

FROM THEORY TO PRACTICE; METHODOLOGICAL AND ETHICAL ISSUES FOR RESEARCH WITH FIRST NATIONS COMMUNITIES

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ABSTRACT

This paper will review methodological and ethical concerns in two research projects that focused on issues for First Nations people. The first study included a file review, process evaluation, and follow-up study with a First Nations substance abuse treatment centre. The file review was the first of its kind for the centre, and a client profile was developed outlining demographic information and substance consumption patterns. This study was developed based on community needs and was designed to determine the effectiveness of the program. Key issues in this study pertained to community partnership, ownership of data, and capacity building. The second project focused on educational status and its association with risk and protective factors for First Nations youth. This study was also community driven, and key issues involved capacity building, negotiating a contract between the researcher and community, obtaining informed consent and providing meaningful dissemination of the results. This paper will end with a discussion on research and ethical concerns. Issues such as who develops and benefits from the research, who owns the data, how capacity building can be included in the project, protecting community values and traditional knowledge, participation, and responsibility will be considered.

INTRODUCTION

Social science research often takes place in communities with human subjects — for example, investigating hypotheses that differences exist between marginalized communities such as Aboriginal¹ communities and mainstream society. This sort of research has endeavoured to quantify or describe social issues as part of a “scientific” and impersonal research approach (Dickson 2000). There is now growing evidence that there is dissatisfaction with the relationship between communities and university researchers — there is little balance with respect to power: the research mostly benefits the researcher rather than those upon whom the research is conducted (Amen 2001, Maurana and Goldberg 1996, Rappaport 1977, Roesch and Dion-Stout 2003). The positivist paradigm approach to community research has viewed

1 The terms Aboriginal, First Nations, and Native will be used interchangeably and will all be intentionally capitalized. This terminology will be used to define the first inhabitants in Canada, including the Métis, Innu, and Inuit people. The term “Indian” will be used in reference to government policies (e.g., Indian Act). It is not the intention to group First Nations peoples into one homogenous group. We value and respect the diversity of beliefs and attitudes that exist among First Nations people.

community members as subjects of the research project — rather than active partners in the research process — justifying this process as necessary to maintaining “objectivity” (Israel et al. 1998).

A research approach that has challenged some of the more positivist approaches in social science research is the *community action research*, *participatory research*, or *partnership research approach* — where the community of interest engages in the research process as a full partner in the development and implementation of the project, or community factors are considered as contextual influences on the subject studied (Green, et al. 1995).

Despite difficult relationships, Aboriginal scholars entering the research field are questioning how research is conducted, and developing methodologies that are culturally sensitive and appropriate for the communities within which they are working (Smith 1999). The purpose of this paper is to reflect on the process that was used to engage the community in two community-based research projects. The first project was an evaluation of a residential substance abuse treatment centre; the second focused on health-compromising and health-promoting behaviours related to education for Aboriginal youth.

In 1995, Kim van der Woerd was an undergraduate student in psychology and interested in continuing her education in graduate school. Her Ojibway mentor, Dr. Ruth Turner, advised her to consider developing a research program for herself. Ms. van der Woerd went back to her community in Alert Bay and met with various Band Council and community members. She was interested in a project that would benefit the community since she felt they had given her so much. After discussions of some key issues and concerns in the community, it was decided that she would work with their treatment centre in some capacity. The first project began in 1995 and involved an evaluation of the 'N̄amgis Residential Substance Abuse Treatment Centre in Alert Bay. Prior to the actual research project, a “'N̄amgis First Nation Guidelines for Visiting Researchers/Access to Information Contract” was signed which outlined “rules of conduct,” and included “ethical guidelines for research with human subjects adopted March 1979 by the Social Sciences and Humanities Research Council of Canada (SSHRC) re: individual and collective rights” ('N̄amgis First Nations 2002). This contract also included stipulations for publication, noting that researchers would not publish without consent from the 'N̄amgis Band.

This program was founded in 1984, utilized the principles and practices of Alcoholics Anonymous (van der Woerd 1998), and was comprehensive in its endeavour to bestow education, life skills, and Aboriginal tradition-

al knowledge and spirituality to clients. The objectives of the program were identified as:

- create conditions where complete abstinence from substance abuse can be maintained;
- provide treatment wherein overall harm reduction can be accomplished;
- provide health promotion and education information.

The objectives of the evaluation were to develop a client profile, summarize findings for the Client Satisfaction Questionnaire (van der Woerd 1998), assess attitudes toward program components at the completion of the program, and determine abstinence/relapse rates. The objectives were determined in cooperation with the treatment centre staff and community members, and meaningful and effective partnerships were established.

This evaluation was primarily oriented to the information needs of the program staff, giving the staff a sense of ownership and commitment to the results, ultimately facilitating follow-up action. Participating groups included the treatment centre staff, the Band Council, and the 'Namgis Health Board. Their role was to collaborate on the survey development and later assist in locating and contacting former clients of the program. All of the staff members were interviewed to determine their priorities for the survey — what they needed to know with regard to evaluating outcomes for the clients. All recommended questions were recorded and included a draft survey, which was then reviewed again by all staff. This draft survey was pilot tested with three people, and revisions were made again based on their recommendations. The treatment centre staff members were ultimately satisfied with the content of the survey and it was administered with their assistance to former clients of the program.

