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## Linda Cabral, Laura Sefton, and Kathy Muhr on Recruiting People with Mental Health Conditions for Data Collection

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## **Linda Cabral, Laura Sefton, and Kathy Muhr on Recruiting People with Mental Health Conditions for Data Collection**

Hello! We are Linda Cabral, Laura Sefton and Kathy Muhr from the Center for Health Policy and Research at the University of Massachusetts Medical School. We recently completed an evaluation project that involved recruiting people with mental health conditions to participate in individual interviews, focus groups, and surveys regarding their experiences with a mental health peer specialist training program. In 2010, Woodall and colleagues reported that many barriers exist to participating in mental health research, including:

- fear
- suspicion and/or distrust of researchers
- concerns about confidentiality
- transportation difficulties
- severity of illness
- inconvenience
- fear of relapse as a result of participation
- the stigma of mental illness

We wanted to share some tips and lessons learned to address some of these barriers.

**Hot Tip:** Get approval. Before starting data collection, consider applying for Institutional Review Board (IRB) approval. While many evaluations for program improvement purposes do not require IRB approval, if you wish to disseminate your findings to a broad audience, this approval may be necessary to insure that recruitment efforts take into consideration an IRB's requirements for working with vulnerable populations.

**Hot Tip:** Establish trust. To establish trust, the evaluation team members visited the training program and were introduced as people who would be in contact after the training was completed to get their feedback on the training. This informal introduction by a trusted source paved the way for outreach later on.

**Lesson Learned:** Use a script. Having a telephone script was a good tool for initiating a conversation or leaving a message with the intended participant. It helped us to remember to cover key points with potential participants. It also reinforced our concern for their confidentiality as we avoided sharing information with others when leaving a message.

**Lesson Learned:** Be transparent. Once we contacted the participant, we were transparent about the purpose of the evaluation, who was funding it, and how their information would be used.

**Lesson Learned:** Provide multiple access points. To increase survey response rates, we brought copies to all in-person interviews, allowing time after the interview for participants to complete the survey. If they required assistance, we were present, and able to do so in real-time.

**Lesson Learned:** Be flexible. To increase our recruitment rate, we were flexible in our interview and survey administration formats. When possible, our first preference was to conduct in-person interviews at a time and place of the person's choice. When this was just not feasible or could have led to a decision to not participate, we offered to conduct the interviews and survey data collections over the phone.