

**BEYOND BENEFITS STUDY
SOCIAL SECURITY ADMINISTRATION**

Thank you for agreeing to participate in this focus group. 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 experiences receiving disability 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 focus group 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 participating in the focus group at any time without penalty. You can choose not to answer one or more of the questions. If you decide not to participate in the focus group, there will be no penalty and your decision has no impact on any decision SSA makes about your current or future disability benefits or payments. 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 focus group 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]

Appendix A-4. Focus Group with Exiters Protocol

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

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

Are you willing to participate in the focus group? Are you willing to have the focus group recorded?

[PAUSE FOR RESPONSE.]

[IF DECLINES RECORDING]

Unfortunately, that means that you cannot participate in the focus group. Thank you for your interest.

[PAUSE FOR RESPONSE.]

OK let's begin.

A. Introduction

To start, I'd like to review the guidelines for this focus group and also facilitate some introductions.

As I previously mentioned, my name is [NAME] and I work for Westat, a research company. I'm joined by [NAME] who will act as a technical assistant during the focus group. We are gathering information for the Social Security Administration about how to improve programs for people with disabilities.

We want everyone to feel comfortable sharing their experiences with us in this group. As part of that, I want to emphasize that everything that is said during this focus group should be kept private. That means that while you can talk to people outside this group about the focus group in general terms, no one should be talking specifically about what was said. For example, you can tell people that you participated in a focus group about people receiving disability benefits, but don't tell people that "so-and-so said this or that." We won't be using any last names, and we've encouraged people to use pseudonyms or nicknames if that makes them more comfortable. If anyone has any concerns about their privacy, please let me know.

All right. Let's start with some introductions. If we could go around, I'd like to ask everyone what name they'd like to be called, and something about your experience receiving Social Security disability benefits. Let's start with [NAME]

[NOTE: AFTER INTRODUCTIONS, CAN GUIDE THE DISCUSSION TO ANY OF THE TOPICS BELOW, BUT DOES NOT HAVE TO BE IN ORDER]

[FOR ALL QUESTIONS, PROBE WHETHER OTHERS IN GROUP HAVE HAD SIMILAR OR DIFFERENT EXPERIENCES/WHETHER THEY AGREE OR DISAGREE]

B. BACKGROUND

Before we dive into the questions I have, I'd like to learn a little about you.

- Who here is currently employed? This could be full time or part time work.
 - What do you do?
- Who here is looking for work?
 - What kind of work are you looking for?
- Did anyone work for pay while receiving disability payments?
- Who has worked for pay since their disability payments ended?

Thank you for giving that helpful background information.

[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.]

C. APPLYING FOR DISABILITY PAYMENTS

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

1. How did applying for benefits make you feel?
2. 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?
3. For how long did you think you would receive payments?
Probe: Did you think that you would return to work full-time one day?

D. RECEIVING DISABILITY PAYMENTS

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

Health and Health Care

4. Did you feel like you were able to get the healthcare you needed while you were on benefits?
Why or why not?
 - a. Does this include general care (annual checkups, etc) as well as specialized care for your impairment?
 - 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?

Employment

5. [if anyone worked while receiving benefits] For those of you who worked while receiving disability payments, 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?
6. For those of you who didn't work while receiving disability payments, did you want to work?
Why or why not?
7. Who here has heard of SSA's Ticket to Work program?
[if anyone has]
 - 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?
8. Are you aware of any services in your community that can help you find a job?

Appendix A-4. Focus Group with Exiters Protocol

- a. Probe: That can help you build a resume? A cover letter? Practice for interviews?
- b. For those of you who have heard of these services, have you ever used any? Why or why not?
- c. For those of you who haven't used these services, would you ever use them? Why or why not?

Barriers

9. While you were on disability, did any of 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?
10. While you were on disability, did any of you find it challenging to get transportation around your local area?
 - a. What types of transportation did you use to get around?
 - b. 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?
11. 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.)?
12. 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?
13. Have any of 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?
14. 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

15. 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?
16. 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?

E. LEARNING PAYMENTS WOULD STOP

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

17. Tell me how you first found out that your disability payments would stop.
- a. 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?
 - b. 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?
 - c. 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?
18. 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?

F. WHEN PAYMENTS STOPPED

Thinking to the time when your payments stopped.

19. 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?

G. PRESENT

Turning to how things are for you now.

20. 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?
21. 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?

H. REFLECTIONS

22. 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?

- 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?
23. 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]