*

___ *Not currently receiving benefits*

I want to ask you a few questions about going off of disability benefits.

1. Was getting off benefits a goal? What led you to make that decision? What steps did you take to get off benefits?
2. Were you worried about losing benefits?
 - a. If so, why is it important to you not to lose benefits? What did you worry would happen if you lost them?
 - b. What about other benefits like Medicare/Medicaid, food stamps, welfare/TANF, and housing? Were you worried about losing them?
3. Did Social Security ever notify you that you had an overpayment?

If yes:

- a. How much was the overpayment?
- b. What did you do to resolve the overpayment?
- c. Did the overpayment cause you to change how much or where you worked? How?

If back on benefits, go to #4; otherwise, skip to Section G

4. Do you plan to try to get off benefits again in the future? Why or why not?

G. Other

1. Before we end, is there anything else you would like to tell me or that you think I should know about what working and going off disability benefits has been like for you?
2. Do you have any suggestions about what Social Security could do to help people with disabilities become employed or stay working?

GO TO MODULE V. INTERVIEW TERMINATION

MODULE V. INTERVIEW TERMINATION

INTERVIEWER: Stop recording now.

That's all of the questions I have. We really appreciate you taking the time to help us with our study. I want to confirm that we have your correct mailing address so we can send you a \$20 gift card.

Which type of gift card would you like, Amazon or Wal-Mart? _____

Name: _____

Address the card should be sent to:

You should receive the gift card in the mail within the next two weeks.

Thanks again. Have a great day.

B. HIGH EARNER SAMPLE PROTOCOLS

This page has been left blank for double-sided copying.

HIGH EARNER SAMPLE RECRUITMENT PROTOCOL

The script is intended to recruit SSI and SSDI beneficiaries who recently worked and had high earnings for interviews about barriers and facilitators to employment and benefit independence. The information collected will be used to deepen SSA's understanding of factors that impact employment success, including people, programs, and employers, among other things.

We will obtain a sample of SSI and SSDI beneficiaries from SSA who, based on SSA administrative data, had high earnings in the recent past and are likely to still have high earnings, or had high earnings in the recent past but are likely to no longer have high earnings.

During the initial recruiting phone call we will explain the study goal, gain interest, verify the sampled person's name, address, and phone number, and determine the sample person's employment and benefit status. The verification of previous/current employment, maintenance of earnings levels, and benefit receipt status will allow us to target the appropriate number of interviews to each of the two groups of interest. This is necessary because SSA administrative data will not contain current information on these characteristics.

We will recruit with the goal of obtaining 30 individuals with high earnings who have sustained high earnings, and 30 who had high earnings but whose earnings have declined or ceased. We will also attempt to achieve approximately one-half of interviewees to be current/former SSI recipients and one-half to be current/former SSDI beneficiaries in each group

Note: If beneficiaries attempt to ask questions about their benefits at any point during the discussion: I'm sorry. I am not an expert on [Social Security disability benefits/Medicare/Medicaid]. So I cannot answer questions or give advice about disability benefits or your personal circumstances.

A. Recruitment

Hi, my name is _____, and I work for a company called Mathematica Policy Research. May I please speak with (beneficiary name)?

If not available, arrange callback.

If gatekeeper says not intellectually capable, explain the goals of the interview and that it is designed for people like their household member. Determine from gatekeeper if the beneficiary has been employed during the past six months, and the earnings trajectory over that period. If meets the study criteria, determine if he or she could likely handle the interview. Suggest that gatekeeper could help beneficiary answer the questions if that permits he or she to participate. If beneficiary comes onto line, reintroduce and continue. If the beneficiary cannot complete the interview with assistance, thank the gatekeeper for his/her time. Do not accept a proxy interview.

I am contacting you today because we are doing a study for the Social Security Administration. The study is about how people with disabilities find and keep jobs. As a thank-you we will send you your choice of a \$20 gift card from Wal-Mart or Amazon for talking to us. The gift card will not affect your benefits in any way if you are receiving any. We would like to talk for about 30-40 minutes on the phone at a time that is good for you.

What we learn from you will help the Social Security Administration do a better job of serving individuals with disabilities through its benefit programs in the future.

Would you be willing to help us with our study? [*Regardless of answer, continue with next paragraph*].

Your participation in this call will be voluntary. Whether or not you participate will have no effect on your Social Security benefits now or in the future. There is no risk to you participating. You can stop the interview at any time. You also do not have to answer any question you don't feel comfortable answering.

[If reluctant]: We would really appreciate your help with our study. It is only by talking to people that SSA can understand what works and what doesn't work for people who may be trying to work and get off benefits. Would you be willing to talk to us? We want to talk to you whether or not you are currently receiving cash benefits.

[If still reluctant] Is there any information I can provide to relieve any concerns you have? *If yes, provide information or offer to provide SSA contact for more information: Elaine Gilby, 202-358-6449, elaine.gilby@ssa.gov if legitimacy of the study is a concern.*

[If no, terminate call.]

[If agrees to participate] Thank you for helping us with our study. [Go to Section B screening questions]

B. Screening Questions

Before we schedule an interview, I want to confirm some information and ask you a few questions to make sure you are eligible for our study.

INTERVIEWER: Refer to contact sheet and update contact sheet as necessary based on responses below.

1. I have your name as _____. Is this correct?
2. I have your age as _____. Is this correct?
3. Are you currently working for pay or self-employed?
Yes: _____ [Skip to 5]
No: _____ [Continue to 4]
4. Did you work at a job for pay at any time during the past six months (since last _____)?
Yes: _____ [Continue to 6 and mark question 5 as earnings declined]
No: _____ [Go to screener termination Section D]
5. Thinking about how much money you made from working over the past six months (since last _____), did it:
Stay about the same: _____ (steady earnings)
Mostly go up: _____ (increased earnings)
Mostly go down: _____ (earnings declined)
Go up and down: _____ (earnings not steady)
6. I understand that in the past you received Social Security disability benefits. Are you currently receiving disability benefits?
Yes: _____ [Skip to Scheduling Section C]
No: _____ [Continue to 6a]

6a. Did your benefits end because you were working or because of some other reason?

