

**FINAL EAZI CONSUMER TO CONSUMER SURVEY
RESPITE INSTRUMENT FOR FAMILY MEMBER/GUARDIAN OF A
PERSON WITH A DISABILITY**

June 22, 2007

Respondent Number: _____

Introduction:

Hello, my name is *(State your first and last name)*, and I am meeting with you today to talk with you about the home-based services an individual under your care receives through the Division of Developmental Disabilities, otherwise known as DDD. By participating in this interview you are helping to create a new way for DDD to know if they are doing a good job with home-based services and giving them important information about improving the quality of those services. I will be asking you questions and writing down your answers here. *[Show the survey to the Respondent]* Please keep in mind that I am a family member of an individual with a disability that has volunteered. I have been trained to conduct these interviews, but I am not a professional interviewer.

The interview should take 30 minutes to an hour to complete, depending on how you answer the questions. It is important that you understand that your answers are confidential and anonymous. This means that all information is reported as a group response and no one will know which answers are yours. Your personal information, like your name or address, will not be shared with anyone who provides services or with DDD. This way, you don't need to worry about hurting someone's feelings or having your services taken away because of how you answer the questions. The survey results will be handled by a neutral research team, the Social Research Laboratory, at Northern Arizona University.

Please remember that there are no answers that are right or wrong, and you will not be judged by the answers you give. If you would like to add comments after you answer any of the questions, just let me know and I will write them down. If I come to a question that you do not wish to answer, just say "skip" and we can move on to the next question. Also, if

you wish to stop this interview at any time, please say so and I will stop the interview right away.

Before I start, do you have any questions?

If “Yes” → Find answers to common questions on the Respondent FAQ sheet. Answer any questions that you can.

Ok then, let’s begin.

About the services you receive

1. We understand that the individual with a disability receives respite services through DDD. Is this correct?

Interviewer: If Needed: Respite Services

Definition: Respite care-someone comes to your home to give you a break when you need it.

If participant does not seem to recognize the “respite” service by this title, ask them to describe the service to see if it matches the definition above. Check ONE.

- Yes
- No → *Contact staff at the SRL for instructions*

For this interview I will ask questions just about their respite services. As you answer the questions in this interview, please focus on their **respite** services that they receive through DDD.

Interviewer: If the respondent says that the individual w/ disability has more than one respite provider, or has had many over time, ask them to focus their answers on one provider who currently works with the individual. If they do not have a current provider, focus on one of their more recent providers.

2. First, please tell me about the services that the individual with a disability receives from their respite provider. In other words, what does the respite provider do with them when they go to their home?

Record Below:

Finding Respite Providers

Now I would like to ask you some questions about finding respite providers.

3. Is it difficult for you to find respite providers for the individual under your care?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No Answer)
- Not applicable (Does not apply)
- Does not want to answer this question

4. How often do they need to find a new respite provider?

Interviewer: Read if necessary. Check ONE

- Less than 3 months
- 3-6 months
- 7-12 months
- 1-2 years (over 1 year to under 2 years)
- More than 2 years
- Don't know
- Unclear response OR No response (No Answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

5. Does the individual go for long periods of time without the respite services that they need? **Check ONE**

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No Answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

Self-Determination: Choices About Their Respite Services

Now I would like to ask you some questions about the individual's choices with respite services.

6. Do they get to choose their respite provider? **Check ONE**

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (does not apply)
- Doesn't want to answer this question

7. Do they choose where they receive their respite services?
Check ONE

Interviewer: if needed: the location of the services

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No Response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

8. Do they decide when they receive their respite services? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

9. Are they able to schedule their respite services during times that they need them most? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

Now I'd like to ask you questions about the choices the individual makes when they are working with their respite provider.

10. Does the respite provider try to help them speak their mind; for example, talk about their true feelings? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

11. Does the respite provider pay attention to their choices, such as what they like to eat, where they want to go or what they want to do?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

12. Does the respite provider encourage them to try different things?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

13. Does the respite provider allow them to make their own mistakes?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

14. Does the respite provider help them go places or do errands in the community such as shopping, movies, sport events, religious services or other community events?

Check ONE

- Yes → *Go to Q14a*
- No → *Skip to Q15*
- Sometimes → *Go to Q14a*
- Don't know → *Skip to Q15*
- Unclear response OR No response (No answer) → *Skip to Q15*
- Not applicable (Does not apply) → *Skip to Q15*
- Doesn't want to answer this question → *Skip to Q15*

14a. *If yes/sometimes to Q14 →*

Does the individual choose where they want to go?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

Service Providers - How They Communicate

Alternative Methods/Alternative Device to Communicate

15. Now I would like to ask you some questions about how the individual's respite service provider communicates with them. I'd like to remind you that all of your answers are confidential and will not be connected to your name or any other identifying information.

