

**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 currently receive disability-related payments from SSA and are currently going through the continuing disability review (CDR) process to determine if their disability became less severe and are no longer qualified for benefits. We will use what we learn to identify services that 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 life now, what types of support you'd like to receive if your payments stopped, 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.]**

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

Appendix A-1. In-Depth Interview with Possible Exiters Protocol

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?
 - **[IF NO]** Have you worked for pay at any point since you started receiving disability-related payments? This could include both formal and informal (under the table) work.
 - **[IF YES]** Tell me a little about your work experience since you started 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 applying for disability-related payments from SSA and to your life now, to what would happen if your payments ended, to 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. If payments stopped, E. 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 has 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 you feel about applying for benefits?
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?
 - 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. Are 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. In general, how would you describe your health while receiving payments?
 - a. Since you started receiving benefits, has your health improved, stayed about the same, or gotten worse over time? Please describe.
9. Do you get annual checkups since you started receiving benefits?
[IF YES]
 - a. Are you able to get the care you need? Why or why not?
 - b. Do you feel comfortable going to a doctor? Do you feel like your doctor understands your needs? Do you feel your doctor can help you? Why or why not? Do you feel your doctor treats you fairly? Why or why not?
[IF NO]
 - c. Do you want to get annual checkups? Why or why not?
 - d. Do you feel you are able to get the care you need? Why or why not?
 - e. Do you feel comfortable going to a doctor? Do you feel your doctor can understand your needs? Do you feel your doctor can help you? Why or why not? Do you feel a doctor would treat you fairly? Why or why not?
10. Have you sought treatment for your condition(s) that limits your ability to work since you started receiving benefits?
[IF YES]
 - a. What type of doctor(s) do you see? How often?
 - b. Are you able to get the care you need? Why or why not?
 - c. Do you feel comfortable going to a doctor? Do you feel your doctor can understand your needs? Do you feel your doctor can help you? Why or why not? Do you feel the doctor treats you fairly? Why or why not?
[IF NO]
 - a. Do you want to get treatment? Why or why not?
 - b. Are you able to get the care you need? Why or why not?

Appendix A-1. In-Depth Interview with Possible Exiters Protocol

- c. Do you feel comfortable going to a doctor? Do you feel your doctor can understand your needs? Do you feel a doctor can help you? Why or why not? Do you feel a doctor will treat you fairly?

Employment

11. [IF HAS WORKED FOR PAY]

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

[IF HASN'T WORKED FOR PAY]

- d. Did you have a desire 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. Do you ever have trouble paying your rent or otherwise having stable housing? Have you ever been 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. What kind of transportation do you use to get around your local area?

Probe: Public transit? Car? Other?

- a. Do you own a car? Do you drive it?
- b. Is 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. Do you have reliable access to the Internet at your home?

Appendix A-1. In-Depth Interview with Possible Exiters Protocol

- a. **[IF NOT]** Do you access the Internet in other places (e.g., public library, retail stores or restaurants, etc.)? How do you access the Internet?
17. Do you find it difficult to afford enough food?
 - a. If yes, how do 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, 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 like you cannot get access to help you may need because of discrimination? Can you tell me a little more about that?
19. Are there any other challenges you face while on disability that you wish you had help with?
 - a. What kind of help would you want?

Social Support

20. Who do you turn to for help or support, if anyone?
Probe: Friends, family, community organizations or advocacy groups, churches or religious groups?
 - a. Are they helpful to you? **[If YES]** How are they helpful to you?
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. IF PAYMENTS STOPPED

Let's imagine that you had a friend who received disability payments, and they received a letter telling them their benefits would stop.

22. How would you tell your friend to prepare for their benefits ending?
 - a. Do you think they would need help or support from others? If so, from whom?
 - b. Do you think they would be able to get the help they needed to prepare? If so, from whom?
23. How do you think their health would change if their payments stopped? Overall? Related to your disability?
24. Would stopped payments impact their ability to...
 - a. Get around your local area?
 - b. Access the Internet?
 - c. Get enough to eat?
 - d. Keep their housing?

- e. Get access to health care when they needed it?

E. FUTURE AND REFLECTIONS

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

- 25. 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]
- 26. 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?
- 27. 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. Do you think any of these would be helpful if you were told your benefits were going to end?
 - a. How would you prefer to be told about available programs (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?
- 28. If money were no object, what programs would you design to help people on disability meet their needs?
- 29. If money were no object, what programs would you design to help people whose disability payments were ending?

Thank you for your participation. We will send you a \$40 gift card by mail. May I please have your mailing address?

[CONFIRM ADDRESS FOR MAILING INCENTIVE]

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