Off benefits due to earnings: _____ [Go to Scheduling Section C]

Never on benefits: _____ [Go to termination Section D]

Off benefits for reason other than work: ____ [Go to termination Section D]

C. Schedule Eligible Respondent

2. When would be a good time for us to call you? The call would take about 30 to 40 minutes. *(Refer to times available on interview calendar, if none convenient to beneficiary, write down generally convenient times and say that we will call them back to confirm a time)*

3. Is the phone number we are talking to you on now the best one to use or should we call another number?

This one (note number dialed) _____

Other _____

That's all of the information I need right now. One of my colleagues will call on (appointment time) to speak with you. Thanks again. Have a great day.

INTERVIEWER: Update contact sheet with relevant information from the phone screen.

D. Termination for Ineligible Respondents

Based on the information you have given me, it appears that you are not eligible to participate in our study. Thank you for taking the time to answer my questions. Goodbye.

HIGH EARNER SAMPLE INTERVIEW GUIDE

The following protocols are intended to elicit information from working-age Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries about facilitators and barriers to employment and benefit independence. The information collected will be used to help the Social Security Administration (SSA) better understand the personal, environmental, and employment factors that help or hinder beneficiaries in their effort to find and keep a job.

Beneficiaries will be recruited and screened for the interviews by telephone. We will obtain a sample from SSA of SSI, SSDI, and concurrent beneficiaries who have achieved high earnings in the prior six months and were or were not able to sustain high levels of earnings. During the initial recruitment call, we will have verified the sampled person's name, age, address, and phone number, and determined whether the sample person receives benefits, is employed, and if employed, the level of their current earnings relative to the prior six months. In Module I, we will confirm employment status again at the beginning of the interview and determine other characteristics that are important for question routing.

The following protocols are intended to elicit information from SSI and SSDI beneficiaries about facilitators and barriers to employment and benefit independence. Module II will be administered to beneficiaries who achieved high earnings during the prior six months but were not able to sustain them. Module III will be administered to beneficiaries who achieved high earnings and were able to sustain them. At the end of each of these modules, screening questions will determine whether respondents should continue to Module IV for questions about benefit suspension or skip to the interview termination Module V.

Note: If beneficiaries attempt to ask questions about their benefits at any point during the discussion: I'm sorry. I am not an expert on [Social Security disability benefits/Medicare/Medicaid], so I cannot answer questions or give advice about disability benefits or your personal circumstances. If you'd like, you can call the Social Security toll-free number. That number is 1-800-772-1213 or TDD 1-800-325-0778.

Introduction

See contact sheet for information from initial screen.

[After scheduled interviewee is on the line] Hello, this is _____ from Mathematica Policy Research. We set an appointment to talk now. Is this still a good time? I am calling to talk with you to learn more about the things that help people with disabilities find work and continue working. The Social Security Administration wants to learn how well their programs meet people's needs. We know how hard it is to find and keep jobs so we would like to understand how you were able to reach your success. We want to learn about what worked in helping you to succeed and anything that made it hard for you to keep working.

My questions will take about 30 to 40 minutes to answer. As a thank you for talking with me, we will send you a \$20 gift card to your choice of either Amazon or Wal-Mart. The gift card will not affect your benefits in any way if you are receiving any. At the end of our talk, I will make sure I have your right address for mailing the gift card.

You can choose not to answer any questions you don't want to. Your answers will be kept strictly confidential and our reports will not use your name or identify you personally. Further, SSA will not use this information to decide whether you can stay on disability benefits. We are talking to you only to collect information for research. This call will be recorded so that I can refer to it when writing up my interview report. Is it OK to begin now?

MODULE I. CONFIRM CURRENT EMPLOYMENT AND BENEFIT STATUS

INTERVIEWER: Start recording now.

First, I would like to confirm some information you told us previously.

Interviewer: Correct information on contact sheet if necessary based on responses below.

If currently working based on phone screen:

1. I understand that you are now working at a job for pay or are self-employed. Is that correct?

Yes [Go to 2]

No [Continue to 1a]

- 1a. So you are not currently employed at a job for pay or self-employed?

Clarify status. If not currently working skip to 3. Otherwise, continue to 2.

2. I also understand that, over the past six months...(refer to contact sheet and continue as appropriate)

The money you have earned from working has been steady. Is that correct?

OR

The money you have earned from working has gone up. Is that correct?

OR

The money you have earned from working has gone up and down. Is that correct?

OR

The money you have earned from working has gone down. Is that correct?

If correct, skip to 4

If not correct, clarify status, note on contact sheet for interview routing, and skip to 4.

Terminate interview if never worked while on benefits or does not acknowledge ever receiving benefits. Note reason(s) for interview ineligibility on contact sheet.

If not working based on phone screen or above:

3. [OK] I understand that you are not working now, but that you worked in the past while receiving Social Security disability benefits. Is that correct?

If correct, continue to 4

If not correct, clarify status. Terminate interview if never worked while on benefits or does not acknowledge ever receiving benefits. Otherwise, continue.

All respondents:

4. Are you currently receiving disability benefits from Social Security?

PROBE: This includes either Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI).

INTERVIEWER: Note on contact sheet for Module IV screen:

- ___ Currently receiving benefits (Go to 5)
- ___ Not currently receiving benefits (Continue to 4a)
- ___ Never received benefits (Terminate interview if does not acknowledge ever receiving benefits. Note reason(s) for interview ineligibility on contact sheet.)

