

Circles of Light

PROJECT



FINAL REPORT

**Vision Care and Rehabilitation Problems and Solutions
Emerging through a Culturally Appropriate Participatory Action
Research Process with First Nations Peoples
— Recommendations for Health Service Providers and Policy Makers**

Data collection, analysis and regional reports:

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Final Report prepared by:

The Canadian National Institute for the Blind
National Service Development and Research

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*For purposes of this paper, the term Aboriginal includes all people who identify with
Aboriginal heritage and includes all Inuit, Metis or First Nations.*



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I. EXECUTIVE SUMMARY

In the past, there was virtually no input from Aboriginal people in regard to program development for most services to their community members. The virtual exclusion of the community has not benefited service delivery and has not produced any successful models. This report summarizes the results of a traditional consultation and participatory action research project carried out by the Canadian National Institute for the Blind (CNIB) from the fall of 2002 to the summer of 2004, and funded by Population Health Fund of Health Canada. The first purpose of the project was to identify the care and support needs of the Aboriginal people and/or their family members living with blindness and vision impairment. A second purpose of the project was to identify potential links to existing support services and agencies for eye care and medical attention and intervention. A third purpose of the project was to share information and knowledge gained with Aboriginal agencies.

The goals of the project were to:

- Identify obstacles that prevent Aboriginal people in Canada from gaining access to vision services.
- Identify gaps in existing services.
- Define culturally specific aspects of the experience of vision loss.
- Utilize a traditional consultation process and Participatory Action Research in developing a culturally appropriate service model.
- Identify community assets, resources and potential partnerships in implementing suggested service models after the project is complete.

In 2002, the Circles of Light project was begun, funded by a contribution from the Population Health Fund of Health Canada. Based on findings from a previous local project in Alberta, and the challenges of service provision across the nation, it became time to examine what aboriginal people might want in terms of a program delivery model related to vision loss and vision health.

The Circles of Light project objectives were to:

- Consult with Aboriginal communities in western (Saskatchewan), central (Ontario) and eastern Canada;



- Hold 9 consultations in the above noted regions;
- Define the needs of the three client age groups;
- Define a service delivery framework applicable and flexible for all Aboriginal peoples;
- Document potential health policy impacts for vision care;
- Partner with local community health care providers and Aboriginals.

Typical of many projects, the actual achievements of the Circles of Light Project differed from the objectives. We:

- Consulted with on- and off-reserve Aboriginal people from urban and rural Northern Ontario, the entire province of British Columbia, and the urban centre of Calgary, Alberta;
- Included representation from Metis and First Nations, but could not include Inuit peoples (see “Limitations of Project”);
- Held 6 consultations in the above noted regions, from March of 2003 to March of 2004;
- Defined the principles on which to base an appropriate service model from the perspective of the consulted groups;
- Partnered with local community health groups to conduct the consultations;
- Documented requirements for policy and service change in order for vision care to be delivered appropriately;
- Learned the limitations of projects involving the far north;
- Disseminated findings back to regional partners through the production of our final report.

The actual process of each set of consultations involved the following stages:

Stage 1: Focus groups with aboriginal participants and service providers and given a set of specific guiding questions for discussion.

Stage 2: Analysis of data collected in stage one, and organization of data into categories for discussion in Stage three.

Stage 3: Focus groups reconvened with original participants, but open to new participants.



Stage 4: Writing of individual regional location report was based on findings in each of the three age-divided groups of participants. In both stages 1 and 3, demographic and evaluation data were also collected.

The Royal Commission on Aboriginal Peoples (RCAP) recommends that a community consultation process follow a standard of best practice, which must include oral knowledge, fair representation of all community life, viewpoints from older and younger generations, and observation of traditional protocol. This traditional consultation process was woven into the Circles of Light Project. In addition, we used a method called participatory action research or PAR. It is not necessary to wait until data is collected, analysed and discussed because action can take place as a direct and immediate result of the research process. The project represented an attempt to combine the RCAP best practice standard and the principles of participatory action research.

Finding locations involved developing successful relationships in the local community. The contacts in the Aboriginal communities were developed by the consultant researcher, through pre-existing contacts or new ones developed through the project. The three locations for the work were North Bay, Ontario (with participants from as far north as Cochrane), Calgary, Alberta (with participants mainly from the urban centre of Calgary), and British Columbia (with participants from all over the province). In each location, a written framework for the local project was signed between the local partners and the CNIB. Participants in each location were recruited with the assistance of our location partners.

The findings of this research are grouped into six major categories. QSR software was used to code the data from the three location reports. All three location groups identified the following as issues that significantly affected their communities: a lack of awareness about vision impairment and the needs of members with vision impairments; a lack of awareness of the resources that are available with regard to vision health and vision loss, and ways of accessing them; a need for funds to create and /or maintain services and programs; a lack of knowledge about how to access funding from governments and bands in order to create, maintain and deliver services; a



need for community control over delivery models for services (culturally appropriate delivery will build trust); and a need for transportation to services. In addition, each group identified unique challenges. A recurring theme across all three groups and across the challenges they identified was the need to train and employ professionals who are aboriginal or possess adequate knowledge about first nations' cultures and values. Culturally appropriate service delivery was seen as providing opportunities for empowerment of the community, building of trust and exercising of community control over the services they use.

This report identifies numerous strengths and limitations of the process. A particular strength was the aboriginal consultant utilized to collect the data in the communities and write the location reports. A noted limitation was the time-consuming nature of the methods employed. Each location took several months to organize.

In contradiction to our expectation that a universally applicable aboriginal service delivery model would emerge from this consultation process, it was discovered that a "one-size-fits-all" approach would not work in every part of Canada or with different First Nations peoples. However, the evidence does indicate some commonalities that must be incorporated as basic principles on which any aboriginal program delivery model must be based. These principles are: culturally appropriate service delivery; community and individual control over service structures and delivery models; continuing funding to ensure program viability and stability over the long term; transportation needs must be supported in order to facilitate participation in any vision health care or rehabilitation program; sighted members of aboriginal communities require education about the needs of members who have vision loss and how to support them appropriately to maintain their independence and full participation. Detailed findings from each location are available in individual reports available by request from the CNIB National Office.

What people told us has direct implications for vision health policy. First of all, vision care and rehabilitation service must be made available to all aboriginal peoples. At the moment there is a patchwork of services, and the evidence on cataracts generated through this report indicates that some



people are going blind due to a lack of access to service. Cataract is a completely curable eye condition, through surgery that effectively prevents blindness. If aboriginal adults are becoming blind because of cataracts (as indicated by our demographic data), then we must assume (like in developing nations and poor regions of the world) they are suffering from a lack of access to appropriate and timely eye care from experts (ophthalmologists).

Secondly, access specifically to vision rehabilitation services is severely limited. Not surprisingly, and supported by findings reported by the National Aboriginal Health Organization, there simply is not enough service available, particularly in remote communities. Therefore, aboriginal people are not aware that they can maintain their independence even with vision loss, through rehabilitation teaching. Third, having vision care available is vastly different from getting to it. The lack of transportation and home-visiting for the elderly are key issues that arose repeatedly during the course of this research. People are saying, “create policies that allow for us to get where we need to go, or allow for the professional to come to us.” Many of the participants live in remote areas, and even those in urban communities complained of costs.

While several CNIB divisions have had extensive experience in providing service to aboriginal communities or individuals, evidence produced in this project suggests that service providers need not be from the CNIB or another rehabilitation agency. While Aboriginal participants often indicated that the CNIB was seen as housing expertise on vision care and rehabilitation, they also indicated quite consistently that they would like service to be provided within their communities, and if at all possible, by aboriginal people in a culturally appropriate manner. They also stated they wished to have more knowledge and information about vision loss available to them through courses and reading material. This report contains concrete recommendations for service providers, policy makers and public awareness and education.





II. INTRODUCTION¹

This report summarizes the results of a traditional consultation and participatory action research project carried out by the Canadian National Institute for the Blind (CNIB) from the fall of 2002 to the summer of 2004, and funded by Population Health Fund of Health Canada.

The first purpose of the project was to identify the care and support needs of the Aboriginal² people and/or their family members living with blindness and vision impairment. Communities and community members must be involved in defining, developing, and implementing programming. The Circles of Light Community Consultation was a stepping stone in opening a forum for discussing the dynamics and potential development of culturally appropriate programming needs that are compatible to the community and community members' perception of their culture and social environment.

