

GROUP INTERVIEW: POLICY MAKERS AND COLLABORATORS

Introduction: Welcome and thank you for participating in this group discussion. Before we begin, let us briefly introduce ourselves. My name is [first facilitator's name] and this is [second facilitator's name]. We both work for _____, a private research company in _____. Let's go around the room and have each of you give your name and affiliation (if you represent a specific organization).

Let me tell you why you're here. 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 P&A program is one of ____ P&A programs in ____ states that have been randomly selected to participate in the evaluation. As a collaborator with the P&A on a systemic advocacy issue, you all are important sources of information regarding how the P&A approaches systemic advocacy and the role community organizations and individuals play.

Purpose: The purpose of today's group discussion is to learn about your experiences with the [NAME OF P&A] systemic advocacy activities 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 Westat 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 _____ 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.]

Do you have any questions at this point?

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

_____.

1. Would you please tell us how that issue first became important to you or your organization?
2. What initiated your relationship with the P&A and your organization (you) becoming involved in this issue with the P&A?
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. Where did the P&A fit in?

- What did it do?

Probe:

- Researched and analyzed background information
- Drafted white papers, reports, other documents
- Attended meetings with policymakers
- Obtained input from the developmental disabilities community
- Made appearances at legislative and other meetings
- Made presentations
- Other _____

- b. Was its main role to lead the activities or participate in them?
5. 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

6. Based on your experiences with these systemic advocacy activities, what role do you think the P&A 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 _____

Those are all the questions we have for you today. Do you have any questions before we end this discussion?

We'd like to thank you again for taking the time to answer our questions. Please don't forget to take your expense form and return envelope so you will be reimbursed for your expenses in coming here today.