- 4a. When did you last receive disability benefits from Social Security?

PROBE: Your best estimate is fine [approximate timeframe is OK, probe regarding how many months/years ago last received benefits].

Terminate interview if does not acknowledge ever receiving benefits. Note reason(s) for interview ineligibility on contact sheet.

5. How old were you when you first became limited in the kind or amount of work or other daily activities you could do? Your best guess is fine.

INTERVIEWER: If earnings have not been steady, have declined, or stopped, go to Module II. If earnings have been steady or increasing, go to Module III

MODULE II. EARNINGS NOT STEADY, DECLINED OR STOPPED

Responses to all open-ended items should be followed with standard probes such as: “Please tell me more about that.” “And then what?” “How did that happen?” and “Anything else?”

Use the subquestions and probes following each open-ended question below as needed to elicit more detail from the respondent.

If under age 30, go to Section A; otherwise, Skip to Section B

A. (Under age 30 only) School and Early Work Experience

I would like to start by asking you about your experiences at school.

1. Did having a disability make it difficult for you to go to school or to finish school? Why or why not?
 - a. Did you graduate from high school?
 - b. (if graduated high school) Did you ever go to college or vocational school after high school? Did you graduate?
 - c. What kinds of things helped you with your disability while you were in high school [or college]?
 - d. (if applicable) Why didn't you graduate from [high school/college]?
2. How old were you when you first started receiving disability benefits?
3. (If appropriate based on age of first benefit receipt) Did you ever have a steady job before you went on benefits?

If yes: Were any of the jobs you had in your chosen field or career at the time, or did you consider them just temporary jobs?

If worked in chosen field/career: Has your disability caused you to change the types of jobs you can do or to change your career? If so, how and why?

B. (All) Initial Work Attempts/Starting to Work

1. [Now] I would like to /ask you to think back to the time when you most recently began working. How and why did that happen?

Address the following questions if not covered in answers to questions above:

- a. Why did you want to work? What led you to make that decision?
- b. How did you go about finding a job and starting to work? Who helped you?
- c. How did you find your job? Was it difficult to find a job? Why? What barriers did you face?
- d. Did you get any services to help you find a job or get ready for work? How important were these things in helping you get back to work at the beginning?
- e. Was getting off benefits a goal? What led you to make that decision?
- f. Were you worried about overpayments or losing benefits if you worked?

If so, did your concern about overpayments or losing benefits affect the type of job you looked for or the amount of time you were willing to work?

2. Why did this job work out for you (willing company, accommodation, transportation, OJT program)?

3. Why did you start working when you did?

Did something change? (Health, access to transportation, finished school, needed more money)

4. What was most important in helping you start working?

5. What help or supports did you use or receive, if any?

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

6. Were there any supports you needed to start working but did not have? How could these have helped?

7. Is there anything else that we didn't talk about that you think was important to your being able to start working?

C. While Working

1. Now I would like to ask you about how things went for you after you started working [at your last/current job]. How [did it go/is it going]? [What was it like when you were working?]

Address the following questions if not covered in answers to questions above:

- a. What things went well and helped you to work [when you had this job]?
- b. What were the most important things that helped you work [when you had your job]?
- c. What supports did you use or receive when you first started? [What supports do you use now?]

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

- d. What was your biggest work-related challenge? Why? How did you deal with this?
 - e. What other issues did you face with working?
2. Are there any supports or assistance that you [don't/didn't] have but that would [have made/make] it easier for you to keep working? How would they help you?
3. Is there anything else that we didn't talk about that you think was important in helping you to keep working [when you had this job]?

D. Reducing or Stopping Work

You told me earlier that.....(*refer to contact sheet for appropriate status*)

You are no longer working.

OR

The money you make from working has gone down over the past six months.

OR

The money you make from working has gone up and down over the past six months.

2. What were the most important reasons [you stopped working/your earnings went down/your earnings went up and down]? Why?

Probe with a few examples from the following list, if needed.

Personal	Employer or Work-Related
<ul style="list-style-type: none"> • Child or elder care issues • Transportation issues • Housing issues • Needed assistive equipment or a device • Getting ready took too long • Change in health or functioning • People who were helping stopped 	<ul style="list-style-type: none"> • Needed accommodations • Problems with physical workspace (accessibility) • Schedule was too taxing, too many hours • Job was too stressful, hard, couldn't handle it • Dissatisfied with job • Got fired or laid off

3. What might have helped you to [stay working /stay earning the same amount]?
 - a. Are there any supports you need that you do not have? How would these help you?
4. Did you stop working, reduce your hours, or do something else because you were worried about losing benefits?
 - a. If so, why is it important to you not to lose benefits? What do you worry will happen if you lose them?
 - b. What about other benefits like Medicare/Medicaid, food stamps, welfare/TANF, and housing?
5. Were you worried about overpayments?
 - a. Have you ever received an overpayment notice from Social Security? If yes, what happened and how was it resolved?
 - b. If worried but never received overpayment: What do you worry will happen if you receive an overpayment notice?
6. (IF CURRENTLY EMPLOYED) Is there anything we haven't discussed that might make you have to work less or stop working?
7. Is there anything else that we didn't talk about that you think was important when thinking about why [you started earning less/you stopped working/your earnings were not steady]?

E. Future Work Efforts

1. Thinking about the future, do you think you will [go back to work/be able to earn more from working]? Why or why not?
 - a. What will affect your decision?
 - b. What would have to be different for you to be able to [start working again/earn more]?
 - c. What supports do you need that you do not have?
2. Is there anything else we didn't talk about that you think would be important for you to [work again/earn more from working]?