A second purpose of the project was to identify potential links to existing support services and agencies for eye care and medical attention and intervention. Many Aboriginal communities are located in remote areas with little or no access to the necessary specialized services. Access to the full range of specialist or traditional services cannot be made at all times to all communities. The barriers to accessing these services are multiple and include lack of transportation, lack of childcare, differences in language and culture, and issues of federal/provincial jurisdiction. It can be very fruitful to create alliances with supporting organizations outside the community that will support community initiatives.

A third purpose of the project was to share information and knowledge gained with Aboriginal agencies. Both positive and negative results will aid in the enhancement and refinement of traditional project development knowledge within the Aboriginal milieu and expand the understanding of partnership experiences for mainstream organizations.

The goals of the project were to:

- Identify obstacles that prevent Aboriginal people in Canada from gaining access to vision services.

¹ All quotes are from research participants.

² For purposes of this paper, the term Aboriginal includes all people who identify with Aboriginal heritage and includes all Inuit, Metis or First Nations.



- Identify gaps in existing services.
- Define culturally specific aspects of the experience of vision loss.
- Utilize a traditional consultation process and Participatory Action Research in developing a culturally appropriate service model.
- Identify community assets, resources and potential partnerships in implementing suggested service models after the project is complete.

This report summarizes all of the work of the project, and assesses the level of our success in achieving our project purposes and goals.

CNIB Mandate



"All this information is helpful, but all levels of governments and all others involved must grasp understanding of what's needed and implement them."

Established in 1918, the Canadian National Institute for the Blind (CNIB) now serves 105,000 Canadians of all ages, through 1,000 staff and 20,000 volunteers working out of 57 centres across Canada. The CNIB also acts as a consultant and resource agency to the helping professions, government departments, and private industry. Our mission is to provide relevant, specialized services nationwide. We also aim to support and/or conduct research about vision, to ensure the continued development of services. We will support medical research and influence public policy, and the development of technology to help people who are blind or visually impaired lead independent lives.

The CNIB provides service through four presenting services: rehabilitation services, library services, technical aids services and information and public education.

We provide comprehensive habilitation, rehabilitation and library services to any Canadian declaring a problem in living with vision loss.



The 1994 CNIB Consumers First Study recognized the needs of Aboriginals. The report called for the sharing of best practises models and the use of a collaborative approach to consultation within the Aboriginal community.

Three Client Groups

The CNIB is committed to service to people of any age. For the purposes of this community consultation process, the researcher divided along the same age lines as those provided by the Government of Canada. Children and their caregivers participated in the “youth” circles (up to age 14), working age adults had their own circles (15-64 year olds), and older adults (seniors), aged 65 and over participated in the third grouping. A full description of the participants is included in this report under “Framework and Methodology.”

Rationale for the Project

Estimations of the population size of the First Peoples of Canada since the stabilization of the North American land masses 5,000-8,000 years ago range between 221,000 to 2 million. In the early 1400’s tuberculosis, influenza, scarlet fever and measles, brought by European colonization, ravaged the Aboriginal populations reducing the population by half every one hundred years. According to the 1991 Canadian data, the total population is between 626,000 and just over 1,000,000 depending on the definition and data source. The majority of registered Indians live on-reserve (58.1%) or in urban settings (41.9%).

The National Aboriginal Health Organization (NAHO) reports that the Aboriginal community carries a disproportionate share of the illness burden compared to the general Canadian population, as follows:

- Life expectancy 8 years lower than general population;
- Infectious diseases more common;
- Incidence of heart, lung disease and cancer rising;
- Diabetes affects 6% of Aboriginal adults compared with 2% in the general population;



- Overall rates of injury are high, indicative of problematic social conditions, especially addiction and poverty.

The fertility rate for the Aboriginal population is 69% higher than for the general population. In 1996, the ratio of children under five per 1000 was 491 for Aboriginal people compared to 241 for all others. Almost half (46%) of registered Indians live on reserve.

Furthermore, First Nations communities are more affected by the following social issues, as compared with the general population:

- Fetal alcohol syndrome
- Shortage of transportation services
- Shortages of food
- Lack of appropriate housing and sanitation services
- Lack of self esteem
- Loss of identity

In the 1991 Aboriginal Peoples Survey (APS), of the total Canadian Aboriginal population who responded to the disability question (117,090) 24% (28,560) identified as having a seeing disability. Of those with a seeing disability, 10,555 (the majority), live on reserve. Strongly linked to the severity, early on-set and high percentages of disability and eye related reported disability are the socio-economic factors prevalent in Aboriginal communities. There is a huge gap in available documentation about eye related disease in the Aboriginal population. The only emerging eye related research available is focused on issues of diabetic retinopathy. However, a statement can be made that despite this lack of research the eye related disease in the Aboriginal community is expected to be disproportionate on all accounts. For example, the prevalence of diabetes is not well documented but it is suspected that the rate is very high in some Aboriginal communities. Information on the incidence of diabetic retinopathy among Aboriginal peoples is completely inadequate.³

³ Maberley, D. 1999. Diabetes and Diabetic Retinopathy in Canadian Aboriginal Peoples: A Literature Review. www.interchange.ubc.ca/bceio/DR_paper.html, as quoted in CNIB, 2003. "Determining the Needs of Blind and Visually Impaired Aboriginal Peoples in Atlantic Canada", unpublished report.



A History of Work with Aboriginal Clients



"I learned more about the CNIB. It was a good learning experience."

From its inception, the CNIB has sought to provide services to all residents of Canada regardless of ethnicity. In the 1920s and 30s, CNIB staff, as part of medical teams, travelled by dog team in the north, focusing on prevention of blindness through screening. In 1986, an office was opened in Yellowknife, NWT and in 2000 an office was opened in Whitehorse, Yukon Territory. These two territories are perhaps the age of Europe, but have a total population of less than 100,000.

Until very recently in Canada, there was virtually no input from Aboriginal people in regard to program development for most services to their community members. The virtual exclusion of the community has not benefited service delivery and has not produced any successful models.

In 1994, the CNIB completed a study of the service needs for Aboriginal people in the Northwest Territories, funded largely by the Department of Indian and Northern Affairs and co-sponsored by the Dene Band, and Dene Cultural Institute. The resulting report highlighted the need to recognize the importance of native language and asserted the need for the use of native language in Aboriginal program development.

In 2000-2001, the CNIB BC-Yukon Division, in partnership with the Eye Clinic, University of British Columbia, and the BC Aboriginal Health Centre jointly developed a telemedicine project funded by the National Diabetes Initiative to ameliorate and diagnose the complications of blindness due to diabetes.

In 2001-03, the CNIB Atlantic Division, in partnership with the Health Research Unit, Memorial University of Newfoundland, studied the needs of blind and visually impaired Aboriginal Peoples in Atlantic Canada. Like the present study, the Atlantic study utilized participatory action research (PAR) to identify resources for developing and maintaining effective service delivery in the three communities consulted. The identified resources



included: establishing a community wellness committee to coordinate efforts in prevention of vision loss and blindness; partnering with a variety of organizations and programs inside and outside the community; establishing multidisciplinary teams (ophthalmologists, optometrists, vision nurses, rehabilitation professionals, etc.); access and timely referrals for clients to services and follow-up; integration and rehabilitation support within the community.⁴

The CNIB has long experience serving Aboriginal persons. Most particularly, we have had a special interest in this population in the following regions of the country: Newfoundland and Labrador, Northern Ontario, Saskatchewan, Alberta, Northern British Columbia, the Northwest Territories and the Yukon. The CNIB has identified that vision rehabilitation and support services have never adequately reached into Aboriginal communities in either the urban or rural areas of Canada. Therefore, our Aboriginal Services strategy now flows directly from the consistent recommendations from the Royal Commission on Aboriginal Peoples:

To include Aboriginal people, as decision makers, in program development that directly affects them, their families or their community. Recommendation 3.3.25 (b)

To employ Aboriginal people in the fulfilment of directives whenever practicable. Recommendation 3.3.24 (b)

To ensure that all efforts are taken to ensure cultural relevancy in all phases of programming, project development and implementation. Recommendation 3.3.24 (c)

To evaluate programs using appropriate tools and measures, as defined by each community. Recommendation 3.3.24 (d)⁵

⁴ Health Research Unit, Memorial University and CNIB (2003). "Determining the Needs of Blind and Visually Impaired Aboriginal Peoples in Atlantic Canada", unpublished report, p. 49.

