

**Services and Supports People
with Disabilities Need to Stay
Employed**

May 30, 2013

Noelle Denny-Brown
Bonnie O'Day
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Policy Research

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The authors are responsible for the information included in this report. All conclusions and views expressed are those of the authors and do not represent the views of any state or federal agency.

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I. OVERVIEW

A. Policy Context

Higher earners with disabilities in the workforce often need services and supports to attain and maintain employment which are not necessarily captured by public program claims-based analysis. As individuals with disabilities achieve sustained employment, they have more experience with using services and supports and have an informed perspective on their needs that can help to inform state and federal policy. This study sought to engage a sample of workers with disabilities with higher earnings to learn what services and supports were effective in promoting their employment goals. These could include services and support paid for by public or private sources, no-cost supports, supports paid for out-of-pocket by the worker and/or policies or accommodations.

B. Study Questions

Using the results of qualitative interviews with 15 workers with disabilities who volunteered to participate, this report presents a snapshot of the strategies that these employed people with disabilities use to become and stay employed. These individuals all had higher annual earnings, defined as at least 250 percent of the poverty level, or about \$28,000 for a single person.

The study examined the services and supports these individuals use on and off the job and how they obtain them. We had these specific study questions:

- What types of health services and employment supports do employed individuals with disabilities who earn at least 250 percent of the poverty level need to stay on their jobs and advance their careers?
- Where do workers with disabilities obtain these supports, and what strategies do they use to obtain and, where applicable, pay for them?
 - To what extent do workers with disabilities obtain the health services and employment supports they need through private health insurance plans?
 - To what extent do employers pay for these supports for their employees with disabilities?

- To what extent do workers with disabilities pay for these services and supports out of pocket, and how much do they typically pay each year?

The findings from this study will help inform the Centers for Medicare & Medicaid Services (CMS) about the strategies that workers with disabilities use to obtain the supports they need to gain and maintain employment. As policies are strengthened to promote earnings and employment, assuring workers with disabilities that they have dependable access to services they need could entice greater numbers of them to find and keep competitive employment and discourage them from limiting their earnings to retain their Medicaid eligibility (Stapleton et al. 2006).

C. Key Findings

- **Respondents used creative approaches to find employment.** A majority of individuals said they used the services of their State Vocational Rehabilitation Agency (SVRA), a One-Stop Career Center, or another employment agency to prepare them for or help them find employment.
- **The majority of respondents require some accommodations to perform their job.** Most respondents need some supports and job accommodations to sustain their employment, but overall these supports and accommodations are not costly or resource intensive for employers to provide.
- **The most frequently cited support provided on the job was staff support, which encompasses informal and formal supports as well as additional supervision.** Four respondents reported receiving formal staff supports on the job. The majority of respondents reported receiving informal supports, which most often were natural supports put in place as needs were identified on the job.
- **Universal design features have made workplaces more accessible to individuals with a broad range of disabilities.** Most environments, buildings, and products are now designed with built-in accessibility features to facilitate easy access for individuals with diverse needs and backgrounds. Respondents reported working in inclusive workplaces and utilizing equipment commonly used by all employees in the workplace.
- **The types of employment supports and accommodations used on the job vary by the individual's type of functional limitation.** Respondents utilized a wide variety of employment supports and accommodations on the job, and the type of support used often differed due to the functional needs of workers.
- **Accessible and reliable transportation is critically important to finding and keeping a job.** For respondents with significant physical and sensory disabilities,

reliable transportation not only increased their independence and integration into the community but it also made competitive employment possible.

- **Assistance with personal care needs and household activities is important for individuals with significant physical disabilities and some individuals with visual impairments.** Two respondents with physical disabilities receive personal assistance with their activities of daily living. Many respondents with physical and sensory disabilities also receive assistance with such activities as shopping and housekeeping. Most often these supports were provided by volunteers or family members.
- **Out-of-pocket expenses for personal health services and employment supports varied substantially.** Out-of-pocket costs for services and supports utilized on and off the job ranged from nothing to \$14,800 per year for personal care assistance (PCA), durable medical equipment, coinsurance payments for prescription drugs and outpatient therapy, assistive technology, service animals, and medical goods and services.
- **Individuals with physical disabilities used creative strategies to obtain adaptive equipment that effectively met their needs.** Examples of strategies include making the necessary adaptive equipment or finding ways to obtain it at a discounted price.
- **Most respondents negotiated with their employer to have needed supports and accommodations in place at the start of their employment but adjusted accommodations while on the job.** For example, one man requested a large computer monitor when he started work and negotiated staff support for proofreading documents later to assist with formatting documents.
- **Many respondents used strategic thinking by obtaining employment at organizations that provide services primarily to individuals with disabilities, or that have a track record of reaching out to individuals with disabilities.** Seven of the fifteen people we interviewed worked for disability service organizations; others worked for companies that had made special efforts to make their services and products accessible. Working for employers that reach out to people with disabilities made it easier for individuals to obtain necessary supports and accommodations on the job.

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II. METHODS AND SAMPLE

A. Recruitment and Screening

We used two strategies to recruit individuals for this study. First, the CMS project officer contacted disability service organizations, such as the National Association of State Directors of Developmental Disabilities Services and the National Council on Independent Living, to request their assistance in recruiting participants. Organizations who agreed to do so shared information about the project with their staff and workers with disabilities. After individuals stated interest in participating in the project and provided permission, a member of the organization sent the contact information of these individuals to Mathematica or the CMS project officer, who forwarded it to our team lead.

Second, the Mathematica team reached out to service and advocacy organizations and support groups not contacted by the CMS project officer, such as the American Foundation for the Blind, a listserv for visually impaired employed women, and a listserv for deaf and hard of hearing individuals. The same process was then used to obtain contact information for individuals who indicated that they would consider participating. Recruitment and screening took into account that workers with disabilities affiliated with any particular group or organization could have more than one disabling condition not necessarily apparent based solely on organization participation.

The team provided each potential participant a one-page project overview (Appendix A), explained the study screening criteria, and answered their questions. If they agreed to participate, we set up a 15- to 20-minute telephone screening interview (Appendix B), to ensure that each individual met the screening criteria. We looked for individuals with the following characteristics:

- Have a visual, hearing, psychiatric, physical, or intellectual disability
- Are employed at least 20 hours per week
- Earn at least 250 percent of the poverty level, or about \$28,000 for a single person, or above
- Have work support needs related to their disabilities
- Are willing to talk about the supports they need and, where applicable, how they pay for them

Individuals who passed the screening interview were invited to participate in a full-length interview. We asked each participant to read and sign a consent form, sent to them via email, which described the interview, protections to confidentiality, and our intention to audio-record the interview (Appendix C). We offered to interview the respondent at a time of his or her convenience, including during the evening or on a weekend, and asked what type of accommodation, if any, they would need to participate in the interview. We conducted the interviews during February and March, 2013. We provided each participant with a \$50 Amazon gift card as a token of our appreciation for participating.

B. Interview Guide

We developed two interview guides, one for individuals with physical and sensory disabilities (Appendix D) and the other for individuals with psychiatric and intellectual disabilities (Appendix E). We pilot tested the interview guide with a worker with a physical disability and made slight modifications based upon his feedback. The interview guides covered the following topics:

- Current employment
- Type of disability
- Disability-related services, supports, and accommodations needed when seeking work and on the job
- Disability-related services and supports used in preparing for and traveling to and from work
- Medical care and related services

- Methods of paying for employment services and supports

To provide insight into these topics, we asked each participant to describe a typical day, emphasizing the health services and employment supports they used to prepare for work, travel to work, and perform their job duties. Interviews lasted between 60 and 90 minutes. Most were conducted by phone though two were conducted via Google-chat, at the participants' request.

C. Participant Characteristics

We interviewed 15 workers with disabilities (Table 2.1). Four respondents said their primary disability was physical; 4 reported a visual disability, 4 reported a hearing disability, 2 reported a psychiatric disability, and one reported an intellectual disability. Most respondents also reported a secondary disability. Considering both the primary and secondary disabilities, 6 of the 15 individuals had a physical disability, 9 had a sensory disability, 4 had a psychiatric disability, and 3 had an intellectual/developmental or learning disability. Five respondents were in their 20s, 5 were in their 30s or 40s, and 5 were 50 to 60. They tended to be Caucasian and highly educated; most had household incomes over \$50,000. Four had household incomes over \$75,000 whereas only one had an income of less than \$30,000. Eleven of the 15 respondents had been recipients of Social Security disability benefits at some point in the past; 1 was receiving such benefits at the time of the interviews.