F. Screen for Module IV

1. Earlier you told me: (*refer to contact sheet for appropriate status*)

You are not currently receiving disability benefits [Go to 2]

OR

You are receiving disability benefits [Go to 3]

2. Did your benefits stop because you were working?

Yes [Skip to Module IV]

No [Continue to 2a]

- 2a. Why did your benefits stop?

INTERVIEWER: If reasons why disability benefits stopped are unrelated to work and earnings, go to Section G; otherwise go to Module IV.

3. At any time during the past year, were your benefits stopped because you were working?

Yes [Skip to Module IV]

No [Continue to Section G]

G. Other

1. Before we end, is there anything else you would like to tell me or that you think I should know about what working has been like for you?
2. Do you have any suggestions about what Social Security could do to help you or other people with disabilities become employed or stay working?

GO TO MODULE V. INTERVIEW TERMINATION

MODULE III. STEADY OR INCREASED EARNINGS

Responses to all open-ended items should be followed with standard probes such as “Please tell me more about that.” “And then what?” “How did that happen?” and “Anything else?”

Use the subquestions and probes following each open-ended question below as needed to elicit more detail from the respondent.

If under age 30, go to Section A; otherwise, Skip to Section B

A. (Under Age 30) School and Early Work Experience

I would like to start by asking you about your experiences in school.

1. Did have a disability make it difficult for you to go to school or to finish school? Why or why not?
 - a. Did you graduate from high school?
 - b. (if graduated high school) Did you ever go to college or vocational school after high school? Did you graduate?
 - c. What kinds of things helped you with your disability while you were in high school [or college]?
 - d. (if applicable) Why didn't you graduate from [high school/college]?
2. How old were you when you first started receiving disability benefits?
3. (If appropriate based on age of first benefit receipt) Did you ever have a steady job before you went on benefits?

If yes: Were any of the jobs you had in your chosen field or career at the time, or did you consider them just temporary jobs?

If worked in chosen field/career: Has your disability caused you to change the types of jobs you can do or to change your career? If so, how and why?

B. (ALL) Initial Work Attempts/Starting to Work

1. [Now,] I would like to ask you to think back to the time when you started working at your current job. How and why did that happen?

Address the following questions if not covered in answers to questions above:

- a. Why did you want to work? What led you to make that decision?
- b. How did you go about finding a job and starting to work? Who helped you?

- c. How did you find your job? Was it difficult to find one? Why? What barriers did you face?
- d. Did you get any services to help you find a job or get ready for work? How important were these things in helping you get back to work at the beginning?
- e. Was getting off benefits a goal? What led you to make that decision?
- f. Were you worried about overpayments or losing benefits if you worked?

If so, did your concern about overpayments or losing benefits affect the type of job you looked for or the amount of time you were willing to work?

2. Why did this job work out for you (willing company, accommodation, transportation, OJT program)?
3. Why did you start working when you did?
 - a. Did something change (health, access to transportation, finished school, needed more money)?
4. What was most important in helping you start working?
5. What supports did you use or receive, if any?

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

6. Were there any supports you needed to start working but did not have? How could these have helped?
7. Is there anything else that we didn't talk about that you think was important to your being able to start working?

C. While Working

1. Now I would like to ask you about how things went for you after you started working at your current job. How is it going?

Address the following questions if not covered in answers to questions above:

- a. What things worked well when you first started?
- b. What are the most important things that help you work now?
- c. What supports did you receive when you first started, and what do you receive now?

Probe with a few examples from the following list, if needed.

Training/rehabilitation	Employer-related supports	Other Supports
<ul style="list-style-type: none"> • Training or education • Job search assistance • Vocational rehabilitation • Assistive equipment/devices 	<ul style="list-style-type: none"> • Company willing to hire • Company willing to accommodate • Company allowed part-time/flexible schedule • Company allowed work from home • Support from coworkers/boss 	<ul style="list-style-type: none"> • Assistance from family/friends • Assistance from church/charity/other private organization • Assistance from counselor/case manager • Help with personal care • Reliable transportation • Child or elder care

- d. What has been your biggest work-related challenge? Why? How do/did you deal with this?
 - e. What other issues have you faced with working?
2. Are there any supports or assistance that you don't have but that would make it easier for you to keep working? How would they help you?
 3. Is there anything else that we didn't talk about that you think was important when you first started working or that is important now to make it so you can keep working?
- D. Ongoing Work Effort
1. I would like to ask you about things that might make it easier for you to keep working. What will help you to keep working?
 - a. Are there any supports you need that you do not have? How would these help you?
 2. What kinds of things might make you need or want to work less or stop working?
 3. Is there anything else we didn't talk about you think will be important for you to keep working?

If earnings increased over past six months, go to Section E (refer to contact sheet for appropriate status).

Otherwise, skip to Section F.

E. Earnings Increase (If earnings increased in past six months)

1. Earlier you told me that your earnings have gone up over the six months.
 - a. Why did they go up?
 - b. What did you do to increase your earnings?
 - c. Did you use any new supports or assistance to increase your earnings? How did these help you to increase your earnings?

F. Future Work Efforts

1. Thinking about the future, do you think you will continue to work or try to earn more? Why or why not?
 - a. What will affect your decision?
 - b. What would have to be different for you to be able to work or earn more?
 - c. What supports do you need that you do not have?
2. Is there anything else we didn't talk about that you think would be important for you to keep working or to work more?

G. Screen for Module IV

1. Earlier you told me ... (*refer to contact sheet for appropriate status*)

You were not currently receiving disability benefits [Go to 2]

OR

You were receiving disability benefits [Go to 3]

2. Did your benefits stop because you were working?

Yes [Skip to Module IV]

No [Continue to 2a]

- 2a. Why did your benefits stop?

INTERVIEWER: If reasons why disability benefits stopped are unrelated to work and earnings, go to Section G; otherwise go to Module IV.

