

Confidentiality and Privacy Issues

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CONFIDENTIALITY and PRIVACY ISSUES

- South Carolina encountered issues of confidentiality and privacy during the use of telephone surveys for POMP II and National POMP.
- Discussion of these issues/problems will hopefully lead to best approaches to handle these issues.

CONFIDENTIALITY

- During POMP II and National POMP surveys, AAA's and Local Service Providers raised issues of confidentiality.
- Many Local Service Providers would not provide lists of persons for sampling purposes.

- Only where a client had been assessed and had signed a release of information, would the Local Service Provider provide the client's name for the surveys.
- Local Service Providers are concerned over potential liability issues.

- The confidentiality issue was a concern particularly for Information, Assistance and Referral calls.
- Some service providers do not consider IA&R a service.
- South Carolina chose to work with the AAA for POMP II from regional lists or from Local Service Providers that would cooperate.

- In the case of National POMP, AAAs were hesitant to participate due to time and cost.
- The State Office on Aging assisted by pulling names from the client information system used statewide. (AIM is the system)
- Persons were chosen where clients had signed consent forms.
- Exception was for Information, Assistance and Referral. Names had to be provided from the AAA or a Local Service Provider.

- For both POMP II and national POMP surveys South Carolina's AAAs all agreed to send persons to be surveyed a letter that they would be contacted and that this is a legitimate survey. Its purpose is to improve services and obtain additional Federal and State funding.

PRIVACY ISSUES

- During implementation of National POMPS some Local Service Providers refused to provide names and telephone numbers for surveys/
- Privacy issue was raised when the State Office on Aging requested to provide caregivers for home delivered meals and home care clients.

- The AIM system only lists emergency contacts. These people, in many cases, are not the caregivers. They have not consented to be contacted.
- Many recipients do not wish to have relatives know that they are receiving services.
- Solution: S.C., Westat and AoA agreed to have Westat ask person receiving services and being surveyed who the caregiver was. Also, would they mind being surveyed.

- Issues of access, confidentiality and privacy has caused AoA to issue a letter stating that AoA has the authority to survey persons receiving services.
- South Carolina's research indicates that the following authorizes such surveys:
- **Federal Laws:** ** Older American's Act;
** Government Performance Result's Act of 1993;
** Paperwork Reduction Act, with Office of Management and Budget (OMB) approval
- **State Law**
- **State Policies and Procedures**
- **State Quality Assurance Standards**

- There is still considerable concern on the part of our Aging Network about potential liability.
- Ultimately, issues such as these may require a court decision.