Table 2.1. Participants' Disability Status and Demographic Characteristics

No.	Disability Type (P = primary, S = secondary)			ID	Current/ Former SSI/SSDI Recipient?	State	Age	Gender	Race/ Ethnicity	Annual Household Income	Highest Level of Education	Marital Status	
	Physical	Sensory	Psychiatric									Married ^a	Single
1	P				Y	TN	43	M	W	> \$100,000	Graduate school	X	
2	P	S	S		N	PA	47	F	W	\$ 75–\$100,000	Graduate school	X	
3	P				Y	NY	60	F	W	> \$100,000	Graduate school	X	
4	P				Y	PA	39	F	W	\$40–\$50,000	Graduate school		X
5	S	P			U	MD	50	F	W/A	> \$100,000	Graduate school	X	
6	S	P			Y	CA	50	M	W	\$50–\$75,000	College	X	
7		P			Y	MI	53	M	W	\$50–\$75,000	Graduate school	X	
8		P			N	DC	31	F	W	\$30–\$40,000	Some graduate school		X
9		P			Y	MD	23	M	W	\$40–\$50,000	College		X
10		P	S	S	Y	NV	28	F	W	\$30–\$40,000	College		X
11		P			Y	DC	28	M	W	\$50–\$75,000	College		X
12		P			Y	IL	26	F	W	\$30–\$40,000	Some graduate school		X
13			P	S	Y	CA	52	F	AA	\$50–\$75,000	High school		X
14			P		Y	MD	32	F	W	\$20–\$30,000	Some graduate school		X

∞

	Disability Type (P = primary, S = secondary)				Current/ Former SSI/SSDI Recipient?	State	Age	Gender	Race/ Ethnicity	Annual Household Income	Highest Level of Education	Marital Status	
	Physical	Sensory	Psychiatric	ID								Married ^a	Single
15				P	N	TX	28	M	W	\$30–\$40,000	Some college		X

^a Includes domestic partnerships.

A = Asian; AA = African American; F = female; ID = Intellectual disability; M = male; SSDI = Social Security Disability Insurance; SSI = Supplemental Security Income; W = white, Y = Yes; N = No; U = Unknown.

D. Study Limitations

This study provides a snapshot of the support needs of 15 workers with disabilities from their own perspectives. We had a short window of time to conduct the interviews. Therefore, the study is based upon a small non-random sample of individuals, seven of whom work for organizations that provide services primarily to individuals with disabilities. Although this study provides insights into how competitively employed disabled individuals obtain what they need to be employed, the findings are produced from a small sample and may not necessarily reflect what the overall population might need, or how those needs might be supported.

III. KEY FINDINGS

This section summarizes the study findings, which are organized by study question. These findings are based on semi-structured, qualitative interviews to obtain the perspectives of 15 individuals with a variety of disabling impairments. Personal accounts from individual respondents can provide valuable insights into the types of services or supports that are used on and off the job. Consequently, this section presents a few descriptions of the experiences of individual study participants.

A. Types of Health Services and Employment Supports Workers with Disabilities Need to Find and Keep their Jobs

Respondents used creative approaches to find employment. A majority of individuals said they used the services of their State Vocational Rehabilitation Agency (SVRA), a One-Stop Career Center, or another employment agency to prepare them for or help them find employment. Their SVRA helped them pay for college tuition, books, adaptive equipment, or other expenses to obtain an education. A male respondent said the SVRA helped him adapt his van with a lift and hand controls, which he used to attend interviews. Others relied on personal contacts. For example, one individual had a friend that helped her get a job with her current employer. Another woman told us that her eye doctor suggested that she apply for her current job. She said that the employer's website was accessible to her with a screenreader, which enabled her to apply independently. A deaf woman attended a job fair, where she made an important contact with her employer; another was hired after she completed an internship with her current employer. Still other respondents said they used support groups and spiritual practices to give them the confidence and energy to look for work.

The majority of respondents require some accommodations to perform their job. Most respondents need some supports and job accommodations to sustain their employment, but

overall these supports and accommodations are not costly or resource intensive for employers to provide. Respondents reported receiving between two and eight on-the-job supports provided by employers, which can be categorized as formal and informal supports, flexible work schedules, and modifications to individual workstations (Table 3.1).

Table 3.1. Types of Services, Supports, and Accommodations Used on and off the Job

Types of Services and Supports Used to Obtain Employment	Types of Services, Supports, and Accommodations Used on the Job, by Purchaser/Provider Type	Types of Services, and Supports Used off the Job, by Purchaser/Provider Type
Respondents with Physical Primary Disabilities (n = 4)		
<ul style="list-style-type: none"> • Modified van • Vocational rehabilitation services • One-Stop Career Center 	<p><u>Paid by Employer</u></p> <ul style="list-style-type: none"> • *Powered wheel chair • *Wheelchair elevator seat • *Modified van with lift • Raised desk • Corner desk • Informal staff supports • Personal attendant for travel • Formal staff support • Flexible work schedule • Ability to work from home • Emergency paid time off • *Space heater • *Air conditioner • *Ear piece • Computer “built-in” accessibility software • Large widescreen computer monitor • Wireless keyboard • *Ergonomic chair <p><u>Paid by Insurance</u></p> <ul style="list-style-type: none"> • *Prosthetic leg <p><u>Paid Out of Pocket</u></p> <ul style="list-style-type: none"> • Female urinal • *iPhone • *Wheelchair • Reachers • Hand-controlled vehicle <p><u>Paid by Other Sources</u></p> <ul style="list-style-type: none"> • *Spouse drives them to work • Cane 	<p><u>Paid Out of Pocket</u></p> <ul style="list-style-type: none"> • Beazy board • Shower chair • Hand-held shower • Roll-in shower • Ergonomic furniture • Transfer board • Personal attendant for shower • ADA sink • Breathing machine • Dressing stick • Compression shrinkers • Crutches • Prosthetic socks • Shoe gloves • Coinsurance payments for outpatient therapy <p><u>Paid by Insurance</u></p> <ul style="list-style-type: none"> • Prescription drugs • Medical supplies • Counseling services • Ankle-foot orthotics (AFOs) • *Prosthetic leg <p><u>Paid by Other Sources</u></p> <ul style="list-style-type: none"> • Family support • Moveable cabinet • Home modifications

Table 3.1 (continued)

Types of Services and Supports Used to Obtain Employment	Types of Services, Supports, and Accommodations Used on the Job, by Purchaser/Provider Type	Types of Services, and Supports Used off the Job, by Purchaser/Provider Type
Respondents with Sensory Primary Disabilities (n = 8)		
<ul style="list-style-type: none"> • Vocational rehabilitation services • Telescopic lenses • Friend who worked for current employer • Employer’s job application website was accessible • Parents purchased all needed equipment • Internships • Interpreter • Communication Access Real-time Translation (CART)^a • National Technical Institute for the Deaf job fair 	<p><u>Paid by Employer</u></p> <ul style="list-style-type: none"> • *Laptop screen reader • Taxi • Book and document reader • Braille Note Apex • *Telescopic lenses • Large monitor • *iPhone with accessible apps • Mac laptop with built in accessibility • Interpreter • UbiDuo communication device • Video remote interpreting (VRI) • Training on how to use accessible technology • Informal staff support • Formal staff support • Additional supervisor support • Teacher’s aide • Change in job duties • Ability to work from home • Emergency paid time off • Change in training materials • Flexible schedule • Videophone with video relay system • High quality Internet service for better videophone quality <p><u>Paid by Insurance</u></p> <ul style="list-style-type: none"> • Nebulizer • Hearing aids • Cochlear implant and speech processor • *Contact lenses and glasses <p><u>Paid Out of Pocket</u></p> <ul style="list-style-type: none"> • Person who reads mail once a week • iPad • Mac laptop • Apple TV • Dog food, veterinarian, other care/services for guide 	<p><u>Paid by Insurance</u></p> <ul style="list-style-type: none"> • Family counseling • Acupuncture • Therapist • Prescription medication • *Cochlear implant and speech processor • *Contact lenses and glasses <p><u>Paid Out of Pocket</u></p> <ul style="list-style-type: none"> • *Talking clock • Vibrating/bed-shaking alarm • Fire alarm • Door bell light flasher • Book reader • Concierge service for 24/7 access to a doctor • Some medications • ID maker • Bar code reader • Screen reader • Color identifier • iPhone with various apps • iPad with accessible apps • Tablet computer with Skype • Laptop with webcam • High quality Internet service for better videophone quality • Coinsurance payments for prescription medication • Coinsurance payments for outpatient therapy • Interpreter for therapy sessions <p><u>Paid by Other Sources</u></p> <ul style="list-style-type: none"> • Videophone • Video relay service • Interpreter for therapist

Table 3.1 (continued)

Types of Services and Supports Used to Obtain Employment	Types of Services, Supports, and Accommodations Used on the Job, by Purchaser/Provider Type	Types of Services, and Supports Used off the Job, by Purchaser/Provider Type
	<ul style="list-style-type: none"> dog • Taxi • Batteries for speech processor • Public transit card <p><u>Other</u></p> <ul style="list-style-type: none"> • *iPhone with voiceover app • *Instant Messaging/Google iChat • *Service animal • Screen reader • Braille embosser • *Braille note-taker • Computer with speech generator • Specialized audio desks for the consoles with Braille labeling • White cane • Laptop-based recording system • Family provides transportation • Videophone 	
Respondents with Psychiatric Primary Disabilities (n = 2)		
<ul style="list-style-type: none"> • One-Stop Career Center services • Acupuncture • Spiritual practice • Support groups 	<p><u>Paid by Employer</u></p> <ul style="list-style-type: none"> • Work cell phone • Staff support • Additional supervisory support • Change in training materials • Flexible work schedule • Work remotely • Separate room for examinations • Private tutoring • Additional advisor support <p><u>Paid by Insurance</u></p> <ul style="list-style-type: none"> • *Z coil shoes • Anxiety medication for business flights <p><u>Paid Out of Pocket</u></p> <ul style="list-style-type: none"> • *Psychiatric service dog • *Ear plugs 	<p><u>Paid by Insurance</u></p> <ul style="list-style-type: none"> • High blood pressure medication • Prescription medications • Psychiatrist <p><u>Paid Out of Pocket</u></p> <ul style="list-style-type: none"> • Acupuncture • Special foods for chewing difficulty • Vitamins <p><u>Paid by Other Sources</u></p> <ul style="list-style-type: none"> • Wellness tools • Online peer support group

Table 3.1 (continued)

Types of Services and Supports Used to Obtain Employment	Types of Services, Supports, and Accommodations Used on the Job, by Purchaser/Provider Type	Types of Services, and Supports Used off the Job, by Purchaser/Provider Type
	<ul style="list-style-type: none"> *Wellness tools (for example, candles, electric waterfalls, soft music) 	
Respondents with Intellectual/Developmental Primary Disabilities (n = 1)		
<ul style="list-style-type: none"> Vocational rehabilitation services 	<p><u>Paid by Employer</u></p> <ul style="list-style-type: none"> Additional supervisor support Informal staff support Informal job coach Fluorescent light filters Change in job duties—not required to drive Change in job schedule/breaks Work from home with permission <p><u>Paid Out of Pocket</u></p> <ul style="list-style-type: none"> *Ear plugs 	<p><u>Paid by Insurance</u></p> <ul style="list-style-type: none"> Prescription medication <p><u>Paid by Other Sources</u></p> <ul style="list-style-type: none"> Counseling

Note: Other sources of coverage include a variety of nontraditional forms of payment, as well as instances in which a payment source was not specified.