3. At any time during the past year, were your benefits stopped because you were working?

Yes [Skip to Module IV]

No [Continue to Section G]

H. Other

1. Before we end, is there anything else you would like to tell me or that you think I should know about what working has been like for you?

2. Do you have any suggestions about what Social Security could do to help you or other people with disabilities become employed or stay working?

GO TO MODULE V. INTERVIEW TERMINATION

MODULE IV. BENEFIT SUSPENSE

Refer to status on contact sheet for skip at question 3 below:

___ *Currently receiving benefits*

___ *Not currently receiving benefits*

I want to ask you a few questions about getting off of disability benefits.

1. Was getting off benefits a goal? What led you to make that decision? What steps did you take to get off benefits?
2. Were you worried about losing benefits?
 - a. If so, why is it important to you not to lose benefits? What did you worry would happen if you lost them?
 - b. What about other benefits like Medicare/Medicaid, food stamps, welfare/TANF, and housing? Were you worried about losing them?
3. Did Social Security ever notify you that you had an overpayment?

If yes:

- a. How much was the overpayment?
- b. What did you do to resolve the overpayment?
- c. Did the overpayment cause you to change how much or where you worked? How?

If back on benefits, go to #4; otherwise, skip to Section G

4. Do you plan to try to get off benefits again in the future? Why or why not?

A. Other

1. Before we end, is there anything else you would like to tell me or that you think I should know about what working and going off disability benefits has been like for you?
2. Do you have any suggestions about what Social Security could do to help you or other people with disabilities become employed or stay working?

GO TO MODULE V. INTERVIEW TERMINATION

MODULE V. INTERVIEW TERMINATION

INTERVIEWER: Stop recording now.

That's all of the questions I have. We really appreciate you taking the time to help us with our study. I want to confirm that we have your correct mailing address so we can send you a \$20 gift card.

Which type of gift card would you like, Amazon or Wal-Mart? _____

Name: _____

Address the card should be sent to:

You should receive the gift card in the mail within the next two weeks.

Thanks again. Have a great day.

This page has been left blank for double-sided copying.

APPENDIX B

INTERVIEWEE VIGNETTES

This page has been left blank for double-sided copying.

A. KIM

Kim, an employed, young adult concurrent beneficiary, was a third-year college student majoring in chemistry when she was in a devastating car wreck a few years ago. She sustained a traumatic brain injury and a spinal injury and was told her cognitive abilities had dropped to the level of a 6th grader. Kim had to drop out of college to recover from the accident and to relearn such basic skills as speaking, reading, and writing.

During her multi-year rehabilitation process, Kim's speech therapist suggested she seek services through the state VR agency. Kim followed this advice. She had recently given birth and needed more income than she was receiving from Social Security. Also, she wanted to prove to herself and those around her that she was, in fact, capable of working and doing "normal" things even though she had a disability. She told her VR counselor that she was not ready to jump back into a four-year college and finish her degree, but she was interested in participating in a training program that would help make her employable.

The counselor suggested a dental assistant training program because it aligned with Kim's interest in health and medicine. Kim completed dental assistant training, paid in full by the state VR agency, (including transportation, books, and uniforms). Her mother helped her with her resume, and the dental training school helped her secure an internship with her toddler's dentist. The transition went smoothly. Because the internship—and her eventual shift to part-time employee at the dental office—was with her daughter's dentist, an individual she knew and liked, rejoining the workforce was easier than it might have been under different circumstances. Also helpful was the fact that the office was close to Kim's home. From the beginning, Kim liked working and being in a professional setting. Her employer has been impressed with her skills, and she was recently promoted from an office assistant (primarily doing paperwork) to a hands-on dental assistant.

Still, her efforts have not been without difficulties. When Kim was working as an intern, she did not qualify for child care benefits and had to rely on her family to take care of her 3-year-old daughter until the internship became a paid job. These days, she sometimes has back pain when she is assisting the dentist chair-side. Although she prefers the hands-on work to the administrative functions, she believes she would not be able to do it all day because of the pain it causes her. Another issue that Kim faced during her return to work was an overpayment from Social Security. Even though she sought out information regarding how much she could work without losing her benefits and stayed within the limits, when she received the settlement from the accident, she was not only no longer eligible for SSI (though she continued to receive SSDI), she learned that some portion of her earlier SSI payments would have to be returned. This was frustrating for her because she had been diligent about educating herself on how to avoid overpayments. She is now paying back the overpayment at \$55 a month.

Moving forward, Kim would like to earn enough to get off benefits. She likes her job, but she does not want to be a dental assistant for the rest of her career and aspires to go back to school to become a dental hygienist or make some other upward move in the field. She also hopes to be able to find a long-term job where she can sit sometimes and stand sometimes to avoid aggravating her back injury. She recently started participating in the TTW program and is excited about the support as she begins to pursue additional schooling or a new job.

Kim said she wishes that Social Security could provide more assistance to mothers with disabilities, especially with child care during the period when they are involved in job training and internships. She also wishes Social Security would provide more information about the programs offered and make sure beneficiaries know it is possible to earn money through work and also receive benefits. If her speech therapist had not told her about VR services and the possibility of working while receiving benefits, she might not have pursued dental assistant school and sought employment.

B. NICK

Nick is a former SSI beneficiary with high earnings. The amount of work he was capable of doing decreased about 15 years ago after he had heart surgery. He received SSI benefits for many years after the surgery but those cash benefits stopped after he took a job as a front desk security guard at a condominium building because the SSI payment of \$800 per month was insufficient to support his lifestyle.

Before the surgery, he had worked as a bartender but after surgery, he could no longer lift heavy objects or stand for long periods of time. He worked with the state VR agency to find a new career requiring minimal movement and low stress. The agency helped him complete training to get a security license.

