

*Data Collection with Vulnerable  
Populations: Issues and Practice Tips*

Workshop Presented at CES Annual Conference  
Charlottetown, June 4, 2006



672 Dupont Street, Suite 402  
Toronto, ON M6G 1Z6  
Telephone: (416) 469-9954  
Fax: (416) 469-8487  
Email: [melissa@cathexisconsulting.ca](mailto:melissa@cathexisconsulting.ca)

# Agenda

---

- 9:00**      **Introductions and Defining Vulnerable Populations**
- 9:20**      **Issues Related to Evaluations Involving Vulnerable Populations**
- 9:25**      **Privacy and Consent Issues**
- 10:00**     **Interviews**
- 10:15**     **Focus Groups**
- 10:30**     **Break**
- 10:45**     **Surveys**
- 11:00**     **File/Data Review**
- 11:15**     **Observation/Site Visits**
- 11:30**     **In-Depth Case Studies**
- 11:45**     **Literature Review**
- 11:50**     **Wrap-Up and Workshop Evaluation**

## How do you define “Vulnerable Populations”?

---

Please take a moment to think about your own personal working definition of “vulnerable populations” .....

Each person will present to the group his/her own definition as they introduce themselves and the organization/department they are affiliated with.

## What Makes a Person Vulnerable?

---

- Limited rights
- Relative power imbalances
- Limited resources
- External stigma/stereotypes
- Limited knowledge/information
- Illness or disabling condition
- History of abuse
- Loss of family
- Loss of culture/historical roots

## What Populations Have Vulnerable People?

---

- Children/Youth
- Persons with Disabilities
- New Immigrants/Refugees
- Aboriginal People
- Visible Minorities
- People living in poverty
- Psychiatric Consumer-Survivors
- People with Substance Use Problems
- Women
- Others? (gay/lesbian population, seniors)

## Definition

---

Vulnerable populations are defined as "those individuals or groups who have a greater probability than the population as a whole of being harmed and experiencing an impaired quality of life because of social, environmental, health, or economic conditions or policies."<sup>[1]</sup>

[1] This definition and population description is an adaptation of those by Barker, R.L. (1995). *The Social Work Dictionary*. (3rd ed., p. 404), Washington, DC: National Association of Social Work and Rothman, J. (1994). *Practice with Highly Vulnerable Clients* (pp. 5-8), Englewood Cliffs, NJ: Prentice-Hall.

## Evaluation Design – Issues

---

**Issues** to consider in designing the evaluation:

- Impact of exclusion from intervention (experimental design)
- Appropriateness of the evaluation/data collection methodology for specific groups/information
- Cooperation of the program client group and appropriate stakeholders in the planning phase
- Unintended impacts or effects
- Need for contingency planning

## Privacy and Consent – Issues

---

- Personal information in a protective climate – going beyond ethics
- Compliance with relevant legislation
  - *Privacy Act*
  - *Personal Information Protection and Electronic Documents Act (PIPEDA)*
  - Provincial legislation

## Personal Information and Consent

---

- “personal information” - information about an identifiable individual; does not include the name, title or business address or telephone number of an employee of an organization.
- Consent - the agreement of someone to provide their personal information for the purposes identified to them.

## Privacy and Consent – Practice Tips

- Designate a Privacy Officer in your organization
- Limit data collection to that which is genuinely required
- Obtain express written or verbal informed consent (as appropriate) for each element of the evaluation (e.g. client files, opinion survey, school records, police/court records)

## Privacy and Consent – Practice Tips (Cont.)

---

- Provide information about the evaluation to the participants in a meaningful manner and form, using ‘clear language’
- Give the participants the opportunity to ask questions
- Inform clients that it is their right to withdraw consent at any time
- Submit approval requests in a timely manner

## Interviews – Issues

---

- Hidden/hard-to-reach populations - recruitment may be difficult and time consuming
- Language issues
- Need for assistive technology to communicate
- Obtaining consent
- Characteristics of interviewer
- Accessibility
- Sensitive information being sought
- Encouraging participation vs. being coercive (remember Willowbrook studies?)