^a CART is a real-time captioning method in which a trained operator uses keyboard or stenography methods to transcribe spoken speech into written text.

ADA = Americans with Disabilities Act.

* = used on and off the job.

MOST RESPONDENTS NEED SOME ON-THE-JOB SUPPORTS AND ACCOMMODATIONS**Example 1:**

JB is an editor who works full time. To better manage his multiple sclerosis, JB's employer has allowed him to work primarily from home and maintain a flexible work schedule. These accommodations work well with his editing duties. He uses two low-technology supports, an ergonomic chair and an air conditioner, which alleviate impairment-related health issues that made it difficult for him to sustain employment in the past. The rest of the work supports JB uses are considered typical work equipment provided to the average worker at his job, such as a laptop with built-in accessibility features, a large computer monitor, and an ergonomic keyboard.

Example 2:

KJ manages projects at a government agency. Though legally blind, KJ uses only two assistive technology supports to do his job—telescopic lenses (scopes) and a large computer monitor. Both of these supports were purchased by his employer. In addition, KJ negotiated with his employer for additional staff support to proofread his written work.

Example 3:

SO, who is blind, works for a retail store and uses a device that has built-in features that translate printed information on the screen into audible speech. Otherwise, SO generally uses the same devices on the job as her sighted coworkers and receives minimal support from her coworkers and supervisor, including help scanning barcodes or finding products for customers. Her job responsibilities were also modified so that she does not have to close the store at the end of the work day. SO is accompanied by her guide dog, which helps her navigate the public transit system to and from work.

The most frequently cited support provided on the job was staff support, which encompasses informal and formal supports as well as additional supervision. Four respondents with sensory and psychiatric impairments reported receiving formal staff supports on the job; these supports included a paid reader, a proofreader, a teacher's aide, and a secretary who assists with producing some emails and documents that the respondent dictates. The majority of respondents reported receiving informal supports, which most often were natural supports put in place as needs were identified on the job. For example, one respondent who is deaf reports that when she's participating in a large group meeting, her colleagues send her notes

during the meeting summarizing information covered. Another individual with a developmental disability reports that colleagues interpret for him what individuals meant when speaking on teleconference calls.

Ten respondents cited modifications to individual workstations as an important accommodation. The types of modifications differed according to the worker's functional limitations. For example, for workers with severe physical disabilities, employers modified the height or configuration of their desk to remove physical barriers and also provided wireless keyboards to facilitate access to their computer. With respondents who have sensory impairments, employers provided communication devices, assistive technology, large computer monitors, and interpreters (Table 3.1).

Increased flexibility was the next most frequently cited accommodation, reported by nine respondents. Individuals noted that increased flexibility, such as a flexible work schedule, ability to work remotely from home, or additional emergency paid time off, facilitates their job performance in a competitive employment setting. Several respondents took a particular job because they knew the flexibility in the position would accommodate their disability well. Flexibility in the workplace has become the norm in many organizations and is particularly important to workers with needs associated with a disabling condition.

Universal design features have made workplaces more accessible to individuals with a broad range of disabilities. Most environments, buildings, and products are now designed with built-in accessibility features to facilitate easy access for individuals with diverse needs and backgrounds. Respondents reported working in inclusive workplaces and utilizing equipment or supports commonly used by all employees in the workplace. The types of universal design technology or equipment provided to workers include large computer monitors, wireless keyboards, phones with accessibility features, and the ability to send and receive instant and text

messages. These supports help individuals with a broad range of disabilities, reading levels, and communication styles to perform their jobs effectively.

Several respondents also reported that certain devices, such as iPhones and iPads, enable them to easily access an array of assistive technology applications. Four respondents reported using features on an Apple iPod or Mac laptop that adapt the product to the individual's needs, such as the VoiceOver gesture-based screen reader application, Siri, and Sticky Keys. Apple includes assistive technology in its products as standard features, and its products are also commonly used. Most respondents who use an Apple product pay for the product and associated service costs, such as cell phone plans, out of pocket.

EFFECT OF UNIVERSAL DESIGN SUPPORTS ON AND OFF THE JOB

Example 1:

SO is visually impaired. She uses Apple products on and off the job, just as her sighted peers do, to assist customers with making purchases, checking email, and finding online information she needs for her job. She also uses Apple products to complete several daily activities. For example, she uses her iPad and iMac to check email and surf the web, an iPod to listen to music, an Apple TV to watch television, and an iPhone to make calls and even purchase Starbucks coffee. Apple products effectively meet her communication needs both on and off the job.

Example 2:

JB uses many types of technology and equipment available to the general public. Instead of buying accessibility software or assistive technology, JB uses accessibility features built into her Mac laptop, such as the "zoom-in" feature to enlarge print on the screen and Sticky Keys to help with typing. In addition, instead of buying products out of medical or adaptive catalogues, JB purchases ergonomic furniture from furniture and equipment retailers, so she can work from home.

The types of employment supports and accommodations participants said they used on the job vary by the individual's type of functional limitation. Respondents utilized a wide variety of employment supports and accommodations on the job (Table 3.1), and the type of supports used often differed due to the functional needs of workers. Respondents with physical

disabilities used durable medical equipment more than individuals with any other type of disability. Three respondents with physical disabilities use a wheelchair on and off the job; two of these use a motorized wheelchair with a feature that raises and lowers the seat. That feature, which is reportedly not covered by many health insurance plans, enables individuals to safely and independently transfer to and from the wheelchair to other locations, such as the bed, and also complete several activities of daily living.

Ten respondents reported that their employer modified their individual workstation to facilitate their job performance. Respondents with physical disabilities were provided with an ergonomic chair, a wireless keyboard, or a raised or corner desk (Table 3.1). Respondents with sensory impairments often need assistive technology to meet their communication needs. Individuals reported using a telescopic lens; large computer monitor; software applications that provide speech output; video phone; and nonvisual communication devices such as a screen reader, note taker, or Braille printer, to complete job duties. Some individuals with sensory impairments also reported requiring interpreter and proofreading services.

Respondents with intellectual or psychiatric disabilities did not generally use these accommodations. One respondent with an intellectual disability receives informal job coaching from a colleague in addition to extra supervisory support. Individuals with psychiatric impairments tended to use flexible work arrangements, prescription medications, and outpatient therapy.

TYPES OF EMPLOYMENT SUPPORTS AND EQUIPMENT VARIED BY THE TYPE OF DISABLING IMPAIRMENT

Example 1:

DW has a significant physical impairment; he uses several supports on and off the job that enhance his mobility and enable him to perform a variety of physical activities. For DW the most critical support needed to obtain and maintain employment, besides his power wheelchair, is his modified van, which provides him with reliable, accessible transportation. In terms of getting ready for work, DW emphasizes that without his transfer board it would be difficult for his wife to help him transfer from bed to shower chair to wheelchair. On the job, DW's employer raised his desk to allow him to navigate freely in his wheelchair. Finally, DW stresses that the raise and lower feature on his wheelchair seat is critical because it helps him to reach items in high places, sit upright in his wheelchair, and complete several activities of daily living.

Example 2:

PA is deaf. In addition to his hearing aid, PA uses a variety of supports on and off the job to accommodate his hearing impairment. On the job, PA uses an interpreter, a video relay service (VRS), email, or instant messaging to communicate with individuals who are not proficient in sign language. He chooses the appropriate tool depending on the length of the communication and the location of the other individual (in the office or off site). Off the job, PA uses a VRS to call friends and family, a vibrating alarm to wake up in the morning, and a flashing door bell that notifies him of visitors.

B. Other Supports Used to Prepare for or Get to Work

Accessible and reliable transportation is critically important to finding and keeping a job. For respondents with significant physical and sensory disabilities, reliable transportation not only increased their independence and integration in the community, but it also made competitive employment possible. Three respondents with physical disabilities reported using a modified vehicle to travel to and from work. One respondent paid for his first modified vehicle out of pocket; his employer later purchased a modified company van for his use. The state vocational rehabilitation agency funded the cost of a van lift for another respondent. A third respondent took out a loan to fund the out-of-pocket cost for a hand-controlled vehicle. Family members of two other respondents drive them to and from work each day; and respondents with

visual impairments take public transportation, walk, or pay out-of-pocket for taxi rides to and from work.