Nick found his security desk position on craigslist. He received no help finding or applying for the job. “I have my mental faculties,” he said, “so therefore, I’m very capable of going on the interview, sending somebody a resume. That doesn’t take very much effort.” He did, however, have some difficulty finding a job in the security field that did not require much movement.

Nick thinks this job is a good fit for him. It is low stress and does not require heavy lifting or excessive movement. He likes being around people and enjoys serving the residents. Although he struggles with his health and wishes his boss would be more understanding about taking time off for medical situations, he believes it would be hard to find a replacement job if he were to lose this one.

Despite Nick’s relative contentment with his position, he has had a great deal of difficulty during his time working and receiving benefits. One of the biggest problems Nick encountered was overpayments. Even though he believes he correctly reported his earnings to SSA each month, Social Security sent him a notification of overpayment that asked him to pay back almost \$3,000 in benefits. He is working with a lawyer to fight the overpayments because he firmly believes he accurately reported his wages. Nick also encountered problems with his medical benefits. He was enrolled in Medicaid before he began receiving Social Security benefits. When he no longer received Social Security benefits due to his earnings, he lost Medicaid. He had to go to the local Medicaid office and prove he was still eligible, an effort that was frustrating and time-consuming. Nick heavily relies on Medicaid to cover the costs of his many prescription medications and regular medical appointments.

Nick is unsure about the future. His recent frustration working with SSA regarding overpayments has made him question whether having a paying job is worth the trouble. “I’m not making much more than if I was just collecting disability without harassment letters [from SSA] every month that I owe money,” he said. Moreover, he has serious concerns about his health. He believes that even when his health is stable, he could not physically or mentally handle working more than the four days per week he currently works. Furthermore, he fears that his health will decline—he has been to the emergency room twice in the past two months for gastro-intestinal issues and heart problems. If he were to end up in the hospital for an extended period and earn no money, he would not be able to pay rent or his bills. “You just never know from one day to the next if you are disabled what’s going to happen,” he said, “and there’s a certain security knowing

you're going to have monthly income coming in." Even though Nick enjoys working, he thinks it might make more sense to receive benefits than to work.

C. RAMONA

Ramona is a 25-year-old single mother with a psychiatric disability. She was homeless from her late teens to early 20s and began receiving SSI and SSDI benefits at age 21. She had been actively searching for work for two years prior to that, but she found that no one would hire her because of her anxiety and panic attacks.

High school was a challenge. She was capable of performing well academically, but the issues she faced at home were severe and she fled that environment, dropping out of school and becoming homeless. She eventually sought assistance from a community organization that serves homeless youth and young adults. The organization provided stable, safe housing and she worked with a tutor to obtain her GED.

Ramona then attempted post-secondary education, but struggled during her first two semesters because of illness and pregnancy. She sought services at the school, but the only type offered was extended time to complete assignments or tests. Looking back, she says she would have benefitted from additional testing accommodations, such as reader service for tests. However, at the time she was unaware that such services existed.

Ramona recently moved to a new city and enrolled in post-secondary school. She is taking her classes online, which is a good fit because she can focus on her school work when she has time available and can complete the courses at her own pace. Ramona searched for jobs through the work-study program and found an office job on campus. She used none of the school-based services to help her with the search because she found them too confusing to navigate. Her employer was very accommodating, even during the hiring process. At the time of her first interview, she could not arrange for child care. Upon hearing of her situation, her employer allowed her to bring her daughter to the interview.

As a part-time employee, she has a flexible schedule to accommodate child care, school assignments, and counseling appointments. In contrast to her previous employers, Ramona finds the current one “understanding and so much more open to hiring someone with a disability.”

Child care and transportation are ongoing potential barriers to remaining employed. For example, she travels by bus about four hours per day round-trip to drop off and pick up her daughter at day care and go to work. A car would make the trip easier but she cannot afford one. She also looked into day care benefits through TANF, but was told she did not qualify because she receives disability and not TANF benefits.

Ramona’s earnings are unstable and are dependent on the number of hours she works. Recently, she required time off to care for her sick daughter and to address issues regarding her benefits. Although she is working with a service provider through TTW, she received a notice that a continuing disability review is being conducted, and she took off additional time to address that.

During the time she has been working, Ramona’s benefits have changed. SSI benefits have been stopped completely; she still receives SSDI. She received an overpayment notice for about

\$700. To resolve that issue, Social Security takes \$20 out of her paycheck every month. She also receives food stamps, but that benefit has decreased since she has been working.

In the future, Ramona would like to permanently get off of SSA benefits through full-time work. For now, part-time work allows her to “dip (her) feet in the pool” and offers the best way to acclimate to working while developing a support network. However, she does have concerns about being able to save enough money if she transitions to working more hours in a full-time position. “If you have no savings or safety net or anything,” she said, “how would you jump off benefits?” But she is hopeful that by furthering her education and obtaining a degree, she can earn enough to not be on benefits ever again.

D. ALICE

Alice is a 33-year-old high-earning SSDI beneficiary who has had bipolar disorder for three years. She is currently unemployed and receiving cash benefits.

Her most recent job was working for her mother at a day care center. She had been looking for other jobs, but felt most comfortable working for her mother, who understood her disability. Alice enjoyed working with children, but found it too difficult to manage both her job and her disability. Because Alice was perpetually responsible for the children, she could not take breaks when she felt she needed them or work a reduced schedule. Alice said, “When it got overwhelming, there was no out, because I was the only one with my kids.”

Alice stopped working because she was afraid she couldn’t keep with it in the long run and also that she would lose benefits if she kept earning money. “I did enjoy working, and I believe that when I get my medication stable... I’ll probably be able to sustain a job for a longer period of time,” she said. “But it’s a little bit scary, because if I do get a job and I go over however many months [the TWP allows], I would lose my Social Security.”

