

**BEYOND BENEFITS STUDY
SOCIAL SECURITY ADMINISTRATION**

Thank you for agreeing to participate in this interview. My name is [NAME] [if have someone else there, introduce them as well]. [I/we] work for Westat, a research organization based in Rockville Maryland. The Social Security Administration, or SSA, has hired Westat to conduct the Beyond Benefits Study.

During the Beyond Benefits Study, we collect information about the needs of adults across the country who used to get disability-related payments from SSA but stopped receiving those payments because SSA determined that their disability became less severe and so they no longer qualified for benefits. We will use what we learn to identify services that may help people who stop getting disability-related payments and are thinking about going back to work or finding a better job. The study also gives SSA information that may improve the agency's disability-related programs and policies.

Today, we'd like to hear about your journey with receiving disability payments, your experience when you learned you would no longer be receiving those payments, your life now, and your goals for the future.

We previously sent you an informed consent sheet, explaining your rights in participating in this study. Did you have any questions about that information? [ANSWER QUESTIONS]

I just want to remind you of some of the key points about your rights. This is a research study. Your participation in this interview is voluntary. Your answers will be used for research purposes only. Taking part in the study, or choosing not to take part, will not affect any decision SSA makes about your disability benefits or payments now or in the future.

You can stop the interview at any time without penalty. You can choose not to answer any question. If you get frustrated or anxious at any point, we can take a break, skip a section, or stop the interview. If you get upset during the interview, we can offer you a referral to crisis management services that you can use if you want. However, if you tell [me/us] that you are planning to hurt yourself or someone else, [I am/we are] required by the law to notify appropriate authorities.

At the end of the study, we will submit a report to SSA summarizing the needs of people who live with or are recovering from a disability. We may use quotes from you or others in our reports but no one's name will be linked to those quotes.

We have planned for this interview to last up to one hour. At the end, you will receive a \$40 Visa gift card by mail to thank you for your participation.

Do you have any other questions? [ANSWER ALL QUESTIONS]

Finally, with your permission, I would like to record this interview to help [me/us] recall what was said. Are you okay with me recording? [PAUSE FOR RESPONSE]

[IF AGREES TO RECORDING]

I'd like to start the audio recording now. [TURN ON THE RECORDER.]

Appendix A-2. In-Depth Interview with Exiters Protocol

For purposes of the recording, I am going to ask you:

Are you willing to participate in the interview? Are you willing to have the interview recorded?

[PAUSE FOR RESPONSE.]

[IF DECLINES RECORDING]

All right, that's fine. Is it all right if I take notes?

[PAUSE FOR RESPONSE.]

OK let's begin.

A. BACKGROUND

Before we dive into the questions I have, I'd like to confirm some information about you:

- Are you currently employed? This could be full time or part time work.
 - **[IF YES]** What do you do for work? When did you start this job? About how long after you stopped receiving disability payments did you start working?
 - **[IF NO]** Have you worked for pay at any point since you stopped receiving disability-related payments? This could include both formal and informal (under the table) work.
[IF YES] Tell me a little about your employment experiences since you stopped receiving disability-related payments.
- **[IF NOT CURRENTLY EMPLOYED]** Are you currently looking for work?
 - **[IF YES]** What type of work are you looking for? What are you doing to look for a job?

Thank you for giving that helpful background information.

To start things off, I'd like to have you tell me your story in your own words, from your experience receiving disability-related payments from SSA, to how your life changed when you stopped receiving benefits, to your life now and your goals for the future. You can start the story anywhere you like, giving as much detail as you're comfortable with, and I'll ask questions if I need to understand something better.

[NOTE: Use the questions under B. Applying for disability payments, C. Receiving disability payments, D. Learning payments would stop, E. When payments stopped, F. Present, G. Future and reflections, to help prompt the interviewee to continue to talk about relevant topics. You do not need to ask each question if it does not apply or the interviewee already addressed the topic.]

B. APPLYING FOR DISABILITY PAYMENTS

Let's talk about how you felt when you first started receiving disability-related payments.

1. Why did you apply for disability benefits? How did applying for benefits make you feel?
2. About how long was it from the time you started having problems working to the time you submitted an application for disability benefits?
3. How did you first find out about the disability benefits program at SSA?
 - a. How much did you know about the disability benefits program when you applied?
 - b. Did anyone help you complete the application process?
4. How did you think receiving disability payments would change your life, if at all?
 - a. Your income? (Probe for more income and ongoing/dependable income)
 - b. Your health?
 - c. The healthcare you receive?
 - d. Other aspects?

5. For how long did you think you would receive payments?
Probe: Did you think that you would return to work full-time one day?