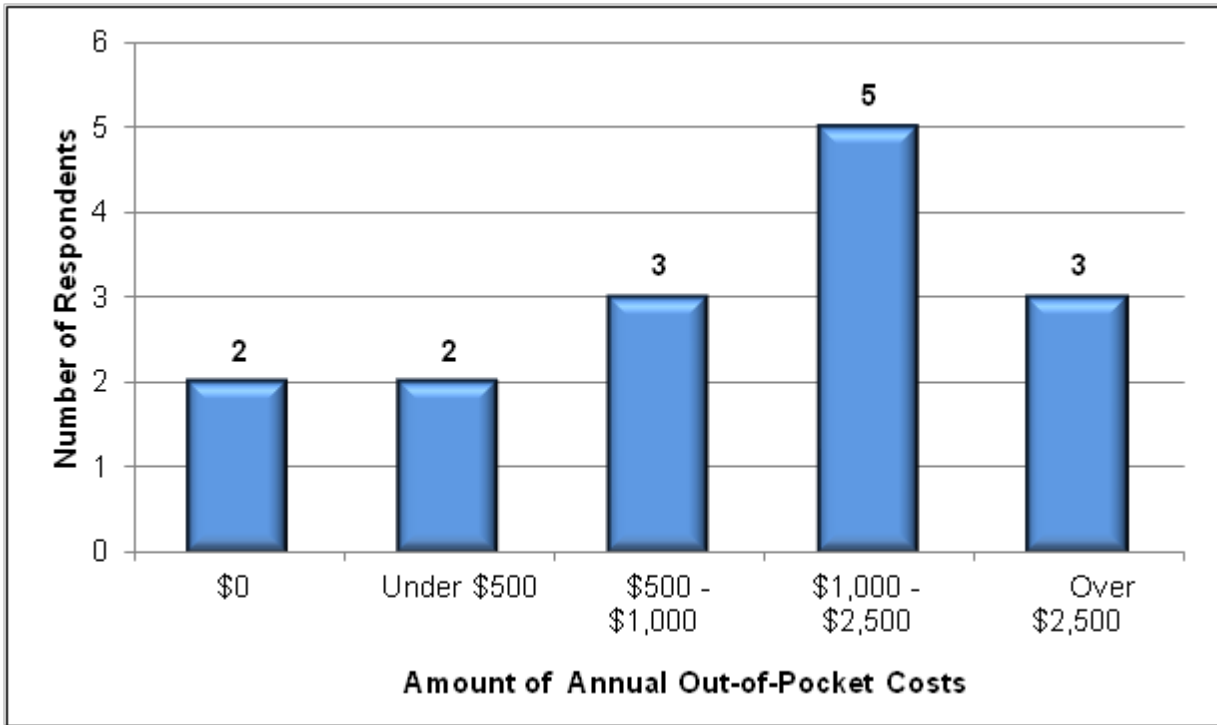
Assistance with personal care needs and household activities is important for individuals with significant physical disabilities and some individuals with visual impairments. Two respondents with physical disabilities receive personal assistance with their activities of daily living, which is not a covered service through their employer-sponsored health insurance plan. One respondent noted that he used to hire a PCA to help him with his personal care needs, but the service was costly and required a minimum of two hours of service per visit, which was much more than he needed. His spouse now assists him with these activities of daily living. Another respondent utilized her local Center for Independent Living to interview candidates and hire a PCA, whom she pays out-of-pocket. Most respondents with physical disabilities and some respondents with visual impairments also reported receiving assistance with activities such as shopping, reading mail, laundry, and housekeeping.

C. Strategies Used to Obtain and Pay for Health Services and Employment Supports

Out-of-pocket expenses for personal health services and employment supports varied substantially. These variations are due in large part to differences in individuals' limitations as well as the scope of insurance coverage. Out-of-pocket costs for services and supports utilized on and off the job ranged from nothing to \$14,800 per year. Two individuals with sensory impairments reported incurring no out-of-pocket costs. Five respondents reported spending \$1,000 to \$2,500 on costs for durable medical equipment, a tablet personal computer with accessibility features, a vibrating alarm clock, iPhones, and coinsurance payments for prescription drugs and outpatient therapy (Figure 3.1). One respondent spends \$5,000 per year on out-of-pocket costs for transportation, medications, and a concierge service for a primary care physician, which includes round-the-clock access. Two respondents spend over \$8,000 per year

on out-of-pocket costs for personal care assistance, orthopedic shoes, wellness tools, and a psychiatric service dog.

Figure 3.1. Estimated Annual Out-of-Pocket Costs for Services and Supports Used on and off the Job



Note: Annual out-of-pocket costs are self-reported by study participants. Respondents were asked “About how much do you spend a week, a month, or a year out-of-pocket on these supports or services?” We calculated annual expenditures based on their responses.

OUT-OF-POCKET EXPENSES VARIED SIGNIFICANTLY**Example 1:**

DH, who has a physical disability, employs a PCA to help her shower and dress each day. Her employer-sponsored health insurance does not cover her PCA services; therefore, she must pay over \$8,000 each year out-of-pocket for this expense. DH feels that her neurological muscular condition will become more debilitating in the future and fears she will not be able to afford the additional PCA services that she might need to accommodate her progressing needs.

Example 2:

KJ is legally blind; his employer-sponsored health insurance refused to cover the telescopic lenses (scopes) he needs to work. However, KJ's employer has agreed to pay for these scopes and any associated repairs. In addition, his employer has paid for two other work supports, a large computer monitor and proofreader services, he needs to do his job. Since KJ does not use any additional medical supports off the job, he does not incur any out-of-pocket costs related to his visual impairment.

Example 3:

SO is visually impaired. Her employer provides her with most of the work supports she needs to do her job, with the exception of her guide dog. SO's guide dog helps her navigate the public transit system to travel to and from work each day. SO received her guide dog and guide dog training lessons at no cost through a guide dog school, which is funded through private donations. Each year, she spends about \$800 to \$1,000 on dog food, veterinarian bills, and other miscellaneous items for the dog.

Individuals with physical disabilities used creative strategies to obtain adaptive equipment that effectively met their needs. One respondent with a significant physical disability relies on handmade adaptive equipment to address her personal care needs. She designed a self-standing transfer board; a raised toilet seat that can be used with that board; and a reacher to help her gain control of objects beyond her reach, all of which were made by a family member. Two individuals leveraged their resources to obtain wheelchairs that properly fit them and met their needs at a discounted price. For example, one respondent used her own funds to purchase a wheelchair that was discounted because her friend worked for a wheelchair manufacturer. Another respondent reported that after his motorized wheelchair malfunctioned some years ago, he obtained employment at a wheelchair manufacturer where he receives free

wheelchairs as an employee benefit. That same individual, who has a physical disability, consulted with occupational and physical therapist friends who suggested using a specific type of transfer board to facilitate safe and easy transfers from his bed to his wheelchair. Other individuals negotiated with former employers to take their equipment with them when they left their jobs. Still others obtained their equipment from the SVRA.

INDIVIDUALS USED CREATIVE STRATEGIES TO FIND EMPLOYERS OR OBTAIN ADAPTIVE EQUIPMENT THAT EFFECTIVELY MET THEIR NEEDS**Example 1:**

MI navigates the system and finds ways to more affordably obtain the equipment, transportation, and home modifications that she needs to remain independent at home and in the workplace. For example, she was able to purchase a costly wheelchair at a discounted price because her friend worked at a wheelchair company. When she first learned to drive, her SVRA would not pay for a modified car with hand controls because the vehicle she hoped to purchase was not less than three years old. Consequently, her parents purchased the car and MI obtained funding from a nonprofit organization so she could get hand controls for her vehicle. For her current car, she bought a used one and negotiated with the car dealership to add \$1,000 to the loan amount to cover the cost of installing hand controls. When purchasing her home, MI worked with the Federal Housing Administration to obtain a mortgage; she also negotiated with an area contractor who equipped her home with accessibility features at no or low cost.

Most respondents negotiated with their employer to have needed supports and accommodations in place at the start of their employment but adjusted accommodations while on the job. Respondents identified to employers at the time of hiring the types of supports and reasonable accommodations they need on the job, and they worked directly with their employers to have the necessary supports put in place. In some cases, additional supports were later provided in response to evolving needs or changes in job duties. For example, one respondent with a visual impairment reported that his colleagues identified errors in documents he wrote. To address this issue, additional staff support was provided to proofread documents that he produced. Another respondent with visual and physical impairments used a paid reader to read documents to her; however, she later used the reader less because many documents are now available and accessible online. One respondent who is a teacher reports that she did not request to receive a teacher's aide, but her employer requested she have one to assist her, as needed, on the job.

Many respondents used strategic thinking by obtaining employment at organizations that provide services primarily to individuals with disabilities, or that have a track record

of reaching out to individuals with disabilities. Seven of the fifteen people we interviewed worked for disability service organizations; others worked for companies that had made special efforts to make their services and products accessible. Working for employers that reach out to people with disabilities made it easier for individuals to obtain necessary supports and accommodations on the job. Such organizations include disability service and advocacy organizations, human service organizations, companies that manufacture durable medical equipment, and companies that value making their services and products accessible. Another respondent attended a school for deaf individuals and obtained her job at a government organization through a job fair held at that school. Meeting the employer at the job fair convinced her that the employer valued deaf employees. Still another person with a sensory disability started his own business, using equipment that was purchased by his SVRA to ensure that his needs for accessing printed information and for a flexible work schedule were met.

