

GROUP INTERVIEW: POLICY MAKERS, COLLABORATORS, AND GRANTEES

[Interviewer]: Thank you for taking the time to talk with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for _____, a private research company in _____.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This DD Council is one of ____ DD Councils in ____ states that have been randomly selected to participate in the evaluation. You were invited to participate in this group discussion because of your involvement with the DD Council on systems change and advocacy issues related to people with developmental disabilities (and family members).

Purpose: The purpose of today's group discussion is to learn about your experiences with the [NAME OF DD COUNCIL] systems change/advocacy activities on a specific issue and your thoughts about the impact of these activities. This discussion will last about 1 ½ to 2 hours.

Logistics: Before we begin, let me explain a few practical things. You have two forms in front of you—an expense reimbursement form, and a consent form. After this meeting, please complete the reimbursement form and mail it to _____ so we can reimburse you to cover your expenses in coming here today.

Consent: The second form is a consent form. Before we begin this session, please read and sign the consent form, which indicates your willingness to participate in our discussion. Please remember that you do not have to answer any questions you don't want to answer, and you may also leave this meeting at any time.

[COLLECT CONSENT FORMS.]

Finally, we would like – with your consent – to record this discussion. This will allow us to focus our full attention on what everyone is saying, and it eases the burden of note-taking. The recording is for _____'s use only. We will not be giving it to anyone else. Is there anyone who objects to us recording this discussion? [WAIT TO HEAR IF THERE ARE OBJECTIONS.]

All of you were assembled today because you worked on a particular systems change/advocacy issue or had an interest in this issue. The issue we will be talking about is

_____.

Do you have any questions at this point?

Let's start by everyone stating their first name and saying something about how you interact with people with developmental disabilities.

1. Would you please tell us how that issue first became important to you or your organization?
2. What initiated your relationship with the DD Council and your organization (you) becoming involved in this issue with the DD Council?
3. Please describe some of the activities that took place in the past year (3 years, 5 years) related to this issue and your organization's particular involvement.

Probe:

- Research and analysis of background information
- Drafting white papers, reports, other documents
- Drafting policy or legislation
- Attending meetings with policymakers
- Obtaining input from the developmental disabilities community
- Making appearances at legislative and other meetings
- Making presentations
- Receiving input on the issue
- Responding to input
- Other _____

4. What were some of the outcomes of these activities? Provide examples.

Probe for:

- Barriers to services eliminated

- New barriers to services prevented
 - New laws/policies/procedures/practices established
 - Existing laws/policies/procedures/practices enforced or implemented
 - Corrections made by agencies, providers, or facilities
 - Complaints of abuse, neglect, or discrimination remedied
 - Services to traditionally unserved or underserved populations increased
 - Knowledge and skills among DD Network program participants increased
5. Based on your experiences with these systemic advocacy activities, what role do you think the DD Council played in ...
- a. Building and maintaining a collaborative relationship with your organization to achieve common goals and objectives? Please explain.
 - b. Helping you to understand issues affecting people with developmental disabilities and their families? Please explain.
 - c. Meeting the goals and objectives of this issue? Please explain.
 - d. Other _____

That ends all of our questions. Do any of you have any questions of your own?

Again, we would like to thank you for taking the time to answer our questions.