## Interviews – Practice Tips

---

- Build in plenty of time for recruitment
- Set up interviews through trusted intermediaries
- Use Privileged Access Interviewers (PAI)
- Train a trusted member of the community to conduct interviews
- Obtain consent in the form most appropriate
- Telephone interviews may enhance privacy
- Use a snowballing approach
- Use professional interpreters whenever possible

## Focus Groups – Issues

---

- Sometimes focus groups are inappropriate (i.e. with some Aboriginal communities)
- Recruiting issues
- Accessibility considerations
- Group dynamics can pose difficulties
- Impact of using interpreters
- Seeking personal information
- Ensuring privacy and consent

## Focus Groups – Practice Tips

---

- Use ‘talking circles’ or other types of groups
- Telephone focus groups: accessibility & privacy
- Make childcare available if appropriate
- Provide refreshments
- Offer honoraria to cover participants’ expenses
- Establish ground rules at the outset
- Use cool-down techniques to quell frustrations
- Record session or take ‘public notes’

## Surveys – Issues

---

- Provides breadth not depth
- Literacy levels
- Response rates can be a problem
- Group may feel “over consulted”
- Not all methods appropriate for all groups (e.g., a web-based survey may not be ideal with seniors)
- Complexity and sensitivity of information being sought
- Privacy and confidentiality

## Surveys – Practice Tips

---

- Make sure a survey is the best vehicle
- Keep surveys simple – use ‘clear language’
- Use illustrations/pictures within the survey
- Video surveys for persons who are deaf
- Conduct face-to-face surveys - use professional interpreter services
- Survey completion rates are likely to increase with endorsement from trusted individuals
- Pilot the survey tool whenever possible

## File/Data Review – Issues

---

- Is dependent on the completeness and quality of record-keeping by service providers
- Often contain sensitive identifying personal information
- Original purpose of records may not include evaluation
- Approvals may be required
- Could undermine trust relationship between program staff and clients

## File/Data Review – Practice Tips

- Identify requisite approval processes at the outset
- Work with program staff to verify data quality
- Collect only necessary data
- Obtain 'masked' data
- If personal information is required, obtain informed client consent.

## Observation/Site Visits – Issues

---

- Accessibility/gaining entry
- Privacy - Obtaining consent
- Confidentiality - Sense of lack of anonymity
- Language issues
- Characteristics of observer – gender, age, culture, experience, other traits

## Observation/Site Visits – Practice Tips

---

- Obtain informed consent
- Develop clear guidelines to define what to observe
- Share guidelines with those being observed
- Be open-minded and non-judgmental
- Use audio visual technology if possible
- Ask questions of staff afterwards
- Be conscious of unwritten power relationships

## In-Depth Case Studies - Issues

---

- Intrusive - requiring in-depth, detailed, contextual and holistic description of the case to closely capture personal experience
- Involves data linkage
- Requires experience in qualitative methods to conduct in-depth case studies
- Similar to other data collection issues (i.e., accessibility, consent, language, privacy, confidentiality, need for interpretation, interviewer traits, etc.)

## In-Depth Case Studies – Practice Tips

- Full informed consent is crucial – ensure the subject understands all aspects of the case study approach to be used
- Build sense of trust (e.g., use the same facilities, meet people informally and let them get to know you)
- Train trusted program staff to assist with collecting case study data

## Literature Search - Issues

---

- Information is not directly related to the program and its participants
- Available research may be limited:
  - Quality
  - Breadth
- Terminologies may differ depending on discipline and definitions - making key word search difficult

## Literature Search – Practice Tips

---

- Consult experts to seek possible sources of literature unavailable through internet searches – researchers typically have literature not readily available
- Consider sending out surveys to resources to construct own document sources
- Snowballing - consider unconventional sources for literature (i.e. associations, community groups, researchers/students, etc.)

## Wrap-up and Workshop Evaluation

---

### **I lost my talk**

**by Rita Joe**

I lost my talk  
The talk you took away  
When I was a little girl  
  
At Shubenacadie school.  
You snatched it away:  
I speak like you  
I think like you  
I create like you  
The scrambled ballad about  
my world.

Two ways I talk  
Both ways I say  
Your way is more powerful.

So gently I offer my hand  
and ask  
Let me find my talk  
So I can teach you about  
me.

*(Used with the kind  
permission of the author. )*