D. Other Lessons Learned

Most respondents earned enough to transition off of the SSI/DI benefit rolls. Eleven respondents received Supplemental Security Income (SSI) or Supplemental Security Disability Insurance (SSDI) benefits at some point in the past; five received SSI and six received both SSI and SSDI benefits. Ten of these individuals subsequently transitioned off the disability rolls because their earnings reached a level that made them ineligible for these benefits. Through individual effort, tenacity, and high expectations of family, friends, and doctors, these individuals sought an education, established careers, and marshaled the resources they needed to be successful. Most of these workers said that their family members expected them to work and that they themselves never questioned that they would do so. Some of these participants said they realized that they would be consigned to a life of poverty and would live out of the mainstream of life if they did not pursue employment and earn enough to leave the rolls.

**MOST RESPONDENTS RECEIVED SSI/SSDI BENEFITS IN THE PAST BUT LATER
TRANSITIONED OFF THE DISABILITY ROLLS AFTER BECOMING
SUCCESSFULLY EMPLOYED**

Example 1:

TJ, who is blind, was kicked out of his parents' home when he was only 16. He received about \$329 per month in SSI payments, which barely covered his essential expenses. TJ tried to find employment but experienced hiring discrimination because of his vision impairment. As a result, he tried everything from "selling drugs to telemarketing" to supplement his fixed income. Finally, he applied for services from the SVRA to start his own business. Because of his earnings from this business, he no longer receives SSI or SSDI benefits.

Example 2:

DH received SSI and Medicaid from childhood through college. The SVRA paid for her tuition and books during her undergraduate career and her last year of graduate school (she has both a law degree and a master's degree in business administration). After completing her education, DH was consistently employed and received employer-sponsored health insurance. As a result, DH has not received or needed SSI or other public benefits since she completed her education.

A few respondents said they went without services or supports they needed due to the out of pocket costs. The services that the respondents expressed a need for were physical, occupational, or speech therapy. Although some of these services were covered by employer-sponsored insurance, a few respondents said the coinsurance payments were too costly or the number of sessions was too limited. Although these individuals felt the service would have been beneficial, they decided to forego receiving the service because they felt they could not afford the out-of-pocket cost.

**SOME RESPONDENTS WERE UNABLE TO ACCESS PHYSICAL OR
OCCUPATIONAL THERAPY BECAUSE OF INABILITY TO AFFORD THE OUT-
OF-POCKET COSTS**

Example 1:

JB needs to attend physical therapy (PT) three to four times a week for his multiple sclerosis. Though PT was covered by his insurance, JB was unable to afford the \$40 to \$60 coinsurance payment for each visit. He was able to negotiate with his PT provider to pay what he could afford and he therefore accessed some PT sessions. Despite the reduced cost, JB ultimately had to discontinue PT because he could not afford the recurring expense. These sessions helped him move his neck, hands, and arms without much pain, which in turn made it easier to work on his computer. Though JB learned some PT exercises he can do at home, he still feels that discontinuing PT has adversely affected his ability to do his job.

Example 2:

MW uses her hands to maneuver her wheelchair throughout the day. As a result she has severe carpal tunnel syndrome in both hands and has to wake up half an hour early each morning to do hand exercises to get her hands moving. In order to alleviate the pain in her hands and the rest of her body, MW would need to attend physical therapy sessions. Though her insurance covers it, MW opted to not get physical therapy because she could not afford the coinsurance payments. She thinks that if she were able to access PT, she would be able to better manage her carpal tunnel syndrome and get more rest before her work day begins.

Example 3:

BA had speech therapy as a child but stopped accessing it after he went to college. Interested in improving his ability to speak to coworkers, BA recently decided to obtain speech therapy sessions. His employer-sponsored health insurance covered only 11 sessions. Unable to pay the full cost of the additional sessions on his own, BA decided to discontinue them.

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IV. CONCLUSIONS

This study explored how workers with disabilities obtain and, where applicable, pay for the services and supports they need to find and keep work, by conducting in-depth, qualitative interviews with a convenience sample of 15 workers with a variety of disabilities. We examined the types of services and supports they need, who pays for them, and how they obtain them. We wanted to know the extent to which the employer, private health insurance, or other sources covered these expenses and the extent to which individuals paid for needed services themselves. The individuals we interviewed had incomes of at least \$28,000 and they were not generally eligible for public benefits, such as Social Security Disability or Medicaid benefits.

The results of this study underscore the diversity of solutions that workers with disabilities use to solve the problems of finding and keeping a job that pays at least a moderate salary. An individual's specific needs, the nature of the job, and the extent to which the costs for services and supports are covered by health insurance or other sources all play a role in determining the specific challenges that workers with disabilities will encounter and the solutions they will have to devise. Most of the individuals who participated in this study have cobbled together—usually with the help of employers, coworkers, and family—an array of services and supports that allow them to keep working at jobs that pay them enough to stay off public disability programs. Some respondents must incur substantial out-of-pocket costs to maintain access to the services and supports they need.

The small sample of individuals who participated in this study precludes us from making conclusions that are broadly generalizable. We do not know whether the experiences reported by this group of workers are similar to the experiences of other workers with various disabilities who also earn at least moderate incomes from their jobs. Given the diversity of their needs, the inherent variation in jobs, and the continued evolution in communication technologies, workers

with disabilities will probably always have to rely on their own creativity, ingenuity, and good fortune to assemble the services and supports they need to keep working. This study provides a glimpse into how 15 individuals have accomplished this goal, but studies with larger samples will be necessary to provide staff at CMS and other policymakers with the more in-depth information they need to help workers with disabilities effectively address the challenges of finding and keeping competitive employment.

REFERENCES

Stapleton, D., B. O'Day, G. Livermore, and A. Imparato, A. "Dismantling the Poverty Trap: Disability Policy for the Twenty-First Century." *The Milbank Quarterly*, vol. 84, no. 4, 2006, pp. 701—732.

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APPENDIX A

PROJECT INFORMATION SHEET

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WORKERS WITH DISABILITIES PROJECT

Questions and Answers

Below we have answered some questions that you may have about the Workers with Disabilities Project. If you have more questions or need more information, please contact Stephanie McLeod at SMcLeod@mathematica-mpr.com or 1 (855)724-1202 (toll free).

What is the purpose of this project and why is it needed?

This project will help us understand what health services and work supports that employed individuals with disabilities use, how they get these supports and services, and who provides and pays for them. What we learn may help the federal Medicaid agency understand more about what services and supports workers with disabilities like you need to keep working.

Who is conducting and paying for this project?

Mathematica Policy Research (Mathematica) will be conducting this project. Mathematica is a research organization that conducts policy research and program evaluations to help agencies learn how to do a better job at providing health, education, and other services. You can learn more about us by going to our website at www.mathematica-mpr.com. The Centers for Medicare and Medicaid Services, which is the federal Medicaid agency, is paying for this project.

Who will participate in this project?

We would like to speak with workers with physical, sensory, psychiatric, and learning/intellectual disabilities between the ages of 21 and 64 who are earning more than \$28,000 per year.

What questions will we ask you?

We will talk with you by phone, Skype, or in any other way you prefer for a half-hour to an hour. We will ask you what services and supports you need to get ready for work and to do your job. We will also ask you how you receive these supports and who pays for them.

If you participate in the project, what happens to the information you provide?

All information you share with us will remain confidential, meaning that your name or other information that could identify you will not be used in any report we write from this study.

Will I receive any benefit from the study?

In addition to helping us with a valuable project, you will receive a \$50 gift card as a thank you for your participation.

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APPENDIX B
SCREENING TOOL

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SCREENING TOOL

Hello, may I please speak to [insert name of contact]?

My name is [insert name] and I am calling from Mathematica Policy Research in regards to the workers with disabilities project.

[If referred by an organization]

I received your contact information from [insert name of referring organization].

[If contacted us directly]

I received your [email/phone call] about your interest in participating in the project, and am calling to follow up.

I'd like to talk with you about this project to find out whether you will be able to participate. Also, I can answer any questions you have about the project.

Do you have a few minutes to speak with me today?

[If No]

When would be a better time to speak with you?

[If Yes]

Great! So, there are three important things I'd like you to know before we begin.

First, let me tell you why we are doing this project. We are doing this project because the agency that runs the Medicaid program asked us to help them learn more about what services and supports working people with disabilities need to become employed and stay employed. What you say to us could help policy makers better understand what services you and others like you need.

Second, I have to find out whether you can participate in this project by asking you some questions. I'm going to ask these questions in just a moment.

The third important thing is that all your answers are confidential. That means we will not tell anyone what your answers are, not the organization that gave us your information, not the Medicaid agency, not your employer, no one.

Finally, we appreciate your willingness to talk with us. Even if you can't participate in the project, we want to say thank you for volunteering and for answering my questions.

Ok. Do you have any questions for me at this point?

Great! Let's get started. I'm going to ask you several questions which I'd like you to answer to the best of your ability. Please let me know at any point if you have any questions.

Question #1

What disabling conditions do you have? Do you have any other health conditions? [**Note:** If the respondent reports having multiple impairments, list all of them, but also ask what their primary disability is.]