⁵ Royal Commission on Aboriginal Peoples, Report of the Royal Commission on Aboriginal Peoples, Volume 3: *Gathering Strength*, 1996.



Mainstream programs such as the CNIB can contribute to improving Aboriginal health and social conditions in two important ways: by encouraging and supporting the development of health and social service delivery under Aboriginal control, and by improving the appropriateness and effectiveness of the CNIB services provided to Aboriginal people who are blind or visually impaired.

Services can support development of health and social service programs directed to eye health and vision rehabilitation under Aboriginal control by:

- encouraging collaboration between CNIB and Aboriginal services,
- supporting efforts to develop,
- supporting Aboriginal networking,
- support Aboriginal centres, and
- negotiation of partnerships

In 2002, the Circles of Light project was begun, funded by a contribution from the Population Health Fund of Health Canada. Based on findings from the Blood Reserve project, and the challenges of service provision across the nation, it became time to examine what aboriginal people might want in terms of a program delivery model related to vision loss and vision health. Having designed the process and written the draft proposal to Population Health Fund, the Aboriginal consultant who had conducted the Blood Reserve project was hired to coordinate the “Circles of Light” project.

Project Objectives

The Circles of Light Project objectives were to:

- Consult with Aboriginal communities in western (Saskatchewan), central (Ontario) and eastern Canada;
- Hold 9 consultations in the above noted regions;
- Define the needs of the three client age groups;
- Define a service delivery framework applicable and flexible for all Aboriginal peoples;



- Document potential health policy impacts for vision care;
- Partner with local community health care providers and Aboriginals.

Project Outcomes

Typical of many projects, the actual achievements of the Circles of Light Project differed from the objectives. We:

- Consulted with on- and off-reserve Aboriginal people from urban and rural Northern Ontario, the entire province of British Columbia, and the urban centre of Calgary, Alberta;
- Included representation from Metis and First Nations, but could not include Inuit peoples (see “Limitations of Project”);
- Held 6 consultations in the above noted regions, from March of 2003 to March of 2004;
- Defined the principles on which to base an appropriate service model from the perspective of the consulted groups;
- Partnered with local community health groups to conduct the consultations;
- Documented requirements for policy and service change in order for vision care to be delivered appropriately;
- Learned the limitations of projects involving the far north;
- Disseminated findings back to regional partners and through the production of our final report.



III. FRAMEWORK AND METHODOLOGY



"We know there are more children and older people in each of the communities who need help."

Traditional consultation process

The Royal Commission on Aboriginal Peoples (RCAP) recommends that a community consultation process follow a standard of best practice, which must include:

- Oral knowledge
- Fair representation of all community life
- Viewpoints from older and younger generations
- Observation of traditional protocol

Participatory Action Research

Participatory Action Research (or PAR) is utilized increasingly as a suitable methodology with oppressed or marginalized groups. It typically involves democratization of the knowledge process — people normally shut out from research and information become involved in the research itself. When used in a health context, PAR permits people to “solve their own problems and plan actions to achieve their own vision of health.”⁶ PAR allows people to create new knowledge and develop ways to share that knowledge and create change through the planning of actions (in this case program models) based on this new knowledge. CNIB and Memorial University (see footnote 3) had previously listed the following essential qualities of the PAR approach:

- Involves the participation of ordinary people in problem posing and solving;
- Is educational for both researchers and participants;
- Includes collective action for change;
- Provides a direct link between research and action;
- Is practical, timely and useful to the community.

⁶ Health Research Unit, Memorial University and CNIB (2003). “Determining the Needs of Blind and Visually Impaired Aboriginal Peoples in Atlantic Canada”, unpublished report, p. 49.



In PAR, the “action” is often integrated with the actual participatory research phase. People design what they wish to see happen, they create action plans, which can then be acted upon when the research is complete. It is not necessary to wait until data is collected, analysed and discussed because action can take place as a direct and immediate result of the research process. This was an important goal of the “Circles of Light” project. Furthermore, PAR has a social change emphasis — the goals of research are to engage in action that reverses inequalities, empowers the “have-nots”, and ultimately transforms society so power is based in grassroots organizations and individuals. Our goals however were more modest: we wished to achieve simply the beginnings of partnerships that would allow for the participating communities to begin the process of empowerment and change by beginning to understand what they needed through the process of coming together in focus groups to express: a) challenges; b) supports required; and c) program models desired.

The project represented an attempt to combine the RCAP best practice standard and the principles of participatory action research.

Organizational Partnerships



“We need to learn how to work together and help one another.”

Each consultation grew out of the development of partnerships between the Canadian National Institute for the Blind and key Aboriginal organizations in the local community. Local organization partners allocated a staff person or committee to assist in contacting community members, drafting and distributing public notices, finding free public information centres for announcements, organizing local arrangements including room and food, Elders, volunteers, and assisting with the Stage Three group facilitation process.



The list is as follows:

North Bay, Ontario:

North Bay Indian Friendship Centre

Calgary, Alberta:

Region 3 Aboriginal Community Health Council

Calgary Health Region (enabled above council to participate by assisting with ethics approval through University of Calgary REB)

Canada Red Cross, Calgary Region

City of Calgary, Calgary Urban Aboriginal Initiative

British Columbia:

B.C. Aboriginal Network on Disability Society

First Nations Health Committee

Together with the community organizations listed above, the CNIB has developed connections with local Aboriginal Human Resource Development Agreement Holders (AHRDA's) as potential offices to carry out the programs requested by the people who participated in this project.

Recruiting Locations and Participants



"Native people need to know what is out there for them."

Locations

Finding locations involved developing successful relationships in the local community. The contacts in the Aboriginal communities were developed by the consultant researcher, through pre-existing contacts or new ones developed through the project. In **North Bay**, Ms. Many Guns had developed positive relationships in her previous work with the CNIB, thus the request to conduct the research received an immediate and positive response. In **British Columbia**, Ms. Many Guns worked through the B.C. Aboriginal Network on Disability Society, a self-advocacy network of



consumers with disabilities. This was a new partnership, and very successful. In **Calgary**, where Ms. Many Guns' business is located, and where she has a long history of relationships in the Aboriginal community, partnerships were established for the project with a number of community partners. The Calgary Health Region—Region 3 Aboriginal Community Health Council, the Calgary Urban Aboriginal Initiative, the Canadian Red Cross, the Calgary CNIB office and the CNIB National office through the consultant researcher, formed a steering committee. This caused complexities but allowed for a diversity of input to the project. The partnership with the Calgary Health Region required ethics approval from the University of Calgary. This was again a complex process but ensured approval for our research process and resulted in important documentation on file at the CNIB.

In each location, a written framework for the local project was signed between the local partners and the CNIB.

Participants

Participants in each location were recruited with the assistance of our location partners. By utilizing the participant evaluation form question, "how did you hear about the Circles of Light?" it is possible to determine the ways in which the consultation information was disseminated. Recruitment posters were developed and faxed to large numbers of community organizations, and posted. However, in North Bay for example, it was word of mouth that informed 36 of the 59 total participants (both focus group sessions, including service providers). Copies of the recruitment posters are included in Appendix D. A \$50.00 honorarium was offered to each consumer participant in the focus groups. (Service providers were not provided with an honorarium.) Elders asked to preside over the proceedings and provide a smudge and opening prayers, were also provided with an honorarium, as well as appropriate gifts.

Some locations created special announcements for radio, but most utilized fax to send the poster to their members. Uniquely, the arrangement in British Columbia was able to recruit a large number of participants because it took place during a conference for Aboriginal people with disabilities, and the consultation was provided as a workshop within the conference context.



Recruitment was not always easy, however, and in both North Bay and Calgary the originally scheduled consultations were rescheduled for several weeks to a month later because the partners required more time to recruit participants. However, once the delays took place, enough participants registered in order for the consultations to proceed.

The Data Collection Process



"We need to have a single place where we can find out information about workshops, programs, projects and funding so we can access as much information and resources as possible."

Here again, one notes the difference between an original plan and the reality in implementation. The original ***planned*** process involved three stages:

Stage 1 — Consumer Focus Groups: children, working aged, seniors. Data collection was intended to focus on identification of problems and solutions related to vision loss and vision care. Community members were to review focus group results before going to the next stage.

Stage 2 — Front line workers were to define barriers and solutions related to working with Aboriginals with visual impairments. This information was to be reviewed and confirmed by them before moving to the next stage.