Do they use any alternative methods or assistive devices to communicate? (e.g, sign language, augmentative communication devices, communication boards, etc.) *Check ONE*

- Yes → **Go to Q16 (next question)**
- No → **Skip to Q19**
- Sometimes → **Go to Q16 (next question)**
- Don't know → **Skip to Q19**
- Unclear response OR No response (No answer) → **Skip to Q19**
- Not applicable (Does not apply) → **Skip to Q19**
- Doesn't want to answer this question → **Skip to Q19**

16. Is the respite provider able to communicate with them using this method? *Check ONE*

- Yes → **Skip to Q19**
- No → **Go to Q17 (next question)**
- Sometimes → **Go to Q17 (next question)**
- Don't know → **Skip to Q19**
- Unclear response OR No response (No answer) → **Skip to Q19**
- Not applicable (Does not apply) → **Skip to Q19**
- Doesn't want to answer this question → **Skip to Q19**

17. Does the individual's respite provider use someone else to assist in communicating with them? *Check ONE*

Interviewer: If needed, this person would assist the provider in using an assistive device or alternative method to communicate.

- Yes → **Go to Q18 (next question)**
- No → **Skip to Q19**
- Sometimes → **Go to Q18 (next question)**
- Don't know → **Skip to Q19**
- Unclear response OR No response (No answer) → **Skip to Q19**
- Not applicable (Does not apply) → **Skip to Q19**
- Doesn't want to answer this question → **Skip to Q19**

18. Does the person that assists the provider in communicating with them do a good job? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

Language Used to Communicate

19. Does the individual with a disability communicate with their respite provider in the language that they prefer? *Check ONE*

- Yes → **Skip to Q21**
- No → **Go to 19a (next question)**
- Sometimes → **Go to 19a (next question)**
- Don't know → **Skip to Q21**
- Unclear response OR No response (No answer) → **Skip to Q21**
- Not applicable (Does not apply) → **Skip to Q21**
- Doesn't want to answer this question → **Skip to Q21**

19a. Does the respite provider use an interpreter to communicate with them? *Check ONE*

Interviewer: If needed, Language interpreter will interpret other languages such as Spanish, Navajo or Hopi.

- Yes → **Go to Q20 (next question)**
- No → **Skip to Q21**
- Sometimes → **Go to Q20 (next question)**
- Don't know → **Skip to Q21**
- Unclear response OR No response (No answer) → **Skip to Q21**
- Not applicable (Does not apply) → **Skip to Q21**
- Doesn't want to answer this question → **Skip to Q21**

20. Does the interpreter do a good job? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

General Communication Issues

21. Does the individual's respite provider listen to what they have to say? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

22. When the respite provider talks to them, is it easy for the individual to understand what the provider is saying to them? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

About Service Providers-How They Do Their Job

Now I would like to ask you some questions about how the individual's respite service provider does their job.

23. Is their respite provider on time? *Check ONE*

- Yes → *Skip to Q25*
- No → *Go to Q24*
- Sometimes → *Go to Q24*
- Don't know → *Skip to Q25*
- Unclear response OR No response (No answer) → *Skip to Q25*
- Not applicable (Does not apply) → *Skip to Q25*
- Doesn't want to answer this question → *Skip to Q25*

24. *If no/sometimes in Q23 →*

Does the respite provider let them know if they are running late?
Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

25. Does the respite provider take time to get to know them and what they enjoy doing? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

26. Does the respite provider understand what is important to them?
Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

27. Does the respite provider encourage them to complete tasks that they are good at? ***Check ONE***

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

28. Does the respite provider encourage them to try tasks that are difficult for them? ***Check ONE***

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

29. Does the individual have a good relationship with their respite provider? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

30. Does the respite provider treat them with respect? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

31. Is the respite provider courteous and polite to them? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

32. Does the individual think their respite provider treats them in a way that is appropriate for their age? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

33. Does the individual think the respite provider works hard to meet their needs?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

34. Does the respite provider do what they tell them they are going to do? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

35. Do you think the respite provider is properly trained? *Check ONE*

- Yes → **Skip to Q36**
- No → **Go to Q35a**
- Sometimes → **Go to Q35a**
- Don't know → **Skip to Q36**
- Unclear response OR No response (No answer) → **Skip to Q36**
- Not applicable (Does not apply) → **Skip to Q36**
- Doesn't want to answer this question → **Skip to Q36**

35a. **If no, sometimes in Q35** → What training do you think their respite provider needs so they can do a better job?

36. Does the respite provider complete tasks the way the individual asks them to? *Check ONE*

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

37. Does the respite provider try new ways of doing things with them?
Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

38. Is their respite provider an active member of the service planning team? *Check ONE*

Interviewer: Referred to as: "IFSP (Individualized Family Service Plan-for young children; ISP (Individualized Service Plan); or PCP (Person Center Plan Team)."