Question 2

Are you currently receiving any public benefits, such as Supplemental Security Income (aka SSI), Social Security Disability Insurance (aka SSDI), Medicare or Medicaid?

- No
- Yes

If yes:

- SSI
- SSDI
- Medicaid
- Medicare
- TANF
- Other _____

Question 3

Have you received any of these benefits in the past?

- No
- Yes

If yes, which ones? For how long did you receive these benefits? About how long ago was this?

- SSI
- SSDI
- Medicaid
- Medicare
- TANF
- Other _____

Question 4

Are you currently employed?

- No
- Yes

If yes, how many hours a week do you work?

On average is your income:

- Below \$28,000
- \$28,000 to \$50,000 per year
- \$50,000-\$75,000 per year
- \$75,000 or more per year

Do you work for an employer, or are you self-employed?

- Employer
- Self employed

Question 5

Did you require any work support or accommodations to get your current job?

Do you require work supports/accommodations (such as assistive technology, personal aides, specialized equipment, etc) to do your job now?

- No
- Yes

Question 6

Are your work supports covered by your or your partner's health insurance, your employer, or do you pay some or all of them out-of-pocket? (Check all that apply)

- Covered by your health insurance
- Covered by your partner's health insurance
- Covered by your employer
- Pay out of pocket
- Other

And the final question...

Question 7

Are you willing to talk with me and my colleague about the work supports you need and how they're paid for?

- No
- Yes

Do you have any questions for us about this project at this point?

Would it be ok with you if we call you back to ask you more questions?

[If does not pass the screening or if we are not sure if we want to interview:]

OK. We want to make sure that we talk to workers who have different kinds of jobs and need different kinds of services and support. So, I need to check to see if we still need to talk to someone in your particular situation. I will get back to you within a week to let you know one way or the other.

Thank you again for your time.

Goodbye!

[If passes the screening]

Congratulations, you passed the screening. Next, I am going to tell you a little more about the questions we will be asking you when we call back so you'll know what to expect.

- We will call you at a time that works for you. If you prefer to talk in the evening or during the weekend, we can talk to you during those times. The call will last about one hour.
- We're able to use other modes of communication beside a phone if you would like us to (i.e. Google-chat, Skype, TTY/TDD, etc). How would you like to talk to us (e.g. telephone, Google-chat, Skype, TTY/TDD, etc)?
- Like today, all your answers will be confidential, meaning we will not share anything you say with anyone or any organization. Also, you can stop the call whenever you want. Participating in this project is entirely up to you.
- Finally, you will receive a \$50 gift card, which we will send to you after the call.

Do you have any questions?

Great! Now let's schedule a good time for the call. What would be a good date and time for you?

Thank you so much for your time. By the end of today, I will send you an email with the time and date for the call, and I'll call the day before to remind you. If you have any questions or comments at any time please feel free to contact me at [insert contact information]. Goodbye!

APPENDIX C
PARTICIPANT CONSENT FORM

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PARTICIPANT CONSENT FORM

[**Note:** This information will be sent to the interviewee prior to the interview, or read to them at the beginning of the interview.]

The aim of this project is to:

- Understand the types of supports and services working individuals with disabilities use on and off the job including what supports workers with disabilities used to get their job and what they use to stay employed at their current job.
- Understand how individuals with disabilities obtain and pay for work supports, services, and other types of assistance
- Inform the federal Medicaid agency, known as the Centers for Medicare and Medicaid Services (CMS), about the strategies that workers with disabilities use to obtain the work and health supports and services they need

I agree that to take part means that I am willing to:

- Answer questions about the services I use or need
- Allow the discussion to be audio-taped
- Allow the project team to use and share information I provide in the form of group results only, without using my name or other personal information. That means, if we decide to quote you, we won't use your name or any information that could identify you.

I understand that my participation is voluntary, that I can choose not to answer any question, and I can withdraw at any time without being penalized or disadvantaged in any way.

I understand that the project team will keep all written and audio taped information in a secured data file. Only the members of the project team will have access to the recording and it will be destroyed at the end of the project.

I understand that all information I share will remain confidential, meaning that my name or other information that could identify me will not be used in any report that is produced from this study.

I understand that I will receive a \$50 gift card for participating in this interview.

I agree to take part in this project. I have had the project explained to me, and I have read the Project Information Sheet, which I can keep for my records.

Please direct any questions or concerns to:

Bonnie O'Day
Mathematica Policy Research
Boday@mathematica-mpr.com
202 264-3455

Print Name: _____

Provided Verbal Consent: Yes..... No.....

Name of interviewer: _____

Date: _____

Copy provided to interviewee sent by: email_____ hard copy _____

APPENDIX D

INTERVIEW GUIDE FOR INDIVIDUALS WITH

PHYSICAL AND SENSORY DISABILITIES

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INTRODUCTION [5 MINUTES]

Hello, may I please speak to [insert name of contact]?

This is [insert name(s)] from Mathematica Policy Research with the project on workers with disabilities. As a part of this project, we are calling to talk with you about the health services and supports that you use on and off the job. This discussion should last about 60 minutes. If it goes longer than half an hour and you'd like to break our discussion into two parts, we can schedule a second appointment to finish the discussion at a later time. Is this still a good time to talk?

Terrific! To start, I'd like to thank you for speaking with us today about the types of work supports that you may have used to get your job and what you use to do your job now. As you may know, we are doing this project because the agency that runs the Medicaid program asked us to help them learn more about what services and supports working people with disabilities need to become employed and stay employed. What you say to us could help policy makers better understand what services and supports you and others like you need.

Now, we'll cover several topics during our discussion, including your employment and medical condition; the services, supports, and accommodations you use on and off the job; and how you obtain them.

Our discussion today will be audio recorded to ensure that our meeting notes are accurate. Only members of the project team will listen to the recording and we will destroy it at the end of the project. This is also a good time to emphasize that all information you share with us will remain confidential, meaning that your identifying information will not be used in any report that is produced from this project. Your responses today will be combined with the responses collected from other people who participate in the project. If we decide to directly quote you in our report, we'll be sure to first get your consent and we won't attach your name to the quote.

We want this to be an informal discussion so please feel free to answer the questions with examples of your experience. If a question is unclear please feel free to let us know, and we will be glad to clarify further.

Do you have any questions before we begin?

Okay, let's get started.

Topic Area 1: Employment [5 minutes]

First, we're going to spend a few minutes talking about employment.

1. Tell me about your job. Where do you work? What's your occupation?
2. How long have you worked at this job?
3. Are you employed part time, full time, or self employed?
 - If self employed, how long have you been self employed?
4. How many hours do you work per week, and what's your general schedule (i.e., mornings, afternoons, or weekends)?

5. Before you started working, were there any services, supports or accommodations you used to help you get your job?
6. Have you ever received services or supports from a one-stop career center, or your state or local vocational rehabilitation office? If so, when?
7. What (if anything) did your doctor(s) say to you about working before you got your job? What are they saying now that you are working?
8. What did your family tell you about working before you got your job? What are they saying now that you are working?

Topic Area 2: Type of Disability [5 minutes]

Now, I'd like to spend the next couple of minutes talking about your medical condition or disability.

1. You told us when we talked earlier that you had/were [fill in impairment or medical condition from the screening interview]
2. About how old were you when your condition or disability began?
3. Does your employer know you are a person with a disability?
 - Did you tell your employer about your disability or medical condition?
 - Do you think your employer is aware of your disability or medical condition?

Topic Area 3: Needed/Desired On-the-Job Supports, Services and Accommodations [10 minutes]

The next topic that I'd like to cover relates to on-the-job supports and accommodations that you need to work. Many individuals with disabling conditions use some type of employment support or require some type of accommodation to do their job. The types of employment supports or accommodations used vary widely due to the nature of each individual's disability and we'd like to find out what support(s) or accommodation(s) you use.

1. Do you use any of the following supports on the job?
 - Personal assistance (e.g. personal attendant, etc)
 - Service animal/dog guide
 - Staff support that other employees in your organization don't use. (what does the staff do for you?)
 - Sign language interpreters, CART reporter, or other interpretation
 - Assistive technology (e.g. alternative keyboards, Braille embossers, speech recognition programs, large print or speech software)
 - Adaptive furniture (e.g. adjustable tables)
 - Is there anything I've left out like peer supports?
 - Was there someone who helped you communicate with your employer?
 - How do you get to work?

[NOTE: If the respondent isn't familiar with this term, explain that assistive technology is any product or device that provides additional accessibility to individuals who have physical, sensory, or cognitive impairments.]

2. Have you received any of the following accommodations to do your job?
 - Change in job duties, such as when an employer modifies one's job responsibilities so they're better suited to the individual's condition
 - Change in job schedule or breaks (i.e., work irregular or fewer hours than other workers)
 - Change in job location (e.g., work from home)
 - Informal job supports (e.g., supervisor writes out employee's work schedule or provides one-on-one training to learn new job task that they don't provide to other workers)
3. Do you use any other types of work supports or accommodations at work, aside from those that I mentioned already?

Topic Area 4: Provision of On-the-Job Supports, Services and Accommodations [15 minutes]

Now that you've explained the types of supports and accommodations you use on-the-job, I'd like to spend some time talking about how you've accessed these job supports and accommodations. I'd like to talk about each job support and accommodation separately.

First, you mentioned using [insert job support/accommodation].