Stage 3 — All participants in stages one and two were brought together and divided according to interest in one of three age groupings. Each individual in each group to utilize "nominal decision making" to vote for their three favourite "projects." The project with the most votes chosen from that group and then discussed as a program model design.

The ***actual*** process of each set of consultations involved the following stages, adapted from the theoretical model above:



Stage 1 — Focus groups with aboriginal participants, divided into three age-related groups, and given a set of specific guiding questions for discussion (see below). Service providers (“front line workers”) involved in their own groups sessions at the same time, similar topics for discussion (e.g. challenges and solutions). Thus “stage two” above was collapsed into the same consultation, and did not really appear as a separate stage. Data in this stage was collected on cassette tape and/or on flipchart paper by group facilitators. Consent forms were signed for taping sessions.

Stage 2 — Analysis of data collected in stage one, and organization of data into categories for discussion in Stage three. (Data synthesized by consultant researcher in between stages two and three.) All data collected in the sessions of stages one and two was reviewed and placed into categories. Categories were determined by frequency of topic. The key topics discussed were then named either “program” or “project”. In preparation for Stage three sessions, a card was made with the name of the “project”, and on the reverse were listed the reasons this topic was thought to be important. The reality was that the researcher interpretation and organization of data into categories was in fact a research stage not acknowledged in the initial proposed model.

Stage 3 — Focus groups reconvened with original participants, but open to new participants. While the initial goal was to go back to the same people with organized “projects”, in fact, new people became involved in both North Bay and Calgary, and their input was very valuable. Not having been involved in Stage One, they could vote and discuss with a fresh insight. Researcher used a voting process called “nominal decision making” (see below) to have each age-related group or “band” elect a chosen program model that they would want to implement. Data was collected on flip chart paper, and in notes of facilitator.

Stage 4 — Writing of individual regional location report based on findings in each of the three age-divided groups of participants.



“Nominal Decision Making Process”

The process of selecting a particular project as the one most wanted by a group (or “band”), was as follows, determined by the consultant researcher:

- Each band was to name a “chief” to lead the discussion; recorders were volunteer facilitators;
- Have a discussion about all the projects brought forward as a result of Stage One work, and discuss which project has the most value (about one hour);
- Cast three votes for favourite projects (participants were permitted to place more than one vote on one project, see “Limitations of Project Process”);
- Add up the votes and select the project with the most votes;
- Discuss where the program or project should be located;
- Discuss who should staff the project;
- Discuss other aspects not covered by these questions.

Additional methods

In both stages 1 and 3, demographic and evaluation data were also collected. (See Appendix E for demographic questionnaire and Appendix F for the evaluation form). This final report summarizes the entire project, blending findings from the three locations. For a detailed description of each location consultation, contact the CNIB National Department of Service Development and Research. The final reports for each location were reviewed by the partners prior to dissemination, and then disseminated by the CNIB and the partners to those requesting them from within the participant communities and organizations.

Community Profiles

Each community is described in detail through community profiles in each of the individual location reports. The detailed location reports provide



information on the number of self-identified Aboriginal people, their nation, and their gender living in each community represented in the study. These statistics are derived from Statistics Canada Aboriginal People's Survey 2001 and Statistics Canada 2001 Census of Canada Community Profiles. The individual location reports are available (in electronic format only) by request from the CNIB National Department of Service Development and Research.



IV. RESULTS



"We would like to be involved in deciding who works with us, not just be part of a system."

Demographics

From all locations, there were seventy-five (75) participants with visual impairments who completed the demographic questionnaires, and each consultation also included a group of service providers who worked amongst themselves in stage one, and integrated with others in stage three. The service providers were not counted by the researcher consultant, thus there is no report on their demographics. Most were direct service providers either in vision health (such as CNIB staff) or in social services (such as Indian Friendship Centres). Sixty-one (61) of the aboriginal participants with visual impairments (henceforth called "consumers") were working-age, reflecting the general Aboriginal population both on- and off-reserve. Only in British Columbia (where the consultation took place at a provincial conference of the British Columbia Aboriginal Network on Disability Society (BCANDS)) were the groups fairly evenly divided. In both Calgary and North Bay, the groups significantly matched the general portrayal through Statistics Canada: a very small number of participants in the younger age groups and in the senior age groups, a large bulge in the working age population participating.

There were often different consumers participating in Stage three than in Stage one. Therefore, the new group would be asked to complete the demographic questionnaires. The number above represents the total number completing a questionnaire, whether they participated in Stage One only, Stage Three only, or both Stage one and Stage three.

The following table reports further demographic breakdown of the three locations:



Location	Participant Number	Additional disabilities	M/F	General Health
North Bay	31	23	11/19	Fair to Excellent
Calgary	38	21	22/16	Very Poor to Excellent
B.C.	26	20	12/14	General Health not reported by consultant
Most common reported health conditions:				
		Cataracts	25	
		Diabetes	18	
		Glaucoma	9	

Other health conditions noted were: cancer, high blood pressure, effects of stroke and epilepsy. It is important to note that, despite our hypothesis that injury would be a significant cause of eye or vision problems (as proved to be the case in the CNIB/Memorial University Atlantic Canada study); in fact this was not the case in this study. In all three locations, injury was not reported as a significant cause of eye or vision problems. It is interesting to note that vision loss due to cataracts has been substantially reduced, almost eradicated, in the general population. To have visual impairment as a result of adult-onset cataracts is comparable to the statistics one sees in developing nations; it is now rare in Europe, Australia, Great Britain and North America because cataracts are operable.

The participating consumers, who reported their home place, came from the following communities:

North Bay, Ontario Consultations: North Bay (Central north city), Nipissing Reserve, Cochrane (far north town), Parry Sound (Central north town), Timmins, Ontario (far north city), Temagami First Nation, Mishkeegogamang, Ojibways of Pic River, Eagle Village, Moose Factory, Chapleau Cree First Nation, Constance Lake Reserve, Wolf Lake First Nation, Moosonee, three unreported.

Calgary, Alberta Consultations: Calgary (major city) (all).

British Columbia Consultations: Vancouver (5), Chemainus 13 Reserve (Vancouver Island), Lower Similkameen First Nation (Interior south B.C.), Metlakatla Band on Lax Kw’alaams Reserve (Far north coastal), Okanagan



First Nation (Interior south), Okanagan-Similkameen First Nation (Interior), Pauquachin First Nation (near Vancouver, lower mainland), Port Alberni (Vancouver Island town), Prince George (northern Interior town), Seton Portage First Nation (Interior south).

Findings



"We want a First Nation staff person who is knowledgeable in the needs of First Nations people, one who has first hand information."

The findings of this research are grouped into six major categories. QSR software was used to code the data from the three location reports. The categories of data, however, were to some extent pre-determined by the consultant researcher. As stated in the Methods section of this report, the consultant researcher collected data according to certain questions asked during stage one "workshops", and synthesized this data during stage two, into particular groupings. In Stage three, she presented particular program model questions such as "where should this program be located?" which then naturally generated discussion along certain lines. (Please note the discussion on "limitations of the study"). We have used the researcher's guiding questions to group the resulting data.

1. What are the primary challenges/barriers?

The three sets of consultations asked participants to identify the primary challenges their communities face in terms of supporting members who have vision impairments. All three location groups identified the following as issues that significantly affected their communities:

- Lack of awareness within their communities about vision impairment and the needs of their members with vision impairments;
- Lack of awareness within the community of the resources that are available with regard to vision health and vision loss, and ways of accessing them — a need for an advocate within communities was a related challenge;
- Lack of funds to create and /or maintain services and programs within



their communities, particularly in the current context of cutbacks to health care, and lack of knowledge about how to access funding from governments and bands in order to create, maintain and deliver services;

- Lack of community control over delivery models for services (culturally appropriate delivery will build trust);
- Lack of support with transportation to services.

In addition, each group identified unique challenges.

Calgary identified needs to:

- Recognize and honor the contributions vision impaired youth can and do make to their communities;
- Reduce/remove the barriers that vision impaired youth face in accessing post secondary education and employment;
- Develop stronger networks between agencies within the city in order to strengthen their capacity to support community members who have vision impairments;
- Create a network of healers and traditional counselors within bands;
- Develop holistic service delivery models;
- Create better housing with running water and furnaces;
- Create in-home services for seniors.