Participating groups met at the completion of the project to discuss the findings, identify problems, and make plans to improve the performance of the program. The advantages of using this approach were: we examined relevant issues; we enhanced the understanding of all points of view; we built on shared commitment to the program; and there was an increased likelihood that the evaluation findings would be used to improve future performance.

This program evaluation included active participation by staff from beginning to end and beyond. This process added extra time to the staff's already burdened schedules, but resulted in team building and continued commitment to the program. This participatory evaluation made it possible to

recognize shared interests among those doing the work, the people the work was designed to reach (clients), and other stakeholders.

At the completion of the evaluation project, a meeting was held to determine what the community's needs were for a subsequent research project. Many community members were interested in focusing on issues related to health and education for youth. A meeting was held in Alert Bay between Kim van der Woerd, the 'Namgis Band Council, the School and Health Boards, the School Principal, and Youth Program Coordinators to review a proposal for this study. The project included the administration of a survey to youth in the community assessing health and education attitudes and behaviours. This project was introduced to the meeting participants and time was spent outlining specific concerns by the community regarding Aboriginal youth who had dropped out of school. Every aspect of the "Aboriginal Youth Health Survey Information and Invitation" letter was then reviewed, along with the parent/guardian and youth versions of the informed consent forms. The Aboriginal Youth Health Survey was then reviewed for readability and content. Many suggestions were offered, including the addition and removal of specific questions. The method of participant recruitment, location of data collection, the ethnographic component, and remuneration were also reviewed. The meeting concluded with the signing of the "'Namgis First Nation Guidelines for Visiting Researchers/Access to Information Contract" between the researcher and the community ('Namgis First Nations 2002). Finally, the Band Council drafted a letter of approval for the study. The procedure is outlined below.

All youth in Alert Bay between the age of 12 and 25 were mailed an information and invitation letter, inviting them to participate in this study. A parent/guardian informed consent form was included with the information letter. Potential participants were advised that completing the survey would take approximately one hour of their time, and that they would be compensated \$10.00. Furthermore, they were advised that the information they gave would be completely anonymous and not for use by any outside organization.

Upon completion of the Aboriginal Youth Health Survey (AYHS), participants were asked to sign a receipt indicating payment of the \$10.00 remuneration. Participants were also asked whether they would be interested in being involved in subsequent interviews or focus groups that occurred as a result of this study. If they were interested, they were asked to put their name and contact information on the bottom of the receipt. The participants were

thanked for their involvement, and fully debriefed. One youth was hired to assist in the administration of the project.

To some extent, this project maintained a community-based approach. Many Band Council members, teachers and elders promoted youth participation in the AYHS. Furthermore, many youth were interested in the progress of the project, frequently referring to it as “our project,” or making comments like “we need to get more youth to participate.”

Remarks made by participants during the administration of the AYHS were recorded. Frequently asked questions included: “why are you doing this project,” “why are you paying us,” and “what is going to happen to the information later.” A few participants made reference to being “over-studied” and that they didn’t like “information taken from Native people.” Feedback on the AYHS questions included: “all right,” “easy,” “interesting,” “negative,” “stupid,” and “awesome.” Finally, when participants were asked whether they would be interested in participating in future projects related this study 52 (40 percent) of the participants said that they would be interested in doing this.

Upon completion of this project, results were disseminated to interested community members in two meetings — the first at the T’lisala’gilakw School gym, and the second with members of the Band Council. In both meetings, the first author presented the findings, and a discussion ensued, talking about those findings, and where to go from there. In addition, two papers were published in *The Canadian Journal of Native Education*, and *The BC Counsellor* — both papers were reviewed and approved by the Band prior to submission for publication (van der Woerd 2002, van der Woerd and Cox 2003). This paper has also been reviewed and approved.

Both of these studies attempted to maintain a community driven participatory approach, involving community members in the design and implementation of the projects. Every attempt was made to approach these projects utilizing the BC ACADRE (Aboriginal Capacity and Development Research Environment) four R’s:

- *Respect*: by appreciating and welcoming the diverse views and opinions of the people worked with.
- *Relevance*: by engaging in a project that was directed by the community, based on their interests or needs.
- *Reciprocity*: by bringing the research back to the community through dissemination and continued work on identified issues.

- *Responsibility*: by ensuring that the work was conducted ethically and by building on the strengths of the community.

While some individuals have rejected social science research, others have reflected on how this approach can be improved. Smith (1999) has called for increased participation in research by Indigenous peoples and their increasing self-determination through the articulation of specific rejections of Western methodologies (i.e., methodologies that do not include the involvement of Aboriginal people when they are being researched), improved practices, and a reformulation of culture and tradition in research. Swisher and Tippeconnic (1999) have also stated that it is necessary for First Nations people to become involved in *producing* research rather than participating merely as subjects.

Kim van der Woerd continues to work with her community and is forever indebted to them for their unyielding support through her education journey. It is hoped that as more and more Aboriginal scholars are trained, they can begin or continue to embrace methodologies that are respectful, relevant, reciprocal, and responsible to the people that they work with.

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