1. When did you begin to use [insert support/accommodation] that you spoke of earlier?

[Probe as needed: Did you use this support/accommodation at a prior job, when you started working at this job, or after you were working at your current job for a period of time?]
2. How did you get access to the [insert support/accommodation] that you spoke of earlier? For example, did you [insert appropriate probe below]:
 - Did you or your employer purchase the [insert type of AT device] yourself when you started working, or was it something that you already owned?
 - Did you work with a VR counselor to identify and put on-the-job supports in place?
 - Did you talk with your employer to have this support arranged, or did someone else, such as a voc rehab counselor, talk to your employer?
 - When did you/your voc rehab counselor talk with your employer to have this support arranged?
 - Who provides the [insert support/accommodation]?
3. Who pays for the [insert support/accommodation]?
4. Does the [insert provider/funder] pay for 100 percent of the cost or only a portion?
 - If the [insert provider/funder] pays for only a portion of the cost, how is the difference funded?
 - [If employer provides or pays] Did you negotiate this support when you were hired or after you had worked there for a while?

Second, you also mentioned using [insert job support/accommodation].

[NOTE: Repeat the above-mentioned questions/probes for each support/accommodation that is cited.]

Topic Area 5: Other Types of Supports Used When Not at Work [15 minutes]

The next topic that I'd like to discuss with you relates to other types of supports and services that you use when preparing for and getting to work.

1. Do you use any equipment, devices, or technology to help you prepare for or get to work?, such as:
 - Durable medical equipment (e.g. wheelchairs, walkers, canes)
 - Prosthetic and orthotic items (e.g. braces, therapeutic shoes, artificial limbs/eyes, ostomy supplies)
 - Speech generating devices
 - Adaptive equipment (e.g. adaptive eating utensils, dressing stick, handheld shower)
2. Do you receive any personal assistance (e.g. personal attendant or other in-home support, etc) or assistance from a family member or friend when getting ready for work?
3. Do you receive any assistance from a VR counselor?
4. Do you use any assistive technology when preparing for work?
5. Do you use any other types of supports, services, devices, or assistance when getting ready for work? If so, which ones?
6. How do you get to work? Do you drive, use public transit, use accessible transportation, or get a ride to and from work?

Again, I'd like to spend a few minutes talking about how you've accessed each of these supports. First, you mentioned using [insert type of support/device/equipment/assistance].

1. When did you begin to use this support/device/equipment/assistance that you spoke of earlier?

[Probe as needed: Did you use this support/device/equipment/assistance at a prior job, when you started working at this job, or after you were working at this job for a period of time?]
2. How did you get access to the [insert support/device/equipment/assistance] that you spoke of earlier? For example, did you [insert appropriate probe below]:
 - Purchase the [insert product/device/equipment] yourself when you started working, or was it something that you already owned?
 - Who did you consult with to identify these types of supports or services, if anyone?
 - Who did you talk with (if anyone) to arrange personal assistance or transportation to and from work?
 - Did you reach out to or get referred to a provider who supplied the [insert support/device/equipment/assistance]? If so, who referred you to this provider?

3. Who provides the [insert support/service/device/assistance/equipment]?
4. Who pays for the [insert support/service/device/assistance/equipment]?
5. Does the [insert provider/funder] pay for 100 percent of the cost or only a portion?
 - If the [insert provider/funder] pays for a portion of the cost, how is the difference funded?

Second, you also mentioned using [insert support/service/device/assistance/equipment/assistance].

[NOTE: Repeat the above-mentioned questions/probes for each support/device/equipment/assistance that is cited.]

Topic Area 6: Medical Care and Related Services [10 minutes]

Now, I'd like to talk with you about the medical care and services that you receive.

1. What type(s) of health insurance do you have (e.g. HMO, PPO)?
2. Who provides this insurance (e.g. Kaiser, Aetna etc)?
3. Who pays for this insurance coverage (e.g. yourself, employer, or spouse/partner)?
4. Do you think your insurance coverage adequately covers all of the work supports that we've talked about so far? If not, why not?
5. Have you tried to get your insurance company to pay for any of the supports we've talked about? If so, has your insurance company denied you coverage for any of the on or off the job supports or services you mentioned? If so, which supports or services were denied?
 - Physical, occupational, or speech therapy
 - Assistive technology
 - Adaptive equipment
 - Counseling or psychiatric services
 - Specific medication
 - Personal assistance or other in-home support
 - Other
6. If your insurance company denied you coverage for these supports or services, did you still get access to these services or supports?

If Yes,

 - How were they paid for?
 - Do you currently use these services/supports?

If No,

 - Why not?
 - Has not having this service/support affected your ability to get to work or perform your job duties? How so?
 - Has denial of supports or services ever prevented you from getting to work or maintaining employment?

[Note: If the interviewee said they receive Medicare or Medicaid, ask questions 4-6 about Medicare or Medicaid coverage.]

Topic Area 7: Illustrative example [10 minutes]

I'd like to switch gears for a moment to talk about your typical work day. Walk me through a typical work day, from getting up in the morning to going to bed at night. . .

[NOTE: At each activity, probe for need for supports or assistance. Inquire how it is obtained and paid for.]

Topic Area 8: paying for the supports [5 minutes]

Moving on, we've talked quite a bit about employment supports which are so important in helping people keep their job or advance their careers. During our discussion, you mentioned using about [insert number of services/supports cited by respondent] different services and supports on-the-job.

1. About how much do you spend a week, a month, or a year out-of-pocket on these supports or services?
2. How many people live in your household? Do they help to provide this support? What do they have to give up in order to provide your support (e.g. employment or leisure time)?
3. Do you use any tax incentives or tax breaks to help you pay for the assistance you need?
 - a. Is this a federal or state tax break?
4. Does your employer offer a flexible spending account?

If yes, do you use them?

 - What types of supports/services do you charge to your flexible spending account?
 - Have you been denied reimbursement for any of these supports/services by your flexible spending account?

Topic 9: Demographics [5 minutes]

Finally, I need to ask just a few demographic questions:

1. What is your age?
2. What is your race or ethnicity?
3. Note the respondent's gender
4. What is your primary language?
5. What is your marital status?
6. What is the highest level of education that you completed?
 - Grammar/elementary school
 - Junior high/middle school

- High school
 - GED
 - Vocational school
 - Some College
 - College
 - Graduate School
7. What is your zip code
8. Do you live in an urban or rural area?
- Urban
 - Rural
9. In which category does your total before-tax household income fall?
- \$2,500 or less
 - \$2, 501 to \$5,000
 - \$5,001 to \$10,000
 - \$10,001 to \$20,000
 - \$20,001 to \$30,000
 - \$30,001 to \$40,000
 - \$40,001 to \$50,000
 - \$50,001 to \$75,000
 - \$75,001 to \$100,000
 - More than \$100,000
10. How many people live in your household?
11. Do you own or rent your home?

Final Thoughts [5 minutes]

Before we end our discussion, is there any other information about employment supports that you would like to share with us that was not covered already?

And finally, before we end this call, I'd like to explain how we will use the information you just gave us. In the next few weeks, we're going to talk with several other people who are also participating in this project. Then we'll look at all the answers and figure out what common work supports and health services people are using and purchasing. We will then write a report for CMS that tells them what work supports people are using and how they are paying for them. We'd be happy to send you a copy of our report. Would you like one? [Collect email or address.]

I appreciate you being so candid when speaking with us today.

Make arrangements to send the \$50 gift card.

Thank you for your contribution on this important project. Goodbye!

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APPENDIX E

INTERVIEW GUIDE FOR INDIVIDUALS WITH

INTELLECTUAL AND PSYCHIATRIC DISABILITIES

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Introduction [5 minutes]

Hello, may I please speak to [insert name of contact]?

This is [insert name(s)] from Mathematica Policy Research with the project on workers with disabilities. As a part of this project, we are calling to talk with you about the health services and supports that you use on and off the job. This discussion should last about 60 minutes. If it goes longer than half an hour and you'd like to break our discussion into two parts, we can schedule a second appointment to finish the discussion at a later time. Is this still a good time to talk?

Terrific! To start, I'd like to thank you for speaking with us today about the types of work supports that you use to do your job. As you may know, we are doing this project because the agency that runs the Medicaid program asked us to learn more about how people with disabilities pay for health services, personal assistance, assistive technologies, and supported employment. Our discussion today may help policy makers better understand what services you and others like you need.

Now, we'll cover several topics during our discussion, including your employment and medical condition; the services, supports, and accommodations you use on and off the job; and how you obtain them.

Our discussion today will be audio recorded to ensure that our meeting notes are accurate. Only members of the project team will listen to the recording and we will destroy it at the end of the project. This is also a good time to emphasize that all information you share with us will remain confidential, meaning that your identifying information will not be used in any report that is produced from this project. Your responses today will be combined with the responses collected from other people who participate in the project. If we decide to directly quote you in our report, we'll be sure to first get your consent and we won't attach your name to the quote.

We want this to be an informal discussion so please feel free to answer the questions with examples of your experience. If a question is unclear please feel free to let us know, and we will be glad to clarify further.

Do you have any questions before we begin?

Okay, let's get started.

Topic Area 1: Employment [5 minutes]

First, we're going to spend a few minutes talking about employment.