North Bay identified a need for:

- Funding for corrective lenses.

B.C. identified the following needs:

- On-reserve mobile vision services;
- Support with development of employment skills such as computer literacy;
- More nurses who are knowledgeable about vision health and vision loss.



A recurring theme across all three groups and across the challenges they identified was the need to train and employ professionals who are aboriginal or possess adequate knowledge about first nations' cultures and values. Culturally appropriate service delivery was seen as providing opportunities for empowerment of the community, building of trust and exercising of community control over the services they use.



"There should be funding to hire a staff with experience and training for Aboriginal people. We want our own programs delivered by Aboriginal people in our community."

2. What supports are required?

B.C. identified a need for books in alternative formats and for a toll free phone line that could provide information and advocacy. Calgary identified a need for supports for parents of vision impaired children, for example to take the children to appointments or programs, in order to reduce the burden parents bore. These supports should span all systems that may be involved in children's and families' lives, such as education, health care and employment. They also articulated a need to develop educational supports for the community in order to enable them to maintain their health (for example eye health) and traditional activities such as hunting, to educate service providers about vision health issues, to inform the community about what is available in terms of vision services in other provinces, and to promote independence for members who live with vision loss. The North Bay group also identified a need for education to learn how to promote independence while supporting community members with vision impairments.

3. What program is desired?

After identifying the challenges their communities faced and the types of supports they required, the groups engaged in a process of articulating the type of program or service that would best fit their needs. The groups were divided into different Bands, who articulated the types of programs they felt were required.



B.C.: The Wolf Packs Band (youth aged 17-21) felt that a series of workshops with a fundraising component (to support program delivery) would be most appropriate. These workshops would focus on the development of personal skills and provide information about vision loss and vision services. In essence, these workshops would empower individuals to lead full and independent lives and the community to better understand and support vision loss issues. The Eagle Band (working aged persons, 25-64) also desired a personal development program that would include a “Blind Education Transportation” to promote accessibility of the program. The Eye Opener Band (seniors aged 65+) desired a program to assist housebound elders in their homes, provide services and advocacy, and Braille literacy. The focus of this program should be proactive rather than reactive, should have a peer component in order to build trust and understanding among seniors living with vision loss, and should have stable and continuing funding. The Urban Nations Band chose an adult education program for youth, working age adults and seniors.

Calgary: The White Eagle Band (working aged persons aged 25-64) chose an education program that would be structured to educate the community at large, service providers such as addictions counselors, educators and other stakeholders about vision loss issues. This option was also selected by the Erminskin Band (seniors aged 65+) members. This band also wanted to incorporate a home care program to assist seniors in the Calgary area by bringing services to them and a transportation service for travel to appointments, meetings and other events.

North Bay: The Hungry Band (youth) chose a “More Teachers for Blind Children Project” to provide Braille literacy and knowledge about how to use resources. The Eye Band (working aged) selected a fundraising program to assist working age blind and vision impaired people to attend workshops, acquire corrective lenses and technical vision aids, and support for adjustment to progressive vision loss. The Tribal Band (seniors) chose a transportation assistance program combined with a fundraising component to enable seniors in the region to travel to workshops and other events related to vision loss.



4. What is the scope of the program?

B.C.: The program should encompass all levels of the community in order to elevate the level of understanding about and ability to support vision loss. Support to families, mentorship and promotion of communications skills were seen as primary activities required to promote independence and empower individuals. Advocacy was also seen as a key component of the program.

Calgary: This group also focused on broad based advocacy and dissemination of information about vision loss and available resources, especially financial resources.

North Bay: The scope of the program should focus on financial issues and provide funding for corrective lenses, technical aids and transportation.

5. How would you staff the program?

All three groups felt that staffing of the programs should be focused on Aboriginals who possess high levels of knowledge and expertise about vision health and vision loss, and who speak the indigenous languages. Training should be provided to Aboriginals in order to increase the numbers of Aboriginal service providers. Staffing should be both full-time and part-time in order to offer comprehensive coverage of hours, including evenings and weekends. The programs should include outreach/community worker positions. Elders should be involved in program delivery (peer component) and agencies such as the CNIB should be approached to provide training for service providers.

6. Where would you locate the program?

There was wide variation in the locations that were recommended, reflecting the regional geographic specifics pertinent to each group. Generally, the groups identified both places (cities, towns, reserves) and facilities (Indian Friendship Centres, band offices, community health centres, schools and community centres) that would be the most appropriate locations within their areas. However, the Calgary group advocated for a central, downtown Calgary location, close to bus routes.





V. STRENGTHS AND LIMITATIONS OF THE PROCESS

Following is a description of the strengths and limitations of the project and process as assessed by the CNIB national office research department. No formal evaluation process took place, although evaluation was included as a part of the PAR process, and the evaluation form is included in Appendix F.

Strengths of the Process

- The greatest strength of the process was the Aboriginal consultant/-researcher. Because the consultant was Aboriginal and had a deep understanding of the traditional consultation process (having designed it for previous projects), she was able to make good contacts in the First Nations communities, and create possibilities for the community consultations. Guided by CNIB national office knowledge about the government reporting process, the PAR process, and issues in vision loss, the consultant/researcher engaged directly with people and with the data in order to produce comprehensive location reports (available by request from the CNIB).
- The process allowed participants to state their own needs and wishes in their own words.
- Participants had the opportunity to listen to others, and learn from each other, generating project ideas and discussing them before voting through the “nominal decision making process.”
- The “nominal decision making process” allowed people to express their own votes, without discussing any further with others.
- Findings from the PAR process with aboriginal peoples will be respected by policy makers, because this process relies on consumers themselves for input about what they want.
- While a “one-size-fits-all” model was not generated, the process generated themes that are common to all locations.
- Dividing people into age-related working groups provided strength to the content generated.



- The process was designed to be flexible, and thus we have generated a new and effective model for future consultations with Aboriginal communities.

Limitations of the Process

All research processes and community consultation projects contain limitations in both initial design and in the project process. Following is a description of the limitations of this project.

- The project coordinator, as a hired private consultant working in Calgary, was too distant from the CNIB national office headquarters. This distance required excellent ongoing communication, not always available. It was difficult at times to mark the progress of the project, and in the end, the inability to gain effective insight through monitoring meant we could not renew the contract.
- In terms of design, groups were given very specific choices to make in Stage Three, which limited responses. For example, asking people “who will staff the service?” builds in an assumption that whatever will be proposed will require “staff.” This, of course, will limit the imagination of people with respect to what a “service” or “program” will look like. In another example, there were times when the process could not accommodate a key barrier at all. Because of the narrow purpose of the process, participants did not know how or when to discuss a barrier such as the Indian Act, for example. Perhaps because in-depth individual interviews were left out of the initial design, rich data on people’s perspectives could not be included in the results.
- The process of community consultation, including the arrangements for the workshops, local recruitment of participants, and all other logistics, is a time-consuming one. Because the project was time-limited due to the funding agreement, it was difficult to meet the requirements of the project within the allotted time frame.
- The process of involving a northern First Nations community was not successful. It took several months for the consultant researcher to establish the correct contacts to hold a consultation; due to the expense and time involved with travel to Iqaluit, a telephone



consultation was arranged. It took far too long to then arrange for Stage three of the process, by which time, the community members who had participated in Stage one no longer were available; and the office that had helped the researcher was unable to find other participants.

- It was difficult to obtain participants for the consultations in North Bay, Iqaluit and Calgary. These difficulties existed for various reasons. Anyone planning such consultation in the future must be aware that the recruitment time required for focus group research in the native community is about two months.
- The planned method immediately had to be adapted to the requirements in each location. For example, because of the travel requirements for the researcher, it did not make sense to hold an entirely separate focus group day with service providers. In fact, Stage two was consistently integrated into Stage one by the researcher, with service provider groups taking place on the same day as consumer groups. In another example, in British Columbia, the researcher could not wait a week to deliver stage three; she needed to collapse the data from Stage One on the first day, after that workshop, and then deliver Stage three on the second day. This may have been hugely limiting given that she did not have a week to work with the data, but only one night. Thus the theory set forth in the initial research proposal was not in fact the reality when coordinating the data collection process.
- In-depth interviewing with key stakeholders was not included as a part of this process. This limited the ability of the researcher to harvest rich quotes representing themes in the data. The analysis was therefore not as inductive as one might like in Participatory Action Research.
- The “nominal decision making process” or voting required of participants, was limited in its ability to pull out a model that represented everyone’s wishes. Potentially, a few people could vote for only one project with their three votes, and that project could be selected but not fully represent the group’s views.
- The design of the project did not build in a feedback session, so that results could be commented upon by participants prior to publication of a report. In British Columbia, for example 4 out of 11 evaluative comments referred to the desire to see results before commenting on the effectiveness of the consultations. Due to the time and budgetary



constraints of the project, it was not considered possible to provide the participants with the findings prior to the production of a report, but in an ideal world, this would be the most indicative of participatory action research.