Alice is determined to get back to work eventually and is working with her doctor to determine the appropriate medication to control her symptoms. “I want more than disability,” she said, “I want to be the same person I was before I was disabled [and] to be able to do the same things I was doing before I got sick.”

E. MIKE

Mike is a 26-year-old SSI beneficiary. He is currently an employed high earner and receives cash benefits, but his income is unstable. He has had a physical disability, due to a back injury and subsequent surgery, since he was 23. He worked as an industrial air conditioner repairman prior to his injury but can no longer do that job due to the lifting and travel it requires.

Even as he dealt with complications and physical limitations after surgery, Mike was able to return to school, and he graduated from a computer training program. His school accommodated him by changing the location of his classroom from the second floor to the ground floor. His family transported him to and from classes.

Upon graduation, Mike found it hard to find a job that didn't require heavy lifting. "I was homeless for about a year before I started getting benefits and I was still looking for work after my surgery," he said. "It was hard because nobody wanted to accommodate me." Eventually, Mike found a technician position through a friend's supervisors at a company that was willing to accommodate his needs.

Mike has been in his current position as a technician for a year. He enjoys the work and describes his company as supportive and willing to be flexible with his work schedule, which enables him to attend doctor's appointments or miss work when back pain increases. "I actually feel comfortable here at this company because they're really patient, they're really friendly, the owner is really nice [and] knows my situation, and it's motivating," he said. It is also helpful that the job is less than two miles from his home; other jobs he considered were more than an hour's drive away.

Although this job is less physically demanding than the one he had before surgery, Mike still struggles with some of the movements that are required of him. "[If] I bend down wrong [one day], the following day I might not be able to make it into work, or I might be off of work for the next week or two, because of just one wrong movement," he said. "There are times that I can't make it into work due to my low back surgery... There have been times that I've only worked 60 hours in two weeks."

Earning a steady income and getting off benefits is a goal for Mike, who wants to provide a better future for his children. "The benefits [aren't] enough. [It's not enough to] just get by like a single person without kids.... [I have] a 5-year-old and a 3-year-old, and they deserve something a little bit better. I can't just try to rely on a little bit of income," he said. With his children as his motivation, Mike has persevered and has tried to work as much as his health allows. He would like to earn enough someday that his Social Security benefits are discontinued, but he is grateful for the help he receives. "I want to progress so I can have a steady income so that way I don't have to rely on my benefits," he said. "They are a great help right now because even though I have a job, when times are tough and sometimes if I don't work, they're still there helping me out and it's actually been a really great benefit."

F. CYNTHIA

Cynthia is an employed high-earning beneficiary who formerly received SSI benefits. She began working for a delivery service in her mid-20s. She did not attend college and although she originally regarded the job as a way to pass time after getting married and moving to a new town, she stayed with the job for more than 25 years.

In her early 50s, Cynthia was in a serious accident which damaged her right hand, and in delivery work, having two functioning hands is essential. “Well, practically from the first day of my accident my goal was to go back to work,” she said. “I’m a worker. I come from a working family and that’s just the way it is.... In my mind, I was thinking, ‘Oh, I’ll be back to work in three months. Not a problem.’ ... [M]y first surgery was in July. Then I had another surgery in October and after my second surgery I was thinking, ‘Oh, not a problem. I’ll be back to work by Christmas.’”

Cynthia’s road to recovery, however, was difficult. She realized that the nerve damage in her hand would keep her out of work for much longer than she had originally anticipated. She received sick leave from her job immediately after the accident, but as her leave was about to run out she felt panicked over the delays in returning to work. She consulted a lawyer to figure out her options, and was advised to submit her application for SSDI benefits. She was told that her application might take a long time to process, and as her sick leave and emergency funds dwindled, she grew ever more worried. Her SSDI application was accepted after a few months. At that point, she was able to enter a “leave without earning” status with her employer, which kept her job open for one year (but did not pay sick time). She lived off SSDI and focused on rehabilitating her hand.

Cynthia was diligent about attempting to regain use of her hand. She found a physical therapy and rehabilitation clinic that was a valuable part of her recovery. After many months in rehabilitation, she decided she wanted to try to go back to work. Mostly, she attributes her desire to return to work to her desire not to be “dependent on the government.” The company gave her a delivery route and offered only one accommodation—a hook she could use instead of scissors (which she could no longer operate) to cut plastic and straps. “I’m not one to ask for any special things because I can’t quite do the job. I’m very determined to do the job,” she said. On the advice of her physical therapist, she purchased a pair of battery-heated gloves to use during winter, as the nerve damage in her hands leaves her more susceptible to frostbite. Otherwise, she covers her route knowing she is slower than she used to be, but she puts in longer work hours to get the job done.

Cynthia said it would have been easier to go back to work had she known that workers are offered a trial period to try working without losing benefits. She was very anxious about losing her SSDI benefits if the job had not worked out. “Then after I went back,” she said, “then I got this notice in the mail from [Social Security] saying that there was a trial period to make sure that you could go back to your job. And what a relief that was. Oh, my God.” Because she puts in more hours to do her job than it might take others, she feels that her quality of life has suffered. But, she said, “Well, just going off disability is actually a good day for me because of my independence, like I explained to you... Everything fell into place for me. What more can I say? I’m just very grateful for that.”

G. RACHEL

Rachel is a high-earning beneficiary with stable earnings who receives SSDI benefits. She was diagnosed with lung cancer in her 40 but continued to work full-time as a social worker. It was not until several years later that her condition deteriorated. She also developed back problems and depression and became unable to work.

Rachel decided to return to work a few years later out of financial necessity. At the time, she had applied for but not yet received SSDI and needed income. Her job search was difficult. She used many formal and informal services to seek work, including newspapers, craigslist, and online job forums. She also went to her state VR agency, but the counselor there told her the agency could not help because she had a master's degree and experience. At the point of nearly giving up the search, she spoke with a neighbor about her difficulties. That individual happened to hold a leadership position at a local mental health counseling center. He forwarded her resume, and she was soon hired as a mental health counselor.