C. RECEIVING DISABILITY PAYMENTS

Let's talk about your life while receiving disability payments.

Disability Income

6. How was your experience receiving disability payments different than what you expected, if at all?
a. How was it better?
b. How was it worse?
7. Were you able to afford everything you need with your disability payments? Why or why not?
Probe: Pay bills, get enough food, keep housing

Health and Health Care

8. Since you started receiving benefits, did your health improve, stay about the same, or get worse over time? Please describe.
9. Did you get annual checkups since you started receiving benefits?
[IF YES]
a. Did you feel like you were able to get the care you needed? Why or why not?
b. Did you feel comfortable going to a doctor? Did you feel your doctor could understand your needs and help you? Why or why not? Did you feel your doctor treated you fairly?
- [IF NO]
c. Did you want to get annual checkups? Why or why not?
d. Do you feel you were able to get the care you needed? Why or why not?
e. Do you feel comfortable going to a doctor? Do you feel your doctor can understand your needs and help you? Why or why not? Do you feel your doctor treated you fairly?
10. Did you seek treatment for the condition(s) that limited your ability to work since you started receiving benefits?
[IF YES]
a. What type of doctor(s) did you see? How often?
b. Did you feel you were able to get the care you needed? Why or why not?
c. Did you feel comfortable going to a doctor? Did you feel your doctor can understand your needs and help you? Why or why not? Do you feel your doctor treated you fairly?

[IF NO]

Appendix A-2. In-Depth Interview with Exiters Protocol

- a. Did you want to get treatment? Why or why not?
- b. Did you feel you were able to get the care you needed? Why or why not?
- c. Do you feel comfortable going to a doctor? Do you feel your doctor can understand your needs and help you? Why or why not? Do you feel your doctor treated you fairly?

Employment

11. [IF WORKED FOR PAY]

- a. What type of work did you do?
- b. What was your experience like working while managing a disability?
 - i. What did you like about it?
 - ii. What didn't you like about it?

[IF NO]

- d. Did you want to work while you received disability payments? Why or why not?

12. Have you heard of SSA's Ticket to Work program?

[IF YES]

- a. What is your impression of it?
- b. Did you participate in the Ticket to Work program?
 - i. [IF YES] What was your experience like?

13. Are you aware of any services in your community that can help you find a job?

- a. Probe: That can help you build a resume? A cover letter? Practice for interviews?
- b. [IF YES] Have you ever used any of these services? Why or why not?
- c. [IF NO] Would you ever use any services like that? Why or why not?

Barriers

14. While you were on disability, did you ever have trouble paying your rent or keeping stable housing? Were you ever homeless, or are you now homeless?

- a. Are you aware of any services in your community that can help with housing?
 - i. [IF YES] Have you ever used any of these services? Why or why not?
 - ii. [IF NO] Would you ever use any services like that? Why or why not?

15. While you were on disability, what kind of transportation did you use to get around your local area?

Probe: Public transit? Car? Other?

- a. Do you own a car? Do you drive it?
- b. Was it a challenge to get around?
- c. Are you aware of any services in your community that could help you with transportation?
 - i. [IF YES] Have you ever used any of these services? Why or why not?
 - ii. [IF NO] Would you ever use any transportation services? Why or why not?

16. While you were on disability, did you have reliable access to the Internet at your home?
 - a. **[IF NO]** Did you access the Internet in other places (e.g., public library, retail stores or restaurants, etc.)? How did you access the Internet (e.g., library computer, cell phone, a friend's computer, etc.)?
17. While you were on disability, did you ever find it difficult to afford enough food?
 - a. If yes, how did you cope with this?
 - b. Are you aware of any services in your community that could help you to get enough food (food pantries, SNAP, etc.)?
 - i. **[IF YES]** Have you ever used any of these services? Why or why not?
 - ii. **[IF NO]** Would you ever use any services like that? Why or why not?
18. Have you experienced any discrimination related to your impairment, or related to other aspects of your life? [race/ethnicity, gender/gender identity, sexuality, age, etc.]
 - a. How has your experience with discrimination affected your ability to make ends meet, if at all? To get help?
 - b. Do you feel you cannot access help you may need because of this discrimination? Can you tell me a little more about that?
19. Were there any other challenges you faced while you were on disability that you wish you had help with?
 - a. **[If YES]** What kind of help would you have wanted?

Social Support

20. Who did you turn to for help or support while you were on disability, if anyone?
Probe: Friends, family, community organizations or advocacy groups, churches or religious groups?
 - a. Were they helpful to you? IF YES, how were they helpful?
21. Are there any support organizations in your area that you wish you had been able to get help from, but could not or did not feel comfortable getting help with? If so, why?