1. Tell me about your job. Where do you work? What's your occupation?
2. How long have you worked at this job?
3. Are you employed part time, full time, or self employed?
 - a. If self employed, how long have you been self employed?
4. How many hours do you work per week, and what's your general schedule (i.e., mornings, afternoons, or weekends)?

5. Before you started working, were there any services, supports or accommodations you used to help you get your job?
6. Have you ever received services or supports from a one-stop center or through your state or local vocational rehabilitation agency? If so, when?
7. What (if anything) did your doctor(s) say to you about working before you got your job? What are they saying now that you are working?
8. What did your family tell you about working before you got your job? What are they saying now that you are working?

Topic Area 2: Type of Disability [5 minutes]

Now, I'd like to spend the next couple of minutes talking about your medical condition or disability.

1. You told us when we talked earlier that you had/were [fill in impairment or medical condition from the screening interview]
2. About how old were you when your condition or disability began?
3. Is your disability visible to your employer?
 - If not, did you tell your employer about your disability or medical condition?
 - If not, do you think your employer is aware of your disability or medical condition?

Topic Area 3: Needed/Desired On-the-Job Supports, Services and Accommodations [10 minutes]

The next topic that I'd like to cover relates to on-the-job supports and accommodations that you need to work. Many individuals with disabling conditions use some type of employment support or require some type of accommodation to do their job. The types of employment supports and accommodations used vary widely due to the nature of each individual's disability and we'd like to find out what support or accommodation you use.

1. Do you use any of the following supports on the job?
 - Service/therapy animal
 - Additional training that is not needed by other employees in your position
 - Additional supervision
 - A counselor or other person who helps you when you have problems on the job or with your employer?
 - Staff support (what kind of support do other staff provide?)
 - Job coach
 - Assistive technology (e.g. reading machines, voice output software, talking calculators, PDAs)
 - Is there anything I've left out like peer supports?
 - Was there someone who helped you communicate with your employer?

[NOTE: If the respondent isn't familiar with this term, explain that assistive technology is any product or device that provides additional accessibility to individuals who have physical, sensory, or cognitive impairments.]

2. Have you received any of the following accommodations to do your job?
 - Changes to training materials and examinations
 - Changes to job instructions or reference manuals
 - Change in job duties, such as when an employer modifies one's job responsibilities so they're better suited to the individual's condition
 - Change in job schedule or breaks (i.e., work irregular or fewer hours than other workers)
 - Change in job location (e.g., work from home)
 - Informal job supports (e.g., supervisor writes out employee's work schedule or provides one-on-one training to learn new job task that they don't provide to other workers)
3. Do you use any other types of work supports or accommodations, aside from those that I mentioned already?

Topic Area 4: Provision of On-the-Job Supports, Services and Accommodations [15 minutes]

Now that you've explained the types of supports and accommodations you use on-the-job, I'd like to spend some time talking about how you've accessed these job supports and accommodations. I'd like to talk about each job support and accommodation separately.

First, you mentioned using [insert job support/accommodation].

1. When did you begin to use [insert support or accommodation] that you spoke of earlier?

[Probe as needed: Did you use this support/accommodation at a prior job, when you started working at this job, or after you were working at your current job for a period of time?]
2. How did you get access to the [insert support/accommodation] that you spoke of earlier? For example, did you [insert appropriate probe below]:
 - Did you or your employer purchase the [insert type of AT device] when you started working, or was it something that you already owned?
 - Did you work with a job coach to identify and put on-the-job supports in place?
 - Did you talk with your employer to have this support arranged, or did someone else, such as a job coach, talk to your employer?
 - When did you/your job coach speak with your employer to have this support arranged?
3. Who provides the [insert support/accommodation]?
4. Who pays for the [insert support/accommodation]?
5. Does the [insert provider/funder] pay for 100 percent of the cost or only a portion?
 - If the [insert provider/funder] pays for only a portion of the cost, how is the difference funded?
 - [If employer provides or pays] Did you negotiate this support when you were hired or after you had worked there for a while?

Second, you also mentioned using [insert job support/accommodation].

[NOTE: Repeat the above-mentioned questions/probes for each support/accommodation that is cited.]

Topic Area 5: Other Types of Supports USED WHEN NOT AT WORK [15 minutes]

The next topic that I'd like to discuss with you relates to other types of supports and services that you use when preparing for and getting to work.

1. Do you access or use any of the following services or supports to help prepare for or maintain employment? Such as:
 - Medication
 - Counseling or psychiatric services
 - Case management
 - Peer support
 - Behavioral skills training
 - Speech or language therapy
 - Cueing or coaching to help you get ready for work
2. Do you receive any personal assistance (e.g. personal attendant or other in-home support, etc) or assistance from a family member or friend when getting ready for work?
3. Do you use any assistive technology when preparing for work?
4. Do you use any other types of supports, services, devices, or assistance to prepare for work? If so, which ones?
5. How do you get to work? Do you drive, use public transit, use accessible transportation, or get a ride to and from work?

Again, I'd like to spend a few minutes talking about how you've accessed each of these supports. First, you mentioned using [insert type of support/service/device/assistance].

6. When did you begin to use this support/device/equipment/assistance that you spoke of earlier?

[Probe as needed: Did you use this support/service/device /assistance at a prior job, when you started working at this job, or after you were working at this job for period of time?]

7. How did you get access to the [insert support/service/device /assistance] that you spoke of earlier? For example, did you [insert appropriate probe below]:
 - Purchase the [insert AT device] yourself when you started working, or was it something that you already owned?
 - Who did you consult with to identify these types of supports or services, if anyone?
 - Who did you talk with (if anyone) to arrange personal assistance or transportation to and from work?
 - Did you reach out to or get referred to a provider who supplied the [insert support/service/device/assistance]? If so, who referred you to this provider?

8. Who provides the [insert support/service/device/assistance]?
9. Who pays for the [insert support/service/device/assistance]?
10. Does the [insert provider/funder] pay for 100 percent of the cost or only a portion?
If the [insert provider/funder] pays for a portion of the cost, how is the difference funded?

Second, you also mentioned using [insert support/service/device/assistance].

[NOTE: Repeat the above-mentioned questions/probes for each support/service/device/assistance that is cited.]

Topic Area 6: Medical care and related services [10 minutes]

Now, I'd like to talk with you about the medical care and services that you receive.

1. What type(s) of health insurance do you have (e.g. HMO, PPO)?
2. Who provides this insurance (e.g. Kaiser, Aetna etc)?
3. Who pays for this insurance coverage (e.g. yourself, employer, or spouse/partner)?
4. Do you think your insurance coverage adequately covers all of the work supports that we've talked about so far? If not, why not?
5. Have you tried to get your insurance company to pay for any of the supports we've talked about? If so, has your insurance company denied you coverage for any of the on or off the job supports or services you mentioned? If so, which supports or services were denied?
 - Speech or language therapy
 - Assistive technology
 - Counseling or psychiatric services
 - Specific medication
 - Personal assistance or other in-home support
 - Case management
 - Peer support
 - Other
6. If your insurance company denied you coverage for these supports or services, did you still access these supports or services?

If Yes,

 - How were they paid for?
 - Do you currently utilize these supports or services?

If No,

 - Why not?
 - Has not having these supports/services affected your ability to get to work or perform your job duties? How so?
 - Has denial of coverage or reimbursement for supports or services ever prevented you from getting to work or maintaining employment?

[Note: If the interviewee said they receive Medicare or Medicaid, ask questions 4-6 about Medicare or Medicaid coverage.]

Topic Area 7: Illustrative example [10 minutes]

I'd like to switch gears for a moment to talk about your typical work day. Walk me through a typical work day, from getting up in the morning to going to bed at night. . .

[NOTE: At each activity, probe for need for supports or assistance. Inquire how it is obtained and paid for.]

Topic Area 8: Paying for the supports [5 minutes]

Moving on, we've talked quite a bit about employment supports which are so important in helping people keep their job or advance their careers. During our discussion, you mentioned using about [insert number of services/supports cited by respondent] different services and supports on-the-job.

1. About how much do you spend a week, a month, or a year out-of-pocket on these supports or services?
2. How many people live in your household? Do they help to provide this support? What do they have to give up in order to provide your support (e.g. employment or leisure time)?
3. Do you use any tax incentives or tax breaks to help you pay for the assistance you need?
 - a. Is this a federal or state tax break?
4. Does your employer offer flexible spending accounts? If so, do you use them?

If yes

- What types of supports/services do you charge to your flexible spending account?
- Have you ever been denied reimbursement for any supports or services by your flexible spending account?

Topic 9: Demographics [5 minutes]

Finally, I need to ask just a few demographic questions.

1. What is your age?
2. What is your race or ethnicity?
3. Note the respondent's gender
4. What is your primary language?
5. What is your marital status?
6. What is the highest level of education that you completed?
 - Grammar/elementary school
 - Junior high/middle school
 - High school

- GED
 - Vocational school
 - Some College
 - College
 - Graduate school
7. What is your zip code?
8. Do you live in an urban or rural area?
- Urban
 - Rural
9. Do you own or rent your home?
- Own
 - Rent
10. In which category does your total before-tax household income fall?
- \$2,500 or less
 - \$2, 501 to \$5,000
 - \$5,001 to \$10,000
 - \$10,001 to \$20,000
 - \$20,001 to \$30,000
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11. Do you own or rent your home?

Final Thoughts [5 minutes]

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I appreciate you being so candid when speaking with us today.

Thank you for your contribution on this important project.


Goodbye!

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