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

38a. Do you feel their provider should be more active in planning for their services or attending their annual planning meeting?

Interviewer: The purpose of the annual planning meeting is to plan for the services needed each year to support the personal priorities of the individual.

- Yes → **Go to Q38b**
- No → **Skip to Q39**
- Sometimes → **Go to Q38b**
- Don't know → **Skip to Q39**
- Unclear response OR No response (No answer) → **Skip to Q39**
- Not applicable (Does not apply) → **Skip to Q39**
- Doesn't want to answer this question → **Skip to Q39**

38b. Could you please explain how they should be more active in planning for their services?

39. Does their respite provider ask them or a family member about their needs, such as equipment, services or information, which is not readily available to them? *Check ONE*

- Yes → **Go to Q39a**
- No → **Skip to Q40**
- Sometimes → **Go to Q39a**
- Don't know → **Skip to Q40**
- Unclear response OR No response (No answer) → **Skip to Q40**
- Not applicable (Does not apply) → **Skip to Q40**
- Doesn't want to answer this question → **Skip to Q40**

39a. **If yes, sometimes in Q39 →**

Does their respite provider partner with them and TRY to assist them in finding support items or other resources that they may need?

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

40. Do you think the individual feels safe with their respite provider?
Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

41. Do you think the individual can trust their respite provider?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

42. Does the respite provider keep the individual's personal information, such as files, health information, progress notes, or incident reports confidential so that it is not shared without your or their permission?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

43. Does the respite provider respect the individual's privacy; like their personal belongings, their personal space, and their private life?

Check ONE

- Yes
- No
- Sometimes
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

Helping us put all of your ideas together about their respite services

Now I would like to ask you some questions to help us summarize your thoughts about the individual's respite services.

44. Would they say the respite services are improving their life?
Check ONE

- Yes → **Go to Q44a**
- No → **Skip to Q45**
- Sometimes → **Go to Q44a**
- Don't know → **Skip to Q45**
- Unclear response OR No response (No answer) → **Skip to Q45**
- Not applicable (Does not apply) → **Skip to Q45**
- Doesn't want to answer this question → **Skip to Q45**

44a. If yes or sometimes in Q44 → How are these services improving their life? *Record Below*

45. Overall, do you think the individual is satisfied with their respite services? Please explain. *Record Below*

46. What would you say needs the most improvement with the respite care services that are provided through DDD? *Record Below*

46a. Does the individual receive services through an independent provider or through an agency?

Interviewer: An independent provider is an individual that is contracted directly through DDD. They do not work through an agency.

- An independent provider → **Skip to Q46c**
- An agency → **Go to Q46b (next question)**
- Don't know → **Skip to Q46c**
- Unclear response OR No response (No answer) → **Skip to Q46c**
- Not applicable (Does not apply) → **Skip to Q46c**
- Doesn't want to answer this question → **Skip to Q46c**

46b. Could you please tell me the name of the agency?

Interviewer, if needed: This information will be used to improve services within the agency as a whole. The agency will NOT be told your provider's name.

46c. Now I would like to ask a general question about DDD (The Division of Developmental Disabilities). Overall, in thinking about home-based services provided through DDD, on a scale of 1 to 5, with a 1 as poor and a 5 as excellent, how would you rate DDD for the job they are doing in providing home-based services to the individual under your care? On a scale of 1 to 5 (1=poor; 5=excellent)?

- 1 Poor
- 2
- 3
- 4
- 5 Excellent
- Don't know
- Unclear response OR No response
- Not applicable (Does not apply)
- Doesn't want to answer this question

46d. What would you say needs the most improvement with the home based services that are provided through DDD? *Record Below.*

46e. What would you say is the BEST about the home-based services provided through DDD? *Record Below.*

About the Interview

Now I'd like to ask you some questions about the interview.

47. Were there any questions in the interview that were confusing? If yes → Please explain. *Record Below*

48. Were there any questions in the interview that made you uncomfortable? If yes → Please explain. *Record Below*

49. Are there any questions about their respite services that you wish I had asked? *Record Below*

50. Do you have any general comments about the interview?

Record Below

51. And lastly, would it be OK for the Social Research Lab to call you with any follow-up questions that may arise?

- Yes
- No
- Don't know
- Unclear response OR No response (No answer)
- Not applicable (Does not apply)
- Doesn't want to answer this question

Thank you for taking the time to complete this very important survey. We recognize that it's not always easy to see how results from these interviews can lead to positive changes in a large service agency like DDD. Many times, these changes are made slowly. We also believe that the best way to improve services for the people who use them is to give you the opportunity to tell us about them. In the end, results will be reported in a group format so that DDD can improve home-based services. Again, thank you for your contribution.