Rachel has been at her position for approximately five years. She enjoys all aspects of the job and believes it is a good fit for her training as a social worker. She has not required any special accommodations. She described her employer as very supportive.

Rachel recently lost benefits due to earnings and received her last check in December 2014. Although she had a long-term goal of getting off benefits, she was not anticipating her benefits would end as abruptly as they did. She had recently completed a continuing disability review and had not received any notifications from Social Security after it was submitted. Because she received no communication, she assumed she continued to qualify for disability benefits.

Rachel's earnings are generally steady, but they fluctuate slightly. She tries to work no more than 14 to 15 hours per week but in some cases, her job requires her to work a few more hours and she earns over the SGA level by \$30 or \$40. Rachel had been unaware that her small fluctuations in earnings could affect her eligibility. She filed an appeal of the termination as well as an appeal of the request to pay back the \$16,000 overpayment she received. The matters have not yet been resolved.

Losing benefits placed a financial strain on Rachel and has effectively cut her income in half. To increase her income in light of the changes in her benefits, she explored taking on more hours at her current job, but her organization can offer her only part-time work. She plans to search for full-time work, even knowing she does not have the stamina to work full-time due to cancer treatments. At the time of her interview, Rachel was negotiating a job offer with a social service organization offering full-time work and benefits.

Rachel suggested that Social Security modify the SSDI regulations to follow the same rules as SSI. She thought that having a gradual dollar-for-dollar reduction would be a "smoother transition" to eventually leaving the benefit rolls.

H. SHARON

Sharon is a 49-year-old SSDI beneficiary with psychiatric and intellectual disabilities. She was working until a few months ago, when she required gall bladder surgery. Throughout the years she was in school decades ago, she received supports like extra time on tests, but she began receiving benefits only about four years ago. Before she received benefits, she worked as a receptionist for seven years.

Most recently, Sharon worked as a bus driver, a job she held for six months. She had not been looking for work, but an acquaintance convinced her to apply because the job listing promoted its flexibility in accommodating people with disabilities. When she started working, Sharon was concerned about overpayments and benefit cessation. She was worried that the job might not work out and that she would have to begin applying for disability benefits all over again.

The two-month training process was difficult for her. She disliked the strict rules and time limits on tests and breaks. The environment was competitive and at times negative and critical. Positive peer pressure (from her fellow trainees) kept her going through that time, she said. She also wanted her family to be proud of her and was attracted by the idea of having a career rather than just another job.

The competitiveness of the training environment carried over to the job, she said. Sharon also had a difficult time with the work schedule because the days were long and the schedule changed often. The employer was not willing to make accommodations for her limitations without written documentation of a disability. Sharon did not document her disabilities with doctor's notes within the time frame given. One of the accommodations she requested was to be assigned to a location closer to her home when the company transferred some employees to other locations. This request was denied because she had difficulty producing the documentation of her disability the company requested. She appealed the decision to a higher level, but the issues were not resolved to her satisfaction.

Ultimately, the primary reason Sharon left her job was her surgery. She could have returned to her job, but decided not to because she regarded the work environment as too negative and she believed the stress could worsen her condition. She did note some things her employer could have done to support her, including creating a more positive work environment, being more willing to accommodate her limitations, and allowing her to work at the location closer to her home. She also wishes there had been a human resources staff person to check in on her and monitor how she was doing during the training and the first months on the job.

I. JOSH

Josh is an employed young adult SSI beneficiary. He has developmental disabilities and graduated from high school with the help of a school-based program for students with special needs. After graduation, he joined a county-funded job-preparation program, where he obtained work experiences in construction, sanitation, retail, and other fields. Through this program, he became acquainted with Breakthrough House, where he was exposed to more tasks and learned about his work-related strengths and weaknesses. Josh also had a job coach through the state VR agency. He did not find his experience with the job coach beneficial, but the VR agency worked with Breakthrough House to find a coach who met his needs. Josh has enjoyed working full-time for two years through Breakthrough House cleaning beaches with two other people with disabilities and a job coach.

Josh has anger issues and difficulty communicating with others. These issues make it hard for him to work in certain environments. One of the reasons this job is a good fit for Josh is that he is supervised by a job coach throughout the work day. The job coach provides transportation to and from work, monitors Josh's progress with work, and also acts as a mediator if Josh has issues with other crew members. Josh also takes advantage of a job counselor, who works off site with the employees at Breakthrough House to address anything he feels isn't being handled on the job.

Getting off benefits is not a goal for Josh at this point, as he earns \$4 an hour, which is not enough to live on without benefits. Since he started working his current job, Josh's benefits have decreased. Josh lives with his parents, who help support him, but his job allows him to earn his own spending money and to be more independent. Josh's mother noted that if Josh could obtain a minimum wage job in the community, the family would start to think about dropping benefits. Josh plans to continue to work and try to increase his earnings.

Josh received supports throughout his school years, including speech therapy and anger management. His mother noted that these services are not available to him as an adult, but that they could be instrumental to his obtaining a job in the community. Improving his communication abilities would be especially beneficial. She thinks that when such services are discontinued after graduation, many people with disabilities retreat into their old habits. She would like to see them continued into adulthood.

www.mathematica-mpr.com

Improving public well-being by conducting high quality,
objective research and data collection

PRINCETON, NJ ■ ANN ARBOR, MI ■ CAMBRIDGE, MA ■ CHICAGO, IL ■ OAKLAND, CA ■ WASHINGTON, DC

MATHEMATICA
Policy Research

Mathematica® is a registered trademark
of Mathematica Policy Research, Inc.