D. LEARNING PAYMENTS WOULD STOP

Now think back to when you found out your disability payments would stop.

22. Tell me how you first found out that your disability payments would stop.
 - a. How long before payments stopped were you notified?
 - b. How did you react when you found out?
 - c. Were you surprised to find out that your disability payments would stop? Why or why not? Did you agree with SSA that your disability was less severe than it was when you first started receiving benefits?
 - d. Was it easy to understand the letter that SSA sent notifying you that payments would stop?
 - i. Do you remember being confused by anything SSA said in the letter?

Appendix A-2. In-Depth Interview with Exiters Protocol

- e. Did you contact SSA with any questions after receiving the notification letter?
[IF YES]
 - i. What questions did you have for them?
 - ii. How did you feel after talking with someone from SSA?

23. In the days and weeks after you were notified payments would stop, how did you prepare for losing benefit payments?
- a. What help or support did you feel you **needed** from others? What help or support did you actually **get** from others? Family, friends, community agencies, others?
 - b. Did you have any ideas how you were going to replace the income you would lose from disability payments?

E. WHEN PAYMENTS STOPPED

Thinking to the time when your payments stopped.

24. Did you feel prepared when your payments stopped?
- a. What do you think made you feel prepared/unprepared?
25. How did your health change when your payments stopped, if at all? Overall? Did your health related to the condition for which you received disability benefits change?
26. Did the payments stopping impact your ability to...
- a. Get around your local area?
 - b. Access the Internet?
 - c. Get enough to eat?
 - d. Keep your housing?
 - e. Get access to health care when you needed it?
 - f. Afford co-pays for medications or doctor or clinic visits?
 - g. Afford medications you were taking at that time?

F. PRESENT

Turning to how things are for you now.

27. Since you stopped receiving disability payments, what has changed in your life?
- Probe: Changes in:
- a. How you view your situation?
 - b. Your ability to take care of yourself (and your family)?
 - c. Your employment situation?
 - d. Your ability to get around your local area?
 - e. Your Internet access?
 - f. Your ability to get enough to eat?
 - g. Your ability to keep your housing?
 - h. Your ability to access health care when you need it?
 - i. Your ability to pay for medications or doctor visits you needed?
 - j. Other aspects of your life?

28. Is your health better or worse today compared to when you received disability payments?
 - a. In general, do you feel you are getting the care you need? Why or why not?
 - b. [if impairment has not been fully resolved] Do you feel you are getting the care you need related to [impairment]? Why or why not?
29. What are some of the challenges you face in your daily life, if any?
 - a. Does anything help you address these challenges? If so, what kinds of things (or people or supports) help you now?
 - b. Are there any additional supports you wish you had to help you?
30. Who do you turn to for help or advice? Family, friends, community organizations, church or religious groups, advocacy groups, others?
31. [IF EMPLOYED] Tell me about your current job.
 - a. How did you find your job?
 - b. How long have you had this job?
 - c. Do you like your job? If yes, what do you like about it?
 - d. If you don't like your job, or parts of your job, what do you not like about it?
32. [IF LOOKING FOR WORK] Tell me about your job search.
 - a. What kind of work are you looking for?
 - b. Are you looking for part-time or full-time work?
 - c. Have you applied for any jobs yet? If yes, what has been your experience?
 - d. If you were offered a job today, would you be available to work?

G. FUTURE AND REFLECTIONS

Let's turn to your goals and hopes for the future.

33. Where do you hope to be in your life in one year?
 - a. In 5 years?
 - b. In 10 years?
[Probe on: employment, health, social support, Covid-related concerns]
34. Which of those goals do you think will be easiest to achieve? Why?
 - a. Which will be hardest to achieve and why?
 - i. Is there any kind of assistance or support that you think could help you achieve those more difficult goals?
35. The SSA offers different programs to people who are transitioning off of disability payments, such as connections to employment networks that help with career planning and counseling, connections to vocational rehabilitation agencies that can provide training for different jobs, and connections to organizations that can help with legal support and accommodations. Looking back, would you have found any of those helpful when you were told your benefits were going to end?

Appendix A-2. In-Depth Interview with Exiters Protocol

- a. Did you know about these support programs before you lost your benefits? If yes, how did you learn about them? Would you prefer to learn about available programs in some other way (e.g., email, text, phone, paper brochure, other)?
 - b. How do you think SSA could introduce these kinds of transition programs so that people would want to participate?
36. What advice would you give to someone who just found out that their disability-related payments will be ending?

Thank you, that's all the questions we have.

[CONFIRM ADDRESS FOR MAILING INCENTIVE]