- The process was intended to involve representation from all of the aboriginal sectors in Canada: Indians, Metis and Inuit. Unfortunately, due to the problems in obtaining data from northern Canada, Inuit peoples are not included in the project as originally intended.



VI. CONCLUSION



"We need to know what options there are. We need information to teach our family, neighbours, school children, and community members about blindness."

In contradiction to our expectation that a universally applicable aboriginal service delivery model would emerge from this consultation process, it was discovered that a "one-size-fits-all" approach would not work in every part of Canada or with different First Nations peoples. However, the evidence does indicate some commonalities that must be incorporated as basic principles on which any aboriginal program delivery model must be based. The first three principles listed below are requirements in order to build trust in aboriginal communities.

1. Culturally appropriate service delivery:

- Aboriginal service providers with knowledge of vision health and vision loss issues, and/or supported by knowledgeable non-aboriginal professionals and experts;
- Availability of services in First Nations languages;
- Community elders involved in programs.

2. Community and individual control over service structures and delivery models

3. Continuing funding to ensure program viability and stability over the long term

4. Transportation needs must be supported in order to facilitate participation in any vision health care or rehabilitation program. Also, transportation is a key factor in gaining access to vision health appointments and management of vision (and other) health concerns, as well as community recreation and leisure, ceremonies and other



community events. Attendance at our consultations, for example, was dependent on access to transportation, mainly from family members.

5. Sighted members of aboriginal communities require education about the needs of members who have vision loss and how to support them appropriately to maintain their independence and full participation.

Location-specific Findings


Detailed findings from each location are in individual reports available by request from the CNIB National Office.

As stated in our Introduction, we sincerely hope that the results of this project will be shared widely amongst Aboriginal and mainstream organizations and utilized as a basis for future planning in health service delivery. We believe these findings have significant implications not only for vision health policy and program delivery, but also in the broader health context. These implications are discussed in the following section.



VII. IMPLICATIONS OF THE FINDINGS

Recommendations for Service Provision

 ***"We need help in our homes from trustworthy people. We would like to be involved in deciding who comes to our homes."***

The evidence produced in this project suggests that service providers need not be from the CNIB or another rehabilitation agency. While several CNIB divisions have had extensive experience in providing service to aboriginal communities or individuals, people who participated in this consultation process made it very clear that it was not necessary for a mainstream rehabilitation agency to do so. This would lead the CNIB and other rehabilitation offices to ask, "what is our role?" Clearly, there is expertise on low vision, vision care and vision rehabilitation, that lies within the service providing offices of the CNIB. Aboriginal participants often indicated that the CNIB was seen as housing expertise on vision care and rehabilitation, knowledge and information they would like to have. However, they also indicated quite consistently that they would like service to be provided within their communities, and if at all possible, by aboriginal people in a culturally appropriate manner. How can these two realities be best blended to create an appropriate and timely vision care and rehabilitation system for aboriginal peoples? On the one hand, we have expertise housed in a mainstream (Western European derived) agency/professional field. On the other, we have the desire of the people to receive services in a culturally appropriate way and from aboriginal service providers. They also stated they wished to have more knowledge and information about vision loss available to them through courses and reading material. Thus, we recommend the following:

1. CNIB offices and aboriginal community leaders partner together to provide training to general health care providers presently available in the communities (such as public health nurses), to people who are trying to adjust to vision loss, and to sighted people in the community



(and family members). This training would involve increasing skill development of professionals (including aboriginal nurses) in determining vision loss issues, and in making appropriate referrals. For people with adjustment issues, training would involve relaying information about vision loss, perhaps in the form of a videotape that would be available over a long period of time, rather than in time-consuming and costly live training modules. Funding for such a project can be sought at the national level from a variety of federal and private sources: Population Health Fund of the Public Health Agency of Canada; National Aboriginal Health Organization; Canadian Institutes for Health Research; and private foundations interested in public education projects. Any education project must be developed with involvement of aboriginal peoples from its inception through to conclusion. If a national advisory committee is formed, the membership must be 51% aboriginal, and the project coordinator must be aboriginal. This kind of project would ensure that information packages are developed by aboriginal people and disseminated to aboriginal people and others in an appropriate and timely manner.

Recommendations for Health Policy

What people told us has direct implications for vision health policy.

1. First of all, vision care and rehabilitation service must be made available to aboriginal peoples. At the moment there is a patchwork of services, and the evidence on cataracts generated through this report indicates that some people are going blind due to a lack of access to service. Cataracts are completely curable through surgery that effectively prevents blindness. If aboriginal adults are becoming blind because of cataracts (as indicated by our demographic data), then we must assume (like in developing nations and poor regions of the world) they are suffering from a lack of access to appropriate and timely eye care from experts (ophthalmologists).



2. Secondly, access specifically to vision rehabilitation services is severely limited. Not surprisingly, and supported by findings reported by the National Aboriginal Health Organization, there simply is not enough service available, particularly in remote communities. Therefore, aboriginal people are not aware that they can maintain their independence even with vision loss. One woman was observed to be in attendance at a meeting with a male companion, who did everything for her, and led her by the hand. He had not been trained in proper “sighted guide” technique, and she relied on him. Rehabilitation teaching is simply not available to aboriginal people who are losing their vision. Many participants spoke of the desire to learn Braille. The researchers felt this was an example of the lack of participants’ knowledge about what is available to them, and that “learning Braille” was what they imagined they needed to learn. In other words “learning Braille” actually means “teach me everything I need to know in order to manage as a blind person.”
3. Third, having vision care available is vastly different from getting to it. The lack of transportation is a key issue that arose repeatedly during the course of this research. Also the need for home visiting for the elderly. In both cases, people are saying, “create policies that allow for us to get where we need to go, or allow for the professional to come to us.” People are resourceful when they need to be, but having no public transportation system severely limits access. Many of the participants live in remote areas, and even those in urban communities complained of costs.

Recommendations for Public Awareness and Education

Even where access may be available, people talked to us about wanting more information. Following are some recommendations for governments, aboriginal communities, people who provide low vision service of any kind and family physicians and public health nurses.

1. Ensure the population knows what to look for; ensure that family physicians working with aboriginal populations have an eye clinic or



mobile unit to refer for eye care, particularly for patients with diabetes.

2. Ensure that as much information as possible is provided through pamphlet, video and other sources in relevant languages, so that people have easy access to basic information about eye conditions and treatment, and about vision rehabilitation.
3. Adopt the Vision 2020 (World Health Organization) policies for aboriginal people and ensure this information is disseminated amongst the population and amongst professionals. Vision 2020 calls for massive public awareness about vision loss and treatment.
4. Work with local CNIB offices and other rehabilitation agencies to create information packages of the most use to aboriginal peoples.



VIII. APPENDICES

APPENDIX A: LOCATION AGREEMENTS

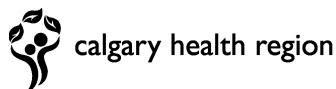
CIRCLES OF LIGHT PARTNERSHIP AGREEMENT

The Partners:



The Canadian National Institute for the Blind (CNIB)
1929 Bayview Avenue, Toronto, Ontario M4G 3E8

and



Calgary Health Region (CHR)
Aboriginal Community Health Council



and



The Canadian Red Cross Southern Alberta Region

The Agreement:

The Partners will jointly collaborate on the Circles of Light Project for the Calgary region in the following way:

1. The Canadian National Institute for the Blind (CNIB) agrees to conduct a three stage qualitative community consultation process at a location agreed to by the CHR Aboriginal Community Health Council. This process follows the principles of participatory action research guidelines. (See attached backgrounder)
2. Dates and times will be mutually agreed upon and added to this agreement.
3. Number or approximate number of participants will be mutually agreed upon and added to this document.
4. The CNIB and the CHR Aboriginal Community Health Council agree to follow all ethical research protocols.
5. The CNIB will analyze the research data.



6. The CNIB will provide copies of all stages of the research to the NBIFC.
7. The CNIB will maintain confidentiality and anonymity of participants by changing names and personal indicators in accordance with professional standards.
8. The CNIB will be responsible for all costs directly associated with the research process such as honorariums, room rental, equipment, and food costs.
9. The CHR Aboriginal Community Health Council and The Canadian Red Cross will assist the research by inviting community members to the community consultation process who are blind or visually impaired, their families, frontline service providers and appropriate stakeholders.
10. The CHR Aboriginal Community Health Council and The Canadian Red Cross shall assist with distribution and or notice of the community consultation process.
11. The CNIB will be the owner of the research and report.
12. The CHR Aboriginal Community Health Council and The Canadian Red Cross will assist with local distribution of the results and report.

The CNIB is not responsible, nor obligated to the Partner or the community for implementation of any results or outcomes identified in the process or for follow-up on any of the recommendations raised in the community consultation process.

Signed:

CNIB Representative

Date

CHR Representative

Date



CIRCLES OF LIGHT COLLABORATION AGREEMENT

The Partners: *(Collaborators)*



**The Canadian National Institute for the Blind (CNIB)
1929 Bayview Avenue, Toronto, Ontario M4G 3E8**

and

**B.C. Aboriginal Network on Disability Society
(BCANDS)**

The Collaboration Agreement:

The Partners will jointly collaborate on the Circles of Light Project for the British Columbia region in the following way:

13. The Canadian National Institute for the Blind (CNIB) agrees to conduct a three stage qualitative research process at Richmond B.C. This research process follows the principles of participatory action research guidelines. (See attached backgrounder)
14. The date and times have been mutually agreed upon. The best dates are September 21 – 23, 2003.
15. The number or approximate number of participants has been mutually agreed upon. We have determined that we would target 10 people per session of youth, working aged, seniors and front line service providers or caregivers in the first and second sessions and ten per each age group in the final session.
16. The CNIB and the BCANDS agree to follow all ethical research protocols, including cultural protocol.
17. The CNIB will analyze the research data.
18. All research results belong to the Partners. The CNIB will provide copies of all stages of the research to BCANDS.
19. The CNIB will maintain confidentiality and anonymity of participants by changing names and personal indicators in accordance with professional standards.



20. The CNIB will be responsible for all costs directly associated with the research process such as honorariums, room rental, equipment, transportation, translation and food costs.
21. The BCANDS will assist the research by inviting Society members to the research process who are blind or visually impaired, their families, frontline service providers, caregivers and appropriate stakeholders.
22. The BCANDS shall assist with distribution and or notice of the research process through the Society infrastructure.
23. The BCANDS will assist with local distribution of the results and report.
24. CNIB will provide the Final Report of the research to the BCANDS on or before March 2004.
25. CNIB is responsible for Braille and translations to participant languages.
26. CNIB is responsible to notify BCANDS of further initiatives that flow from the research project.

The CNIB is not responsible, nor obligated to the Partner for implementation of any results or outcomes identified in the process or for follow-up on any of the recommendations raised in the research process.

Signed:

CNIB Representative

Date

BCANDS Representative

Date



CIRCLES OF LIGHT PARTNERSHIP AGREEMENT

The Partners:



The Canadian National Institute for the Blind (CNIB)
1929 Bayview Avenue, Toronto, Ontario M4G 3E8

and



The North Bay Indian Friendship Centre (NBIFC)
980 Cassells Street, North Bay, Ontario P1B 4A6

The Agreement:

The Partners will jointly collaborate on the Circles of Light Project for the North Bay region in the following way:

27. The Canadian National Institute for the Blind (CNIB) agrees to conduct a three stage qualitative community consultation process at a location agreed to by the NBIFC. This process follows the principles of participatory action research guidelines. (See attached backgrounder)
28. Dates and times will be mutually agreed upon and added to this agreement.
29. Number or approximate number of participants will be mutually agreed upon and added to this document.
30. The CNIB and the NBIFC agree to follow all ethical research protocols.
31. The CNIB will analyze the research data.
32. The CNIB will provide copies of all stages of the research to the NBIFC.
33. The CNIB will maintain confidentiality and anonymity of participants by changing names and personal indicators in accordance with professional standards.



34. The CNIB will be responsible for all costs directly associated with the research process such as honorariums, room rental, equipment, and food costs.
35. The NBIFC will assist the research by inviting community members to the community consultation process who are blind or visually impaired, their families, frontline service providers and appropriate stakeholders.
36. The NBIFC shall assist with distribution and or notice of the community consultation process.
37. The CNIB will be the owner of the research and report.
38. The NBIFC will assist with local distribution of the results and report.

The CNIB is not responsible, nor obligated to the Partner or the community for implementation of any results or outcomes identified in the process or for follow-up on any of the recommendations raised in the community consultation process.

Signed:

CNIB Representative

Date

NBIFC Representative

Date



APPENDIX B: QUESTIONNAIRE FOR STAGE ONE

QUESTIONNAIRE

Choose your team leader. You have two hours. Let each of the participants answer each of the questions. Try to make it through each of the questions.

TEAM LEADER — Please read aloud for everyone

When talking about problems it is important that when you mention a problem you also talk about your solution or a way to prevent the problem. The facilitator and the rest of the group should always remind the speakers to tell them what the solution would be.

QUESTIONS — One at a time

1. Please describe your visual problem?
2. What services do you use to assist you today? (issues – solutions)
3. What other services do you need?
4. Where do you think a service would be most accessible in your community for a project?
5. What is the main personal barrier you experience for getting service?
6. Is there other important information we need to know to develop a good service delivery for you?

We are holding another group work session on March 5, 2003. We will be working with today's information to build a potential service delivery model.

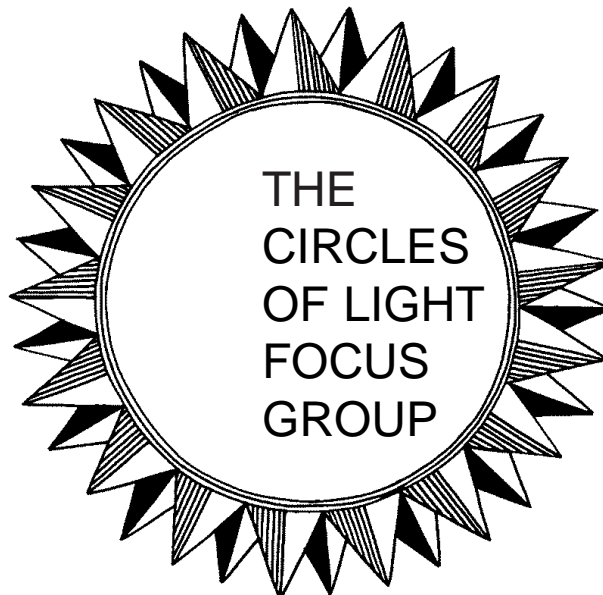
For the next session — is there anyone you believe should be invited into the process?



APPENDIX C: POSTER SAMPLES



**You are cordially invited
to attend**



The Purpose is: **To gather information about your experience as a blind or visually impaired Aboriginal person in your community.**

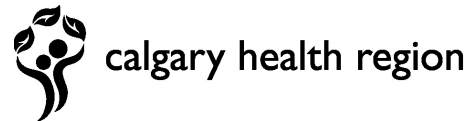
Where: **North Bay Indian Friendship Centre
980 Cassells St. North Bay, ON**

When: **Monday, 17 March 2003
10-12 am — Youth and Seniors
1-3 pm — Working Age Adults and Frontline Workers**

Lunch is provided to participants/escorts/guardians
\$50 Honorarium for participants
Minimum of 10 participants per group required.
Please call Betty Kataquapit @ 472-2811 ext 25 to register

For more information contact:
Linda Many Guns at (403) 560-5027





Canadian Red Cross



Region 3
Aboriginal Community
Health Council

Rescheduled

THE CIRCLES OF LIGHT

New dates are:

SESSION ONE

When: February 23, 2004

Time: 9:30 am – 1:00 pm

SESSION TWO

When: March 1, 2004

Time: 9:30 am – 1:00 pm

Where: McDougal Centre, 455 6 Street SW Calgary, Alberta

You are invited to participate in a focus group session if you are a blind or visually impaired Aboriginal and live in or get services in the Calgary area. One focus group is for front line service providers who work with blind or visually impaired Aboriginal people in all areas of life.

A \$50 honorarium will be paid to blind and visually impaired participants. Please call ahead to confirm your attendance and registration at 560-5027.



APPENDIX D: RESEARCH CONSENT FORM, CALGARY



CIRCLES OF LIGHT RESEARCH CONSENT FORM CALGARY, ALBERTA

We would like to ask you to take part in a focus group research study. This consent form explains the study and the interviewer will discuss the study with you, answer your questions, keep confidential any information which could identify you personally and be available during the study to deal with problems and answer questions.

Partnership: Partnership between CNIB National Office and Calgary, Alberta

Purpose of the Study: The purpose of the Circles of Light Survey and Focus Groups is to gather information about your experience as a blind or visually impaired Aboriginal person in your community. The results from this survey will form in part a National service delivery model for blind and visually impaired Aboriginal people in Canada.

Confidentiality: The research team will take all the necessary precautions to ensure that your personal information is kept confidential. Strict measures are in place to protect your personal information, the data files, and to restrict access to the data. All identifying personnel information (name, address, phone number) will be stored separately and will only be used to contact you in the future for follow-up research. General policies and procedures will be followed to ensure authorized use.

Participation in the Study: Your participation in this study is strictly voluntary. You may refuse to participate or you may withdraw from the study at any time.



Questions: Please feel free to ask the interviewer any questions that you may have. You may also contact the Calgary Native Friendship Center. If your questions or concerns are still not addressed, you can call Linda Many Guns at 403-275-0656. Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

By signing this letter, the individual gives free and informed consent to participating in this project.

Participant Signature: _____

Participant Printed Name: _____

Date: _____

Are you interested in receiving additional information regarding this study?

Yes No

If yes, are you interested in information about other studies or information about Aboriginal health issues?

Yes No

CONTACT INFORMATION:

Name _____

Address _____

Phone Number _____



APPENDIX E: DEMOGRAPHIC QUESTIONNAIRE

Linda Many Guns, B.A., LLB., M.A., Many Guns Traditional Consulting Inc.
CIRCLES OF LIGHT, Y.W.S. SURVEY, NORTH BAY, ONTARIO

A. PERSONAL BACKGROUND INFORMATION

1. Age — What is your age this year?
 1-15 15-65 65+
2. Gender
 Male Female
3. Name of First Nation or Inuit Community where you currently live.

4. In the last 12 months, what proportion of time did you spend living in this community?
 Less than one-quarter (25%) of the time
 Between one-quarter (25%) and one half (50%) of the time
 Between one half (50%) and three-quarters (75%) of the time
 All of the time
 Don't know
 Refused
5. Do any of your ancestors belong to any of the following Aboriginal groups?
 - A. North American Indian Yes No Don't Know
 - B. Metis Yes No Don't Know
 - C. Inuit Yes No Don't Know
6. Are you an Aboriginal person, that is, North American Indian, Metis or Inuit?
 Yes, North American Indian
 Yes, Metis
 Yes, Inuit
 No



7. Do you live in an Urban Area Rural Area Remote Area
8. Do you work in an Urban Area Rural Area Remote Area

B. LANGUAGE AND EMPLOYMENT

1. Do you understand or speak an Aboriginal language? Yes No
2. What Aboriginal language or languages do you speak?
-
3. Are you currently working for pay (wages, salary, self-employment)?
 Yes No Refused

C. HEALTH

1. In general, would you say your health is
 Excellent Very Good Good Fair Poor Don't Know
2. Do you have any difficulties with the following activities?
- A. Hearing Yes No
 - B. Seeing Yes No
 - C. Communicating Yes No
 - D. Walking Yes No
 - E. Climbing stairs Yes No
 - F. Bending Yes No
 - G. Learning or doing similar activities Yes No
3. Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do?
- A. At Home?
 Yes, sometimes Yes, often No
 - B. At work or at school?
 Yes, sometimes Yes, often No, not applicable
 - C. In other activities, for example, transportation or leisure
 Yes, sometimes Yes, often No



4. Have you been told by a doctor, nurse or other health care professional that you have any of the following health conditions? Only include conditions that have lasted at least six months or are expected to last at least six months. If yes, at what age were you first told (years)?

- A. Cataracts Yes No Age _____
- B. Glaucoma Yes No Age _____
- C. Effects of stroke Yes No Age _____
- D. Epilepsy Yes No Age _____
- E. Diabetes Yes No Age _____
- F. Cancer Yes No Age _____
- G. High Blood Pressure Yes No Age _____

5. Has your diabetes (all types)...

- A. Affected your vision (e.g. retinopathy)?
 Yes No Don't Know
- B. Affected your circulation other than your heart?
 Yes No Don't Know
- C. Resulted in infections?
 Yes No Don't Know

6. In the past 12 months, have you had any of the following tests or examinations?

- A. Cholesterol test Yes No Don't Know
- B. Vision/ Eye exam Yes No Don't Know
- C. Blood pressure test Yes No Don't Know
- D. Blood sugar test Yes No Don't Know
- E. Complete physical examination Yes No Don't Know

7. Is your eye related health condition the result of an injury?

- Yes No

8. In the past 12 months, have you seen or talked on the telephone to an Eye Doctor (such as an ophthalmologist or optometrist)? Yes No

9. Do you wear glasses or contact lenses to see up close? Yes No

10. Do you have any difficulty seeing ordinary newsprint?

- Yes No Don't Know



11. How much difficulty? Mark only one.
 Some difficulty A lot of difficulty
 Cannot see at all Don't know
12. With your glasses or contact lenses, do you have any difficulty seeing ordinary newsprint?
 Yes No Don't Know
13. How much difficulty? Mark only one.
 Some difficulty A lot of difficulty
 Cannot see at all Don't know
14. Do you wear glasses or contact lenses to see at a distance?
 Yes No Don't Know
15. How much difficulty? Mark only one.
 Some difficulty A lot of difficulty
 Cannot see at all Don't know
16. Do you have any difficulty clearly seeing the face of someone across a room, that is, from 4 metres or 12 feet?
 Yes No Don't Know
17. How much difficulty? Mark only one.
 Some difficulty A lot of difficulty
 Cannot see at all Don't know
18. With your glasses or contact lenses, do you have any difficulty clearly seeing the face of someone across a room, that is, from 4 metres or 12 feet?
 Yes No Don't Know
19. How much difficulty? Mark only one.
 Some difficulty A lot of difficulty
 Cannot see at all Don't know
20. Did someone interpret (translate) the questions (in whole or in part)?
 Yes No
21. If yes, who provided assistance with interpretation?
 Support Worker Family Member Other





APPENDIX F: PARTICIPANT EVALUATION FORM

An evaluation form was distributed at the end of stage three to each location. The one page evaluation form included six questions with a rating option from one to five, five being best. Two other questions ask participants first about how they heard of the workshop(s) and then by asking an open-ended question to elicit their comments for and/or against the process.

It is pertinent to qualify the evaluation process from an Aboriginal perspective. In many Aboriginal worldviews it is not culturally appropriate to ask a person to evaluate another person or to talk about another person in a negative way. This stems from the belief that in the Aboriginal community, all people are entitled to follow their paths and that we all learn from our mistakes. Our only role is to be there to support others through their learning experience. Having said that, and knowing the cultural conflict this poses, the aboriginal consultant believed it was important to collect comments and evaluations from those willing to share. She did not believe that asking for the forms to be filled out is culturally offensive if the activity is always optional and voluntary.

As result of these underlying cultural considerations, some of the participants in the group did not feel comfortable filling out an evaluation of the process.

EVALUATION RESULTS

1. Did you have adequate notice to attend?

POOR 1 2 3 4 5 BEST

2. Were the facilities accessible?

POOR 1 2 3 4 5 BEST

3. Was the presentation style appropriate?

POOR 1 2 3 4 5 BEST



4. Did you enjoy the workshop experience?
POOR 1 2 3 4 5 BEST
5. Did you say what you thought was important?
POOR 1 2 3 4 5 BEST
6. Would you attend another process like this again?
POOR 1 2 3 4 5 BEST
7. How did you hear about the Circles of Light?
(Several responses indicated multiple sources)
- Poster
 - Radio
 - Newspaper
 - Word of Mouth
 - Referred
 - NBIFC Health Outreach Worker
 - NBIFC
 - A Friend
 - Fax and by phone

Comments:

