A Study of Deaf-Blind Demographics and Services in Canada

A Report Prepared for the Canadian National Society of the Deaf-Blind

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1. Acknowledgements

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Colleen Watters, Michelle Owen and Stan Munroe
December, 2004

2. Executive Summary

A Study Of Deaf-Blind Demographics and Services in Canada represents a unique collaboration between the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). This is the first time that CNSDB (which represents the needs of those with acquired Deaf-Blindness) and CDBRA (which primarily but not exclusively meets the needs of persons with congenital Deaf-Blindness) have had the opportunity to work together to collect information about persons in Canada with this dual disability.

The project was intended to produce a report containing (1) demographic information about persons in Canada with acquired Deaf-Blindness and those who are congenitally Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates and (5) directions for future research. This complements the National Registry Project, that obtained information on 777 persons with this dual disability.

This research located some of the balance of Canadians who were not registered as Deaf-Blind during the National Registry Project conducted by the Canadian Deafblind and Rubella Association from 1999-2001. This study determined there was an estimated total of 3306 Deaf-Blind Canadians. This included persons with acquired Deaf-Blindness and those who are congenitally Deaf-Blind. It is believed this number underestimates the total Deaf-Blind population due to the difficulty in reaching individuals with this dual disability. Further research is required to locate additional members of this population and to document the needs for Intervention and other services that are currently not being met. The information gathered adds to the current registry database, identifies and evaluates existing services that are available and accessible to persons who are Deaf-Blind and provides important quality of life data about the personal stories of the barriers and successes experienced by this population, their service needs and recommendations for additional services. It enhances significantly already published data on Deaf-Blindness in Canada. This project provides up-to-date and relevant information that will be maintained and continually updated by the Canadian Deaf-Blind Council (a joint body composed of the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association.)

To complement the demographic information gathered during the course of the research, ten focus groups were convened across the country to collect quality of life data from persons who are Deaf-Blind and parents/advocates. During these sessions, consumers and parents/advocates overwhelmingly recommended that federal and provincial governments provide increased funding for comprehensive Intervention services for persons who are Deaf-Blind to facilitate their access to community services and daily living. Those communities, that do not currently have Intervention programs, should put these initiatives into place. In addition, there is a need to decrease waiting times for services and to provide emergency pools of Intervenors for evening and weekend times (this applies to children, families and adults who regularly receive Intervention services during the day), medical and other emergencies and vacations. Federal and provincial governments should increase funding for Intervention training programs to enhance the numbers of trained professionals working with those who are Deaf-Blind.

Consumers and parents/advocates pointed to the need for the implementation of public awareness programs to highlight the needs and capabilities of persons who are Deaf-Blind and to reduce the misconceptions among governments, the service sector and the general public about the uniqueness of this dual disability. In addition, respondents who are Deaf-Blind and parents/advocates identified the need for federal and provincial governments to implement assistive devices programs for those not currently involved in education or work, to increase the quality of life for persons who are Deaf-Blind. This would provide increased access to information, offer opportunities for enhanced communication through email and assist consumers to improve writing skills. Parents and consumers alike also expressed the need for increased information about assistive devices and the availability of training in the use of this type of technology.

It is the responsibility of professionals, service organizations and the provincial and federal governments to implement the recommendations outlined in this report and to provide the additional services which are desperately needed by Canadians who are Deaf-Blind.

Introduction

For many years, people who are Deaf-Blind and their families, advocacy and service organizations and professionals have recognized the necessity of developing a better understanding of the numbers of persons in Canada who are Deaf-Blind.

Historically, organizations designed to meet the needs of persons who are blind and associations serving individuals who are deaf have been unable to respond to the needs of Canadians with this dual sensory loss.

In the 1980s, a special task force (The Task Force on Services to Deaf-Blind Persons in Canada) was appointed by the Federal Government to report on service needs for persons who are Deaf-Blind in this country. In 1984, the task force tabled its report to the Federal Advisory Committee on Services to Deaf-Blind Persons in Canada. This document was entitled: 'Task Force On Services to Deaf-Blind Persons in Canada in 1984'. Recommendation Number 21 of that report stated "only through accurate statistical data on Deaf-Blindness and Deaf-Blind persons in Canada can appropriate services be planned and delivered." Until recently, nothing concrete developed from these recommendations.

The Canadian National Institute for the Blind (Deaf-Blind Services) attempted to develop a Registry to meet the task force recommendations, but found it necessary to abandon its efforts for financial reasons. With this background, the Canadian Deafblind and Rubella Association (CDBRA) undertook a project to establish a National Registry of Canadians who are Deafblind, funded by Human Resources Development Canada.

A total of 777 persons who indicated they had Deaf-Blindness volunteered for the National Registry Project during the period 1999-2001. The report suggested that this number represented 10-15% of the total Canadian population of persons with this disability.

The Canadian National Society of the Deaf-Blind (CNSDB) (a consumer advocacy organization representing Canadians who are Deaf-Blind) believed it was extremely important to better determine the total population and geographic distribution of persons with Deaf-Blindness within Canada. Furthermore, they wanted to ascertain the numbers with acquired Deaf-Blindness, with a particular focus on the senior population because of the increasing number of individuals who are aging. It is believed that the Registry project was significantly over-represented by persons with congenital Deaf-Blindness and underrepresented those with acquired Deaf-Blindness. Verifying the existence and geographic location of these individuals would provide a more valid description of the status of the Deaf-Blind population in Canada. This would greatly assist service organizations, governments and community groups that provide or advocate for services and supports to meet the needs of this population.

With this in mind, the CNSDB joined with the Canadian Deafblind and Rubella Association (CDBRA), to undertake the Deaf-Blind Demographics and Services in Canada Project. Funding was obtained from The Social Development Partnerships Program, Human Resources Development Canada (now Social Development Canada). The Canadian Centre on Disability Studies (CCDS) (a research and education organization located in Winnipeg, Manitoba) was contracted by the sponsoring organizations to coordinate the research portion of the project.

A Study Of Deaf-Blind Demographics and Services in Canada was intended to produce a report containing (1) demographic information about persons in Canada with acquired Deaf-Blindness and those who are congenitally Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates and (5) directions for future research. This complements the National Registry Project that obtained information on 777 persons with this dual disability.

This research located some of the balance of Canadians who were not registered as Deaf-Blind during the National Registry Project. The study found an estimated total of 3306 Canadians who are Deaf-Blind. This includes persons with acquired Deaf-Blindness and those who are congenitally Deaf-Blind. It is believed this number underestimates the total Deaf-Blind population due to the difficulty in reaching individuals with this dual disability. The information gathered adds to the current registry database, identifies and evaluates existing services that are available and accessible to persons who are Deaf-Blind and provides important quality of life data about the personal stories of the barriers and successes experienced by this population, their service needs and recommendations for additional services. It enhances significantly already published data on Deaf-Blindness in Canada. This project provides up-to-date and relevant information that will be maintained and continually updated by the Canadian Deaf-Blind Council (a joint body composed of the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association).

3.1 Project Overview

This report presents the findings of "A Study of Deaf-Blind Demographics and Services in Canada" that was designed to collect (1) demographic information about persons in Canada with acquired Deaf-Blindness and those who are congenitally Deaf-Blind; (2) data about the service needs of persons who are Deaf-Blind and their parents/advocates; (3) information about the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) documentation of the existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates and (5) recommendations and directions for future research. This initiative began in June 2003 and concluded in November 2004.

4. Project Implementation

A Management Committee was established to have overall day to day responsibility for project administration and the preparation of reports to funders. The Presidents of the CNSDB and CDBRA constituted the Management Committee.

The Management Committee hired a Project Coordinator and contracted the services of the Canadian Centre on Disability Studies (CCDS) to undertake the research component of the project.

An Advisory Committee was appointed by the Management Committee to provide overall guidance and direction to project staff, play a central role in the formulation of the research plan and evaluate data collection instruments, offer feedback on project expenditures and draft reports and make recommendations regarding the hiring of research assistants. Members of the Advisory Committee included the two members of the Management Committee and one representative each from CNSDB and the Independent Interpreter Referral Service.

A project team assumed overall responsibility for the implementation of activities. This team consisted of the Advisory committee, Project Coordinator and the Principal Investigator and Research Coordinator from CCDS.

Field research implementation was conducted by two types of Research Assistants: Focus Group Leaders who were hired to facilitate Focus Groups in selected communities and Demographic Research assistants to carry out the demographic research in broad geographic locations.

Where available, the Advisory Committee wished to select qualified persons with Deaf-Blindness as research assistants. Experience working in the Deaf-Blind community was advertised as an asset to applicants for these positions. Consequently, five of the research assistants were Deaf-Blind, one individual was Deaf and the remaining eight had extensive experience working in the Deaf-Blind community.

5. Media Campaign

In addition to the research portion of the project (which will be discussed below), a media campaign was conducted to raise awareness of Deaf-Blindness across Canada and to reach persons who are Deaf-Blind and their families interested in participating in the study and joining the national volunteer registry of persons who are Deaf-Blind. The registry began in 1999 with the launch of CDBRA's National Registry Project and continues as of this writing.

Advance Planning MS&L (a media company located in Toronto, Ontario) was hired to conduct this campaign. They were selected because of their experience coordinating a similar campaign for the 13th Deafblind International World Conference on Deafblindness (DbI) held in Mississauga, Ontario in August, 2003. Only one newspaper article related to Deaf-Blindness appeared in the media. On April 2, 2004, an article was published in "the Globe and Mail" Newspaper (Page A10). A piece entitled “It sucks, but You Realize Life Goes On" was written by Anthony Reinhart and related the story of Megan McHugh, a Deaf-Blind woman living in Oshawa, Ontario.

Lisa Bendall, Managing Editor of Abilities Magazine (Canadian Abilities Foundation) included a profile of the demographic study in the FYI (For Your Information) section of the summer issue. (Abilities Magazine, Summer, 2004, p. 7.)

A 60 second spot and a B-Roll were also produced for airing on television stations across the country. These were designed to raise the profile of Deaf-Blindness and draw attention to the major study findings. The 60-second spot and the B-Roll preceded the launching of a full-scale media campaign to disseminate the findings.

A toll-free number was set up to deal with calls resulting from the media outreach and to respond to inquiries from persons who are Deaf-Blind and their families interested in the project or the volunteer registry.

6. Overview of Research Methodology

The advisory committee formulated the research plan (see below) and agreed to use the definition of Deaf-Blindness developed by the Resource Centre for Manitobans Who Are Deaf-Blind.

Between July and December, 2003, activities were devoted to the development of the project research plan, the formulation and revision of data collection instruments and research assistant training guidelines, the formulation of research assistant job descriptions and hiring and contracting with 16 research assistants who would convene focus groups and gather demographic information. Once data collection instruments were developed and approved by the Principal Investigator and Advisory Committee, the project underwent a successful ethical review through CCDS.

In January 2004, the research coordinator provided training to research assistants. The original plan was to convene two half-day training sessions (one for focus group research assistants and the other for demographic research assistants), both of which would be conducted by conference call. Due to the difficulties of accommodating the schedules of research assistants and the complex communication needs of those who are Deaf-Blind and who indicated they would prefer to do training via e-mail, the original training plan was revised. The research coordinator conducted training sessions using a combination of conference calls, telephone appointments with individual research assistants and e-mail communication. Training was also provided to one research assistant who is Deaf via TTY.

Data collection activities began in February 2004 and concluded in July 2004. The remainder of the project was devoted to analyzing the information collected, the preparation of this report and dissemination of the study findings.

6.1 Definition of "Deaf-Blindness"

In this study, Deaf-Blindness was defined as "a condition, that combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information; even though Deaf-Blind persons may still have varying levels of useful vision and hearing".

6.2 Overview of Data Collection Methods

The project focused primarily on the demographic research and, in particular, on locating those with acquired Deaf-Blindness and seniors not identified through the 1999-2001 CDBRA National Registry Project. The Advisory Committee also believed it was important to acquaint provincial and federal governments, and community groups with the extent of Deaf-Blindness across the country, and an estimate of the numbers of persons who are Deaf-Blind in the population. This would provide a more realistic portrayal of persons with this dual disability and the nature of the service needs of these individuals.

The research methodology included three components: (1) Focus Groups; (2) The gathering of demographic data and (3) Service provider interviews.

The CCDS research team was responsible for carrying out the focus groups, gathering the demographic data and for data analysis. The service provider component of the study was undertaken by representatives from the sponsoring organizations (CNSDB and CDBRA). Throughout the project, the research coordinator provided ongoing supervision and guidance to the 14 research assistants conducting the focus groups and gathering the demographic data.

6.3 Focus Group Meetings

Focus Group meetings for persons who are Deaf-Blind were carried out in Vancouver (British Columbia), Calgary (Alberta), Winnipeg (Manitoba), Sudbury (Ontario), London (Ontario) and Halifax (Nova Scotia). One was originally slated for Montreal (Quebec), but the majority of consumers in Montreal stated they preferred to meet with the research assistant individually rather than participating in a focus group. Thus, data was gathered through individual interviews.

Focus Group sessions for parents/advocates of individuals who are congenitally Deaf-Blind took place in Calgary and Toronto. As above, a focus group meeting for parents/advocates was scheduled for Montreal. However, the research assistant in Montreal experienced difficulties recruiting participants because of ethical issues. Several of the organizations through which the researcher planned to locate parents requested that the project undergo an internal ethics review through their associations in addition to the CCDS ethical review. Because of the time required for these internal reviews, it was not possible to convene a focus group for parents/advocates. Thus, individual interviews with parents/advocates were conducted.

The purpose of the focus groups and individual interviews was to obtain qualitative information about Deaf-Blindness through documenting personal stories of the barriers and successes experienced by persons who are Deaf-Blind and parents/advocates. In addition, information was gathered about: the service needs of persons who are Deaf-Blind and parents/advocates, recommendations for improved services and an overview of the communication devices utilized by those who are Deaf-Blind.

Each focus group accommodated up to eight participants, and was intended to encourage openness and sharing. The focus group and interview data complemented the quantitative information from the demographic research portion of the study.

6.4 Collecting Demographic Information

Research assistants collected demographic information in the following locations: British Columbia / Yukon, Alberta/Nunavut and the Northwest Territories, Saskatchewan, Manitoba, Northwestern Ontario, Southern Ontario, Quebec and the Atlantic Provinces. For the purposes of this study, the north/south boundary of Ontario was an east-west line from the Ottawa River on the east to Sudbury on the west.

These researchers gathered information on the numbers and location of persons who are Deaf-Blind, along with additional pertinent demographic data including age categories, probable causes of the disability and living arrangements. The demographic information was obtained primarily through telephone and e-mail interviews with administrators or directors of community organizations, disability groups that serve people who are Deaf and/or blind, Deaf-Blind individuals, seniors residences, seniors resource centres in the community, personal care homes and personal care home associations, regional health authorities and medical associations. Other sources of contact included: government departments, directors of disability services offices at universities and colleges, etc. (See the section on demographic research for more details).

6.5 Service Provider Interviews

Service providers for persons with Deaf-Blindness across Canada were contacted by representatives of CNSDB and CDBRA to document types and quantity of services provided, service needs, service expansion plans, staff training and service gaps.

6.6 Data Analysis and Dissemination

The individual reports from the focus group leaders and demographic research assistants were analyzed for this report. These reports are summarized in Appendix F. The final project report was disseminated to agencies and organizations across Canada serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. In addition, the final report will be posted on the websites of the partner organizations, CNSDB and CDBRA and eventually on the website of the Canadian Deaf-Blind Council (CDBC) when this site is developed. The URL for the CNSDB site is: http://www.cnsdb.ca and the URL for the CDBRA site is http://www.cdbra.ca.

6.7 Outcomes of the Research

Persons who are Deaf-Blind and their families will be made aware of available services and resources within their provinces and communities. Service providers will gain information about the extent of the Deaf-Blind community within their jurisdictions and about resource material available from the Canadian Deaf-Blind Council (CDBC). The CDBC is composed of the CNSDB and CDBRA.

Provincial and territorial governments and their agencies will benefit from having an up-to-date survey of the Deaf-Blind population and the services available to these residents. This will help them determine if the existing services are sufficient, in quality and quantity, to meet the needs of the Deaf-Blind population.

7. Presentation of Research Findings

Some of the data collected were quantitative (the tables and charts containing information on the numbers of persons in Canada who are Deaf-Blind) while other data were qualitative (e.g. results from focus groups/interviews and some of the demographic material). Findings from focus groups and individual interviews are presented with the following indications of numbers or prevalence of responses:

"A few" equals two to five participants;
"many" equals more than five participants;
"most" equals more than half, i.e. the majority of the participants;
"all" equals all participants.

7.1 Findings from Focus Groups and Individual Interviews

In the following sections, the findings from focus groups and individual interviews with persons who are Deaf-Blind and parents/advocates will be presented. Results of the focus groups and interviews with consumers and those with parents/advocates are analyzed separately, following which the major themes from each set of focus groups are compared and contrasted to draw out similarities and differences in the major findings between the two groups of respondents.

7.1.1 Findings From Focus Groups and Individual Interviews with Persons Who Are Deaf-Blind

Focus groups for persons who are Deaf-Blind took place in Vancouver, British Columbia; Calgary, Alberta; Winnipeg, Manitoba; Sudbury, Ontario; London, Ontario and Halifax, Nova Scotia. Intervenors and Sign Language Interpreters were present to provide assistance to the 44 consumers who participated. Computerized note taking and materials in Braille and large print were also available for participants requesting those accommodations. Individual interviews were carried out with six respondents in Montreal using LSQ (Langue Des Signes Quebecoise) i.e. sign language for those who speak French. In total, 44 consumers (29 females and 15 males) ranging in age from their mid-20s to 75 years and over were involved in the focus groups and interviews. The majority (42) had acquired Deaf-Blindness while two were congenitally Deaf-Blind.

During a focus group meeting, consumers were asked about their feelings when they first found out (either when they were young or later in their lives) that they were Deaf-Blind, what they did on a "typical day", how easy or difficult it was to access services in the community, their opinions about the gaps in services to persons who are Deaf-Blind and recommendations for service improvements. They were also asked what assistive devices they utilized to facilitate communication.

7.1.2 How Participants Felt When They First Found Out They Were Deaf-Blind

Participants experienced a variety of feelings when they first found out (either when they were young or later in their lives) that they were Deaf-Blind. For those individuals who experienced hearing loss at a younger age and lost their vision gradually, adjustment to the hearing loss was easier than becoming accustomed to a decrease in their vision. For those whose hearing and vision decreased more rapidly, adjustment to the loss of these dual senses was quite difficult.

Loss of independence was a common thread among all participants. This decrease in independence was accompanied by feelings of loneliness, isolation, depression and emotional struggles. Feelings of sadness, anger, frustration, disappointment and a sense of failure were also expressed. Three individuals talked about being suicidal. One person stated: "Being Deaf is hard enough to cope with. But becoming blind at the same time! I just couldn't live with that. How could I live when I couldn't see what was going on. If I had my choice, I would rather be Deaf."

With respect to the loss of independence, one individual noted: "I didn't like the idea of being dependent on anybody, because like I said I lost it at forty years of age and I was always independent. For somebody as myself who always worked with people with disabilities, it really struck home how bad it was." A respondent who also had a rare disease as a child in addition to her Deaf-Blindness indicated she was teased by other children which increased her feelings of loneliness and isolation during her high school years.

Another prominent theme related to the mobility restrictions experienced by consumers at the point when they were losing their vision. One person explained: "I started to lose some of my peripheral vision and found my mobility was very restricted, I was falling over things all the time, and that's how I sort of really became aware that I had a problem other than my hearing loss; it was more the physical problems that presented themselves, anything below my waist that I couldn't see I would be tripping over, so that's probably something, environmental things that you guys all experience because of the vision loss."

Individuals also described difficulties communicating with those who were not in their immediate social circle as well as challenges conversing with family and friends. One person stated: "One of the disadvantages of having this disability is that you are isolated, (I don't) have many friends because there is immediately a group of people only that can communicate with you." Another individual commented: “When I did become blind, I was extremely frustrated. Communication was hard, to say the least, with my family. I suffered through it, and I stuck in there. We made our way through. I had friends and family coming over that helped me. I learned signs and they learned signs as well. That's now how we communicate."

Many participants with acquired Deaf-Blindness outlined the excellent support they received from the Canadian National Institute for the Blind (CNIB), CNSDB and other service and consumer organizations. However, some respondents indicated they received insufficient support, and others wished that counselors or medical professionals had referred them to appropriate services and supports when they first became Deaf-Blind. They possessed insufficient information about the capabilities of people who are Deaf-Blind or existing services, communication devices, etc. They also noted the lack of available emotional support to assist them in dealing with such a "monumental" change in their lives.

One individual explained: "I was hard of hearing at birth and made an appointment with an optometrist to have my eyes tested, only to discover that my field vision had diminished by 10 degrees. I knew that I had a sight problem before this examination, but had hoped that an operation would improve my vision. I was quite upset to find out that my condition was more serious than I had thought and that I would probably be blind by the age of sixty. Not only did I leave the clinic in a state of shock, but I was also totally devastated, as I had no idea of the services available to Deaf-Blind people." Another person stated: "The change is monumental, nothing is the same afterwards, and you're left with all these feelings and can't sort them out on your own."

A few interviewees expressed disappointment at the loss of current jobs or future employment opportunities. As one consumer put it: "I was devastated. I had to quit my job. I had a view that I was not going to be able to do anything or see anything, and I still once and awhile have that pain." Another person noted: "I am getting disappointed because I don't think I have much opportunity for jobs because usually everything for blind people involves hearing something. How do I feel? I feel disappointed and pretty much like I would like to have a cochlear implant (see definition in Appendix A) or something."

A few participants mentioned the negative societal attitudes they experienced as a consequence of their Deaf-Blindness. One respondent stated how disappointed he was when people looked at him and saw the disability rather than the person.

A few interviewees who were congenitally Deaf-Blind found it difficult to identify their feelings since being Deaf-Blind was all they had ever known. One person indicated that he felt distinctly different and he had the feeling that others did not understand his reality. Another noted that, as a child, she did not put much thought into how she felt about it, stating that she assumed everyone was the same. It wasn't until later in life that she realized the limitations of her disability and by then she had already accepted it.

Several consumers described their changes in attitude as they came to terms with their disabilities: "After two years I sat back and said to myself, what am I doing to myself and why am I doing it to my family. So I just got up one day and I said to my wife, that's it, I said no more sitting down and feeling sorry for myself, I said from now on I'm going to do everything within the means of my limitations that I have." Another participant said: "All I can say from my perspective is just to take one day at a time. It will be worth it".

7.1.3 What Persons Who Are Deaf-Blind Do On A Typical Day

Consumers provided a list of the activities in which they were involved on a regular basis. In some ways, these pursuits were no different from what people without disabilities did. However, several factors influenced the degree to which individuals who are Deaf-Blind experienced “a typical day". Those who possessed sufficient sight and vision to live independently tended to be involved in more activities than those who were less independent. Those who had access to the support of Intervenors (see definition in Appendix A) participated in a greater number of activities as a result. In addition, consumers who were employed, attended college or university or were involved in volunteer pursuits had a greater degree of routine in their day.

Individuals were involved in a wide range of activities. Examples included: managing medications, doing things around the house, i.e. cooking, cleaning, laundry, taking care of children and family, crafts, yard work, home repairs, working on the computer, volunteer work of various kinds, going to exercise or fitness classes, going shopping, going for walks, going to church, reading, watching TV, listening to music, visiting friends, entertaining company, playing cards, fishing, boating, crossword puzzles, involvement in part time work such as working as an Intervenor or for a literacy program, attending college, looking for employment, etc.

A few participants stated they required assistance from home care or support workers due to the nature of their disabilities (they had physical disabilities in addition to their Deaf-Blindness). One participant expressed frustration that workers from home care services did not know American Sign Language (ASL), and thus had difficulty communicating.

The report of one focus group summed up the feelings of many individuals regarding "a typical day". "There is no typical day for any one of these consumers. Their week is full of a variety of activities, some done independently, and some, which require an Intervenor to fulfill. It is clear that in order to participate many community activities; they can only do so with the involvement of an Intervenor."

7.1.4 How Easy or Difficult Is It for Persons Who are Deaf-Blind to Access Services in the Community

Without exception, all focus group participants indicated the major obstacle to accessing services in the community related to the unavailability of sufficient Intervention services. The amount, quality and quantity of services varied from province to province. In British Columbia, for example, focus group participants stated that persons who are Deaf-Blind in their province have no access to Intervention services unless they are involved in education or work activities. Focus group respondents in Halifax noted that only a few Deaf-Blind persons could receive Intervention services, while in Sudbury, there was only one Intervenor to serve the population of Deaf-Blind people in the metropolitan community and surrounding areas. In other locations, participants could only obtain Intervention services for a few hours per week and many individuals talked of long waiting lists for services. In group or supervised facilities where those who are Deaf-Blind reside, individuals have greater access to Intervention services than those Deaf-Blind persons who live on their own in apartments. The quality of services also varied from province to province which, at least in part, can be explained by the quality and quantity of Intervenor and Interpreter training programs.

Some provinces such as Manitoba, have training programs for both Intervenors and Interpreters. Interpreters have opportunities to train as Intervenors if they wish to do so. In other places, Intervenor training is offered by more senior Intervenors. In some provinces (Ontario and British Columbia) Community Colleges provide Intervenor and Interpreter training programs.

Participants described the necessity to depend on friends and family to provide Intervention services when paid or volunteer Intervenors were unavailable. Some were afraid they would wear their relationships with friends and family too thin as a result of needing to depend upon them. One person said: "Our needs are endless, you feel you're constantly asking someone for help and you wonder when they'll start distancing themselves from you and your problems". A few respondents raised the concern that aging family members who had previously offered assistance when Intervenors were unavailable could no longer do so due to failing health. One person mentioned the difficulties that arose when well meaning family members attempted to make decisions for her.

A few participants found it more difficult to undertake home-based activities such as cooking or reading because Intervenors were not always available to assist with these pursuits. Respondents described the difficulties becoming involved in community activities without the assistance of Intervenors. Such activities included taking walks, going shopping or to the bank, doing volunteer work, attending recreation programs or social events, etc. According to one person: “When I have an Intervenor ... I can go grocery shopping. I get along better and faster. I know what is going on around me. I get information and I feel engaged in the world. Having an Intervenor makes me feel fresh, healthy and stimulated." Another person pointed out: "I'm always staying at home. Sometimes I go for coffee. I want to go out shopping... I can't go because the Intervenors are always very busy. I can only go when their schedule is available. That means, I have to put off what I want to do to match the schedule of the Intervenors."

With respect to attending social events, one consumer stated: "Socializing at night can be difficult. If you want to go out at night to a bar for example and then you have to take a cab or bus home at 2:00 in the morning - it is difficult. Buses stop running, and how do you communicate with a cab driver?"

Getting to doctors' appointments and, once there, communicating with medical professionals presented major obstacles. As one individual explained: "If I want to go to the doctor, if I can't get there by myself, ... that's the first thing. The second thing is when I'm there I can't understand what the doctors tell me. So transportation and Intervention, these are two of the biggest barriers to accessing community services."

From the above discussion, it is clear that those who are Deaf-Blind find it easier to access community services with the support of Intervenors and that, when those services are absent or in short supply, participating in daily activities becomes increasingly difficult and often impossible.

The need for an emergency pool of Intervenors to work on a casual or on-call basis in the evenings and on weekends or when regular service providers are on vacation was also cited. Such a pool would be useful in situations where individuals encountered medical or family emergencies. This applies particularly to children, families and adults who regularly receive Intervention services during the day. In a few locations, participants mentioned the availability of emergency services, but this was not the case in all provinces.

When out in the community, challenges arise when service providers at banks, stores, restaurants and other public facilities do not speak clearly or take the additional time to understand the needs of consumers who are Deaf-Blind. One participant stated she was embarrassed to ask individuals to constantly repeat themselves and feared that people would get frustrated with her or form opinions about her cognitive abilities. Another consumer tries to sit or stand in a corner to be able to see the service provider's face and to read their lips. Lighting in public facilities is often poor that makes lip reading or using sign language more difficult. In particular, consumers in one focus group emphasized the invisibility of the hearing loss. One consumer said: "Half of my disability you can't see, its invisible. They can see that I'm a blind person but they can't see that I'm a Deaf person. They can only see the vision loss, they can't see the hearing loss, ...so they take for granted that I can hear fine. Sometimes I don't wear a hearing aid, or maybe perhaps you have your hair down over your hearing aid, so you go to the grocery checkout and somebody talks to you and you say pardon me, pardon me, and they're thinking, what's wrong with you? A lot of times with hearing loss comes the perception that there's a cognitive loss, that you're not smart, and its not that you're not smart, you're not being ignorant, you simply can't hear, and without clear communication, we all can appear that way."

A participant in this same focus group indicated he was disappointed with the support from government and social service agencies. He felt that when he dealt with these organizations he could hear the lack of respect for him in the voices of the very people who were employed to assist him. He commented: "I find that in a lot of cases (name of organizations)...are mandated to assist the visually impaired and people with hearing loss, (representatives from service organizations have good vision and good hearing) and when you go in there a lot of times you are treated with the utmost disrespect. They don't come out and say it verbally, but you can tell by the tone of their voice or their actions... You don't just see it at (name of organization), you can see it all across the city."

Another major communication difficulty related to accessing information via the telephone. Participants relayed how frustrating it was to get answering machines. It was difficult for many of them to hear people's voices on the telephone but almost impossible to make out mechanical sounding voices on answering machines or automated services. One participant talked about a new service from her pharmacy of ordering your prescriptions over the phone. However, when she tried to use the service, she never got past the automated instructions. She stated: "I phone the pharmacy to get medicine and I get a machine with a mechanical voice, can't understand it, so that's a problem for me." A consumer described difficulties obtaining information from government services: "I have a problem, I phone the government, I get a machine, I can't understand the words on the machine, there's a barrier for me to get the information."

Other respondents described problems with telephone relay services including poorly trained staff and difficulties dialing the phone or looking up telephone numbers. Several people identified a possible solution to some of the phone-related problems. A consumer who can speak can call the operator, explain his situation and ask for a "special call". The operator should then dial and connect the individual to his party at no extra charge. Another solution is to call 411 or zero, which can be accessed as a visually impaired person at no charge. The operator will look up telephone numbers in the directory and dial these numbers if requested to do so. Respondents also mentioned the lack of TTYs in some public facilities such as hotels, restaurants, banks, stores, medical clinics, government offices, etc. In some cases, service organizations have TTYs, but these devices are not used on a regular basis.

Utilizing public transportation proved difficult for many consumers because of their limited vision and hearing, and these individuals felt safer traveling with Intervenors. These respondents also mentioned that signs are too high or written in print that is too small to be easily read and bus schedules are not provided in alternate formats e.g. Braille or large print. Focus group participants in a city where there is a subway system noted the absence of Braille labels on entrance doors, walls, platforms, stairs, escalators and elevators and that lighting was poor. It is possible for individuals to become lost in these locations, thus necessitating the need to seek directions from passers-by who do not know sign language or other communication methods utilized by those who are Deaf-Blind e.g. sign language, hand over hand communication, etc. Using the public bus system also presented challenges for consumers in the same focus group because drivers are not familiar with communication methods needed to converse with those who are Deaf-Blind.

Many participants outlined problems with specialized transportation systems for those with disabilities. These included: the use of complicated booking systems that could only be accessed via telephone, scheduling difficulties, not being able to book rides late at night, long waiting times and problems in transferring in and out of vehicles. Staff of these services had access to TTYs, but, in some cases, these devices were not utilized. Comments from several individuals illustrate these challenges. "The only problem I have is with (name of city's) specialized transportation system for persons with disabilities. If they are available, it’s wonderful. I have a loading zone right in front of my house so they can come and get me very easily and bring me home. Sometimes, you're turned down. They don't always give you a ride. The only way I feel this could be helped is if the city gives them more funding. That's sort of out of our hands."

Another user of this same transportation system stated: "I have a TTY. They have one, as well, but they don't use it. My frustration with that service is that I can't understand their voices through the regular phone when I book a ride. I wish that they would use their TTY, as it would make things much clearer for me ... In cases where people with an accent are answering their phones, I have had encounters with misunderstandings as a result." In addition, drivers have insufficient knowledge of the needs of persons who are Deaf-Blind. This included not knowing sighted guide techniques. One person mentioned that she had been abused by the driver of a specialized transportation service.

In terms of traveling independently, some consumers experienced limitations because of the absence of Intervenors to provide orientation, guidance and Intervention services. One participant (who required the assistance of an Intervenor when traveling) said: "If I ever want to travel, I can't travel by myself because I need someone to be with me and tell me what is going on because I don't like the way so-called normal people treat me. They tend to yell at me because I can't hear or treat me like a kid because they think I am mentally handicapped (which I am not). I would rather be with an Intervenor or someone who knows I am a real person."

The physical inaccessibility of public buildings and facilities was also identified as a stumbling block to accessing services in the community for persons who are Deaf-Blind. This included poorly lit areas and building features such as elevators, doors, stairs, etc. that were not labeled in Braille or large print. Room numbers on doors were inaccessible and some signage was located too high to be easily seen. This made it more difficult for consumers to obtain needed information about the surrounding environment. As a related issue, information about available services was not always provided in accessible formats such as Braille, large print or computer disk. Utility bills and restaurant menus should also be available in Braille or large print.

Several participants indicated that medical professionals and other service providers did not understand the role of the Intervenor in facilitating communication with people who are Deaf-Blind. One person noted this was the case with one of his health care professionals. He explained: "My vision and hearing are not always the same, so sometimes I show up to a doctor's appointment and I can hear the doctor fine, the next time I go I've got maybe an infection or something I can't hear a thing, so the doctor doesn't understand the disability, doesn't understand why sometimes I seem to need an Intervenor and sometimes I don't, so there's an education gap in the community." Another consumer stated: "A lot of times when people such as ourselves go in to see the professional people as doctors or ophthalmologists, ... ninety percent of the time if you have somebody with you and if you can see or if you can hear what he is saying, instead of that doctor or nurse ... talking to you directly, they're always talking to the person that came with you. I always tell the doctor, don't talk to my wife, she's not the one with the illness."

The professionals who are employed by organizations providing Intervention and/or Interpreters for people who are Deaf-Blind are guided by codes of ethics or confidentiality requiring employees to keep client-related matters confidential. One focus group member related an incident where an Interpreter violated this code. The consumer had a hearing loss and was also losing his vision. His eye doctor did not mention the impending vision loss but the Interpreter did so. The very unprofessional attitude of this interpreter left a devastating effect on the person who was Deaf-Blind.

Only a few participants were employed full or part time, and employment services were identified as difficult to access. Consumers stated they felt employment counselors were aware of the needs of those who were blind or Deaf but possessed limited knowledge of the concerns of people who are Deaf-Blind. One person said: "Employment counselors are lousy. They give you ideas but don't follow up with support." Another individual explained: "I am getting disappointed because I don't think I have much opportunity for jobs because usually everything for blind people involves hearing something." The lack of Intervention funding and an insufficient number of Intervenors also made it difficult for those who are Deaf-Blind to obtain employment. Participants in one focus group stated they felt it was more costly to accommodate the needs of Deaf-Blind people in the workplace. A few members of this group noted they preferred not to be labeled as Deaf-Blind because "they could still use their remaining vision and wish to avoid any discrimination on the part of employers who were unfamiliar with Deaf-Blindness.”

These same consumers expressed concern about the lack of training opportunities in their province to provide work experience to those who are Deaf-Blind. They also believed that some people who are Deaf-Blind become self-employed not by choice but because they are unable to secure employment in the competitive labour market. Group members felt that an income subsidy should be provided to those who embark on self-employment.

Respondents in all focus groups and individual interviews overwhelmingly indicated that accessing services in the community is made more difficult because members of the general public do not understand the needs of those who are Deaf-Blind, ways of communicating with these consumers or the vital roles Intervenors play in facilitating communication. One participant mentioned that service personnel tried to communicate with him using written notes. While this method is feasible with someone who is Deaf, it does not work with a person who is Deaf-Blind because the notes are written in print that is too small to be easily read. The situation is further compounded because the consumer cannot explain to the service provider why he cannot read the notes. This could communicate the mistaken impression that the Deaf-Blind individual is illiterate. Misunderstandings occur because some people who are Deaf-Blind do not have good

English skills and have difficulty expressing themselves in writing. Intervenors are required to facilitate communication. Access to information would also improve if materials were made available in large print, computer disk, Braille, etc.

Members in one focus group described the gaps in public education and sensitivity training to employers, medical professionals, service providing agencies and the general public. One individual stated: "I don't think the public or the service providers know enough about the problems of people who are Deaf-Blind. I think they all need to be educated as to how they can help us. More workshops are necessary." Another interviewee also shared this view: "There should be lots of education to the public so that they know we exist because most of them don't realize this.”

7.1.5 Participant Opinions About Community Service Limitations

Not surprisingly, difficulties accessing services in the community were also identified as service gaps or limitations. Participants reiterated the points discussed above concerning: the shortage of well-trained Intervenors and the lack of Intervention programs, difficulties communicating with service providers and the general public, problems with public and specialized transportation services, and the accessibility of buildings and facilities. Again, these were emphasized as services that required improvement. Consumers also described the inadequacy of awareness programs in the community to enable members of the general public to learn about the needs of those who are Deaf-Blind. If public education activities were increased, this would alleviate some of the frustrations experienced by citizens who are Deaf-Blind in accessing community programs.

Members of one focus group noted that there is little information provided in accessible formats about services and activities in the community. Accessing information via the telephone was re-emphasized as a service gap, and consumers reiterated the needs for more effective employment and counseling services to people who are Deaf-Blind.

Many individuals mentioned the excellent support received from disability organizations such as the CNIB and groups like CNSDB and CDBRA. However, others were more critical of the supports provided to individuals who are Deaf-Blind. Members of one focus group noted the insufficient numbers of orientation and mobility specialists to work with those who are Deaf-Blind. These specialists should be available for consultation about personal travel. Several participants noted that orientation and mobility personnel are rarely consulted when designing the layout or during the construction of public buildings. Other consumers mentioned the inadequacy of training in alternate communication methods (such as ASL or various forms of manual communication) and that there was a need for additional case management and support services. A number of participants suggested the development of separate organizations to provide a range of supports and services to consumers who are Deaf-Blind including the provision of Intervention programs.

Members of three focus groups indicated that their provinces did not currently operate assistive devices programs for those consumers who are not participating in the workforce or attending school. This makes it difficult for individuals not involved in these pursuits to access technology to enhance the quality of their lives through the increased ability to obtain information, handle correspondence or communicate with the outside world via the internet. For those people who already have technology, there is a lack of financial support for technological upgrades in many provinces. One participant said: "There is a huge list of devices I would like to have, but we don't have an assistive devices program." Consumers in one focus group mentioned that video cameras with LCD displays should be provided to individuals who are Deaf-Blind and who could effectively use the cameras to understand ASL interpretation rather than needing to rely on individualized Intervention services.

Participants in one focus group noted a desire to live in accessible housing close to community services such as public transportation. These individuals felt that this would decrease the isolation they experienced as a consequence of needing to depend on others to drive them to community activities such as recreation programs or shopping. They viewed such housing as being more expensive, and they recommended the provision of housing allowances either as rent subsidies or as financial assistance to those wishing to purchase affordable accessible housing.

7.1.6 Recommended Service Improvements

The following overall recommendations emerged from the focus groups and interviews with consumers:

7.1.6.1 Intervention Services

1. Increase the number of Intervenors to provide services to persons who are Deaf-Blind. Those communities that do not currently have Intervention Programs should put these initiatives into place. In addition, there is a need to decrease waiting times for services and to provide emergency pools of Intervenors for evening and weekend work, medical and other emergencies and vacation times.

2. Increase funding for quality Intervention services and for Intervenor training Programs. An increase in funding for Intervenor Programs could be an asset to improve the quality of Intervenors joining the workforce.

3. Establish an Intervention service provided by an organization with expertise and a mandate to serve people who are Deaf-Blind. This association could have trained staff to work with consumers who are Deaf-Blind. It would provide a variety of programs such as Intervenor services, equipment, Braille and sign language literacy, orientation and mobility, and other training opportunities.

4. In all urban locations having a large community of people who are Deaf-Blind, create centres that provide Intervention and Tactile Interpretation to satisfy their needs for these services.

7.1.6.2 Public Awareness of Deaf-Blindness in the Community:

5. Provide community awareness and education about combined visual and hearing impairment. Increasing community awareness would alleviate the misconceptions experienced by the public. It was suggested that workshops be convened with service providers and those who are Deaf-Blind to share information about Deaf-Blindness, ways of communicating and how service personnel can more effectively assist consumers.

7.1.6.3 Increasing Accessibility of Community Services to Persons Who Are Deaf-Blind

6. Promote better accessibility in public buildings and facilities. There is a need for improved physical accessibility features for people who are Deaf-Blind. Changes should include: improved lighting, accessible signs on doors, stairs, elevators, escalators, etc. Service providers housed in these public facilities should provide information about their offerings in large print, Braille and computer disk.
7. Equip public facilities with telephones, TTYs, etc. accessible to those who are Deaf-Blind.

7.1.6.4 Transportation Services

8. Improve public transportation services for those who are Deaf-Blind. This includes placing bus signs at an appropriate height to be easily read and increasing the size of printed messages, offering bus schedules in accessible formats, etc. Signage in subway stations should also be improved in those cities that have this mode of transportation, and tactile and visual warning strips should be placed at the edges of subway platforms. Lighting and signage at street crossings should also be enhanced so that they can easily be seen by consumers who are Deaf-Blind.

9. Transportation services for people with disabilities should take steps to address long waiting times, improve booking systems and install TTYs. Staff should also be trained in the use of these devices.

7.1.6.5 Counseling and Consultation Services

10. Consultants to those who are Deaf-Blind should be employed by organizations serving persons who are Deaf-Blind. Consultants should act as liaisons essentially connecting the various agencies providing support to people who are Deaf-Blind and service providers in the community. This would enhance the accessibility of community programs.

11. Medical facilities and professionals, counselors, etc. should offer increased support and information about resources in the community to meet the needs of persons who are Deaf-Blind. This would be particularly helpful to those who have recently been diagnosed as Deaf-Blind.

12. Community organizations should expand the range of recreation and social programs offered to those who are Deaf-Blind.

7.1.6.6 Employment Services

13. Workshops should be convened with employers and individuals who are Deaf-Blind to increase awareness of the issues of concern to persons who are Deaf-Blind.

14. Consumer organizations serving those who are Deaf-Blind should increase their advocacy with employers to accommodate the needs of consumers in the work place.

7.1.6.7 Establishment of Rehabilitation Services for Those Who Are Deaf-Blind

15. Organizations serving persons who are Deaf-Blind should establish local rehabilitation services to assist consumers. Ongoing help with learning new skills is required. Training should include acquiring skills in alternative methods of communication, employment, orientation and mobility and training in the use of assistive devices. The above mentioned supports could be provided by an organization similar to the Canadian Helen Keller Centre in Toronto. This centre offers a range of services to those who are Deaf-Blind.

7.1.6.8 Need for Assistive Devices Programs for Those Not Involved In Education Or Work

16. Provinces that do not currently have government-funded assistive devices programs for people with disabilities should provide financial support for such programs to meet individualized needs not related to education or work. This would provide increased access to information, enhance abilities to use the Internet and assist consumers to improve writing skills.

7.1.6.9 Need for More Information in Alternate Formats

17. Service providers, governments and community organizations should provide a greater amount of information in large print, Braille and computer disk to meet the needs of people who are Deaf-Blind.

7.1.6.10 Genetic Testing

18. CNSDB and CDBRA should work together to find the funding to undertake research of specific genetically based causes of Deaf-Blindness, e.g. Usher Syndrome.

7.1.7 Assistive Devices Used by Persons who are Deaf-Blind

Focus group participants indicated that they utilized a variety of assistive devices to assist them in their daily lives. The majority of individuals indicated that they wished to acquire additional devices but that they could not afford them. Devices listed included:

- TTY (some have large monitors)
- Telatouch
- Telebraille
- Computer with screen reader or large print software such as zoom text
- Computer with Braille display

- Braille, large print, larger font on computer screen
- Magnification equipment such as monocular or magnifier
- Magnifying glasses
- CCTV (Closed Caption Television)
- Video Camera with LCD Display
- Telephone with volume control
- Hearing aid with built in FM system
- Smoke detector and fire alarm with flashing light
- AlertMaster (the individual wears a pager that produces different vibrations for different sounds in the home)
- Vibrating alarm for bed
- Special measuring device for liquids
- White cane
- Braille or talking watch.

7.2 Discussion of Findings from Focus Groups and Individual Interviews with Parents/Advocates

Focus groups for parents/advocates of persons who are Deaf-Blind were held in Calgary, Alberta and Toronto, Ontario. Due to difficulties recruiting parents/advocates and the need to obtain internal ethical approval from one of the organizations providing assistance with participant recruitment, the research assistant in Montreal had insufficient time to convene a focus group. He therefore conducted individual interviews with parents/advocates in that location.

Parents/advocates were asked about their feelings when their children became Deaf-Blind, the ages of their sons and daughters when parents/advocates first obtained services for their children and for themselves, the challenges experienced in accessing services in the community and their recommendations for improved services.

7.2.1 How Parents/Advocates Felt When They Realized Their Children Were Deaf-Blind

Parents/advocates in the two focus groups and those interviewed individually shared a variety of feelings in response to this question. A few parents expressed concern about the medical fragility of their children in cases where medical conditions existed in addition to Deaf-Blindness. These parents felt relieved when they realized their children would survive. However, it was not until later that they began to focus on the impact of the Deaf-Blind diagnosis. One parent commented: "Deaf-Blindness at that point did not really matter, ... it was just to keep him breathing..."

Two couples indicated they were currently in the process of having their children diagnosed as "Deaf-Blind". One of these parents stated, "We need to look at a Deaf-Blind approach to help (her daughter) in school. It's like you're in the middle, but no one gives you services." These parents had questions, including: Will an Intervenor be highly trained? Will the school's staff take courses to learn about Deaf-Blindness? Will the teacher have experience in delivering a program to a child who is Deaf-Blind?

Parents who had gone through a series of inaccurate medical diagnoses felt a sense of relief when they finally had a firm diagnosis of Deaf-Blindness. They felt that their children, and they themselves, had been through so much, and the medical profession didn't always have the answers. Coping with the medical stresses left one parent 'numb'. Some parents expressed anger against doctors because their children had been incorrectly diagnosed at birth and there were no anti-natal tests. In one case, a doctor prematurely destroyed the results of blood tests. In other situations, doctors told parents they were exaggerating the nature of their children's disabilities. In still other instances, parents were not informed that their children would be Deaf-Blind.

A parent recounted how she had come to terms with the loss of her child's hearing but was devastated to learn that her child was also blind. The parent of a teenage boy stated: "Finding the words to describe the feelings for the first month. ‘Devastation' is a nice word for what I was feeling. Our whole world had changed. How do you help him? How do you convince the system to help him? They were convinced he would die. 'Don't make too many plans; he won't live past a year or three or four years.' And, if he lives after that? Well, no one prepared us for that."

Another parent found herself totally unprepared for the diagnosis. In her own words she was "Dumbfounded! We left the hospital not knowing ANYTHING was wrong with him, until he had his first seizure at eight months."

A third parent summed up her feelings saying, "We had such a terrible initial diagnosis. I felt devastated then. The pain physically hurt. I thought I will never laugh or smile again. My whole world has changed."

On the one hand, foster parents of a child who was Deaf-Blind told how they felt compassion and helplessness for their "vulnerable, defenseless child." On the other hand, biological parents experienced grief, feelings of guilt and abandonment. "It was a shock, I mean you really felt why me, what did I do?” The feelings of guilt were quickly replaced with a sense of frustration about their inability to communicate with their children. Many parents stated they were still attempting to address the communication issues. Parents outlined their concerns for the future lives of their children. They also experienced frustration when they sought out information about supports and services and found it to be unavailable.

7.2.2 When Parents First Accessed Support For Their Children

Parents responded to questions about the chronological ages of their children when they first accessed support for their sons or daughters and provided various answers to this question.

Parents of children who were diagnosed as infants or toddlers and who had extended hospital stays were able to access support services most rapidly. Services were generally in place by the time the children went home from the hospital. For example, one parent related how his child's Deafness was detected two days after birth, and he began receiving services shortly after that. Other parents recounted similar experiences when their reached school age.

However, not all families received early services. When they did, the information provided was sometimes incomplete. One parent stated that his child was seen by an audiologist at two different healthcare facilities and that the second professional did not trust the diagnosis of the first doctor, which resulted in service delays. Another parent commented that, even though she obtained services when her child was six or seven months of age, information about educational programs available at a special school was not provided to her. The process was longer for a parent who immigrated to Canada when his child was five and a half. Services did not begin until two years after that. Two parents whose sons or daughters were now adults indicated that supports were more difficult to obtain when their children were young and that they were left to figure things out on their own. There was little information available about Deaf-Blindness or this type of information was not forthcoming.

Many parents came up empty-handed when they attempted to access services for their children who were recently diagnosed as Deaf-Blind. One couple was directed to (name of health service) where they fortunately received some early Intervention. Doctors wanted to fit their child with hearing aids right away, and they were directed to see an audiologist. Unfortunately, there were no programs through which they could obtain support for their Deaf-Blind child.

Respondents also realized the necessity to learn sign language to enable them to communicate with their children. However, they encountered challenges accessing suitable courses in sign language and professional guidance. One individual explained: "... I was like, who can I talk to about sign language? They did not know so then we were left to find our own contacts." Another parent commented: "You're just so confused you don't know whether you're coming or going and I don't think a lot of them really knew."

Parents described their feelings when attempting to access supports for their children. They talked about feelings of displacement, isolation and loneliness. Several believed that suitable programming for their children did not exist. They were torn between the two major sensory loss groups of Deaf and Blind. When they approached an organization offering support to those who were blind or visually impaired, they found assistance in dealing with their children's visual impairments. However, associations serving those who are Deaf or hearing-impaired knew nothing about visual impairments. The presence of role models would have been helpful in the lives of their families and would have facilitated the provision of information about available services and supports.

Parents in one focus group discussed the excellent educational support in the form of correspondence courses provided by a local educational clinic . In addition, they noted the difficulties their children encountered in becoming involved in recreation or social activities due to the scarcity of suitable programs, the shortage of Intervenors and the lack of financial assistance.

7.2.3 When Parents First Accessed Support For Themselves

Parents discussed their experiences accessing support for themselves as parents/advocates of children who are Deaf-Blind.

Many parents stated that psychological and social work services, Intervention assistance, night nursing and respite assistance were the most frequent services received. For a child who experienced seizures, these services started shortly after he came home from the hospital and continued as his medical condition changed. His parent explained, "We had night nursing so I could sleep. It was my support... I wouldn't be here without it." A family who immigrated to Canada could not obtain respite assistance during their first year in this country. Other parents identified insufficient respite care and lack of financial supports as salient issues.

Parents mentioned the availability of financial assistance for respite care. However, they were disappointed by the level of payments received. The appeal process was extremely frustrating and time consuming. One couple obtained an appropriate level of financial assistance only after a successful appeal.

The majority of parents in two focus groups agreed that there were very few options for parental support when their children were young. The report from one of these sessions states: "They shared the same feelings of being stranded and on their own using the trial and error method to try dealing with issues as they surfaced. The lack of emotional support and the fact that there was no counseling readily available for them was difficult. They wished there had been some form of service to assist them with their feelings of guilt and isolation."

Some of the parents had other children they were trying to raise while simultaneously coping with the difficulties and stresses of raising children with complex needs. Some siblings felt resentment or anger towards the parents and the children who were Deaf-Blind. Vacations were tough times, particularly when communication barriers emerged between family members. Some siblings felt left out and jealous of the extra parental time spent with the child who was Deaf-Blind.

These parents restated how they were left without counseling to deal with these emotional strains. If they sought counseling services, it would be at their own expense. Most were already expending extra dollars for medical costs, technology, respite care and other services. Counseling was often put on the back burner. In some cases, parents utilized caregivers as part of their support system.

A few parents who were individually interviewed had not yet requested services. One was unaware of existing supports; another felt he did not need services while a third had not asked for assistance because his child was living in a residential rehabilitation centre (this child had physical disabilities in addition to being Deaf-Blind).

7.2.4 Challenges Experienced by Parents in Accessing Services for Their Children

One of the most frequent challenges experienced by parents related to insufficient recognition of the uniqueness of Deaf-Blindness as a disability. Individuals described the complications in finding appropriate programs for their children. One parent stated: "...we were like the round peg trying to fit into the square hole..."

The shortage of Intervenors was mentioned by all participants as a major challenge to accessing services in the community. It was difficult to locate quality Intervenors who understood the diverse needs of children who are Deaf-Blind. A few parents felt their children were being used as guinea pigs by service providers who didn't seem to know how to assist children who are Deaf-Blind. Some parents received Interpreter services through an organization providing supports to those who are Deaf and hard of hearing. In some cases, the level of signing was too high in comparison with the abilities of their children. The Interpreters also lacked other skills such as techniques needed to guide a person who is Deaf-Blind.

In one focus group, the issues of insufficient funding for Intervention services and the scarcity of Intervention hours were salient. In the province where this session took place, parents receive a set amount of funding from the service provider, which can be utilized for respite, Intervention or other services. The higher the rate per hour parents pay for Intervention services, the fewer the hours of programming they can obtain. Once their allotment of funding is expended, parents must mobilize their own resources to finance services. This province runs a summer Intervention program, but when it is not in operation, parents have fewer hours of support. A specified allotment of Intervention funding puts parents in a difficult situation for another reason. If they pay $8 - $10 / hr., they get more Intervention hours but they receive poorer quality service. If parents pay a more competitive wage, they are more likely to attract and retain good workers but they are entitled to fewer hours of Intervention. As one parent stated: "You won't get super experienced, ASL (American Sign Language) fluent, people cheap. It doesn't happen." Two other participants shared the same opinion: "Our kids' lives are like a business... Our whole life is lived with accountability. I wish everyone else had to be as accountable as we do." Many of these parents hired their own Intervenors, accessed the Summer Intervention Program and college students offered additional support. Because of this additional support, their children's learning continued throughout the year. This responsibility was overwhelming. One parent exclaimed, "I hate that I am not his Mom. I am everything but his Mom, to keep it running."

People who lived outside of metropolitan areas found it even more difficult to locate Intervenors. In some cases, parents took time off work (especially during summer holidays and Christmas breaks) because there were no Intervenors available to work with their children.

Parents in one focus group discussed difficulties accessing medical services. Most of them dealt with doctors from hospitals in major urban centres. For parents who lived outside these centres, it was more difficult to get doctors to write referral letters so that procedures could be performed in local hospitals. Many respondents talked about the challenges in accessing services. One parent explained, "I knew at six months she (her daughter) couldn't hear, but it took 12 months until she got hearing aids. We fought for services." Once parents became familiar with the care their child required, there was a hesitancy to go to the hospital. The sentiment was, "Once you go to the hospital you lose power, so everything possible is done at home."

For parents awaiting a diagnosis of Deaf-Blindness, there was the fear that their children would not receive a high-quality education, as educators do not always listen to the views of parents about their children's needs. One respondent described her struggle saying, "Last year, she (her daughter) had three teachers, three resource teachers and three assistants ... This year she has two new Resource Teachers and a new assistant."

Some of the parents who were individually interviewed indicated a need for specialized schools for children who are Deaf-Blind. Some of the children attended schools for those with hearing impairments, and following the curriculum proved difficult. One parent stated that his child was refused by a school for children with hearing impairments because he had insufficient sight. He was also turned down by a school for children who are blind because he had insufficient hearing. The child was subsequently placed in a school with students with learning and behaviour problems.

Locating good-quality schools for children living outside of metropolitan areas presented major challenges, as did finding good quality teachers to work outside city limits. Most educational assistants were not trained to deal with children who have both vision and hearing losses. In one focus group, the general consensus was that their children needed a resource person from a specialized program for children who are Deaf-Blind and not a teacher of the Deaf.

Parents in one focus group discussed their frustrations in dealing with their local school board. They believed that, in many cases, the board was unaccommodating and lacked a firm understanding of the diverse needs of children who are Deaf-Blind. This could result in increased difficulties lobbying for funding and educational supports. One parent commented: "We finally have an Intervenor after six years of asking."

With respect to accessing services, one parent who lived in a rural community found that specialists were at least one to two hours away. Educational services were thirty minutes away and no busing was provided for her child. Parents indicated that some professionals were very cooperative while others made life incredibly difficult. Another parent was told that, when her child enters the school system, she will be restricted to schools in her geographic area. She will be unable to access more specialized programming in another location.

Many parents expressed frustration with the inflexibility of the system. One individual remarked, "They make us live in their box. It's very difficult living in their box without flexibility." She cited an example of night nursing. Because their scheduled nursing time is at the end of the week, if the person misses the shift, the family forfeits the hours. If, however, the nurses were scheduled at the beginning of the week, the family would be able to recoup the hours later.

The majority of parents expressed concern for their children's futures and wondered how they would manage on their own.

Respondents noted that adult education presented difficulties for individuals who are Deaf-Blind. Classes for adult education were usually full and waiting lists were frequent.

7.2.5 Challenges Experienced By Parents In Accessing Supports For Themselves

Parents discussed the challenges encountered in accessing supports for themselves.

For most participants, one of the biggest challenges was accessing family Intervention services. As communication was a large barrier experienced within the family unit, many parents encouraged relatives, especially siblings, to use sign language. Some of them paid for lessons from their own scarce financial resources. They felt this was unfair and was a financial burden to families.

Due to the scarce availability of Intervenors, the majority of respondents in one focus group discussed the necessity of taking on the challenging role of service provider. As a result, they did not enjoy the activities for which they were Intervening. Parents also raised the dilemma of accessing respite and other community services within the small monthly budget they were allotted to purchase these supports. They encountered difficulties locating trained personnel to provide needed services.

With respect to accessing medical services, many parents identified difficulties communicating with doctors and indicated they could not obtain adequate information or direction from the medical profession. One woman shared her experiences. "It's so hard. No one gave me any direction. ... We asked for a meeting. They said: “He (our son) is brain damaged. He is going to die.” Focus group members attempted to give informational pamphlets to medical professionals, but their efforts were ignored. One parent stated: "I needed information, resources, roadmaps, hands-on therapy, contacts. I needed to know: "what can I do to help this child!". A few participants carried out extensive research on their own because they lacked confidence in their doctors to provide them with the needed information about their children's disabilities.

Parents also spend a great deal of time and energy fighting for services and funding. There is never enough money, and the appeal process is one of the only ways of dealing with lack of services. Parents found the most effective way to appeal a decision was to convene a meeting with decision-makers at the family home. This provided a more realistic picture of what it was like to live with Deaf-Blindness. One parent related that her child was cut off home nursing services six months ago. The parent was told that due to citywide cuts she wouldn't need nursing care. Her child's condition and needs had not changed. She was therefore left with the question of why the nursing care should be discontinued.

Parents described the long waiting lists for the majority of services they received. Most of them placed their children's names on these waiting lists once the diagnosis of Deaf-Blindness occurred to avoid long delays in obtaining services. Coordinating all the necessary services was extremely time consuming. One participant explained, "For seven months while my child was in hospital, I was in meetings and on the phone navigating my way through the system."

7.2.6 Recommendations for Additional Services to Be Provided in the Community

Parents outlined recommendations for additional services that should be provided in the community for their children and for themselves.

7.2.6.1 Community Services That Would Benefit Their Children

1. Increase the amount of funding available to parents for Intervention services, respite care and assistive devices.

2. Parents are advocating for their children but there are no advocacy services for children. Supports should be put in place to enable children to advocate for themselves, where appropriate.

3. Improve access to community services for children who are Deaf-Blind and also have physical disabilities by: Increasing wheelchair accessibility in stores and building accessible playgrounds with wheelchair swings, wheelchair maintenance services and an indoor heated pool for therapy swims.

4. Increase medical services and awareness for the older population with rubella syndrome.

5. Increase the number of teachers provided by school boards who come into the classroom to meet the needs of children who are Deaf-Blind.

6. Improve the quality of education for children who are Deaf-Blind so that they have similar opportunities and access to the curricula as children with hearing and vision.

7. Increase the number of orientation and mobility specialists available in schools to meet the needs of children who are Deaf-Blind.

8. Provide more after-school tutoring for children who are Deaf-Blind. This would increase the amount and speed with which classroom material could be covered and assist with homework and assignments, thus minimizing the burden on parents.

9. Improve recreation services for children who are Deaf-Blind. The following accessible types of recreation programs should be provided: swimming; gym; sports teams; drama classes; music; rock climbing; Deaf-Blind club/social gatherings

10. Improve opportunities for children who are Deaf-Blind to interact with other children who are Deaf-Blind and those without disabilities. This would facilitate social development and promote opportunities for development and growth through peer interaction.

101. Establish a program for children who are Deaf-Blind to facilitate the development of social and life skills and relieve the burden from parents of providing instruction in these areas.

7.2.6.2 Community Services that would Benefit their Children and Themselves as Parents/Advocates

1. Establish a "one-stop shop" for service providers where parents can receive a variety of services that would benefit children who are Deaf-Blind and themselves as parents/advocates. This "one-stop" facility would offer a core list of the places they could go to acquire information on Deaf-Blindness and available programs to minimize the amount of energy and time expended to locate needed services. This list should include the names and contact information of Intervenors, along with their areas of expertise to enable parents to match the skills of professionals with the needs of their children. Advocacy assistance for parents could also be provided through this "one-stop shop". This would provide parents with a voice in advocating for needed services, more funding for Intervenors and respite care and increased Intervenor Training Programs

2. Improve service coordination among professionals from various disciplines to facilitate the provision of high-quality services to families of children who are Deaf-Blind. Facilitating multi-disciplinary teamwork among professionals would also strengthen communication among service providers and parents, enable professionals from various disciplines to interpret results of service Intervention in terms of the "whole child", decrease service duplication and lighten the burden on the service system which, in turn, would reduce waiting lists.

3. Provide funding for consultants on Deaf-Blindness to assist parents in preparing for future obstacles they may encounter in accessing services to meet the needs of families. Consultants could offer recommendations related to the development of children who are Deaf-Blind and help parents through transitional times. Information should be made available on programs, assistive devices, funding sources and tips on managing funds.

4. Provide programs offering emotional support and counseling to parents, particularly in the early stages of the development of their children.

5. Establish support groups for parents for information sharing and mutual support.

6. Orientation and mobility instructors should be available to provide tips on how to increase home accessibility for children who are Deaf-Blind. Rehabilitation professionals should offer information on appropriate assistive devices to facilitate the learning of life skills.

7. Organize sessions to provide information to parents about available technology and assistive devices. These sessions would facilitate orientation to new technology and follow-up and assistance in how to trouble shoot difficulties that may arise with assistive technology.

8. Provide more awareness of Deaf-Blindness to the general public. This could facilitate an increase in the numbers of volunteers willing to work in the field, including co-op students from high schools.

9. Increase funding for respite care and Intervention services. More Intervenors need to be recruited and trained. In addition, there should be increased flexibility as to how much to pay Intervenors. Competitive wage scales should be implemented which reflect Intervenors' skills and encourage trained personnel to remain in the field.

10. Promote community college Intervenor Programs to high schools to increase the number of graduates from these programs to provide services to those who are Deaf-Blind.

11. Provide classes in American Sign Language for parents, siblings and other family members of children who are Deaf-Blind.

7.3 Summary of Focus Group Findings

In the previous two sections of the report, the findings from focus groups and interviews with persons who are Deaf-Blind and with parents/advocates were described in detail. Recommendations for service improvements were also delineated. Consumers offered suggestions for improving public and specialized transportation services, the accessibility of buildings and facilities, receiving information via the phone, communicating with professionals and the general public, facilitating the availability of information about Deaf-Blindness and community resources and increasing social and recreation services in the community. In addition, respondents who are Deaf-Blind pointed to the need for consultants to facilitate liaison with the service system and improved rehabilitation services (including counseling, orientation and mobility and employment).

Parents/advocates provided recommendations for improvements in diagnostic, medical and prevention services, educational and after-school supports, additional funding for respite support, increased access to community, social and recreation programs, the

availability of life skills instruction and the provision of consultants in the area of Deaf-Blindness. The consultants would provide information about Deaf-Blindness, service coordination and liaison and referral to community resources. Parents/advocates identified the need for a "one-stop shop" where they can receive a variety of services that would benefit children who are Deaf-Blind and themselves as parents/advocates. to minimize the amount of energy and time expended To locate needed services, this "one-stop" facility would offer a core list of the places they could go to acquire information on Deaf-Blindness and available programs. Counseling and advocacy support could be offered through this resource to ensure the voices of parents are heard by service providers, governments and the community.
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Consumers and parents overwhelmingly recommended that federal and provincial governments provide increased funding for Intervention services for persons who are Deaf-Blind to facilitate their access to community services and daily living. Those communities, that do not currently have Intervention programs, should put these initiatives into place. In addition, there is a need to decrease waiting times for services and to provide emergency pools of Intervenors for evening and weekend work (this applies to children, families and adults who regularly receive Intervention services during the day), medical and other emergencies and vacation times. Federal and provincial governments should increase funding for Intervenor Training Programs to expand the numbers of highly trained professionals working with those who are Deaf-Blind.

Consumers and parents/advocates pointed to the need for the implementation of public awareness programs to highlight the needs and capabilities of persons who are Deaf-Blind and to reduce the misconceptions among governments, the service sector and the general public about the uniqueness of this dual disability. In addition, respondents who are Deaf-Blind and parents/advocates identified the need for federal and provincial governments to implement assistive devices programs for those not currently involved in education or work to increase the quality of life for persons who are Deaf-Blind. This would provide increased access to information, enhance abilities to use the Internet and assist consumers to improve writing skills. Parents and consumers alike also expressed the need for increased information about assistive devices and the availability of training in the use of this type of technology.

7.4 Demographic Data

7.4.1 Introduction

Another focus of the "Study of Deaf-Blind Demographics and Services in Canada was the collection of demographic data on the numbers of persons in Canada who are Deaf-Blind. This portion of the research added to the information gathered in the 2001 National Registry Project conducted by CDBRA. The National Registry Project obtained information on 777 persons across Canada. The current project attempted to focus on locating those with acquired Deaf-Blindness and seniors, the segment of this population thought to be significantly under-represented in the National Registry initiative, as well as those who are congenitally Deaf-Blind but who were not included in the National Registry. The Advisory Committee also believed it was important to acquaint provincial and federal governments and community groups with the extent of Deaf-Blindness across the country. A more accurate estimate of the numbers of persons in Canada who are Deaf-Blind will aid service providers to better understand and plan for service needs.

7.4.2 Research Methodology for Collecting Demographic Data

Eight research assistants collected demographic information in the following locations: British Columbia and the Yukon, Alberta/Nunavut and the Territories, Saskatchewan, Manitoba, Northwestern Ontario, Southern Ontario, Quebec and the Atlantic Provinces. These researchers gathered information on the numbers and location of persons who are Deaf-Blind, along with additional pertinent demographic data including age categories, probable causes of the disability and living arrangements (see Appendix C. for copies of the interview guides for gathering these data).

To locate participants, the researchers contacted administrators or directors of community organizations and schools, disability groups that serve Deaf, Blind and Deaf-Blind individuals, seniors residences, seniors resource centres in the community, medical associations, audiologists, ophthalmologists, regional health authorities, nursing associations, personal care homes, personal care home associations, government departments and directors of disability services offices at universities and colleges.

The research assistants were encouraged to utilize their own networking abilities to find participants, and they suggested additional sources through which to gather demographic information. These included:

- Government Agencies, e.g. Education, Health, Family and Social services;
- Rehabilitation organizations, physiotherapists, occupational therapists, etc.;
- Teaching hospitals, low vision and audiology clinics, etc.;
- Private companies that provide home care, nursing and related services, e.g.: The Victorian Order of Nurses (VON);
- School Districts/School Boards;
- First Nations organizations, band offices etc.;
- Centres on aging, wellness centres, health policy centres, research and policy centres, etc.;
- Various databases including epidemiological databases;
- Internet searches to locate potential sources of information;
- Blindness and Deafness organizations such as CNIB, Canadian Council for the Blind, Canadian Hearing Society, etc.

Researchers were asked to contact ten to fifteen organizations in each category throughout the region. At least three were to be located in large urban centres, three in medium-sized urban centres and three in rural areas. Researchers were encouraged to choose locations in different parts of each region.

The exact organizations contacted varied from region to region, as there were variations in geographic composition, size and number of major centres, the specific associations within the region, etc.

Data were gathered primarily through telephone and e-mail interviews, since researchers were working from their homes and not required to travel.

Prior to the interviews with organizations agreeing to participate, the researchers distributed the consent form and interview guides to participants so that they would have time to assemble the demographic information to respond to the interview questions. The project team emphasized that they were seeking to gather as much information as possible on the numbers of persons in Canada who are Deaf-Blind, their ages, probable causes of the disability and living arrangements.

In some cases, respondents were able to provide complete demographic information about their consumers/members/clients who met the research definition of Deaf-Blindness. In other situations, participants were only able to offer estimated numbers of persons served or were unable to provide numbers.

Research assistants were expected to report on data based on estimates or incomplete information and indicate those situations where participants were unwilling to do the necessary work to respond to the interview questions.

In a few instances, organizations requested an internal ethical review through their ethics committees in addition to the successful ethics review already undertaken by CCDS (see Appendix C). For the most part, these ethical issues were successfully dealt with, although the additional time required for these ethical reviews caused frustration for the research assistants and the participants.

To avoid duplication, researchers were asked not to contact organizations covered in the service provider interviews conducted by representatives of CNSDB/CDBRA. In a few instances, numbers from some of these associations are included in the demographic findings because research assistants had connections with these organizations and decided to contact them.

7.4.3 Summary of Demographic Findings

Complete reports from each of the eight geographical regions (moving from west to east) are presented in Appendix F. In each of the individual reports, the findings and comments are presented under the headings: "Organizations Contacted", "Obstacles Encountered", "Research Findings" and “Summary".

Results of the major demographic findings from all the regional reports, i.e. numbers of persons identified with Deaf-Blindness, classification of Deaf-Blindness (congenital or acquired), age categories, causes of Deaf-Blindness (if known) and living arrangements are summarized by province to provide a Canadian-wide perspective.

7.4.4 Numbers of Persons With Deaf-Blindness

The provincial/regional distribution of persons with Deaf-Blindness is presented in Table 1. Numbers of persons with Deaf-Blindness are shown as estimates and those actually located. The numbers of persons estimated with this disability totaled 3306 which represents an index of 11.00 persons with Deaf-Blindness per 100,000 persons. This index ranged from 3.9 per 100,000 Canadians in Newfoundland/Labrador to 21.05 per 100,000 Canadians in Quebec. Most of the regional researchers believed that their reported official numbers under-estimated the full extent of those who are Deaf-Blind in this country. Researchers in Alberta, Manitoba and Quebec provided estimates beyond the numbers that were reported to them. See their regional reports for further information).

This index of 11.00 represents a significant increase in the numbers of persons with this disability known to Canadian service organizations in 2001 (Munroe, 2001). In the above-mentioned report, the organizations indicated they knew and/or served 1725 persons with Deaf-Blindness during that year. This represents a Deaf-Blindness incidence ratio of 5.75 per 100,000. While the new index represents almost a 100% increase since 2001, researchers believe this index is still near the lower end of the Deaf-Blindness ratio range (10 to 15 per 100,000 persons or 3,100-4,650 Canadians) estimated in the National Registry Study as being the probable incidence of Deaf-Blindness.

The Canadian Council on Social Development (CCSD) gathered statistics (See Appendix G) through the Canadian Community Health Survey (CCHS) on the numbers of persons over the age of 12 with both hearing and seeing disabilities. According to the above-mentioned survey, there were approximately 19,600 individuals aged 12 and over with some degree of both vision and hearing loss (but not complete loss of either sense), an additional 34,700 individuals reporting partial loss of one of these senses and a total loss of the other, and 15,500 reporting a total loss of both vision and hearing. These approximately 69,800 Canadians (aged 12 and older) with combined hearing and vision loss, represents an index of 232.28/100,000. We have no information as to the definition of Deaf-Blindness used in this study. The survey results may have included people who had slight hearing and vision loss but not enough to be classified in our definition as being Deaf-Blind . The CCHS was a large government study and was primarily a quantitative survey with more financial resources at its disposal than the current project. The Deaf-Blind Demographics and Services in Canada report was primarily a qualitative survey designed to document the needs of persons with acquired Deaf-Blindness and those who are congenitally Deaf-Blind and to obtain an estimated total of the population of Deaf-Blind Canadians. (See Appendix G for a summary of the statistics gather through the CCHS survey). The majority of those with both hearing and seeing disabilities (70%) were seniors, with about 15% under age 45 and 15% aged 45 to 64.

For comparison, other countries reporting Deaf-Blindness indices are Norway, who reported 6.9/100,000 in 2000 and the UK which reported their Deaf-Blindness incidence as 40/100,000 (Munroe, op.cit).

Table 1. Distribution of persons with Deaf-Blindness throughout Canada

Province	2001 Population Census	No. of persons Reported with Deaf-Blindness	*Estimated No. of persons with Deaf-Blindness	No. per 100,000
British Columbia/Yukon	**3,936408**	**287**	**287**	**7.29**
Alberta/NT/N	**3,038,915**	**215**	**227**	**7.08**
Saskatchewan	**978,935**	**149**	**149**	**15.21**
Manitoba	**1,119,585**	**172**	**182**	**16.26**
Ontario	**11,410,04**	**700**	**700**	**6.13**
Quebec	**7,237,480**	**1059**	**1523**	**21.05**
New Brunswick	**729,500**	**140**	**140**	**19.19**
Nova Scotia	**908,005**	**63**	**63**	**6.94**
PEI	**135,290**	**15**	**15**	**11.11**
Newfoundland/Labrador	**512,930**	**20**	**20**	**3.9**
Total	**30,007,090**	**2820**	**3306**	**11.00**

* Researchers in Alberta, Manitoba and Quebec provided estimates beyond the numbers that were reported to them

7.4.5 Age Related Information on Persons with Deaf-Blindness

Table two outlines the age distribution by province/territory for those persons in Canada with Deaf-Blindness. Age related information was available for a total of 2754 persons identified with Deaf-Blindness.

Table 2. Distribution of persons with Deaf-Blindness according to age groupings

Province	0-5 years	6-20 years	21-60 +years	61+ years	Total
British Columbia	**50 (17.4%)**	**139 (48.4%)**	**48 (16.7%)**	**50 (17.5%)**	**287**
Alberta/NT/N	**3 (1.4%)**	**18 (8.4%)**	**62 (29.0%)**	**131 (61.2%)**	**214**
Saskatchewan	**0**	**11 (7.4%)**	**78 (52.3%)**	**60 (40.3%)**	**149**
Manitoba	**3 (1.7 %)**	**15 (8.6%)**	**67 (38.3%)**	**90 (51.4%)**	**175**
NW Ontario		**2 (6.2%)**		**30 (93.8%)**	**32**
Southern Ontario	**15 (2.2%)**	**173 (25.9%)**	**285 (42.7%)**	**195 (29.2%)**	**668**
Quebec	**18 (1.7%)**	**40 (3.8%)**	**333 (31.5%)**	**667 (63.0%)**	**1058**
New Brunswick	**2 (2.7%)**	**21 (28.8%)**	**36 (49.3%)**	**14 (19.2%)**	**73**
Nova Scotia	**4(6.4%)**	**14 (22.2%)**	**40 (63.5%)**	**5 (7.9%)**	**63**
PEI	**5 (33.3%)**	**10 (66.7%)**			**15**
Nfld/Lab.		**1 (5.0%)**	**11 (55.0%)**	**8 (40.0%)**	**20**
Total	**100 (3.6%)**	**444 (16.1%)**	**960 (34.9%)**	**1250(45.4%)**	**2754**

Table two indicates that young children have a low representation in the reported population (3.6%), and that the incidence of Deaf-Blindness tends to increase with age. The age breakdown reported for Alberta and Quebec is believed to more realistically represent the true age distribution of Deaf-Blindness across Canada. This is based on the observation that the age group 61+ years is represented as 61.2% and 63.0%, of the total numbers of persons in these provinces, respectively, reporting Deaf-Blindness. This is supported by the UK study on Deaf-Blindness (Munroe, 2001) which indicates that two thirds of the reported population of persons with Deaf-Blindness in the UK are seniors, aged 60 and older.

The above statistics do not provide a clear understanding of the true prevalence of Canadian seniors who are Deaf-Blind. If we had divided the 21-60 year age groupings into separate categories, i.e. 21-45 and 45-60, we may have been able to obtain more significant age-related statistics. However, in formulating the research plan, the researchers considered the ease and reality of obtaining data from various participating organizations.

Some issues are at play to contribute to the under-representation of seniors in the Deaf-Blindness numbers. It is difficult to access the multitude of senior's facilities throughout the country. Many seniors or caregivers in seniors facilities did not think the "Deaf-Blindness' designation was applicable to them. There is also a difference throughout the country in terms of the ability of government organizations to access information on seniors and their disabilities. In the province of Quebec for example, many seniors with Deaf-Blindness are known to the agency (IRD) Institut de Réadaptation en Déficience Physique. This may be why the Quebec numbers more accurately approximate reality than similar data from some of the other provinces.

7.4.6 Type of Deaf-Blindness Reported

In their regional surveys, researchers were asked to determine the prevalence of the two distinct types of Deaf-Blindness, congenital and acquired. Table 3 summarizes the distribution of the numbers of persons throughout Canada with congenital and acquired Deaf-Blindness. Of the total numbers of persons with Deaf-Blindness reported, 2098 were assigned a category of Deaf-Blindness. The remainder were unassigned largely because the classification of Deaf-Blindness was unknown to the responding organizations and researchers.

Table 3. Distribution of reported classification of persons with Deaf-Blindness throughout Canada

Province	**Congenital**	**Acquired**	**Total**
British Columbia	**80 (45.2%)**	**97 (54.8%)**	**177**
Alberta/NT/N	**48 (22.4%)**	**166 (77.6%)**	**214**
Saskatchewan	**30 (61.2%)**	**19 (38.8%)**	**49**
Manitoba	**49 (45.4%)**	**59 (54.6%)**	**108**
Ontario	**267 (40.6%)**	**390 (59.4%)**	**657**
Quebec	**139 (17.8%)**	**644 (82.2%)**	**783**
New Brunswick	**38 (52.1%)**	**35 (47.9%)**	**73**

Nova Scotia	**13 (59.1%)**	**9 (40.9%)**	**22**
PEI	**13 (86.7%)**	**2 (13.3%)**	**15**
Nfld/Labrador	**0**	**0**	**0**
Total	**677 (32.3%)**	**1421 (67.7%)**	**2098**

Of the 2098 persons where the classification of Deaf-Blindness was known, 67.7 % were reported as having acquired Deaf-Blindness while 32.3 % were reported as being congenitally Deaf-Blind. See Appendix A for definitions of congenital and acquired Deaf-Blindness.

The National Registry Project report (Munroe, 2001) indicated that 55.3% of voluntary respondents had acquired Deaf-Blindness. The Deaf-Blind National Registry in Norway noted that 76.5% of the total registrants had acquired Deaf-Blindness (Munroe, op.cit.).

The reported classifications of Deaf-Blindness (congenital or acquired) according to age groupings are summarized in Tables 4 and 5. Comparisons will be made between these two groups with respect to age grouping and not by province.

For age group 0-5 years, a higher proportion (8.1%) was identified as congenital (Table 4) compared to 0.5% of those with acquired Deaf-Blindness (Table 5). This is understandable as the congenital related condition is manifested early in life as opposed to acquired Deaf-Blindness where only one aspect of the condition (Deafness in the case of those with Usher Syndrome) generally occurs within the first five years of life.

Among those with congenital Deaf-Blindness (Table 4), 42.1% were aged 6-20 years compared to 4.4% in that age group who had acquired Deaf-Blindness (Table 5). It is likely that this high proportion of the congenital group reflects the high level of identification (of the cause or etiology of Deaf-Blindness) at an early age and the provision of early services. These supports include: Intervention, specialized education, placement in an alternative living facility, etc. There is a relatively low proportion of those with acquired Deaf-Blindness among the younger age groups. The researchers found interesting differences in the age relationships between the two groups of persons with Deaf-Blindness. It would appear there is no direct age relationship within the congenital group of persons with Deaf-Blindness. According to Table 4, the youngest and highest age groups are in quite similar proportions (8.1% and 6.8%. The 6-20 age range and 21-60 age group are in similar proportions (42.1% and 43.0%).

The lack of identification in some regions could account for the low proportion of the youngest age classification. If this is not the case, then it can be concluded that congenital Deaf-Blindness is truly a very low incidence disability. It might be safe to say that many of the congenital group in age class 21-60 years are Deaf-Blind as a result of congenital rubella syndrome which spread through Canada (and the rest of the world) during the mid – 1960's. During the 1970's, thousands of individuals were born Deaf-Blind due to congenital rubella syndrome.

It is also difficult to explain the significant difference between the incidence of congenital Deaf-Blindness within the age group 6-20 yr between the Province of Ontario (154 of 267 or 57.7%) and the Province of Quebec (14 of 139 reported or 16.5%). This could reflect differences between the two provinces in expertise available to identify persons with congenital Deaf-Blindness. It should be pointed out that those provinces with the highest proportions of persons with congenital Deaf-Blindness in the age category 6-20 years (Ontario and British Columbia) are those with the highest levels of educational services.

The low percentage of older persons with congenital Deaf-Blindness (6.8%) should confirm there is no positive age relationship within this category. Several reasons may account for the low incidence in this age group. These include: the lag time in conducting research to document persons with congenital rubella syndrome (or other causes of the Deaf-Blindness) achieving older age; a higher mortality rate for people with this condition or a problem with identification of the cause of the classification of the disability as being congenital or acquired.

Table 5 illustrates the direct age relationship within the category of acquired Deaf-Blindness. Compared to the congenital group (Table 4), the proportion of each group increases with age, ranging from 0.5% for age group 0-5 yr through 62.4% for the oldest age classification. Compared to congenital Deaf-Blindness, there is a low incidence of acquired Deaf-Blindness up to age 20 when the incidence of this disability rises through the years up to age 60 and then sharply increases among seniors.

Table 4. Reported congenital Deaf-Blindness in Canada according to age-groupings

Age	BC	AB	SK	MN	ON	PQ	NB	NS	PEI	NF	Total	%
0-5yr	17	3	0	2	7	14	2	4	5	0	54	8.1%
6-20yr	56	13	2	5	154	23	11	9	8	0	281	42.1%
21-60yr	7	30	27	30	94	78	21	0	0	0	287	43.0%
61+yrs	0	2	1	2	12	24	4	0	0	0	45	6.8%
Total	80	48	30	39	267	139	38	13	13	0	667	

Table 5. Reported acquired Deaf-Blindness in Canada according to age-groupings

Age Grouping	BC	AB	SK	MN	ON	PQ	NB	NS	PEI	NF	Total	%
0 - 5 yr	0	0	0	0	5	2	0	0	0	0	7	0.5%
6 - 20 yr	6	5	9	0	19	7	10	5	2	0	63	4.4%

21 - 60 yr	**41**	**32**	**1**	**28**	**185**	**163**	**15**	**0**	**0**	**0**	**465**	**32.7%**
61+ yrs	**50**	**129**	**9**	**31**	**181**	**472**	**10**	**4**	**0**	**0**	**886**	**62.4%**
Total	**97**	**166**	**19**	**59**	**390**	**644**	**35**	**9**	**2**	**0**	**1421**	

7.5 Summary and Conclusions

The "Study of Deaf-Blind Demographics and Services in Canada" project represented a unique collaboration between two organizations, the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association, and it is these two groups which will carry the results forward.

The project report contains (1) demographic information about persons in Canada with acquired Deaf-Blindness and those who are congenitally Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates and (5) directions for future research. This complements the National Registry Project, which obtained information on 777 persons with this dual disability.

This research located some of the balance of Canadians who were not registered as Deaf-Blind during the National Registry Project conducted by the Canadian Deafblind and Rubella Association from 1999-2001. The study found an estimated total of 3306 Canadians with acquired Deaf-Blindness and those who are congenitally Deaf-Blind. It is believed that this number underestimates the total Deaf-Blind population. This is due to the difficulty in reaching individuals with this dual disability. Further research is required to locate additional members of this population and to document the needs for Intervention and other services that are currently not being met. The information adds to the registry database, identifies and evaluates existing services that are available and accessible to persons who are Deaf-Blind and provides important quality of life data about the personal stories of the barriers and successes experienced by this population, their service needs and recommendations for additional services. It enhances significantly already published data on Deaf-Blindness in Canada. This project provides up-to-date and relevant information that will be maintained and continually updated by the Canadian Deaf-Blind Council (a joint body composed of the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association).

To complement the demographic information gathered during the course of the research, ten focus groups were convened across the country to collect quality of life data from persons who are Deaf-Blind and parents/advocates. During these sessions, consumers and parents overwhelmingly recommended that federal and provincial governments provide increased funding for comprehensive Intervention services for persons who are Deaf-Blind to facilitate their access to community services and daily living. Those communities that do not currently have Intervention programs, should put these initiatives into place. In addition, there is a need to decrease waiting times for services and to provide emergency pools of Intervenors for evening and weekend work (this applies to children, families and adults who regularly receive Intervention services during the day), medical and other emergencies and vacation times. Federal and provincial governments should increase funding for Intervenor Training Programs to expand the numbers of highly trained professionals working with those who are Deaf-Blind.

Consumers and parents/advocates pointed to the need for the implementation of public awareness programs to highlight the needs and capabilities of persons who are Deaf-Blind and to reduce the misconceptions among governments, the service sector and the general public about the uniqueness of this dual disability. In addition, respondents who are Deaf-Blind and parents/advocates identified the need for federal and provincial governments to implement assistive devices programs for those not currently involved in education or work to increase the quality of life for persons who are Deaf-Blind. This would provide increased access to information, enhance abilities to use the Internet and assist consumers to improve writing skills. Parents and consumers also expressed the need for increased information about assistive devices and the availability of training in the use of this type of technology.

This qualitative research gathered rich data in the form of personal stories of the barriers and successes experienced by Canadians who are Deaf-Blind. The study was limited in that it was based on estimated numbers collected from individuals and organizations believing they served members/clients/consumers who met the study definition of "Deaf-Blindness". A number of associations contacted declined to participate because they felt they did not have consumers/clients/members who met the study definition or were unwilling to devote sufficient time to gather the necessary information to respond to the questions on the demographic interview guide. Data were gathered primarily through telephone and e-mail interviews, since researchers were working from their homes and not required to travel. Perhaps more precise information could have been collected if researchers were located within the communities from which data were being gathered or the project had sufficient funding to enable them to travel to these locations. It should be pointed out, however, that the research was not intended to be a quantitative survey of the numbers of Deaf-Blind Canadians. The richness of the information gathered partially offsets the above-mentioned limitations.

As a result of the research, persons who are Deaf-Blind and their families will be made aware of available services and resources within their provinces and communities. Service providers will gain information about the extent of the Deaf-Blind community within their jurisdictions and about resource material available from the Canadian Deaf-Blind Council (CDBC). Provincial and territorial governments and their agencies will benefit from having an up-to-date survey of the Deaf-Blind population and the services available to these residents. This will help them determine if the existing services are sufficient, in quality and quantity, to meet the needs of the Deaf-Blind population.

It is the responsibility of the Canadian Deaf-Blind Council to advocate for the implementation of the recommendations documented in this report and of professionals, service organizations and the provincial and federal governments to implement them. There is a need for greater awareness among governments, professionals and the general public of the issues of concern to those who are Deaf-Blind. Most Deaf-Blind Canadians are still without Intervention programs or the services they receive are insufficient in quality and quantity to meet their needs. Medical, education, transportation, recreation and support for families should be increased, and assistive devices programs should be implemented in every Canadian province to enhance the quality of life for consumers who are Deaf-Blind. Too many Canadians who are Deaf-Blind remain unknown and unserved due to the absence of communication assistance. Only through advocacy and action on the part of persons who are Deaf-Blind and their organizations, families, professionals and others working in the field can the current situation of Deaf-Blind Canadians be alleviated. This research calls for the development of a comprehensive plan of action to meet the needs of this relatively unknown and under-represented segment of Canadian society.

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Appendix A
Definitions Contained in The Deaf-Blind Demographics And Services in Canada Report

Organizations

- **Canadian Association of the Deaf (CAD)** - A consumer organization of Deaf Canadians providing information, consultation and research related to issues of concern to those who are Deaf.

- **Canadian Centre on Disability Studies (CCDS)** - A consumer-directed, university-affiliated centre (located in Winnipeg, Manitoba) dedicated to research, education and information dissemination on disability issues.

- **Canadian Deaf-Blind Council (CDBC)** - An organization composed of the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). The CDBC was developed to be the holder of information from the Deaf-Blind Demographics and Services in Canada research and to initiate follow-up activities resulting from this initiative.

- **Canadian Deafblind and Rubella Association (CDBRA)** - An organization that began as a parent's organization representing individuals who were congenitally Deaf-Blind. Its mandate indicates it serves all Canadians who are Deaf-Blind.

- **Canadian Hearing Society (CCHS)** - An organization which serves and supports Deaf, Deafened and hard of hearing people, parents of Deaf and hard of hearing children and to educate the hearing public.

- **Canadian National Institute for the Blind (CNIB)** - An agency providing services to blind Canadians.

- **Canadian National Society of the Deaf-Blind (CNSDB)** - A consumer advocacy organization representing Canadians who are Deaf-Blind.

Definitions

- **Deaf-Blind -** A condition, which combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information; even though Deaf-Blind persons may still have varying levels of useful vision and hearing". Definition adopted from Manitoba Association of Persons who are Deaf-Blind.

- **Acquired Deaf-Blind** - A person has acquired Deaf-Blindness if they have become Deaf-Blind after the age of two years. Three types of Acquired Deaf-Blindness are recognized: 1) Pre-lingually Deaf with acquired vision loss; 3) Post-lingually Deaf with acquired vision loss; and 3) Congenital blind with acquired hearing loss.

- **Congenital Deaf-Blind** - A person is congenitally Deaf-Blind if they have become Deaf-Blind before the age of two years.

Communicators

- **Interpreter (ASL/English Interpreters)** - An ASL/English interpreter is knowledgeable in the signed language and the culture of Deaf and hard of hearing persons, and the spoken language and the norms of the (hearing) majority culture. In Canada, interpreters provide communication in both spoken English and American Sign Language (ASL).(Association of Visual Language Interpreters of Canada Website: http://www.avlic.ca/faq%20s.htm.)

- **Intervenor** - A trained professional who acts as the eyes and ears of a person who is Deaf-Blind. An Intervenor assists the person who is Deaf-Blind to communicate effectively and access information.

- **Intervention** - The process that allows an individual who is Deaf-Blind to receive meaningful visual and auditory information so he or she can interact with the environment and be enabled to establish and maintain maximum control over his or her life.

Living Arrangements

- **Respite Care** - Temporary care provided to a child who is congenitally Deaf-Blind (either in the person's home or elsewhere) to give the parents needed time away from their caregiver responsibilities to revitalize their energy.

- **Seniors Complex** - A "Seniors Complex" is an apartment complex where seniors live independently in their own apartments. Some provide support services such as meals, house cleaning, personal care, etc. while others do not.

- **Supported Independent Living Residence** - A "Supported Independent Living Residence" is defined as a housing facility for those who are Deaf-Blind which provides support services to residents. Examples of support services include:

Intervenor services, meal preparation, personal care assistance, etc. These facilities are not personal care homes or group homes. Rotary Cheshire Housing located in Toronto, Ontario or the Deaf Centre Manitoba in Winnipeg are examples of this type of housing.

Communication Methods:

Sources: Advisory Committee members, National Registry Report and "Independence Without Sight or Sound: Suggestions for Practitioners Working With Deaf-Blind Adults" by Dona Sauerburger, American Foundation for the Blind, 1993.

- **Adapted Sign Language** - Used by a person with Deaf-Blindness who places their hands over the hands of the signer to feel the hand movements that indicate words, actions or letters. Also used by persons who are Deaf and have little to no vision. This is also called hand over-hand communication or tactile sign language. In hand over hand communication or tactile sign language, the person who is Deaf-Blind places his or her hands over the signer's hands and receives information through hand movements either in ASL, Signed English or Signed Exact English.

- **American Sign Language (ASL) -** ASL involves a set of signs to indicate letters, words, etc. ASL does not use English word order but has its own structure, syntax and rules. One form of Sign Language is Tactile ASL (See "Adapted Sign Language" above.)

- **Augmented Communication -** Components, techniques, strategies, etc. to augment speech communication in people who have very limited speech capability. This augmentation may involve varying symbol systems, e.g. sign language, pictographs, icons, etc.; sometimes technological applications, e.g. access/interfaces, computers, voice output technology, enlarged screens, etc.

- **Braille - Grade 1**- A system of raised dots that indicate letters of the alphabet. Also called uncontracted braille.

- **Braille - Grade 2** – A system where words are contracted using the embossed/raised dots of braille. Used by persons whose severe vision loss prevents them from reading print, even with magnifiers. Also called contracted braille.

- **British Two-Hand Manual** - A tactile system of spelling each word by tapping different points on the palm of the person who is Deaf-Blind. This communication method is used by sighted Deaf people

- **Closed Caption Decoders -** Are used to pick up captions transmitted over the TV cable which are hidden from view without the decoder. The text of some programs are available for access to television if the person has enough vision to catch the main idea of the program. Another type of captioning is called "Real

Time Captioning", which is a word for word communication and is used in settings where word for word communication is needed. It can be used on a personal laptop computer for one person to view or projected onto a large screen for many people to view.

- **Computerized Note taking** - A note taking system that involves typing into a computer the content of verbal communication. It is not word for word communication. The text of the communication is projected on to a computer screen. This method can be used one on one or projected.

- **Gestures** - Are usually a personally created system of body and hand movements developed by family members or institutional care workers and used with individuals who have not yet developed the ability to use a formal sign language.
-
- **Large print -** Print where the font size has been increased. This type of print can also be placed on a white board or on paper . This is popular with many individuals with low vision.
- **Manual Alphabet** – Is finger spelling where each letter of the alphabet has a finger shape. Used by many persons who are totally Deaf-Blind.

- **Other skills (unspecified)** - Could be Morse Code tapped onto the hand or a vibrating disk. Cued speech is lip reading with hand movements to indicate sounds of speech not indicated on the lips. Tadoma is a method where the person with Deaf-Blindness places their thumb on the lips, index finger on the jaw and the three curled fingers on the throat of the speaker to “read” their speech.

- **Pocket Talker** - A one on one communication device. The person using this device does not wear a hearing aid but instead uses a headset. The person communicating must speak directly into a microphone which goes directly to the headset.

- **Print on Palm (POP)** - A communication method that involves printing letters on the palm of a person who is Deaf-Blind.

- **Signed Exact English (SEE)** - A communication method developed by educators who wanted Deaf children to learn English with English grammar. In this communication method, English word order is utilized and finger spelling is employed to sign letters of the alphabet, etc. Some English words do not have specific ASL signs associated with them. Thus, a codified method had to be invented or adapted with use of ASL signs but in English word order. Even though many signs are the same as those used in ASL, this system is not the same as the method of signing naturally as developed by the Deaf community.

- **Preferred Signed English or PSE -** This is another form of ‘Signed Exact English’. This is a combination of pure ASL and signed exact English. Many people who use PSE make their signs while thinking or speaking in English, leaving out words with no ASL equivalents. (Examples are words such as "the or a"

- **Speech** - Can be expressive and/or receptive and means that the person with Deaf-Blindness once heard or still can hear, through amplification, and is usually augmented by lip reading.

- **Tellatouch** – A mechanical typewriter-type keyboard with the addition of six keys. It is used by persons (who know how) to write braille to communicate with a Deaf-Blind braille reader. The reader places their finger on one braille cell (letter) to receive the message from the person typing out a message. It is a valuable aid for a person who is Deaf-Blind and a braille reader, when travelling alone or in hospital. This machine is no longer produced.

- **TeleBraille** - A telephone device similar to the Tellatouch but has a braille display for persons who are Deaf-Blind and able to read braille.

- **TTY-TDD (Teletype or Telephone Device for the Deaf)** - Are typical keyboard devices with printer displays which connect to the telephone line by an acoustic coupler for the telephone receiver or directly connected to the telephone line by a jack. Messages are typed back and forth to another similar machine; or to the telephone relay operator, who voices the transmitted message to the hearing person being called and keys back the hearing person’s message to the Deaf-Blind person’s device. Some TTYs have large monitors or displays.

- **Writing/Printing** - Used by a person who is Deaf-Blind (Deaf with some remaining vision) to communicate with persons who do not know the Deaf-Blind person’s communication system.

Communication Devices

- **AlertMaster -** A device that vibrates or includes a light to let a person who is Deaf-Blind know when someone is at the door, that the fire alarm is ringing, it is time to wake up, etc.

- **Braille Writer** - A mechanical device with 6 keys and space bar that embosses on braille paper the dots that symbolize letters of the alphabet. The most common mechanical device is the sturdy and heavy Perkins Braille writer.
- **Braille Note QT** - A devise/system which allows a person to type in a preferred language and the person who is Deaf-Blind person can read the typed words in Braille on the device. The person who is Deaf-Blind can type in Braille and the message can be received in the originating language.
- **CC TV Reader (Closed Circuit TV readers)** - A camera that magnifies print (up to 60 times) onto a TV-like screen, with the option of converting the text to the

negative mode (white print on a black background), which is preferred by many people with low vision. This device costs approximately $3,000.

- **Cochlear implants** - Are made up of a microphone placed outside the ear and a processor implanted inside the ear. The processor selects and codes sounds so the brain will understand them. The "messages" are sent directly to the brain, bypassing the parts of the inner ear that don't work. Cochlear implants are now being sought by more persons with Deaf-Blindness.

- **Computer with adapted software -**These are regular computers with are equipped with adaptive software such as a screen reader (a speech program that read the computer screen) or Zoom Text (a program which enables an individual to read the screen using large print). Computers can also be equipped with braille displays which enable individuals who are Deaf-Blind to use braille to read what is on the computer screen.

- **FM/Infrared system** - An amplification sound system with an Infrared or FM transmitter connected to it, and provides hard of hearing persons with compatible receivers to hear a sound track, a performance in theatres and auditoriums, or a church service, etc. directly, and without receiving noises from the audience.

- **Hearing aids -** Used by many people with residual hearing to hear speech, sirens, and environmental sounds. This ability to hear sounds provides persons who are Deaf-Blind with some awareness of the world around them and greatly assists them with their safety. Some hearing aids include built-in FM systems. These devices are called Micro Links. Some FM systems have wireless receivers which clip onto the hearing aids to received signals from FM microphones. These FM receivers draw power from batteries inside the hearing aids.

- **Internet -** A system for individuals to electronically connect with people, via a computer, and obtain information via the World Wide Web. Unfortunately many people with Deaf-Blindness do not have access to training or the resources to purchase a computer to access the Internet.

- **Large Print** - Print that is larger than the standard 12 point font.

- **Magnifiers** - Devices used to magnify print. These include both hand and stand varieties and come in various sizes. Some are equipped with lights.

- **Monoculars** - Ocular devices used outside to read street signs and numbers or used inside to read chalk boards.

- **Pocket Talker** - See Communications Systems above.

- **Slate and Stylus** - A metal or plastic plate with a frame to hold braille paper. The user uses a stylus (a blunt metal rod with a knob) to impress the combination of Braille dots used to indicate letters, etc.

- **Telephone with Volume Control** - These are regular telephones that are equipped with a knob to control the volume to increase the level of sound that can be heard when speaking to a caller.

- **TellaBraille** - See Communication Systems above.

- **Tellatouch**- See Communication Systems above.

Video Camera with LCD Display - A stand-mounted or hand held video camera to project a magnified image onto a video monitor or a television (TV) screen.

Appendix B Media Kit

Appendix B- 1 Fact Sheet: What is Deaf-Blindness?

What is Deaf-Blindness? A condition that combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information; even though Deaf-Blind persons may still have varying levels of useful vision and hearing.

Also known as dual-sensory impairment, multiple-sensory impairment and Deaf/visually impaired, persons identified as Deaf-Blind may have varying levels of vision and hearing capabilities.

Deaf-Blindness is a unique and complex disability.

Categories of Deaf-Blindness

a) Congenital Deaf-Blindness
Persons with congenital Deaf-Blindness have minimal or a complete absence of vision and hearing at birth, or they lose their hearing or vision before (approximately) age two.

Some causes of congenital Deaf-Blindness include:

Prenatal insults - e.g. Rubella virus (German measles), and Cytomegalovirus
Complications resulting from prematurity
Congenital brain damage
Early childhood infections (e.g. Meningitis - caused by bacteria or viruses, resulting in an infection of the meninges, the membrane that covers the brain and spinal cord like a sheath) causing encephalitis (an inflammation of the brain)
Rare chromosomal and unknown disorders (e.g. CHARGE Association - a specific pattern of birth defects. The acronym is: "C" for coloboma, "H" for heart defects, "A" for

atresia choanae, "R" for retardation of growth and development, "G" for genitourinary problems, and "E" for ear abnormalities)
Many from unknown causes

b) Acquired Deaf-Blindness
1) Many individuals with acquired Deaf-Blindness are born Deaf, or become Deaf or hard of hearing before (approximately) age two and subsequently lose their vision.

Typically, the cause of this type of Deaf-Blindness is Usher Syndrome - a genetically inherited condition where hearing loss is usually the first symptom, followed by vision loss. Retinitis pigmentosa (tunnel vision) is the cause of the visual loss.

There are several types of Usher Syndrome. Most individuals with Usher Syndrome are categorized as Type 1, and fit the description described above (born Deaf and then acquire vision loss).

The incidences of Types 2 and 3 Usher Syndrome in the population are growing. In Type 2, persons are born hard of hearing and acquire vision loss. Those with Type 3 are born with normal or near normal hearing, which deteriorates over time together with their vision. Vision loss in both types of Usher Syndrome is caused by Retinitis pigmentosa.

2) Other individuals acquire Deaf-Blindness through:
Accidents (e.g. acquired brain injury);
Aging: Deaf-Blindness through aging refers to people who develop varying degrees of vision (often from macular degeneration) and hearing loss later in life as a result of the natural aging process;

- Diabetes; Infections in childhood.

3) Some individuals with acquired Deaf-Blindness are born blind or visually impaired and acquire their hearing loss later in life.

Status of Deaf-Blindness in Canada
Many of Canada’s congenitally Deaf-Blind individuals were born during the Rubella outbreak of the 1960s and early 1970s. Those individuals are now adults and require specialized services related specifically to Deaf-Blindness and late manifestations of congenital rubella syndrome.

The Canadian Deafblind and Rubella Association maintains a registry of 777 individuals with Deaf-Blindness as part of a study undertaken between 1999 and 2001.

Some estimates say Deaf-Blindness can be found in approximately one in every 300,000 Canadians. It is believed there are thousands more unidentified Canadians with Deaf-Blindness, mostly elderly people who are losing their sight and hearing.

The relative progress that persons with Deaf-Blindness achieve in their life, including their quality of life, is highly dependent upon the time of onset of the disability and the amount of support that they receive.

Common challenges faced by persons with Deaf-Blindness often include (extreme) isolation, lack of access to information such as 'the news', the ability to engage in daily tasks, mobility limitations and feeling unsafe to go into the community alone. Consequently, persons with Deaf-Blindness are often lonely, lack self-esteem and demonstrate an absence of purpose to their lives**.**

How can people with Deaf-Blindness function in society?

Human rights laws guarantee adequate services and support for those who are blind and Deaf, but very few of these services can support the needs of the Deaf-Blind person.

Whether congenital, acquired or developed through the aging process, Deaf-Blind individuals have specialized needs and have a right to appropriate individualized services.

To function independently, people with Deaf-Blindness require:

- Intervenors or communicators, who are trained to be their eyes and ears and who help people with Deaf-Blindness interact with their environment and communities;
- Specialized housing with architectural features developed for individuals who are Deaf-Blind (such as Rotary Cheshire Homes in Toronto; Lions-McInnes House in Brantford, Ontario);
- Hearing aid equipment;
- Dog guides;
- Sound monitors;
- Advanced computer technology to access information on the Net.
- Communication devices such as TTYs (teletypewriter);
- Braille translating equipment;
- Computers with speech translation production and large-print capabilities;
- Services that are available from local Deaf-Blind service organizations such as the Provincial Chapters of the Canadian Deafblind and Rubella Association (CDBRA) and the Canadian Helen Keller Centre (CHKC).

The Canadian National Society of the Deaf-Blind (CNSDB), and the Canadian Deafblind and Rubella Association (CDBRA), also advocates for better services for individuals with Deaf-Blindness.

Appendix B-2
Fact Sheet: 10 Signs That a Loved One May Have Deaf-Blindness or Combined Hearing and Vision Loss

It is estimated that there are thousands of unidentified Canadians with Deaf-Blindness, many of whom are elderly and losing their sight and hearing.

Does someone you know have any degree of hearing loss combined with any degree of vision loss that interferes with communicating and getting information? If so, does this person:

1. Interrupt or speak out (verbally or using Sign Language) at the wrong time because they can't hear or see what's being said?
2. Frequently ask you to repeat yourself?
3. Continue speaking when they are unaware that the person has left the area?
4. Touch you to get your attention?
5. Have difficulty interacting in group settings, such as parties or meetings?
6. Sit closer and turn up the volume on the television?
7. Move you away from strong lights or windows so they can see better, or experience difficulties seeing in dimly lit rooms?
8. Trip or knock over things at home, or walk as though they are dizzy or unbalanced?
9. Forfeit activities they used to enjoy such as talking on the phone, going to movies or knitting?
10. Hold printed materials very close to their eyes?

Consequences of Deaf-Blindness can be distressing for individuals and may include the following:

1. Isolation due to lack of communication and limited access to information;
2. Fear of going out, socializing or a general lack of enjoyment of life;
3. Inability to perform daily tasks such as shopping, grooming, care of their home, and difficulty eating;

4. Lack of self-confidence;

5. An absence of purpose.

Human rights laws guarantee adequate services and supports for those who are blind and for those who are Deaf, but very few of those services can support the needs of the Deaf-Blind person.

The Deaf-Blind population in Canada has a right to appropriate services and adequate support. This includes an Intervenor who acts as their eyes and ears, allowing them to communicate, develop and maintain skills and be full participating members of society.

Appendix B-3
Fact Sheet
Study of Deaf-Blind Demographics and Services in Canada

The Canadian National Society of the Deaf-Blind, in partnership with the Canadian Deafblind and Rubella Association, is conducting a Study of Deaf-Blind Demographics and Services in Canada.

This project, which is funded by the Government of Canada's Social Development Partnership Program, will be completed by June 2004.

The Canadian Centre on Disability Studies (CCDS) has been contracted to assist with the research. CCDS is a consumer directed, national disability organization located in Winnipeg, Manitoba. Because the representatives from the sponsoring organizations involved in this initiative did not have the necessary research skills, the Management Team and Advisory Committee contracted with a bona fide research organization to coordinate all research-related activities. This ensured the study was ethically sound and increased the validity of the study.

The purpose of this project is to:

- Produce a directory of resources containing detailed information about the approximate population and demographics of persons in Canada who are Deaf-Blind;
- Make available a list of accessible services and resources;
- Compile commentaries on the current status of this disability and future directions.

How will Deaf-Blind persons benefit from this project?

Persons who are Deaf-Blind will be made aware of available services and resources within their province and communities.

Service providers will be made aware of the extent of the Deaf-Blind community within their jurisdiction and of available resource material in the future from the Canadian Deaf-Blind Council (CDBC), an organization representing CDBRA and CNSDB.

Provincial and territorial governments and their agencies will benefit by having an up-to-date survey of the Deaf-Blind population and the services available to these residents. This will help them determine if the existing services are sufficient, in quality and quantity, to meet the needs of the population.

Study framework:
Research Assistants are being hired to collect demographic information in British Columbia and the Yukon, Alberta/Nunavut and the Territories, Manitoba, Northwestern Ontario, Southern Ontario, Quebec and the Atlantic Provinces.

Focus Group meetings for persons who are Deaf-Blind are being planned for Vancouver, Calgary, Winnipeg, Sudbury, London, Montreal and Halifax. Focus Group meetings are also planned for parents/advocates of individuals who are congenitally Deaf-Blind in Calgary, Toronto and Montreal.

The purpose of focus group meetings is to obtain qualitative information about Deaf-Blindness through documenting personal stories of the barriers and successes experienced by persons who are Deaf-Blind and their parents/advocates. These meetings will be limited in participation to eight persons and are intended to encourage openness and sharing. The results of these meetings will complement the quantitative information from the demographic research portion of the study.

Service providers will be contacted across Canada to document such things as types and amount of services provided, service needs and plans to expand services, staff training and gaps in service.

Collecting demographic information:
Demographic researchers in their assigned area will gather information on the numbers and location of persons who are Deaf-Blind, along with additional pertinent demographic information including age categories, probable causes of the disability and living arrangements.

This information will be obtained through telephone, e-mail and in-person interviews with administrators, directors of community organizations, disability groups that serve people who are Deaf and/or blind, Deaf-Blind individuals, seniors residences and medical associations.

Appendix B-4
Media release “Deaf-Blind Demographics and Services in Canada”

The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart.
Helen Keller

FOR IMMEDIATE RELEASE

FIRST MAJOR NATIONAL DEMOGRAPHIC STUDY ON DEAF-BLINDNESS IN CANADA

This Project is funded by the Government of Canada's Social Development Partnership Program

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Toronto – February 26, 2004 – The Canadian National Society of the Deaf-Blind in partnership with the Canadian Deafblind and Rubella Association, has launched the first major national demographic study on Deaf-Blindness in Canada.

The objective of this project is to produce a report and directory of resources containing detailed information about the demographics of persons in Canada who are Deaf-Blind, a list of accessible services and resources, commentaries on the current status of this disability and future directions. The study, which will continue until June 2004, is being funded by the Government of Canada's Social Development Partnership Program.

"Human rights laws guarantee adequate services and supports for those who are blind and Deaf, but very few services support the unique needs of the Deaf-Blind person," says Jane Sayer, president of the Canadian National Society of the Deaf-Blind and who herself is profoundly Deaf and legally blind. "This study will help us determine the extent of the Deaf-Blind community in Canada and inform Deaf-Blind persons and their families of the services available to them."

BACKGROUND ON DEAF-BLINDNESS:

Persons are considered Deaf-Blind if they have a combination of any degree of hearing loss with any degree of vision loss that interferes with their communication and ability to acquire information, even though these persons may still have varying degrees of useful vision and hearing.

Deaf-Blindness may occur at birth (congenital) or later in life (acquired) through accidents, disease or aging.

DEAF-BLINDNESS IN CANADA:

Deaf-Blindness is a unique and complex disability affecting thousands of Canadians. Persons with Deaf-Blindness can be described as having acquired or congenital Deaf-Blindness. The causes of Deaf-Blindness are numerous. The leading cause of acquired Deaf-Blindness is aging, while most of Canada's congenitally Deaf-Blind individuals were born during the Rubella outbreak of the 1960s and 70s and are now adults requiring special services. Although Rubella is now rare in Canada, babies continue to be born with Deaf-Blindness from other causes.

(Some estimates say Deaf-Blindness can be found in approximately one in every 3,000 Canadians). There are thousands of Canadians with acquired Deaf-Blindness who have not been identified, whose needs are not being addressed and who are not aware of the services available to them. Persons with Deaf-Blindness are among the most isolated and under-served population in Canada.

HOPE LIES IN INTERVENTION:
To function independently in Canadian society, Deaf-Blind individuals need Intervenors or communicators who are trained to be their eyes and ears and who help people with Deaf-Blindness communicate effectively and access information. Communication is individualized, based on the specific needs and abilities of each person, so Intervenors utilize the specific mode of communication that is preferred by each person with Deaf-Blindness.

STUDY OBJECTIVES:
- To determine an approximate population of individuals in Canada who are Deaf-Blind;
- To track and document existing services for individuals who are Deaf-Blind across Canada;

To inform provincial and territorial governments and their agencies about the population of those who are Deaf-Blind and the services currently available to them;
To inform service providers about the extent of the Deaf-Blind community in their jurisdiction;
Ultimately, to inform persons who are Deaf-Blind about the available services and resources within their province and communities.

BACKGROUND ON THE STUDY PARTNERS:
The Canadian National Society of the Deaf-Blind (CNSDB) is partnering with the Canadian Deafblind and Rubella Association (CDBRA) to conduct the demographic study. CNSDB is a consumer/advocacy group representing individuals who are Deaf-Blind. The CDBRA is an advocacy/service organization primarily representing people with congenital Deaf-Blindness.

Together, these two organizations make up the Canadian Deaf-Blind Council (CDBC). The objective of the Canadian Deaf-Blind Council is to operate as a resource centre for information relating to Canadians who are Deaf-Blind.

The Canadian Centre on Disability Studies (CCDS) has been contracted to assist with the research. CCDS is a consumer directed, national disability organization located in Winnipeg, Manitoba.

The mission of CNSDB is to:
- Advocate for new and improved services for persons who are Deaf-Blind;
- Promote public awareness of issues affecting persons who are Deaf-Blind, and;

- Gather and distribute information that will assist persons who are Deaf-Blind to become full participants in society.

The CDBRA is committed to assisting all persons who are Deaf-Blind to achieve, with Intervention, the best quality of life. CDBRA supports:
- the development and understanding of the philosophy of Intervention
- a wide range of advocacy efforts, and;
- programs to meet the needs of individuals who are Deaf-Blind, their families and professionals in the field of Deaf-Blindness.

For more information, or to arrange an interview with Jane Sayer, President of the CNSDB or Linda Mamer, President of CDBRA, contact Christine Mulkins/Tamara Blitz-Miller, 416-967-3702. For other inquiries about the study or about Deaf-Blindness, contact the Canadian Deaf-Blind Council at 1-866-420-7925.

Appendix C Research Instruments

Appendix C-1 Ethical Review Guidelines

To be completed by Principal Investigators for all studies which involve work with participants, and/or the analysis of data collected from individuals where such data are not commonly available to the public.

The Questions on this form are of a general nature designed to collect pertinent information about potential ethical problems that may arise with the proposed research project. Please provide the CCDS Ethical Review Sub-Committee with the project proposal and your consent form.

Title of Project:

"A Study of Deaf-Blind Demographics and Services in Canada"
Principal Investigator: Michelle Owen

1. Objectives of Study:

The project will produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind, (2) an overview of the experiences (including personal stories of the barriers and successes) and service needs of persons who are Deaf-Blind and their parents/advocates, (3) an overview of the services available in Canada to meet the needs of persons who are Deaf-Blind and parents/advocates and (4) directions for future research.

Throughout the project, an ongoing awareness campaign will be conducted to raise the profile of Deaf-Blindness across the country and interest Deaf-Blind persons and parents/advocates in participating in the research. As part of this awareness initiative, material about Deaf-Blindness and the project will be developed under the guidance of the management committee and project advisory committee.

2. Data Collection

A. What data are being collected? Biographical data (lived experiences in employment or barriers to accessing primary health care, etc.)

Qualitative and quantitative data about the demographics of persons in Canada who are Deaf-Blind; quantitative analysis of secondary data sets from Statistics Canada's 1991 HALS or 2001 PALS Surveys relating to the numbers of people in Canada with both hearing and seeing disabilities; qualitative data about the experiences and service needs of persons who are Deaf-Blind and parents/advocates; qualitative and quantitative data on the services currently available to meet the needs of persons who are Deaf-Blind and parents/advocates and information about the communication tools utilized by participants who are Deaf-Blind.

B. How will the data be collected? (Focus group, survey, questionnaire, structured interviews, unstructured interviews, participant observation, interview guide, other (e.g. journal or diary, personal narrative), etc.

(a) To collect demographic information about Canadians who are Deaf-Blind, in-person, telephone, TTY or e-mail interviews will be conducted with representatives of organizations likely to be in contact with persons who are Deaf-Blind e.g. seniors' organizations, personal care homes, doctors' offices, medical associations, agencies that provide services to persons who are Deaf or blind, disability organizations, community associations, etc. A statistical analyst will conduct secondary analysis of data sets from Statistics Canada's 1991 Health and Activity Limitation Survey (HALS) or 2001 Participation and Activity Limitation Survey (PALS).

(b) To collect data on the experiences and service needs of people who are Deaf-Blind and their parents/advocates, focus groups will be conducted with persons who are Deaf-Blind in six regions of Canada and with parents/advocates in three regions.

(c) To collect data on services available to persons who are Deaf-Blind and parents/advocates, telephone interviews will be conducted with staff of agencies that provide services to persons who are Deaf-Blind and their parents/advocates.

3. Procedures: Please outline procedures to be followed in data collection:

A. How will informed consent be obtained?

Focus group participants and individual interviewees will be required to complete consent forms prior to participating in focus groups or being interviewed. Consent forms are attached. Participants will be able to ask questions about the research prior to signing the consent forms. The forms explain that participants may contact the research coordinator for further information or clarification prior to their focus group or interview.

Once demographic and focus group research assistants have received their consent forms from the research coordinator, they will distribute these forms (along with accompanying interview guides) to participants via e-mail. Participants in the focus groups will return their signed consent forms to the research assistants at the time of their focus groups. Participants in the demographic research will have the option of returning their signed forms by fax to the research assistant or can indicate agreement to participate in the study by e-mailing the research assistant. Consent forms for service provider interviews will be distributed to participants by the project coordinator who will be conducting the interviews. The signed consent forms will be returned to him by fax.

B. How will you make it clear to participants that their participation is voluntary and that they may withdraw from the study at any time without penalty?

Participants will be informed prior to participating in focus groups or interviews that they are free to withdraw from the study at any time without penalty by contacting the researchers. They can also contact the research coordinator. A statement to this effect appears on the consent forms, and they will be informed verbally at the beginning of focus group meetings or interviews.

C. Who will have access to the gathered data and how will this be communicated to participants?

The principal investigator, the project coordinator, the research coordinator and the research assistants conducting the focus groups and interviews will have access to the gathered data. Participants will be informed of this fact prior to participating in focus groups or interviews, and a statement to this effect appears on all consent forms.

D. How will confidentiality be maintained?

Prior to participating in focus groups or interviews, participants will be informed that their responses will be kept confidential, with no names being included on any transcripts (participants will be identified by participant codes) or included in the project report. The names of participants in the demographics research will not be stored with the aggregated data. Statements to this affect appear on all consent forms along with a statement that researchers must obtain the permission of participants before utilizing any quotes that have been attributed to them. Focus group participants are also asked to keep confidential all information shared within the group.

E. How will data be recorded? (Instruments, notes, etc.)
Notes of the proceedings of focus groups and individual interviews, as well as the results of contacts made by the demographic research assistants will be kept. Focus groups and interviews will also be tape recorded for easier transcription. Focus group and interview transcripts and results of contacts made by the demographic research assistants will be kept in paper format and analyzed along with the focus group and interview data.

F. How will data be stored? (For how long, when will it be destroyed, etc.)
Data from focus groups, interviews and demographic research will be maintained in a locked filing cabinet at CCDS for three years following conclusion of the project and then will be destroyed. Tapes of focus groups and interviews will be destroyed once they have been transcribed.

G. What are the plans for future use of data as part of this study or future projects?

The data will be aggregated into a report which will be provided to the funder, Human Resources Development Canada and will be disseminated by the partner organizations (the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association) to all participants in the study. This document will also be provided to agencies and organizations serving Deaf-Blind Canadians and parents/advocates (including the Deaf-Blind Council), disability associations, community groups, governments, etc. A website will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations.

H. Will participants be paid for time spent taking part in the research study?

Participants who are Deaf-Blind and parents/advocates will be provided with honorariums of $50 each for participating in focus groups.

What are the potential benefits to participants from being involved in the research?

Persons who are Deaf-Blind and parents/advocates will be made aware of new services within their provinces and communities to meet their needs. Participants will be able to identify their unmet service needs and the barriers and successes to community involvement. This information can be utilized by the partner organizations in advocacy efforts with provincial, territorial and federal governments. Service providers will be made aware of the extent of the Deaf-Blind community within their jurisdictions and of the availability of resource materials from the partner organizations and the Deaf-Blind Council

(a) What are the costs to participants (e.g. monetary, time, inconvenience, effort)?

Participants will contribute their time to the focus groups or individual interviews and may have additional costs associated with their disabilities, transportation or child care. Disability supports (such as Intervenor services) will be covered by the project, and those who have child care expenses will be reimbursed for these costs. Participants will receive an honorarium which can be utilized to cover their transportation costs.

K. Is there a risk to participants from being involved in the research? If yes, what is the nature of the risk?

No particular risks are foreseen to the participants. The views of focus group participants will be aired in a group setting and thus the researchers cannot positively assure confidentiality. This may pose a risk for some participants.

L. What actions do you plan to take to minimize risks?

Focus group participants will be asked to keep all information confidential within the group.

Signature of the Principal ____

Appendix C-2 Guidelines For Focus Group Research Assistants

January 2004

This document will outline some tips which will be helpful to you in recruiting participants, preparing for your focus group, organizing and conducting the group, analyzing the findings and writing your report to the research coordinator.

Claiming Research-Related Expenditures

1. You will be reimbursed from project funds for the costs of telephone, fax, postage, refreshments for the focus group, facility rental for the meeting (where the facility is not able to bill the project directly for room rental costs) and disability accommodations (such as Intervenor services and ASL Interpreters) incurred by the focus group facilitator while recruiting participants and organizing the session. costs will be covered up to a maximum of $500 for the above-mentioned items when supported by a claim. Please forward details of these costs to Colleen Watters, Research Coordinator by e-mail (wattersc@mts.net) who, in turn, will advise the Project Coordinator, Stan Munroe, that a request for reimbursement will be forthcoming. Please send your bills to Stan Munroe, Project Coordinator, for reimbursement. Expenditures which fall outside the approved list must be discussed with Stan or Colleen prior to requesting reimbursement.

Stan's mailing address is: 1658 4th Avenue W., Owen Sound, Ontario, N4K 4X4. His e-mail address is: stan.munroe@sympatico.ca.

The costs of Intervenors, Interpreters, note takers and other communication needs of participants will be billed directly to the project.

Recruiting Participants

A good number of people for a focus group is six to eight persons. Having more than the ideal number will make it more difficult to manage the discussion and to provide all participants with an opportunity to speak. Having fewer than the ideal number will limit the range of opinions represented and may result in gaps occurring in the discussion.

If you are facilitating a focus group for persons who are Deaf-Blind, locating six to eight individuals for the group would be ideal. The goal of the project is to reach a majority of people with acquired Deaf-Blindness and seniors, in particular seniors 55 years of age and over. A good way to recruit participants is to contact organizations of Deaf-Blind persons, associations of individuals who are blind such as the CNIB and group of Deaf individuals in your region. Groups of parents/advocates of persons who are Deaf-Blind will also be helpful in locating those with congenital Deaf-Blindness. Disability organizations and seniors groups will be other important sources through which to recruit participants.

If you are facilitating a group for parents/advocates of persons who are Deaf-Blind, associations such as the Canadian Deafblind and Rubella Association and organizations of parents of children with disabilities may be helpful.

We are looking for eight parents/advocates of persons who are congenitally Deaf-Blind to participate in this focus group.

Whether you are facilitating a group for consumers or parents/advocates, knowledge of the Deaf-Blind and parent/advocate communities in your region and word of mouth methods can also be useful recruiting methods.

The research coordinator will provide you with a sample recruitment letter, which you can adapt to your region. The coordinator and project advisory committee members in your region will also assist in recruiting. Individuals who are interested in participating in the focus group should be invited to contact the research assistant for further information.

When recruiting participants who are Deaf-Blind, it will be important to reach individuals representing different age groups. These include younger adults over the age of 18, persons who are middle aged and seniors. Both males and females should also be included. In order to be part of the focus group, individuals must be 18 years of age and over, have good communication skills and be capable of understanding the content of the focus group.

Make sure you have contact information for each participant, name, address, telephone/TTY number, e-mail address, etc. This will enable the research coordinator to arrange for their honoraria to be sent out to them following the focus group and for them to receive a copy of the research report. Explain that the contact information will be kept by the researchers but that it will not be given out to anyone else.

The coordinator will check in with you to find out how the recruitment of participants is progressing and will offer whatever assistance she can. She will also draw on the expertise of the advisory committee to help recruit suitable individuals for the group.

The coordinator will provide you with the focus group questions and consent forms to distribute to participants prior to the focus group. If anyone requires braille or other alternate format materials, please advise her. She will ensure that these are made available to you to distribute to the participants.

Prior to the Focus Group

1. Book a facility for the focus group. This can be done in consultation with the research coordinator, as she will have information on locations, which have agreed to host the project and can make the contact. The room where the focus group takes place should be large enough to comfortably accommodate six to eight participants, the facilitators, Interpreters, Intervenors, translators (where applicable) and note takers as well as observers from the advisory committee. The room should have good lighting and be close to washrooms.

2. You will need to book Interpreters, Intervenors and translators. This can be done in consultation with the research coordinator. She will draw on the expertise of a member of the Advisory Committee to assist her in this regard.

3. Arrange for coffee, tea, juice, soft drinks, water and snacks. You may be able to do this with the facility in which the focus group will be held, as they may be able to supply food and drinks. In that case, the bill can be made out to CNSDB and sent to Stan Munroe, project coordinator who will forward it for payment.

In situations where the focus group location cannot supply food and drinks, you can purchase them yourself and then forward the bill to Stan Munroe, project coordinator, who will forward it to CNSDB for payment. If this is difficult for you, contact the research coordinator who will make individual arrangements with you to receive a cheque in advance to purchase food and drinks. .

Since it is a two-hour focus group, cookies, juice, soft drinks, water and coffee and tea (if there is a coffee maker and a kettle available) will be enough.

4. Arrange for a display table for CNSDB/CDBRA brochures, newsletters and other information such as a registry form. (See "Wrap-Up for more details).

5. If companions, Intervenors, etc. come to the focus group with participants who are Deaf-Blind, let them know that the session will last two hours. The persons who accompany them are free to do errands or whatever else they wish during that time. If the companions, Intervenors, etc. wish to stay, book a separate room in the facility

where the focus group is taking place so that they can be comfortable. They cannot participate in the session because this group is for Deaf-Blind persons only. If companions stay in the room where the focus group is taking place, participants may feel less comfortable about sharing information with one another.

Set-up

1. Ensure the room and chairs are arranged so that everyone in the group is comfortable and interpreters and Intervenors are positioned in such a way that everyone can see them. The room must have adequate lighting so that the participants can easily see the Intervenors, Interpreters, note takers, etc.

2. Ensure the tape recorder has been set up to record the session and that tapes and batteries are available. You also need to make sure the recorder is working properly. If research assistants do not have tape recorders with external microphones, the research coordinator will arrange to supply these through the project. Tape recorders with external microphones make good-quality recordings that can be transcribed. Recordings made on portable cassette recorders with built-in microphones are of poorer quality and will make it more difficult to transcribe the focus group.

3. It may be useful to have someone else take notes of the main points from the session so that you have a back up in case the recorder isn't working. The notes will also assist you when you are writing up a summary of the main points from the focus group. Since you will be facilitating the session, it may be difficult for you to take notes as well.

Good note takers should be individuals who can easily follow the flow of the discussion and be able to draw out the main points raised by the participants in answer to the focus group questions.

4. Note takers will receive a $50.00 honorarium following the session.

5. Make sure participants have copies of the focus group questions. Even though the questions will have been distributed ahead of time in formats accessible to the participants (braille, large print, computer disk, etc.), extra copies should be provided for those who may have forgotten to bring their copies with them.

Consent

1. Make sure participants have copies of the consent form and have signed it before the focus group begins. It will be helpful to go through the items on the form and ensure that these are understandable by everyone. Please sign the form as the researcher. Each participant should keep a copy of the form and the researcher should also keep a copy to send to the research coordinator with a summary of the main points from the focus group. If participants are not able to sign a print consent form, verbal consent will be accepted if communicated when the tape recorder is running. This includes verbal consent communicated by participants with the assistance of Intervenors, interpreters, translators, etc.

Facilitating the Focus Group

Preliminaries

1. Before the focus group begins, explain where the washrooms are, that there is food and drink available and identify the various communication methods provided for the session. These include: note taking equipment, Interpreters/Intervenors, etc. If there are translation services available, these should also be outlined.

2. Explain the purpose of the research, what we hope to find out, what will be done with the data and that participants will receive a copy of the final research report. (See attached for a description of its purpose and what we hope to find out.)

3. Explain the purpose of the focus group and what we hope to get out of the group. (See a description of the research for an outline of what we hope to achieve from the focus group. Explain that groups for persons who are Deaf-Blind are taking place in the following cities across Canada: Vancouver/Lower Mainland, Calgary, Winnipeg, Sudbury, London, Montreal and Halifax. Explain that focus groups for parents/advocates are taking place in Calgary, Toronto and Montreal.

4. Indicate that the focus group will last two hours and participants will receive an honorarium of $50.00 for their participation. The cheques will be mailed out following the focus group. Ensure that everyone gives you a name, address, phone/TTY number and e-mail address as contact info. This will allow us to mail out the cheques and send a copy of the final research report to all participants.

5. Have participants introduce themselves, indicate how they heard about the project and what organization they represent.

6. Outline the ground rules for the focus group. Examples include: One person talks/signs at a time, participants are asked to keep confidential what is shared within the group and to respect one another's opinions. (there are no wrong answers). If you disagree with someone, feel free to state your opinion in a respectful manner.

7. Ask participants about their preferences for breaks. Schedule these breaks according to their needs. This will enable individuals to get food and drinks, use the washroom or leave the room for a cigarette, etc.

Discussion of Focus Group Questions

1. Move through the questions in order dealing with one question at a time. Try to allow equal time to discuss each question. Keep in mind that the discussion will flow back and forth between participants. The research coordinator will supply an interview guide containing probes, which you can use to move the discussion along when there is a lull in the conversation. Probes are also helpful if someone gives a one-sentence answer to a question such as: “I agree” but does not elaborate.

2. Keep the focus group flowing smoothly. If someone goes off track or raises something that is not on topic, acknowledge that the comment is interesting but not what we are talking about at the moment. Bring the discussion back to the focus group questions.

3. Make sure everyone has an opportunity to speak. If you notice that someone hasn't said anything or been unusually quiet, gently ask them for their opinion or if they have something to contribute.

4. Be aware of subtle cues such as changes in body language, individuals who seem upset, unusually long silences in the room, etc.

If someone is upset, you may need to take him or her outside the room to talk. Gently ask the person what is going on for them by saying something like: "You seem upset. Would you like to talk about it?" The experiences of other group members may have brought back memories of similar experiences in their own lives. As a result, individuals may feel sad, angry, etc. Once they have had an opportunity to talk, ask them if they feel comfortable going back into the focus group. If they do, both of you can re-enter the session. If they wish to withdraw from the focus group, thank them for their participation and follow up with them after the session to find out how they are doing. In some cases, individuals may wish to be connected with the sponsoring organizations (CNSDB/CDBRA) or with other community resources for more individualized support.

In situations where there are long silences, you may repeat the last idea rose by a participant and ask if others have something to contribute before you move on.

Wrap-Up

1. Once you have covered all questions, ask participants if they have additional comments.

2. Make sure you have contact information for all participants. In the majority of cases, you will have obtained this information during the recruitment phase. However, someone may have accidentally been missed at that time.

3. Explain that their honoraria will be sent out to them following the focus group and that they will receive a copy of the research report. Explain that the contact information will be kept by the researchers but that it will not be given out to anyone else.

4. Ask participants if they are interested in receiving further information about CNSDB/CDBRA or becoming involved in the future activities of these organizations. Please make it clear that they are under no obligation to become involved in future activities of these groups. Take the names of those participants who are interested and send these to the coordinator. She will get in touch with CNSDB/CDBRA and ensure that an organizational representative follows up with them. The coordinator will ensure that you receive brochures, newsletters and other information about CNSDB/CDBRA to distribute to focus group participants.

5. Before everyone leaves, mention that brochures newsletters and other materials about CNSDB/CDBRA are on a display table you have set up for this purpose. Also included with this information is a form for the voluntary registry of persons who are Deaf-Blind. This registry was established five years ago. 777 persons registered during a project which took place between 1999 and 2001.

CNSDB/CDBRA supports continuing with this voluntary registry of persons who are Deaf-Blind.

Please ask participants to distribute the form to persons they know who may wish to join the national registry.

In addition, your training package includes a one-page description of plans by CNSDB/CDBRA to undertake a future study of persons who have Usher Syndrome. Please ask respondents to distribute the information to persons they know with Usher Syndrome who may have an interest in participating in this research.

Data Analysis

When analyzing the information from the focus group, the following points will be helpful:

1. Listen to the recording of the focus group and/or review the notes from the session.

2. Look at the information collected for each focus group question. What were the main points the participants raised in response to these questions?

3. What common themes emerged? In other words, did more than one participant make the same point? If so, how many people made particular points?

4. If major points were made by only one person, what were these points?

5. What interesting stories emerge from the responses to the focus group questions? Can these be used as examples to support any of the major points made by participants?

6. What recommendations for change were made?

7. Did any of the points or recommendations suggest that additional information should be gathered in future studies?

Preparing Your Report of the Focus Group

1. In preparing your 2500-3000 word report for the research coordinator, please include the following information:

A. Begin your report with an introduction, which should include: How many participants were in the group. In the case of a consumer focus group, you will need to note how many people had acquired Deaf-Blindness and the number who were congenitally Deaf-Blind. You will also need to include the number of persons who were seniors 55 years and over. How many participants were male, how many were female, etc.
B. What questions (if any) did focus group participants have about the study, how the information will be reported or disseminated, etc?
C. What were the main points participants raised in response to each focus group question? If a majority of people said they could not get enough Intervenor services, which made communication and participation in the community difficult, mention this. If participants noted recommendations such as there should be more Intervenor services, then put that down. If one or two individuals made a significant point that no one else included, then mention this. You can make statements such as "A majority of people indicated there were insufficient Intervenor services to meet their needs." "Two of eight participants said …"
D. An easy way to write up the report is to use questions on the interview guide as the major headings. The main responses to each question can then be included under the various headings. For example, in the report of a consumer focus group, one heading could be "Getting services in the community". Another heading could be: "Recommendations for additional services". In the report of a focus group for parents/advocates, one major heading could be: "Challenges experienced by participants in accessing supports for their children". Another heading could be: "Challenges in accessing supports for themselves".
E. Within each question on the interview guide, look for major themes or patterns, which emerge, from the discussion and responses, which differ from those themes.
F. Feel free to use examples, stories told by respondents or quotes from participants to enhance your discussion of the basic themes.
G. Once you have outlined the major themes from all the questions, you may want to end with a brief outline of any themes which stand out as important throughout the analysis and a discussion of recommendations for change.

2. Feel free to send a draft of your report to the research coordinator by e-mail. She will look at it, give feedback and suggest changes.

Sending Material to the Coordinator

1. Within one week after your focus group[s], e-mail the participants' contact information to research coordinator Colleen Watters (wattersc@mts.net) so that she can arrange for the project coordinator, Stan Munroe, to send honoraria cheques to the participants promptly. Mail the signed consent forms, notes and tapes from the focus group[s] to the research coordinator in a padded envelope.
The mailing address for CCDS is: Canadian Centre on Disability Studies, 56 The Promenade, Winnipeg, Manitoba, R3B 3H9.

2. E-mail your completed report to research coordinator Colleen Watters (wattersc@mts.net). CCDS uses and prefers Microsoft Word, but we can also accept file attachments in Rich Text or Plain Text formats.

If you want to send your completed report in hard copy, please feel free to do so to the attention of Colleen Watters, CCDS at the above address.

Appendix C-3 Guidelines For Demographic Research Assistants

January 2004

This document will outline some tips that will be helpful to you in collecting demographic data about persons in Canada who are Deaf-Blind. The information in this guide covers how to locate participants, *GATHER INFORMATION FROM a variety of organizations, *ANALYZE the findings, and *WRITE your report for Colleen Watters, Research Coordinator.

Claiming Research-Related Expenditures:

1. You will be reimbursed from project funds for the costs of telephone, fax, postage, fees to obtain statistical information needed for data collection and disability accommodations (such as Intervenor services) *THAT you incur while gathering demographic information. Costs will be covered up to a maximum of $500 for the above-mentioned items when supported by a claim. Please forward details of these costs to Colleen Watters, Research Coordinator by e-mail (wattersc@mts.net) who, in turn, will advise the Project Coordinator, Stan Munroe, that a request for reimbursement will be forthcoming. Please send your bills to Stan Munroe, Project Coordinator, for reimbursement. Expenditures which fall outside the approved list must be discussed with Stan or Colleen prior to requesting reimbursement.

Stan's mailing address is: 1658 4th Avenue W., Owen Sound, Ontario, N4K 4X4. His e-mail address is: stan.munroe@sympatico.ca.

Outline of the Contract:

1. The contract is divided into two phases. The first phase involves locating participants for the study and collecting demographic information from these individuals with respect to persons in Canada who are Deaf-Blind. The second phase includes analyzing the data gathered and preparing a final project report for the research coordinator.

2. The work will begin in January, 2004, and all assigned tasks will be completed by April 30th, 2004.

3. The work involves gathering demographic information about persons in each region who are Deaf-Blind. The data to be collected includes information about age categories, probable causes of Deaf-Blindness and living arrangements.

4. Monthly one-page updates on progress with respect to data collection and analysis must be submitted to the research coordinator.

5. At the conclusion of each phase of the contract (data gathering and data analysis), please advise the research coordinator that the work for those phases has been completed. This will enable Colleen to arrange for payment of the portion of the contract fee for those phases and will be another way of keeping up to date on your progress.

Locating Participants

1. To gather the above-mentioned demographic information, begin by contacting administrators, directors of community organizations, disability groups that serve Deaf, blind and Deaf-Blind individuals, seniors residences, seniors resource centres in the community, medical associations, audiologists, ophthalmologists, regional health authorities, nursing associations, personal care homes, personal care home associations,
government departments, directors of disability services offices at universities and colleges, etc. In addition to contacting all of the major disability organizations within each region (including those that serve Deaf, blind and Deaf-Blind individuals), other key sources of information are government departments that provide services to those who are Deaf-Blind, the health authorities in the region, medical and nursing associations and directors of disability services offices at the major universities and colleges in the region.

2. In addition, please contact 10 to 15 personal care homes, 10 to 15 seniors residences, 10 to 15 seniors resource centres, etc. At least three contacts in each category (i.e. seniors residences) should be located in a large urban centre within your region, three housed in a medium-sized urban centre and three located in rural areas. Efforts should be made to choose locations in different parts of the region.

3. You are also encouraged to utilize your own network of contacts to locate others sources from which the demographic information can be gathered. Your ideas on additional sources of information (which are much appreciated) are listed below:
    A. government departments: Departments of education, health, family and social services;
    B. rehabilitation organizations, physiotherapists, occupational therapists, etc.;
    C. teaching hospitals, low vision and audiology clinics, etc.;
    D. private companies that provide home care, nursing and related services.

The Victorian Order of Nurses (VON) would be one example;
    E. school districts and school boards;
    F. aboriginal and First Nations organizations, band offices etc.;

G. centres on aging, wellness centres, health policy centres, research and policy centres;
H. various databases including epidemiological databases.
I. Internet searches to locate potential sources of information.
J. individuals you know who will be able to provide the demographic information we are looking for.

4. The exact organizations to be contacted to locate participants will vary within each region, as there will be variations in geographic composition, size and number of major centres, the specific organizations within the region, etc.

5. As part of your training package, the research coordinator will provide you with a letter to assist you in recruiting participants. Before distributing the letter, you will need to fill in the region from which you will be gathering the demographic information and indicate how interested persons can get in touch with you. The letter can be distributed to potential participants by fax or e-mail.

6. Make sure you have contact information for each participant, including, name, address, telephone/TTY number, fax and e-mail address. This will enable you to contact them during the data analysis phase in the event you need further information. This will also enable the research coordinator to send them a copy of the research report at the conclusion of the study.

7. The coordinator will check in with you to find out how the location of participants is progressing, and will offer whatever assistance she can. She will also draw on the expertise of the advisory committee to help locate viable sources of information.

Collecting Information From Participants:

1. Once participants have been located, data will be gathered primarily through telephone and e-mail contacts, since there is no budget for travel.

The costs of travel to in-person interviews will be approved only in exceptional cases, and these expenses must be discussed with the project coordinator or research coordinator before being submitted for payment.

2. The demographic questionnaire and a consent form should be sent to all participants prior to the interview, as respondents will need time to gather the information we are looking for ahead of time.

3. In situations where you encounter respondents who are unwilling to provide the demographic information we are seeking, the coordinator can supply an official letter on CCDS letterhead providing additional information about the research and the reasons why the demographic information is important.

4. You can also discuss strategies for approaching respondents with the research coordinator.

5. If you have tried the suggestions outlined in points 3 and 4 above and the respondents still refuse to provide you with the demographic information we are looking for, thank them politely and move on to the next respondent.

6. Through this qualitative research study, the CNSDB/CDBRA is seeking to gather as much information as possible on the numbers of persons in Canada who are Deaf-Blind, their ages, probable causes of Deaf-Blindness and living arrangements. It is important to note that this is a qualitative research study. In some cases, respondents will be able to give you the exact numbers of consumers/members/clients they serve who meet the research definition of Deaf-Blindness. In other cases they will only be able to provide estimated numbers of persons served or no numbers at all.

7. In some cases, you will receive complete information about the age categories of consumers/members/clients, their probable causes of Deaf-Blindness or their living arrangements. In other instances, you will be given estimates or no numbers at all.

8. Please include in the report information you have gathered which is based on estimates and indicate those situations in which you were unable to obtain the material you were seeking because respondents could not provide this information or were unwilling to do the necessary work to gather it.

Consent

1. Make sure participants have copies of the consent form and have signed it before the respondent completes the interview to collect the demographic information. Please sign the form as the researcher. Each participant should keep a copy of the form and the researcher should also keep a copy to send to the research coordinator with a synopsis of the results of contacts made and a report on the data collection and analysis. If participants are not able to sign a print consent form, e-mail consent will be accepted.

The Interview:

1. Explain the purpose of the research, what we hope to find out, what will be done with the data and that participants will receive a copy of the final research report. (See attached for a description of its purpose and what we hope to find out.)

2. Explain the purpose of the interview and that it will last between 15 minutes and one half hour. Explain that demographic information about persons who are Deaf-Blind is being collected in eight regions across Canada: British Columbia/Yukon, Alberta/Northwest Territories/Nunavut, Saskatchewan, Manitoba, Northwestern Ontario, Southern Ontario, Quebec and the Atlantic Provinces.

3. Move through the questions on the interview guide in order. Try to allow equal time to discuss each question.

4. Get as much information as you can for each question. In situations where respondents give information based on estimates, incomplete information or cannot answer the question, get as much data as you can before moving on to the next question.

Wrap-Up

1. Once you have covered all questions, ask participants if they have additional comments.

2. Make sure you have contact information for all participants. In the majority of cases, you will have obtained this information during the recruitment phase. However, someone may have accidentally been missed at that time. Explain that the contact information will be kept by the researchers but that it will not be given out to anyone else.

3. Explain that they will receive a copy of the research report.

4. Before you conclude the interview, mention that you can provide them with brochures newsletters and other materials about CNSDB/CDBRA if they wish further information. Also included with the brochures, newsletters, etc. is a form for the voluntary registry ofpersons who are Deaf-Blind. This registry was established five years ago: 777 persons registered during a project, which took place between 1999 and 2001. CNSDB/CDBRA supports continuing with this voluntary registry of persons who are Deaf-Blind. Please ask participants to distribute the form to persons they know who may wish to join the national registry.

In addition, your training package includes a one-page description of plans by CNSDB/CDBRA to undertake a future study of persons who have Usher Syndrome. Please ask respondents to distribute the information to persons they know with Usher Syndrome who may have an interest in participating in this research.

Data Analysis

At the conclusion of data collection and prior to the beginning of data analysis, please forward to the research coordinator a list of all contacts made during data collection and the results of these contacts. This includes an outline of each contact and whether you were able to obtain answers to the questions on the interview guide, whether incomplete or partial information was provided or whether the respondents could not answer some or all of the questions on the guide. This will assist the coordinator in evaluating your progress in data collection and indicate to her that you have completed the first phase of the contract.

When analyzing the data from the interviews to collect the demographic information about persons who are Deaf-Blind in your region, the following points will be helpful:

1. Review the responses from each interview so that you become familiar with the data you collected.

2. The most logical way to analyze the data is to look at the information gathered for each organizational category separately, moving through the questions on the interview guide in order. For each category, begin by looking at whether the organization serves consumers/members/clients who meet the study definition of "Deaf-Blind", whether the organization keeps records of the numbers of consumers/members/clients served and the total number served. You then look at the numbers of consumers/ members/clients in each age category and, if known, whether they had congenital or acquired Deaf-Blindness and the causes if known) of these disabilities. Finally, total up the numbers of consumers/members/ clients in the various living arrangements outlined on the interview guide.

3. The above-mentioned procedures for data analysis will be helpful in analyzing information for the following organizational categories:

A. community organizations;
B. disability groups that serve Deaf, blind and Deaf-Blind individuals;
C. seniors residences;
D. seniors resource centres in the community;
E. medical associations, audiologists, opthamologists, regional health authorities, nursing associations;
F. personal care homes and data from personal care home associations;
G. government departments;
H. universities and colleges, including disability services offices at these facilities; rehabilitation organizations, physiotherapists, occupational therapists, etc.;
I. teaching hospitals, low vision and audiology clinics, etc.;
J. private companies that provide home care, nursing and related services. (The Victorian Order of Nurses (VON) would be one example);
K. school districts and school boards;
L. aboriginal and First Nations organizations, band offices etc.;
M. centres on aging, wellness centres, health policy centres, research and policy centres;
N. various databases including epidemiological databases.
O. internet searches to locate potential sources of information.
P. individuals you know who will be able to provide the demographic information we are looking for.

4. It will be useful to analyze separately the information for urban and rural locations to see if there are any differences in the data collected.

5. Once you have analyzed and compiled the information in the above-mentioned organizational categories, you can then total up the numbers in these categories to establish totals for the region for each of the questions on the interview guide.

6. Feel free to use tables or charts for analyzing the information you have gathered for the various organizational categories and for establishing totals for your region.

Preparing Your Report of the Demographic Interviews

1. In preparing your 2500-3000 word report for the research coordinator, please include the following information:

A. Begin your report with an introduction, which should include how many participants were contacted in the organizational categories outlined in the analysis section above. Please include a breakdown between urban and rural locations and an indication of the different parts of the region covered. You should also point out any particular problems encountered in data collection, such as unwillingness of respondents to provide information, situations where participants provided incomplete data, etc.

B. What questions (if any) did demographic respondents have about the study, how the information will be reported or disseminated, etc.?

C. An easy way to write up the report is to follow the same procedure utilized in data analysis. This involves compiling the information from each organizational category, noting the differences between urban and rural vocations. Feel free to use questions on the interview guide as the major headings. The main responses to each question can then be included under the various headings.

D. Once you have written up the information you have analyzed by organizational category, you can then present the totals for the region.

E. Conclude with a section which points out any major themes emerging from the demographic analysis and recommendations for future research.

2. Feel free to send a draft of your report to the research coordinator by e-mail. She will look at it, give feedback and suggest changes.

Sending Material to the Coordinator

1. Within one week following the conclusion of data collection, e-mail the participants' contact information to research coordinator Colleen Watters (wattersc@mts.net). Mail the signed consent forms, lists of those contacted and any notes you took during interviews to the research coordinator in a padded envelope

.

The mailing address for CCDS is 56 The Promenade, Winnipeg, Manitoba, R3B 3H9.

2. E-mail your completed report to research coordinator Colleen Watters (wattersc@mts.net). CCDS uses and prefers Microsoft Word, but we can also accept file attachments in Rich Text or Plain Text formats.

If you wish to send your report in hard copy, feel free to do so to the attention of Colleen Watters at the above address.

Appendix C-4 Recruitment Letter For Focus Groups With Participants Who Are Deaf-Blind

January 2004

Dear potential participant in focus groups:

"A Study Of Deaf-Blind Demographics and Services in Canada" is a project being conducted by the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). This project is intended to produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates; and (5) directions for future research.

This research is being conducted for the CNSDB and CDBRA by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), a consumer-directed national research and education organization located in Winnipeg, Manitoba. A research coordinator and research assistants are carrying out focus groups and interviews. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

In order to participate in the research, you must be a person who is Deaf-Blind. Deaf-Blindness is “a condition which combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information; even though Deaf-Blind persons may still have varying levels of useful vision and hearing”. (Resource Centre for Manitobans who are Deaf-Blind).

Your participation will involve answering a series of questions in a focus group about the personal stories of the barriers and successes you experience as an individual who is Deaf-Blind, the supports and services you need, service gaps, recommendations for additional services and the communication devices you use. The focus group will last approximately two hours, and the questions and a consent form are attached to this letter. All responses will be kept confidential by the researchers.

The focus group data will be analyzed and included in a report on the project. This report will be provided to the funder and all study participants. It will also be disseminated by the partner organizations to agencies and organizations serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. A website will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations.

We are looking for eight persons who are Deaf-Blind to participate in a focus group in ___ place (region of the country). A priority for this project is to reach those with acquired Deaf-Blindness (particularly seniors aged 55 and over). Individuals must have good communication skills and be capable of understanding the content of the focus group. If interested, please contact ___, CCDS Research Assistant at ___. Intervenor services, other disability support needs and subsidization of child care costs will be accommodated.

If you have any questions, please contact ___ (Research Assistant) or Colleen Watters, Research Coordinator at (204) 488-0466, by TTY at (204) 475-6223 or e-mail wattersc@mts.net.

Thank you, and we hope to hear from you soon.

Yours sincerely,
Colleen Watters

Research Coordinator

Appendix C-5 Recruitment Letter For Focus Groups With Parents/Advocates Of Persons Who Are Deaf-Blind

January 2004

Dear potential parent of a Deaf-Blind individual:

"A Study Of Deaf-Blind Demographics and Services in Canada" is a project being conducted by the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). This project is intended to produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates and (5) directions for future research.

This research is being conducted for the CNSDB and CDBRA by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), a consumer-directed national research and education organization located in Winnipeg, Manitoba. A research coordinator and research assistants are carrying out focus groups and interviews. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

In order to participate in the research, you must be the parent or advocate of a person who is Deaf-Blind. Deaf-Blindness is “a condition which combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information; even though Deaf-Blind persons may still have varying levels of useful vision and hearing”. (Resource Centre for Manitobans who are Deaf-Blind).

Your participation will involve answering a series of questions in a focus group about your experiences as a parent/advocate of a person who is Deaf-Blind, the challenges you encounter in accessing supports and services in the community for your child and for yourself as a parent/advocate, your opinions about gaps in services and recommendations for additional services. The focus group will last approximately two hours, and the questions and a consent form are attached to this letter. All responses will be kept confidential by the researchers.

The focus group data will be analyzed and included in a report on the project. This report will be provided to the funder and all study participants. It will also be disseminated by the partner organizations to agencies and organizations serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. A web site will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations.

We are looking for eight parents/advocates to participate in a focus group in ___ place (region of the country). If interested, please contact ___, CCDS Research Assistant at ___. Intervenor services, other disability support needs and subsidization of the costs of child care will be accommodated.

If you have any questions, please contact ___ (Research Assistant) or Colleen Watters, Research Coordinator at (204) 488-0466, by TTY at (204) 475-6223 or e-mail wattersc@mts.net.

Thank you, and we hope to hear from you soon.

Yours sincerely,
Colleen Watters
Research Coordinator

Appendix C-6 Recruitment Letter For Demographic Research

January 2004

Dear Organizational Representative:

"A Study Of Deaf-Blind Demographics and Services in Canada" is a project being conducted by the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). This project is intended to produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates and (5) directions for future research.

This research is being conducted for the CNSDB and CDBRA by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), a consumer-directed national research and education organization located in Winnipeg, Manitoba. A research coordinator and research assistants are carrying out focus groups interviews. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

Deaf-Blindness is “a condition which combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information; even though Deaf-Blind persons may still have varying levels of useful vision and hearing”. (Resource Centre for Manitobans who are Deaf-Blind).

Your participation will involve answering a few questions in a short interview with a CCDS research assistant about the demographic information kept by your organization about consumers/members/clients who meet the above-mentioned definition of “Deaf-Blind”, the ages of these individuals, their living arrangements and information about the probable causes of their disabilities (if known). The interview will last approximately 15 minutes to one half hour, and the questions and a consent form are attached. All responses will be kept confidential by the researchers.

The data from these interviews will be analyzed and included in a report on the project. This report will be provided to the funder and all study participants. It will also be disseminated by the partner organizations to agencies and organizations serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. A website will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations.

A CCDS Research Assistant, will contact you to arrange a time for an interview. If you have any questions, please contact him/her at ___ or Colleen Watters, Research Coordinator, at (204) 488-0466 or e-mail wattersc@mts.net.

Thank you, and we hope to hear from you soon.

Yours sincerely,
Colleen Watters
Research Coordinator

Appendix C –7 Consent Form For Focus Groups With Participants Who Are Deaf-Blind

January 2004

I _________ agree to take part in the project entitled: “A Study of Deaf-Blind Demographics and Services in Canada.” This project will produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services in Canada to meet the needs of persons who are Deaf-Blind and parents/advocates; and (5) directions for future research

This research is being conducted for the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association by a research team led by Michelle Owen at the Canadian Centre on Disability Studies (CCDS), and that focus groups and interviews are being carried out by a research coordinator and research assistants. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

My taking part involves answering a series of questions in a focus group about the stories of the barriers and successes I experience as a Deaf-Blind individual, the supports and services I need, service gaps, recommendations for additional services and the communication devices I use. The focus group will last approximately two hours. The questions will be distributed to me by a project research assistant prior to the focus group.

No direct quotations from the focus group will be used without my prior written permission.

I agree that the focus group will be tape recorded to allow the researchers to review and transcribe the discussion. The audio tape will be erased after the discussion has been transcribed. Names of focus group participants, unique personal characteristics, etc. will not be included in any research reports or other publications without my permission. Data obtained in focus groups will be kept confidential, and focus group participants will be asked not to reveal the identities of other participants. I understand, however, that CCDS cannot guarantee that other participants will comply with this request.

The principal investigator, the research coordinator and the research assistants conducting the focus groups will have access to the gathered data. The written focus group data will be stored at CCDS for a period of three years following completion of the project and then will be destroyed.

The focus group data will be analyzed and will be included in a report on the project which will be provided to the funder, Human Resources Development Canada and to all participants in the study.

The report will be disseminated by the partner organizations (The Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association) to agencies and organizations serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. A website will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations.

My participation is voluntary, and I may withdraw from the study at any time without penalty by contacting the researchers. I also may refuse to answer any questions.

I will receive an honorarium of $50 for my participation in the focus group and will be offered a copy of the final research report.

I may be asked if I am interested in receiving information about CNSDB/CDBRA, and I am free to accept or decline. If I choose not to become involved in CNSDB/CDBRA in the future, I may do so without penalty.

If I have any further questions about the study, I can contact the researchers by phone at the Canadian Centre on Disability Studies, (204) 287-8411 (TTY, (204) 475-6223) or by e-mail at ccds@disabilitystudies.ca. I can also contact the Principal Investigator, Michelle Owen, at the same number or by e-mail at researchchair@disabilitystudies.ca or the research coordinator, Colleen Watters, at the same number or by e-mail at wattersc@mts.net.

If I have any ethical concerns about the research, I can contact the Chairperson of the CCDS Research Committee at 56 The Promenade, Winnipeg, Manitoba, R3B 3H9.

In situations where informed consent cannot be obtained in writing due to the nature of a disability, tape recorded consent will be accepted.
Participant signature____
Contact information ____
____
____

Date _______________________

Researcher signature _______________________________________

Date _______________________

One copy to participant and another to the researcher.

Appendix C –8 Consent Form For Focus Groups With Parents/Advocates Of Persons Who Are Deaf-Blind

January 2004

I _________ agree to take part in the project entitled: "A Study of Deaf-Blind Demographics and Services in Canada." This project will produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services in Canada to meet the needs of persons who are Deaf-Blind and their parents/advocates; and (5) directions for future research.

This research is being conducted for the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), and that focus groups and interviews are being carried out by a research coordinator and research assistants. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

My taking part involves answering a series of questions in a focus group about my experiences as the parent/advocate of a Deaf-Blind individual, challenges I encounter in accessing services and supports in the community for my child and for me as a parent/advocate of a person who is Deaf-Blind, my opinions about the gaps in services and my recommendations for additional services. The focus group will last approximately two hours. The questions will be distributed to me by a project research assistant prior to the focus group.

No direct quotations from the focus group will be used without my prior written permission.

I agree that the focus group will be tape recorded to allow the researchers to review and transcribe the discussion. The audio tape will be erased after the discussion has been transcribed. Names of focus group participants, unique personal characteristics, etc. will not be included in any research reports or other publications without my permission. Data obtained in focus groups will be kept confidential, and focus group participants will be asked not to reveal the identities of other participants. I understand, however, that CCDS cannot guarantee that other participants will comply with this request.

The principal investigator, the research coordinator and the research assistants conducting the focus groups will have access to the gathered data. The written focus group data will be stored at CCDS for a period of three years following completion of the project and then will be destroyed.

The focus group data will be analyzed and will be included in a report on the project which will be provided to the funder, Human Resources Development Canada and to all participants in the study.

The report will be disseminated by the partner organizations (The Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association) to agencies and organizations serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. A website will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations.

My participation is voluntary, and I may withdraw from the study at any time without penalty by contacting the researchers. I also may refuse to answer any questions.

I will receive an honorarium of $50 for my participation in the focus group and will be offered a copy of the final research report.

I may be asked if I am interested in receiving more information about CDBRA/CNSDB, and I am free to accept or decline. If I choose not to be involved in CNSDB/CDBRA in the future, I can do so without penalty.

If I have any further questions about the study, I can contact the researchers by phone at the Canadian Centre on Disability Studies, (204) 287-8411 (TTY, (204) 475-6223) or by e-mail at ccds@disabilitystudies.ca. I can also contact the Principal Investigator, Michelle Owen, at the same number or by e-mail at researchchair@disabilitystudies.ca or the research coordinator, Colleen Watters, at the same number or by e-mail at wattersc@mts.net.

If I have any ethical concerns about the research, I can contact the Chairperson of the CCDS Research Committee at 56 The Promenade, Winnipeg, Manitoba, R3B 3H9.

In situations where informed consent cannot be obtained in writing due to the nature of a disability, tape recorded or e-mail consent will be accepted.

Participant signature ____

Contact information ____

Date ______________________

Researcher signature _______________________________________

Date ______________________

***One copy to participant and another to the researcher.*

Appendix C –9 Consent Form For Participants In Demographic Interviews

January 2004

I _________ agree to take part in the project entitled: "A Study of Deaf-Blind Demographics and Services in Canada”. This project will produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) a discussion of the service needs of persons who are Deaf-Blind and their parents/advocates; (3) an overview of the personal stories of the barriers and successes experienced by individuals who are Deaf-Blind and their parents/advocates; (4) an outline of existing services to meet the needs of persons who are Deaf-Blind and their parents/advocates; and (5) directions for future research.

This research is being conducted for the Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), and focus groups and interviews are being carried out by a research coordinator and research assistants. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

My taking part involves answering a few questions in an individual interview about the demographic information kept by my organization on the members/clients/consumers who meet the study definition of “Deaf-Blind”, their age categories, the probable causes of Deaf-Blindness (if available) and their living arrangements. The interview will last approximately 15 minutes to one half hour. The questions will be distributed to me by a project research assistant prior to the interview.

No direct quotations from my interview will be used in the report without my prior written permission. The information I provide will be kept confidential by the researchers.

The principal investigator, project coordinator, research coordinator and research assistants will have access to the gathered data. The written interview data will be stored at CCDS for a period of three years following completion of the project and then will be destroyed.

The interview data will be analyzed and will be included in a report on the project which will be provided to the funder, Human Resources Development Canada and to all participants in the study.
I will also be offered a copy of the research report.

The report will be disseminated by the partner organizations (The Canadian National Society of the Deaf-Blind and the Canadian Deafblind and Rubella Association)to agencies and organizations serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. A website will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations.

My participation is voluntary, and I may withdraw from the study at any time without penalty by contacting the researchers. I also may refuse to answer any questions.

If I have any further questions about the study, I can contact the researchers by phone at the Canadian Centre on Disability Studies, (204) 287-8411 (TTY, (204) 475-6223) or by e-mail at ccds@disabilitystudies.ca. I can also contact the Principal Investigator, Michelle Owen, at the same number or by e-mail at researchchair@disabilitystudies.ca or the research coordinator, Colleen Watters at the same number or by e-mail at wattersc@mts.net.

If I have any ethical concerns about the research, I can contact the Chairperson of the CCDS Research Committee at 56 The Promenade, Winnipeg, Manitoba, R3B 3H9.

In situations where informed consent cannot be obtained in writing due to the nature of a disability, tape recorded or e-mail consent will be accepted.

Participant signature ______________________________________

Contact information _______________________________________

Date ______________________

Researcher signature ______________________________________

Date ______________________

*** One copy to participant and another to the researcher.*

Appendix C-10 Interview Guide For Focus Groups With Participants Who Are Deaf-Blind

January 2004

Introduction

“A Study Of Deaf-Blind Demographics and Services in Canada” is a project being conducted by the Canadian National Society of the Deaf-Blind (CNSDB) and the

Canadian Deafblind and Rubella Association (CDBRA). This project is intended to produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) an outline of the personal stories of the barriers and successes experienced by persons who are Deaf-Blind and their parents/advocates; (3) an overview of the services available in Canada to meet the needs of persons who are Deaf-Blind and parents/advocates and the service needs of these populations; and (4) directions for future research.

This research is being conducted for the CNSDB and CDBRA by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), a consumer-directed national research and education organization located in Winnipeg, Manitoba. A research coordinator and research assistants are carrying out focus groups and interviews. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

During the focus group, you will be asked a series of questions about how easy or difficult it is to participate in daily activities in the community, how easy or difficult it is to get the services you need as a Deaf-Blind person and your opinions about the gaps in services to you as an individual who is Deaf-Blind. You will also be asked about your recommendations for additional services and the communication devices you use (e.g. TTY, tella-touch, computer with a screen reader or large monitor, relay service, etc.) In addition, you will be asked if you wish more information about CNSDB/CDBRA.

The focus group will last approximately two hours. Please sign the attached consent form at the beginning of the focus group so we can include your responses in our project report.

Thank you for agreeing to participate in the study.

Interview Questions

1. When you first found out you were Deaf-Blind either when you were young or later in your life, how did you feel?
2. What do you do on a typical day?
3. How easy or difficult is it for you to get services in the community?
   What makes it easy?
   What makes it difficult?
   What challenges do you encounter?
   How can these challenges be eliminated?
4. In your opinion, what do you feel are the gaps in services to persons? who are Deaf-Blind?
5. How can services to persons who are Deaf-Blind be improved?
6. What devices do you use to communicate? i.e. TTY, braille display, computer with large monitor, which makes the print larger, screen reader, etc.

7. Are you interested in receiving more information about CNSDB/CDBRA? If you would like more information, please tell us how representatives from these groups can contact you?

Appendix C –11 Interview Guide For Focus Groups With Parents/Advocates Of Persons Who Are Deaf-Blind

January 2004

Introduction
"A Study Of Deaf-Blind Demographics and Services in Canada" is a project being conducted by the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). This project is intended to produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) an outline of the personal stories of the barriers and successes experienced by persons who are Deaf-Blind and their parents/advocates; (3) an overview of the services available in Canada to meet the needs of persons who are Deaf-Blind and parents/advocates and the service needs of these populations; and (4) directions for future research.

This research is being conducted for the CNSDB and CDBRA by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), a consumer-directed national research and education organization located in Winnipeg, Manitoba. A research coordinator and research assistants are carrying out focus groups and interviews. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

During the focus group, you will be asked a series of questions about the challenges you experience in accessing services and supports in the community for your child and for you as a parent/advocate of a person who is Deaf-Blind, your opinions about the gaps in services and your recommendations for additional services. You will also be asked if you wish more information about CDBRA/CNSDB.

The focus group will last approximately two hours. Please sign the attached consent form at the beginning of the focus group so we can include your responses in our project report.

Thank you for agreeing to participate in the study.

Interview Questions
1. When you first found out that your child was Deaf-Blind, how did you feel??

2. When did you first access support for your child?

3. When did you first access support for yourself as a parent/advocate?

4. What challenges do you experience in accessing services in the community for your child?

5. What challenges do you experience in accessing services in the community for yourself as a parent/advocate?

6. What additional services would you like to see provided in the community for your child?

7. What additional services would you like to see provided in the community for yourself as a parent/advocate?

8. Are you interested in receiving more information about CDBRA/CNSDB? If you would like a representative of these groups to contact you, please provide your name, address, e-mail, telephone, fax and TTY numbers.

Appendix C –12 Interview Guide For Demographic Research

Introduction
"A Study Of Deaf-Blind Demographics and Services in Canada" is a project being conducted by the Canadian National Society of the Deaf-Blind (CNSDB) and the Canadian Deafblind and Rubella Association (CDBRA). This project is intended to produce a report containing (1) demographic information about persons in Canada who are Deaf-Blind; (2) an outline of the personal stories of the barriers and successes experienced by persons who are Deaf-Blind and their parents/advocates; (3) an overview of the services available in Canada to meet the needs of persons who are Deaf-Blind and parents/advocates and the service needs of these populations; and (4) directions for future research.

This research is being conducted for the CNSDB and CDBRA by a research team led by Michelle Owen, Research Chair, at the Canadian Centre on Disability Studies (CCDS), a consumer-directed national research and education organization located in Winnipeg, Manitoba. A research coordinator and research assistants are carrying out focus groups interviews. This research is being funded by Human Resources Development Canada and has been approved by the CCDS Ethics Review Committee.

In this 15-30 minute interview, you will be asked to answer a few questions about the records kept by your organization on the numbers of clients, members or consumers who meet the definition of "Deaf-Blind" outlined below, their ages and the probable causes of their Deaf-Blindness (if available). You will also be asked for information about their living arrangements. Please take a few moments prior to the interview to gather the information we are seeking.

In this research “Deaf-Blind” is defined as “a condition, which combines any degree of hearing loss with any degree of vision loss that interferes with communicating and acquiring information; even though persons who are Deaf-Blind may still have varying levels of useful vision and hearing.” (Resource Centre for Manitobans who are Deaf-Blind).

"A person who is congenitally Deaf-Blind" is defined as someone who has become Deaf-Blind before the age of two years.

A person who has "acquired Deaf-Blindness" is defined as someone who has become Deaf-Blind after the age of two years.

A "Supported Independent Living Residence" is defined as a housing facility for those who are Deaf-Blind which provides support services to residents. Examples of support services include: Intervenor services, meal preparation, personal care assistance, etc.

A "Seniors Complex" is defined as an apartment complex where seniors live independently in their own apartments. Some of these complexes provide support services such as meals, house cleaning, personal care, etc. while others do not.

Please sign the attached consent form and return it to ___ (Research Assistant) by e-mail or fax so we can include your responses in our project report.

Thank you for agreeing to participate in the study.

Interview Questions

1. Does your organization have clients, members, consumers, etc. who meet the definition of “Deaf-Blind” outlined in the introduction?
___ Yes (*If yes, go to question 2*)
___ No (*If no, go to closing statement)*

2. Does your organization keep records of, or can you identify, the number of your clients, members, consumers, etc. who meet the definition of “Deaf-Blind”?
___ Yes (*If yes, go to question 3)*
___ No (*If no, go to closing statement)*

3. How many of your organization’s clients, members, consumers, etc. meet the definition of "Deaf-Blind"?

4. (a) Are any of these individuals 5 years of age or younger?
___ No (*If no, go to question 4b*)
___ Yes (*If yes:* How many? ____)

If known, how many of them are <u>congenitally</u> Deaf-Blind? ____

If known, how many have acquired Deaf-Blindness? ____

4 (b) Are any of these individuals between 6 and 20 years of age?
___ No (*If no, go to question 4c)*
___ Yes (*If yes*: How many? ____)

If known, how many of them are congenitally Deaf-Blind? ____

If known, how many have acquired Deaf-Blindness? ____

4 (c) Are any of these individuals between 21 and 60 years of age?
___ No (*If no, go to question 4d)*
___ Yes (*If yes*: How many? ____)

If known, how many of them are congenitally Deaf-Blind? ____

If known, how many have acquired Deaf-Blindness? ____

4 (d) Are any of these individuals aged 61 years or over?
___ No (*If no, go to question 5)*
___ Yes (*If yes*: How many? ____)

If known, how many of them are congenitally Deaf-Blind? ____

If known, how many have acquired Deaf-Blindness? ____

5 (a) How many live in private homes (such as houses, apartments, co-ops, etc.)

5 (b) Of those who live in private homes:

How many live with their parents? ____
How many live with other members of their family of origin (e.g. brother, sister, aunt, uncle, grandparent) ____
How many live with a spouse/partner and/or children? ____
How many live alone without support services such as Intervenors/Interpreters, home care services, Meals on Wheels, etc.? ____
How many live alone with support services such as Intervenors/Interpreters, home care services, Meals on Wheels, etc.? ____

5 (c) How many live in group settings (such as supportive independent living residences, group homes, seniors' complexes, personal care homes, etc.)____

5 (d) Of those who live in group settings:

How many live in a supported independent living residence? ____
How many live in a group home? ____

How many live in a seniors’ complex? ____
How many live in a personal care home? ____

5 (e) How many live in other housing arrangements? ____
(please specify)

Closing Statement

Thank you for your participation in this study. The data from these interviews will be analyzed and included in a report on the project which is expected to be completed by the end of June, 2004. This report will be provided to the funder and all study participants. It will also be disseminated by the partner organizations to agencies and organizations serving Deaf-Blind Canadians and parents/advocates, disability associations, community groups, governments, etc. A website will be created for the project, and the final report will be placed on that site. The project site will be linked to those of the partner organizations, CNSDB and CDBRA. The URL for the CNSDB site is: http://www.cnsdb.ca, and the URL for the CDBRA site is http://www.cdbra.ca.

Appendix D National Services Directory

Appendix E Provincial Recommendations from Focus groups

Several provincial recommendations emerged from the focus groups and interviews with consumers.

British Columbia

1. Ways should be developed for people who are Deaf-Blind to use the transportation system of Trans-Link, (the Provincial public transportation company).

2. Provincial financial support should be put towards the provision of an assistive devices program in BC to allow equal access to information, increased ability to write letters and use the Internet.

3. Medical Interpreter Services (MIS) should be educated so they recognize the importance of Intervention services for medical appointments. The title should be Medical Interpreter/Intervenor Services, so as to include services for those who are Deaf-Blind.

Alberta

1. The specialized transportation service for people with disabilities in Calgary should be improved. This includes the provision of a more prompt service with revamped booking systems and decreased waiting times. Access Calgary's dispatch system should be altered to make additional telephone lines available for booking trips. Access Calgary Drivers should be trained in sighted guide techniques.

Manitoba
1. The Winnipeg Handi-Transit service should be expanded. Staff should be encouraged to use their TTYs to facilitate booking of trips by persons who are Deaf-Blind.

2. Home Care staff that work with people who are Deaf-Blind should learn ASL or tactile sign language to facilitate communication with consumers who are Deaf-Blind.

3. The Government should allocate money to social assistance recipients who are Deaf-Blind to enable them to use cabs because they are unable to drive and/or see at night.

4. The provincial government should provide an assistive devises program, including computers to those who are Deaf-Blind to facilitate communication and access to information.

5. Restaurants and store owners should be accommodating to people who require bright lights in order to see.

6. The public sector should hire employees who use ASL to communicate with individuals who are Deaf-Blind.

Quebec
1. The provincial government should create a service called a "Deaf-Blind Taxi" to ensure efficient transportation of passengers who are Deaf-Blind. The fare would cost the same as a bus ticket or a monthly public transport pass. All drivers of this "Deaf-Blind Taxi" would be trained in tactile communication so that they could converse with their passengers.

2. The provincial government should create a “specialized work experience” to employ disabled people in every big city having a large community of Deaf people with a significant field vision loss.

3. The provincial government should institute an income subsidy for self-employed Deaf workers who have a vision loss.

4. The provincial government should create a benefit for Deaf people who have a vision loss. This benefit should be called "Special Housing Assistance Benefit for people who are Deaf-Blind” to help those who live alone and cannot obtain driver’s licenses. The amount of this benefit would be proportional to the beneficiary's cost of rent and take his/her income or disability benefit into account.

5. The provincial government should implement a financial support program to enable families with members who are Deaf-Blind to rent accommodation or purchase houses in areas close to public transport and community services.

6. Telephone companies should maintain analogue telephones for people who are Deaf-Blind despite the fast developments being made in the field of specially adapted telecommunications systems. These two technologies must coexist and be developed together to guard against any computer problems which would leave people who are Deaf-Blind without any means of communication with the outside world.

7. To promote the independence of Deaf-Blind people, the federal government should provide to people, a digital camera with a LCD screen.

8. Hire Intervenors who are Deaf-Blind and who will be trusted by consumers. By sharing their experiences, these professionals can serve as role models for others who are Deaf-Blind.

9. A law should be implemented to compel employers to hire one disabled person for every ten people employed.

Appendix F Regional Demographic Reports

Appendix F – 1 British Columbia and the Yukon

Introduction
A review of the processes suggested for the collection of data as outlined in the “Guidelines to Research Assistants” document provided by the Canadian Centre on Disability Studies was the basis for the procedure utilized in this project. The researcher also reviewed the “Interview Guide for Demographic Research”, “A Study of Deaf-Blind Demographics Ethics Questionnaire” and the interview guide.

In collecting this data a number of methods were utilized. By far, the most frequent method for the majority of respondents was Fax. We also utilized regular mail, e-mail and telephone. Due to the difficult terrain and the inaccessibility of some regions, obtaining viable information from a variety of rural districts was difficult and, in most cases, impossible. Time constraints were also a concern. Participants living in fly-in or boat-in areas were unable to complete the survey. In these cases, we tried to contact the closest health clinics. In two cases, we were able to complete surveys via radiophone.

Organizations Contacted
The following agencies and related organizations were established as resources to obtain the required information:

- The Canadian Deafblind & Rubella Association, BC Chapter
- The Canadian National Institute for the Blind
- Deaf and Hard of Hearing Organizations
- Provincial Outreach Program for Students with Deafblindness
- Provincial Government Agencies

- Ministry of Children and Family Development
- Regional Healthcare Administrations
- Deafblind Services Society of British Columbia
- Council of Service Providers for the Deaf, Hard of Hearing and Deafblind
- Deafblind Council of British Columbia
- Selected Group & Special Care Facilities
- Ophthalmologists
- Audiologists
- Child Development Centres
- Service Agencies
- Post Secondary Education Institutions
- Disability Organizations

The researcher also utilized the National Registry Report as a guideline in conducting the research.

Obstacles Encountered

Since not all participants provided complete responses to questionnaires, it is not possible to balance total numbers with the various components that make up the data. This became very evident when accessing information from government agencies and health care organizations. In these cases, the information has been included even though it did not fully address the questions contained on the interview guide. Some health care organizations were reluctant to complete the interview guide. At the time of the Study British Columbia was involved in a labour dispute. In many cases organizations were aware that they had clients who were Deaf-Blind, but were unable to access any tracking or reporting mechanisms during the labour disruption.

The researcher found previously unreported information regarding the senior population in British Columbia. Most seniors complexes were aware that they had some clients that fit the definition of Deaf-Blindness but were unable to provide any other data. These “best guess scenarios” have not been included in the data report because of the incomplete nature of the responses from these organizations.

Participating organizations provided a large number of general comments on the record keeping ability of the various organizations. Many groups only kept records for the specific population of people with disabilities served.

Respondents from some post-secondary institutions admitted they were not adequately prepared for students with disabilities. These participants generally felt that students with disabilities who wished to pursue their studies would move to larger centers in order to receive the services that would make further education possible.

Participants also noted differences in levels of service received by various ethnic and age groups. Service providers generally felt that First Nations individuals received bad or worse services than their non-First Nations counterparts. They also felt that the senior population was largely marginalized because disabilities were noted as age-related illnesses. Thus, seniors did not receive the required services. In addition, representatives from service agencies indicated that individuals with combined Deaf-Blindness and mental illness did not receive adequate supports.

The researcher considered the possibility of duplication of reported incidences of Deaf-Blindness. This may be the case in some situations. However, officials of the organizations representing Deaf-Blind services estimate that any such duplication will be offset by the cases that are not reported and are therefore not able to access services or support.

Research Findings

Within the province of British Columbia, there are a number of organizations that serve the Deaf-Blind population, such as the Provincial Outreach Program for Students with Deafblindness, Deafblind Services Society of British Columbia and the Canadian Deafblind & Rubella Association – BC Chapter. These groups completed the interview guide. In a few situations, the researchers had assumed that particular associations would provide excellent information but they were unable to fulfill this expectation.

Urban vs. Rural

In 2003, British Columbia had a population of 4,146,580. This was composed of 2,613,248 in urban population zones or 63% and 1,533,332 in rural population zones or 37%. British Columbia is the third largest province in Canada in terms of population and one of the most difficult to access because of geography. Because of the mountainous terrain there are communities in British Columbia with no telephone service or other amenities available in larger urban settings; many communities remain fly-in or boat-in only. In targeting organizations to participate in the demographic study, the researcher wanted to ensure organizations serving the rural population were well represented to make certain the responses were balanced.

The large number of unknowns (110 or just over 38 % of responses) is a result of service agencies recognizing that they have clients who fit the definition of Deaf-Blindness but were unaware of the causes. The lack of tracking or reporting mechanisms accounts for a large number of unknowns. If there were specific databases to track Deaf-Blindness, these numbers would be substantially different.

Table F- 1-1: Deaf-Blind Age Differential

	Congenital	Acquired	Unknown	Total
0 - 5 years	17	0	33	50
6 - 20 years	56	6	77	139
21 - 60 years	7	41	0	48
61+ years	0	50	0	50
Total	***80***	***97***	***110***	***287***

In total, there were 287 reported cases of Deaf-Blindness in British Columbia. After various discussions with Child Development Centres and Seniors Complexes, the researcher feels that the findings in the applicable categories may be low. This could be attributed in part to the lack of staff training on Deaf-Blindness in many of these facilities. Further research would locate additional persons who are Deaf-Blind. During the process of data collection, the researcher found additional individuals who had previously not been affiliated with any Deaf-Blind organization.

It is worthy of note that the majority of the unknown in the 0 – 5 age range and 6 – 20 is due to the lack of information or incomplete medical testing of these age groups. On the questionnaires, the acquired population in the 61+ years age category is generally reported other illnesses (i.e. macular degeneration, strokes) or accidents.

Table F- 1-2: Living Arrangements

Living Arr.	*Total 265*
Private Homes	107
Parents	47
Other Family	2
Spouse	19
Alone without support	3
Alone with support	3
Group Settings	7
Ind. Living Residences	2
Group Home	5
Seniors Complex	6
Personal Care Home	29
Other Living	35

Since not all of the requested information on the interview guide was completed, it is not possible to cross-reference the categories with the totals provided.

The large majority of individuals with Deaf-Blindness are still living in private homes, either with their parents or foster parents or with spouse or other family members.

Additional Information

A number of respondents provided additional information. To reflect this information, it is categorized into the following: Assistive Devices, Professional Intervenors vs. Volunteers, Access to Employment and Sports and Education.

Table F-1-3: Assistive Devices

Assistive Devices	70
Hearing Aids	11
TTY	1
Guide Dogs	4
Wheelchairs	12
Glasses	1

Cane	1
Other	40

The “Other” category includes but is not limited to talking books and magnified screens. Several seniors’ complexes were able to access assistive devices through the Canadian National Institute for the Blind. Children were able to access required technology through various family health plans.

The researcher found that the majority of those utilizing professional Intervenors were school age children who were able to access Intervenors through the public school system. Most adults who had acquired Deaf-Blindness relied on volunteers to access services and these were generally family members. Many organizations working with adults in the acquired population were not familiar with the terminology of “Intervenors” or “assistive devices”.

Access to Employment

This information was provided by service organizations that work specifically with adults with acquired Deaf-Blindness. This was a particular area of concern for these associations, given that the total number of adults who are Deaf-Blind and who are either employed or looking for work is relatively small in light of the total number of adults with acquired Deaf-Blindness that were reported. A large number of adults with either acquired or congenital Deaf-Blindness participate in day programs in order to receive training.

Sports and Education

The adults within the acquired Deaf-Blind population expressed a need for a “normalized” lifestyle. Respondents noted that childhoods were spent with less impairment and that the expectation was to continue to be active and involved as adults. Of those who provided information on sports and education, 25 were involved in sports programs, either on teams such as bowling or in solo activities such as running.

Participant organizations providing this information noted that high school education was possible, further education at a post-secondary institution was very difficult. As was noted in the introduction, respondents from post-secondary institutions indicated their facilities are not adequately established for students with disabilities. Thus, adults who wish to pursue their education are unable to do so.

Summary

Although the researcher found that the urban areas of the province of British Columbia had higher concentrations of individuals with Deaf-Blindness, on a ratio basis those located in urban vs. rural settings are very even. Every attempt was made to contact those complexes where seniors with Deaf-Blindness might be living. The Canadian Deafblind & Rubella Association – BC Chapter (CDBRA-BC) runs a very successful early Intervention program that provides individualized training to families in their homes. The Provincial Outreach Program for Students with Deafblindness (POPDB) runs a successful program that delivers appropriate training to school districts. Both of these programs have done an excellent job of locating children ages 0 – 5 and 5 – 19. These programs were instrumental in our data findings of children in rural settings. Deafblind Services Society of British Columbia was helpful in providing information on congenital Deaf-Blindness in the adult population and has been active in British Columbia providing transition services between the 6 – 20 and 21 – 60 age categories.

Although the researcher attempted to obtain information from the First Nations Band Offices, no data was reported. He was advised that no records were kept containing usable information on Deaf-Blindness. The School for the Deaf in Burnaby indicated that they were aware of First Nations students who fit in the study definition of Deaf-Blindness.

While a significant number of organizations do not currently track Deaf-Blindness as a disability, there was considerable support shown for future tracking if it became necessary or advisable.

Appendix F-2 Alberta/Northwest Territories/Nunavut

The region encompassed by the research consisted of the Province of Alberta, the Northwest Territories and Nunavut. Sixteen respondents are from Alberta and 2 are from the north.

Organizations Contacted
The following list provides a breakdown of contacts by organizational category.

Table F-2-1: Distribution by Organizational Category

Community groups	34
Disability groups	49
*Seniors	199
Public medical	25
**Government	61
Post-secondary education	22
Rehab	36
Private medical	12
School jurisdictions	77
Aboriginal	30

*Seniors is a combination of senior's resource centres, senior's residences and nursing homes.
**Under government the following were included: Alberta Health, Alberta Human Resources and Employment, AISH (Assured Income for the Severely Handicapped), Alberta Children's Services, Alberta Learning (Education), Alberta Seniors, municipal

libraries, municipal disability transportation, municipal diversity and the Worker's Compensation Board (WCB).

3.7% of the 492 organizations invited to participate provided a response on at least one interview guide question.

The research did not confirm a difference between the rural and urban environments. (Here urban is defined as a very large centre such as Edmonton and rural is defined as a smaller location such as Elk Island). In large measure, this was due to the fact that data was obtained from sources that reported for the entire province or territory. If organizational categories, Bethany Airdrie and region-wide reporting are ignored, then 8 Deaf-Blind persons live in rural areas and 9 reside in urban centers. The following list characterizes the participants' location and number of Deaf-Blind persons reported.

Table F-2-2: Participants' Location and number of Deaf-Blind reported

R: rural; U: urban; PW: province-wide; NN: both territories-wide; NT: Northwest Territories-wide; N: no numerical data

WCB	PW	28
CNIB	PW	107
AISH	PW	538
RNA NWT-NU	NN	N
Government of NWT	NT	N
Bethany Airdrie	R	63
Elk Island Schools	R	2
Holy Spirit Schools	R	N
CMC	R	6
ICE	R	N
Bethany Calgary	U	3
Calgary Library	U	N
GSS	U	1
MCF	U	4
Calgary Transit	U	N
Calgary Health Region	U	N
GRIT	U	1

GSS: Good Samaritan Society of Edmonton; MCF: Metropolitan Calgary Foundation of Calgary; CMC: Chateau Mission Court of St. Albert; GRIT: Getting Ready for Inclusion Today of Edmonton; ICE: Independent Counseling Enterprises of Grande Prairie; RNA: Registered Nurses Association of the Northwest Territories and Nunavut

Obstacles Encountered

Several problems were encountered during the research.

- The further north and east one traveled from Alberta into Nunavut, the more difficult it was to find e-mail addresses of potential participants. It may be that Internet and e-mail services in the far north, especially in Nunavut, was not yet common place.

- It was surprisingly difficult to get associations to participate. The list of organizations that responded to the invitation represented a 3.7% participation rate. It was even more difficult to obtain additional information in follow up e-mails. If contact information needed to be verified, e-mails were not answered.

- The potential participants objected to the use of e-mail because it was not thought to be secure. Fax communication was offered. This too was rejected. The researcher's mailing address was requested and forwarded. Participation was still not secured.

- The Freedom of Information and Protection of Privacy Act (FOIP) may have influenced the decision of some associations not to participate. It is difficult to know for sure. People may not have a thorough understanding of what can and cannot be reported under this Act.

- Senior Alberta Learning officials spoke to the students in Intervenor for Deafblind program at Medicine Hat College. The lecture disclosed that 9 Deaf-Blind children are currently enrolled in the Alberta school system. These same officials were unwilling to participate and confirm this figure for the research project.

- Personal knowledge on the part of the researcher indicated that several Deaf-Blind individuals are registered and access special library services. However, the library provided only incomplete data. The database is constructed in a manner that does not distinguish disabilities. Only special needs and regular card membership is identified.

- The issue identified above is not particular to the library. Rather, it is a more general problem. Deaf-Blindness is a distinct disability. Various databases, however, are not programmed for this distinctiveness. Much statistical data related to Deaf-Blindness is under broad classifications such as “sensory disabled”, “special needs clients”, “severe disabilities” or other depending on the first or major diagnosis.

- The research definition of Deaf-Blindness was clear. What is not so clear is the over-all condition of the person who is Deaf-Blind. For example, a person who only loses his hearing and sight can be easily characterized as Deaf-Blind. On the other hand a person involved in a very serious car accident sustains severe and permanent neurological damage from massive head and spinal cord injuries. This individual needs support and attendants for all bodily functions including feeding and elimination. Although the person may also have suffered a hearing and vision loss, the major diagnosis will be more profound. Defining such a person as simply Deaf-Blind minimizes his very serious condition. In this case, other labels will also apply.

- A principle strategy was to communicate with senior officers of the organizations. Many organizations did not publish the e-mail addresses of their officers. An e-mail address of the form info@organization was common. An ongoing strategy of locating current and personal addresses resulted in 2 or more e-mail addresses for the same organization. Once a reply was received, the personal address was also filed in the contact folder.

- After forwarding initial information to the WCB, an official wanted to know if researchers were interested in the number of Deaf-Blind employees or claimants. The term “consumers/members/clients” is sufficiently broad to include employees and claimants. The WCB was advised that both employees and claimants could be counted for research purposes.

Research Findings

Part A: "No" Respondents

In this section participants who answered “no” to the first question (Does your organization have clients, members, consumers, etc. who meet the definition of “Deaf-Blind” outlined in the introduction?) are examined. Three organizational categories are represented, school jurisdictions, public medical (nursing associations) and rehabilitation. One respondent is found in each category. Each filed a signed consent form.

Registered Nurses Association of the Northwest Territories and Nunavut
The Executive Director of the Registered Nurses Association of the Northwest Territories and Nunavut was not aware of any nurse who had sustained hearing and vision loss. In addition, she explained that her association was a professional organization not a front line group providing nursing care. Hence, she had no patient information. She referred me to the Yellowknife CNIB.

Independent Counseling Enterprises (ICE) This organization indicated there were no clients who met the research definition of Deaf-Blindness.

Holy Spirit Catholic Schools
The Coordinator of Student Services also indicated that no learner in his jurisdiction met the research definition of Deaf-Blindness.

Part B: "Yes/No" Respondents

This group of respondents answered “yes” to the first question. In other words there are clients/ members/ consumers who met the research definition of" Deaf-Blind". This group, however, cannot identify or does not maintain records of Deaf-Blind individuals. Hence “no” was the answer for the second (Does your organization keep records of, or can you identify, the number of your clients, members, consumers, etc. who meet the definition of “Deaf-Blind”?) question. Two organizational categories are represented, government with 5 respondents and public medical (health region) with one. Since Alberta Health and Wellness is the Ministry that funds and controls the health regions, it can be argued that all six respondents in this section are in fact in the organizational category of government.

Calgary Public Library
The information in the library database only classifies disabled users as special needs clients. Upon application into the special needs program, medical proof of a disability is required. The details of the disability are not entered into the database, and there is no easy way to alter the database to accept such detail.

Calgary Transit: Safety and Training, Access Calgary
Deaf-Blind individuals use public transportation services. The Safety and Training Department of Calgary Transit does not maintain records of Deaf-Blind persons who access training.

The largest disappointment of the research centered on the data from Access Calgary. Calgary Transit operates the Handibus under the name Access Calgary. Registered persons with disabilities can book door to door service. Numbered files are maintained and drivers are alerted to the specific disability needs of every client. However, the Coordinator of Access Calgary, opted to report “no” for question 2.

NWT Health and Social Services
“Person’s meet the Deaf-Blind definition but records are not maintained” was the response. The absence of records appears to be a feature of the northern landscape. The Yellowknife CNIB is not yet maintaining records of Deaf-Blind persons. The respondent from this organization did not participate but sent an explanatory note. "We do not have any clients registered in the NWT or NU. We are presently working on a survey and there are a number of people in the community who are Deaf-Blind and I hope to let them know about our services over the next year."

Assured Income for the Severely Handicapped (AISH)
This participant produced the biggest surprise of the research. The “yes/no” response was given. On the one hand, AISH officials monitor changes in a client’s medical condition. Numbered files are maintained. At the same time the provincial database cannot identify those who are Deaf-Blind.

Nonetheless, AISH reported that 538 clients or 1.7% of the caseload are “sensory disabled”. This means that an individual could be Deaf-Blind, blind, Deaf or other. It can be concluded that the population of Deaf-Blind AISH clients must be a tiny fraction of 1% of the caseload.

Calgary Health Region
This organization filed a “no” for the second question. In a medical/hospital environment, documentation is maintained. The region administers the low vision clinic,

an audiology department, and nursing homes and extended care facilities through Carewest. It appears that the requested information was nt able to be accessed.

Part C: Complete Data
This category provided the actual numerical responses. Five organizational categories are represented, school jurisdictions, disability groups, government, rehabilitation and seniors. Only one category contains more than one participant.

Rehab: Getting Ready for Inclusion Today (GRIT) Program
One Deaf-Blind client was reported. The child is in the youngest age class, 5 years of age or younger. Whether the child has congenital or acquired Deaf-Blindness is unknown. This child lives in a private home with his/her parents.

School Jurisdiction
The research attempted to locate children who are Deaf-Blind by writing to every school jurisdiction.
Only Elk Island reported in with two. They are school age children with acquired Deaf-Blindness. These two individuals live in private homes with their parents.

At a CNIB Panel discussion on Deaf-Blindness, the researcher met three Deaf-Blind children who attend Calgary schools. Thus, officially 2, unofficially 3 for a total of 5 out of 9 potentially Deaf-Blind children were located.

Government: WCB
A consent form was not filed. Data was provided because the WCB observes FOIP guidelines, which allows public access to WCB information.

Twenty-eight claimants were reported. Four were between the ages of 21 and 60 and 24 were aged 61 or over. Thus 86% of Deaf-Blind claimants are seniors. All had acquired Deaf-Blindness through work related injuries. WCB does not collect and store information dealing with living arrangements. Hence question 5 was answered with “unknown”.

The WCB does not have a category called Deaf-Blind. Instead, the data analyst programmed the database for a list of all workers who sustained permanent vision loss. From this group, the database produced a short list by isolating those workers who also sustained a hearing loss.

Disability Groups: CNIB
The most extensive data was obtained in this category. 107 clients were reported. The data is presented below in table format. The tables are appropriately abbreviated.

Table F-2-3*: *CNIB Disability Groups

Age	**0-5**	**6-20**	**21-60**	**61+**
Congential	**3**	**13**	**29**	**1**
Acquired	**0**	**3**	**28**	**30**
Total	**3**	**16**	**57**	**31**

Several interesting observations can be made. 82% of the clients are 21 years of age or over. 29% are seniors. The CNIB Deaf-Blind caseload is definitely aging. Less than half, 43% of the caseload has congenital Deaf-Blindness. In the youngest age class, only three children have congenital Deaf-Blindness.

Of the caseload, 57% have acquired Deaf-Blindness. Of the caseload over 21 years of age, 66% or 2/3 have acquired Deaf-Blindness. 0% of pre-school children, 19% of children and teens, 49% of adults, and finally, 97% of seniors have acquired Deaf-Blindness. This suggests that, as the population ages, acquired Deaf-Blindness becomes more significant.

Table F-2-4: Living Arrangements

Living Arr.	*Total 107*
Private Homes	0
Parents	28
Other Family	4
Spouse	25
Alone without support	13
Alone with support	5
Group Settings	
Ind. Living Residences	1
Group Home	20
Seniors Complex	11
Personal Care Home	0
Other Living	0

88% of the Deaf-Blind persons have access to some type of support whether in a private or group setting. Only 13 individuals live alone without support. In addition the ratio of private to group living is 2.3:1. It appears private living arrangements are preferred.

Seniors:
MCF, GSS, CMC, Bethany Calgary, Bethany Airdrie
This category was the only one that counted more than one participant. The tables below display category totals.

Again, interesting observations follow from this information. 97% have acquired Deaf-Blindness. Almost 99% are 61 or over. The correlation between advanced age and acquired Deaf-Blindness is very strong.

Table F-2-5: Living Arrangements (Seniors)

Question	*5d (*Of those who live in group settings, How many live in:))
Sup. Inde. Liv. Res.	25
Seniors' Complex	7
Personal Care Home	41
Group Home	1
Total	74

Question	*5e (*How many live in other housing arrangements?)
Other	3 (24 hr care)
Total	3

From the above table, it is clear that seniors living in private arrangements are not represented. Private medical companies providing home care did not participate. Tables 5 and 6 suggest that seniors in significant numbers are placing demands on group facilities. As the population ages, the demand for these facilities will increase as will the related demand on public dollars. The figures are also a barometer of the demand for Deaf-Blind support and Intervention. Increases in the number of seniors will increase the amount of acquired Deaf-Blindness, and this will create a greater demand for Intervention services

Summary and Conclusion

The following tables summarize the data. It should be pointed out that the totals crossover the organizational categories, thus an individual could be counted more than once.

Table F-2-6: Number of Deaf-Blind Persons counted

Rehab	1
Schools	2
WCB	28
Disability Groups	107
Seniors	77
1st Sub Total	**215**
Calgary Schools	3 (unofficial)
Alberta Learning	9 (unofficial)
2nd Sub Total	**227**
AISH	538 (Deaf-Blind unknown)
3rd sub total	**765**

Table F-2-7: Distribution by Age (Alberta/NT/N)

	Congenital	Acquired	Unknown	Total
0 - 5 years	3	0	0	3
6 - 20 years	13	5	0	18
21 - 60 years	30	32	0	62
61+ years	2	129	0	131
				214
Total	**48**	**166**	**0**	**214**

Table F-2-8: Living Arrangements (Alberta/NT/N)

Living Arr.	*Total 371*
Private Homes	78
Parents	31
Other Family	4
Spouse	25
Alone without support	13
Alone with support	5
Group Settings	106
Ind. Living Residences	26
Group Home	21
Seniors Complex	18
Personal Care Home	41
Other Living	3

Summary

- The Alberta CNIB register does not include all the Deaf-Blind persons located in Alberta. The Yellowknife CNIB has only commenced an educational campaign to register people who are Deaf-Blind and live in the north. Northern Canada appears to be lagging behind Alberta in documenting Deaf-Blindness.
- Across categories, 215 Deaf-Blind persons were officially counted and unofficially an extra 12 for a total of 227. Unofficial refers to data obtained through sources other than participating organizations. The AISH figure of 538 contains an unknown number of Deaf-Blind.

Generally, Deaf-Blindness is accepted as a distinct disability. However, various databases conceal Deaf-Blindness under broad classifications. This Canadian research project profiles the need for a clear accounting of Deaf-Blindness in all organizational categories. Alberta Learning now acknowledges Deaf-Blindness as a distinct disability in their database.

The participation rate was 3.7%. Ophthalmologists, home care providers, aboriginal and First Nations organizations declined invitations to participate.

Surprises and disappointments resulted as participants failed to provide highly anticipated data. Disabled transportation and health region data did not materialize.

Acquired Deaf-Blindness leads the congenital type by a ratio of 3.5:1. An aging population is contributing to higher levels of age onset Deaf-Blindness. This last point requires further research. What percentage of seniors develops age onset Deaf-Blindness? Clearly many seniors are not afflicted with this disability. Can risk factors be identified? What are they? Can one predict which Canadians are more likely to develop this disability? Answers to these questions await future research.

Appendix F-3 Saskatchewan

Introduction

The researcher utilized the guidelines for demographic research assistants to assist in determining the types of organizations to contact. Researchers began notifying community agencies and searching the yellow pages, brochures and the Internet to locate other contact sources. Aside from our own agency (CDBRA SK), Saskatchewan does not have any specialized services for people who are Deaf-Blind.

In making the contacts, the researcher began with a telephone call introducing herself, the project and inquiring if the associations supported anyone who met the criteria of "Deaf-Blind". She also asked if the organizations in question would be interested in participating in the survey. It was very important to clearly identify Deaf-Blindness, that it is a dual disability and not for Deaf or hard of hearing or blind or visually impaired persons. The researcher would then follow up with a fax or email of the full introduction to the project, the interview sheets and the consent form for them to review. Responses came back in a number of ways, many were faxed in, a few emailed and a couple of phone surveys were completed with a faxed in consent form to complete the process. Participants expressed interest in the results of the study. A few places were quick to say no and ended the call. Others were not able to participate but were willing to refer the researcher to another department or agency.

Obstacles To Participation

Some of the large companies or government departments refused to participate because gathering this type of information would have been too time consuming. This is unfortunate because their data may have been useful. If the data from the Saskatoon Home Care survey (96 people of 149 Deaf-Blind persons counted) is any indication of what the senior population is like, then the numbers for Saskatchewan would have been significantly higher. The motivation for these types of agencies would have to change to improve participation. One comment from the regional office for the nursing homes was “what is in it for me?”.

Of the surveys completed, services available to individuals vary. Outside of the group of eleven that CDBRA Sask. serves which is Deaf-Blind specific, the younger population receive support and services through the education system while the adults access services through CNIB or a Deaf and Hard of Hearing organization. There appeared to be little consistency in the organizations through which persons who are Deaf-Blind access information or services.

It is difficult to tell where there may be overlap services provided for individuals (i.e.: Canadian Deafblind Rubella Association and Canadian National Institute for the Blind and Saskatchewan Deaf and Hard of Hearing Services). Therefore, the tally may be slightly.

From the data collection the areas that provided the least amount of specific information were “Congenital or Acquired” and the causes of Deaf-Blindness. The data was not available (or would have taken too much time for some agencies to collect). Consequently respondents left these categories blank or marked unknown. Only a small percentage (~ 15%) of the individuals accounted for in the survey had known the cause or medical condition related to their Deaf-Blindness. The bulk of the unknown responses came from the senior population.

The researcher felt that awareness and education is something that would be one of the most powerful tools to aid all of the individuals that are functioning with Deaf-Blindness. If community members and medical professionals were more informed, they would be better able to identify, refer and support these individuals.

Research Findings
Interview Guide Responses
A breakdown of the survey responses completed as follows:

1). Do the Individuals meet the research definition of "Deaf-Blind".
Yes - 19 No - 27

2). Do you keep records of those who are Deaf -Blind)
Yes - 14 No - 5

3). How many meet the definition of "Deaf -Blind"?
149 (159 minus the 10 CDBRA/CNIB overlap)

Table F-3-1: Distribution by Age (Saskatchewan)

	Congenital	Acquired	Unknown	Total
0 - 5 years	0	0	0	0
6 - 20 years	2	9	0	11
21 - 60 years	27	1	50	78
61+ years	1	9	50	60
Total	**30**	**19**	**100**	**149**

Table F-3-2: Living Arrangements

Living Arr.	*Total 285*
Private Homes	85
Parents	11
Other Family	15
Spouse	16
Alone without support	8
Alone with support	35
Group Settings	51
Ind. Living Residences	7
Group Home	14
Seniors Complex	2
Personal Care Home	28
Other Living	13

Table F-3-3: Causes of Deaf-Blindness:

Congenital Rubella Syndrome	**8**
Usher Syndrome	**4**
Childhood Illness	**1**
Misc Syndromes	**3**
Unknown	**133**

For those completing the survey, the following indicates their distribution according to the categories set out in the "guidelines for demographic research assistants".

Individuals	4 (2 Rural, 2 Urban)
Education system/Schools	7 (2 Rural, 5 Urban)

The above finding on the youth population suggests that the education system needs to become more aware of the complexities of Deaf-Blindness and that this population will have growing needs as they mature and meld into the community. From these numbers, surveys for seven students were completed. Five surveys were filled out by a vision and special needs educator because she has former experience working with Deaf-Blind individuals. With more education on Deaf-Blindness in the school systems, more students may be identified with Deaf-Blindness. At this time the students are categorized as multiply disabled.

Disability Groups 28 (Urban)

In this category there were 10 individuals who overlapped in receiving services from CNIB and CDBRA SK. The total count has an adjustment made to account for the overlap.

Senior Residences	6 (Rural)
Medical Assoc./Health Region	96 (Urban)

The highest number of people who are Deaf-Blind are found within the senior population; 98 of the 149 Deaf-Blind persons counted are seniors, which would indicate a strong need to educate the care givers in these facilities to identify and support this population and their changing needs.

Community Org. 8 (Urban)

Total number of Deaf-Blind from the Surveys completed:
10 Rural + 139 Urban = 149

There is a significant difference (10 rural vs. 139 urban). This may be a result of where the services and supports are available.

Of all the contacts made, here is how they fall into the recommended search areas:

A.	Community Organizations	89 (43 Rural, 46 Urban)
B.	Disability groups for Blind, Deaf & Deaf-Blind	4 (Urban)
C.	Seniors Residences	12 (7 Rural, 5 Urban)
D.	Senior Resource Centres	0
E.	Medical Assoc., Health Regions, audiologists, ophthalmologists, Nursing Assoc.	14 (7 Rural, 7 Urban)
F.	Personal Care Homes	11 (2 Rural, 9 Urban)
G.	Government Departments	1 (Urban)
H.	Univ/Colleges, Disability Services, Rehab/Physio	1 (Urban)
I.	Teaching Hospitals, Vision clinics	1 (Urban)
J.	Private Companies	0
K.	School Districts / Boards	9 (2 Rural, 7 Urban)
	-Some statistics were given over the phone from the Special Education Department; 98 blind students and 331 hearing impaired students are registered in Saskatchewan schools.	
L.	Aboriginal and First Nations groups	8 (5 Rural, 3 Urban)
M.	Centers on Aging/Wellness, Research centers	0
N.	Data Bases	0
O.	Internet	0
P.	Individuals	5 (2 Rural, 3 Urban)

Total number of all contacts made: Rural 68 + Urban 87 = 155
With regards to the rural vs. urban statistics, the numbers of contacts were relatively close and the researcher achieved a broad coverage of the province.

Appendix F- 4 Manitoba

Introduction:

The Manitoba portion of the research project began with a review of all project documentation supplied by the Canadian Centre on Disability Studies along with consultations with the local project coordinator. This included the review of documents indicating the processes suggested for the collection of data and the specific questions contained in the questionnaire document.

Two persons, with one person as the lead, acted as researchers and divided up the work accordingly. A previous study, “Developing a National Volunteer Registry for Persons with Deafblindness in Canada” authored by Stan Munroe in 2001, found 38 persons in Manitoba who participated in that study and fit the current project’s definition of Deafblindness. It was noted that there may be a possible total of 80 persons in Manitoba known by various organizations and facilities who would fit into the current definition. In addition, it was felt that this number was under represented. It was clear from the initial stages of this part of the study that we were not talking about a large population of Deaf-Blind persons in Manitoba and a concerted effort had to be made in order to find as many Deaf-Blind persons as possible. This included a concerted effort to reduce the possibility of counting duplication wherever possible.

In Manitoba, the following research process was adopted:

> The Province was divided into regions based on Provincial guidelines (Winnipeg and Central, West man, Eastman, Interlake, Parkland, Southwest, Thompson, Norman Regions or Districts);
> Lists of potential participants were developed using personal contacts, the Winnipeg and Manitoba telephone books. Further contacts were added as the research progressed;
> Researchers placed telephone calls to each contact or organization on the list;
> The study was initiated in the Winnipeg region. Contacts were then made throughout Manitoba by District or Region;
> Researchers explained the purpose of the project to the first contact. If appropriate, the call was transferred to a person with organizational knowledge who could respond to the study questions;

The respondent was asked whether there were staff, members, clients or consumers within their organization who met the research definition of Deaf-Blindness;
If no one qualified, the survey was terminated at that point;

If there were potential persons who qualified, the letter of introduction, the consent form, the interview guide, etc were emailed, faxed, dropped off, or mailed to the respondent;
The contact person was then reached by telephone to complete the interview guide, and the consent form was returned to the researcher if the organization agreed to participate;
Interviewees were also asked for the names of other potential contacts.

Organizations Contacted

The following were the basic agencies, related organizations, and resources (both governmental and non governmental) contacted during the study:

Disability Services, employment equity, Human Resource offices at the major Manitoba Universities and Colleges, and various persons involved with disability organizations on campus;
The Provincial school system - Special Education for Blind and Visual Impaired Services Unit (Kindergarten to Grade 12);
Various Manitoba non government Disability and cross disability organizations, including the local offices of the Canadian National Institute for the Blind, the Resource Centre for Manitobans who are Deaf-Blind, Society for Manitobans with Disabilities, the Independent Living Resource Centre, Manitoba League of Persons with Disabilities, Manitoba Sports and Recreation Association of the Blind;
Various Aboriginal non-profit housing organizations, disability services organizations, and Aboriginal health units;
Various cooperative and non-profit housing organizations including the outside management firms for some of these organizations;
Provincial Audiologists, Physiotherapists, Occupational Therapists, Speech-Language Pathologists, Ophthalmologists, and other service organizations;
Seniors' Services and Rural Home Care Offices or other related organizations;
Seniors' Residences and Personal Care Homes, personal residences;
Various group insurance companies, Manitoba Workers Compensation Board; and
Various, Health facilities - Hospitals, Regional Heath Authorities, etc.

The sources for the data collection varied widely throughout the Province. Two hundred and seventy five organizations, agencies, departments, or individuals were contacted during the course of the research. 58 percent of these contacts were in Winnipeg and 42 percent throughout the remainder of Manitoba. In some cases more than one person was contacted in the same organization. This occurred in situations where different persons were responsible for the various areas of interest to the research. A total of 336 person contacts were made. Where possible, samples in each category were taken in all areas of the Province.

Obstacles Encountered

Only 17 or 5.1% of organizations, government departments, agencies or individuals contacted had knowledge of persons who were both Deaf and Blind. Many organizations or agencies indicated that they did not statistically track persons who were both Deaf and blind. Some stated it would be too much work to assemble the required information from their files. However, some organizations or agencies who had both Deaf and blind clients agreed to review their data bases or talk with other staff or case workers to retrieve the requested information. Except in a few cases, respondents relied on memory of their current and past members, clients, or consumers. Thus, there is the possibility that some persons may have been missed. Some respondents contacted their boards of directors or superiors who declined to participate.

Many rural respondents provided general comments. For example, if Deaf-Blind persons required services, they were taken to Winnipeg. Interviewees repeatedly referred the researchers to four organizations: The CNIB, Intervention Manitoba, Deaf Centre Manitoba or the Resource Centre for Manitobans who are Deaf-Blind in Winnipeg. The above sources proved to be important sources of demographic information.

There is the possibility of duplication of reported incidences of Deaf-Blindness. Many personal care homes reported no one who met the criteria of Deaf-Blindness. However, the researcher was aware of a number of seniors who met the study criteria. It is probable that there were many unreported cases of Deaf-Blindness. One respondent indicated that "individuals in personal care homes are rarely if ever identified as Deaf-Blind". The researchers believe that the demographic information gathered under-represents the Deaf-Blind population in the province.

Research Findings

As anticipated, the researchers met with limited success in finding persons who are both Deaf and blind in the Province. Rural respondents usually directed the researchers to eight primary resources within the city of Winnipeg. These included: The Resource Centre for Manitobans who are Deaf-Blind (RCMDB), the Canadian National Institute for the Blind Manitoba Division (CNIB), the Provincial School system, Intervention Manitoba-CDBRA Manitoba Chapter, Deaf Centre Manitoba, the Manitoba Developmental Centre, one personal care home that had numerous Deaf-Blind residents, and the Society for Manitobans with Disabilities.

A recurring theme emerged early in the study, in that Deaf-Blind persons were not tracked. Researchers relied on the personal contacts of caseworkers and managers. There was limited information available from the various Provincial and Municipal Government offices and Regional Health Authorities other than referrals to specific personal care homes, service agencies and senior's residences.

There was an effort to obtain information from First Nation organizations. Various Urban Aboriginal Housing organizations were contacted. In addition, researchers contacted

Aboriginal disability related organizations and health care providers. These contacts yielded limited success in locating persons who were both Deaf and blind. The seventeen organizations, agencies, or individuals that had clients or knew of Deaf-Blind persons indicated a total of 172 persons who were Deaf-Blind with ten more that they knew of in Manitoba . The Winnipeg rural split for those persons where their residence was known was 118 (70%) in Winnipeg and 50 (30%) in rural Manitoba.

The following tables summarize the results of the returned comments by contacts, and completed questionnaires. In addition, some organizations indicated on the first contact that there were persons who met the definition of Deaf-Blindness. However, upon reviewing the documents sent to them and, in consultation with their boards of directors or the executive director, the decision was made not to participate. These contacts and their comments are noted in the summary tables.

TABLE F-4-1: Deaf-Blind Demographics & Services in Canada – Manitoba Numbers & Ages

Organization or contact	Education Facilities (ii)	Aboriginal Org. (iii)	Therapists, speech Pathologists, etc (iv)	Services, Rural Home Care	Seniors' and Care Homes	Housing – Coop, non profit personal residence	Disability Services & contacts	CNIB	CDBRA	RCMDB	**Totals**
Organization has Deaf-Blind Clients	1	1	3	0	5	3	1	1	10	1	**16**
Organization does not have Deaf-Blind Clients	6	7	103	53	51	28	27				**275**
Number meeting definition	3 (7)	4 (1)	36		44	5 (2)	4	33	10	43	**172 (10)**
Wpg			9		44	5 (2)		25		33	**116 (2)**
Rural (i)		4 (1)	27					8		10	**49 (1)**
Ages 5 or under - Yes		1	2						0		**3**
Congenital			2						2		**2**
Acquired											**0**
Ages 6 to 20 Yes	3 (7)		4					1			**8 (7)**
Congenital			4					1			**5**
Acquired											**0**
Ages 21 to 60 - Yes			25					25		17	**67**
Congenital			15					15			**30**
Acquired			10					1		17	**28**
Ages 61 and over - Yes			6		44	5 (2)		7		26	**88 (2)**
Congenital			2			[1 Deaf]**					2**
Acquired			4		1	[1 blind]** (vii)				26	31**

TABLE F-4-2: Deaf-Blind Demographics & Services in Canada – Manitoba Housing Situation

Organization or contact	Education Facilities (ii)	Aboriginal Org. (iii)	Therapists, speech Pathologists, etc (iv)	Services, Rural Home Care	Seniors’ and Care Homes	Housing – Coop, non profit personal residence	Disability Services & contacts	CNIB	RCMDB	**Totals (v)**
How many live in private homes			6			4 (2)		22	43	75 (2)
In private homes live with:										
Parents/foster parents			5					5 (2)	2	12 (2)
Members of their family of origin			3						1	4
Spouse/partner and/or children									12	12
Alone without support services			2							2
Alone with support services			3		1	1			28	33
How many live in group settings			25		2	1		11	21	60
Disability services:										
Supportive independent living			4					9	9	22
Group home			1							1
Senior’s Complex			1						7	8
Personal Care Home					41	1			5	47
Other housing arrangements			24					3		27

Notes to Tables F-4-1 and F-4-2:

(number) The numbers in brackets indicate further possible persons who are Deaf-Blind and who might be located in Manitoba.

[Deaf]** One person aged 61 and over was congenitally blind but had acquired Deafness.
[blind]**

(i) “Rural” in the table means all areas of the Province outside of Winnipeg.

(ii) In most Universities and Colleges there is a self-reporting voluntary survey for persons with disabilities to declare themselves as a person with a disability. Students must seek service for the assistance from the office of disability services. One contact had a Deaf-Blind registered last year; others did not remember anyone who fit the category. In one case a contact remembered a Deaf-Blind person from 4 to 5 years ago. Within the Manitoba public school system for those aged between 5 and 21 (K to grade 12) there are approximately 650 children who are Deaf or blind or have a combination of Deaf-Blindness, but only “a handful are Deaf-Blind”. The school system does not categorize children as Deaf and blind in a separate category. There are 3 persons for sure but no more than 10 and would take a lot of work to pull out information with not enough time right now.

(iii) An Aboriginal disability organization knew of a cluster of blind persons where there were also 3 or 4 Deaf and blind persons, another person knew of a small child that was Deaf-Blind.

(iv) One contact indicated that persons who live in personal care homes rarely if ever are identified as Deaf-Blind.

TABLE F-4-3: Distribution by Age (Manitoba) **(**for those whose ages were given)

	Congenital	Acquired	Unknown	Total
0 - 5 years	2	0	1	3
6 - 20 years	7	0	7	12
21 - 60 years	38	28	9	67
61+ years	3	31	0	34
Total	**40**	**59**	**17**	**126**

TABLE F-4-4: Living Arrangements (Manitoba) *(for those whose housing arrangements were given)*

Living Arr.	
Private Homes	75
Parents	12
Other Family	4
Spouse	12
Alone without support	2
Alone with support	33
Group Settings	60
Ind. Living Residences	22
Group Home	1
Seniors Complex	8
Personal Care Home	47
Other Living	27

Commentary
Table F-4-1 indicates of the 336 organizations or individuals contacted only 17 or 5.1% had knowledge of persons whom were Deaf-Blind. When considering the cumulative totals from the returned surveys and initial comments of various contacts who did not return surveys, these contacts knew of 182 (with the possibility of a further 10) persons who were Deaf-Blind. This translates, as anticipated, into 116 (and possibly up to 118) located in Winnipeg (65% of the total) and 49 (and possibly up to 50) (28% of the total) located throughout the rest of the Province. (There were some results where a Winnipeg / rural split could not be determined.)

The numbers of Deaf-Blind persons, as per the above table, residing in Manitoba are under-represented. This, as noted, is a result of:

* An under representation from Personal Care Homes;
* Refusal of some contact organizations to participate in the study;
* Most contact organizations did not track Deaf-Blind persons; and

- Only samplings of the potential contacts from each area of the Province were completed.

Appendix F-5 Northwestern Ontario

Introduction

The following sections outline the collection of statistical data to determine the number, age ranges, causes of Deaf-Blindness and accommodation conditions of individuals in Northwestern Ontario living with a combined hearing and vision impairment. This includes the districts of Thunder Bay, Kenora and Rainy River.

The researcher was struck by the sheer landmass of the region he was investigating. Approximately half of the province's landmass is in this geographical area of Ontario. The region hosts a minimal percentage of the population in relation to the most densely populated area, which is located within an hour's drive of its most populated city, Toronto.

The question became, how to divide such a geographically spread out population into service categories which might include people who are Deaf-Blind.

Organizations Contacted

The research was divided into the following categories:
Health Care
Education
Social Services
Aboriginal Services

The researcher contacted sixty-one service providers located in the largest cities, Thunder Bay, Kenora, Fort Frances and Dryden as well as in some of the smaller cities like Sioux Lookout, Nestor Falls and Nipigon. Of these 61, forty-seven or 77% expressed interest in participating in the study. The smaller the town and the farther north the location, service delivery became conversely sparser. Those who participated were genuinely disappointed that they had no or very little in the way of statistical information to offer. The researcher believes this directly corresponds to the level of service that is available in Northern Ontario compared to other parts of the province. It became evident that an unequal ratio of quality Health Care and Education opportunities made Southern Ontario a much more attractive location for people with disabilities to live.

Obstacles Encountered

The large number of organizations that refused to participate was disappointing. The majority of the 14 that declined to participate were Aboriginal Services. The Department of Indian Affairs was unable to provide information and directed the researcher to contact the individual Band Councils. He contacted a variety of First Nations Councils; Friendship Centers; Chiefs Advisory Boards and Band Councils. The overall response was either no response at all to repeatedly left messages, or a feeling of apathy. These contacts seemed to feel that the research was not applicable to them.

Research Findings

Health Care:

In the area of Health Care the Demographic Study survey was forwarded to twenty organizations and ten participated. Only three agencies reported having clients living with a combined hearing and vision loss. Of these three, two reported having clients who were Deaf-Blind but did not keep records enabling them to report statistically. One stated that his organization had 18 clients that met the definition of Deaf-Blind. All 18 were over the age of 61 years, and all were in the acquired category. The other seven agencies reported that they had no clients who met the definition of "Deaf-Blind".

Education:

In the area of Education, the researcher contacted local school boards, the Ministry of Education, as well as the higher education facilities located in Northwestern Ontario. The Demographic Study survey was forwarded to six organizations and five participated. Of the five, one reported having two clients who were Deaf-Blind. The two clients were between the ages of 6 and 20 years, and both living at home with their parents. The other four reported that they had no clients who met the definition.

Social Services:

In the area of Social Services, the researcher contacted agencies that would have a high probability of coming into contact with this specific population. The Demographic Study survey was forwarded to 14 organizations and 11 participated. Of the 11 participants, four reported having clients who were Deaf-Blind and who fit the definition. Two of these associations were not able to provide statistical information. One reported having three clients, all over the age of 61, all with acquired Deaf-Blindness. These three individuals are living in a Seniors Complex. One of the four reporting organizations indicated having clients who met the definition of "Deaf-Blind". However, this association did not keep accurate statistics. This organization indicated an approximate number of between four and 15 individuals. For purposes of the study, the median number of nine was used.

Aboriginal Services:

In the area of Aboriginal Services, the study was forwarded to seven agencies, only one participated. This organization reported having no clients who met the definition.

Table F-5-1: Living Arrangements

Living Arr.	*Total 23*
Private Homes	0
Parents	2
Other Family	0
Spouse	0

Alone without support	0
Alone with support	0
Group Settings	0
Ind. Living Residences	0
Group Home	0
Seniors Complex	3
Personal Care Home	18
Other Living	0

Table F-5-2*: Statistics Summary:*

QUESTION	HEALTH	EDUCATION	SOCIAL SERVICES	ABORIGINAL	TOTAL
Deaf-Blind numbers	18	2	12	0	32
Age 5 & under					
Congenital					
Acquired					
Ages 6 to 20		2			2
Congenital					
Acquired					
Ages 21 to 60					
Congenital					
Acquired					
Ages 61 & over	18		12		30
Congenital					
Acquired	18				18
Private Homes					
Parent Home		2			2
Other family					
Spouse/partner					
Alone w/o support					
Alone with support					
Group Settings					
Ind. Living					
Group Home					
Seniors Complex			3		3
Personal Care Home	18				18
Other					

Table F-5-3: Age Distribution:

	Congenital	Acquired	Unknown	Total
0 - 5 years				0
6 - 20 years			2	2
21 - 60 years				0
61+ years			30	30
Total			**32**	**32**

Summary

Issue #1:

The Northwestern region of Ontario presented many challenges in the gathering of statistical information. There are no agencies providing support, education, or awareness related to vision and hearing loss to these remote areas. The researcher believes that those who reported having no clients lack education in the areas of vision and hearing loss. The term 'Deaf-Blind' would be foreign to most of them and was likely misunderstood despite the description outlined in the package they received. There may well be professionals serving some of these communities who have a background in vision loss, or a background in hearing loss, but they are seen as two separate things. The understanding of Deaf-Blindness as a 'dual disability' does not exist in the majority of areas contacted by the researcher.

For example, in the area of Health Services, the researcher contacted 20 organizations/agencies; the majority of them were all Seniors Homes or Complexes. Of those, ten either declined to participate or didn't respond to repeatedly left messages. These groups most likely felt that the research was not applicable to their clients. Of the ten who responded, seven reported none that fit the definition, two reported clients who would fit but did not keep statistics. Yet, one agency reported having 18 clients and there were documented statistics. It is highly unlikely, if not impossible, that 18 persons who were Deaf-Blind chose to attend one facility. What is much more likely is that someone with a background or an awareness of vision and hearing loss worked at that facility and viewed it as important enough to document.

The researcher believes there are many more people who are Deaf-Blind in Northwestern Ontario than indicated by the statistics in this report. More accurate on-site documentation is needed. The research should be undertaken by someone with a background in Deaf-Blindness to assist in identification and education.

Issue #2:

The Northwestern region of Ontario has the additional challenge of trying to gather information from very small, somewhat insular communities. These communities are exactly that, "communities", and outside interference is not always welcome. It appears that many of these smaller communities take on a ‘take care of our own’ attitude and identification. Client assessments are not pursued. To most of us, a demographic study of this nature is a good thing as it lays the foundation to argue for the needs of a particular disability group. However, it can be viewed as a negative thing by small communities who are accustomed to their ways.

To gather more accurate information in resistant communities, it would be advisable for people within those communities to undertake the research, contact people who already are familiar with the ways, customs, language, and with who the members feel comfortable sharing information. If the recommendation from Issue #1 were implemented, the researcher and the contact person in the community could join together in the gathering of the statistical data.

Appendix F-6 Southern Ontario

Introduction

At the beginning of this project, the researchers consulted with the Ontario Ministry of Municipal Affairs to determine the exact boundaries of “Southern Ontario”. For administrative purposes, the province of Ontario is divided into five regions: Central, Eastern, Western, North-western and North-eastern. Southern Ontario encompasses the Central, Eastern and Western regions. We informed the Research Co-ordinator and the Northern Ontario Research Assistant. The boundary area was approved by the above-mentioned persons and by the project co-ordinator.

The researchers obtained population density figures from the most recent Population Statistics available online from SmartGrowth Ontario which are as follows:

Table F-6-1: Population Statistics

REGION	POPULATION	% OF SOUTHERN ONTARIO
Central	7565000	70.5
Eastern	1548700	14.4
Western	1616800	15.1

Based on the percentage of population in each region, the researchers focussed 70% of our inquiries on Central Ontario and 15% each on Western and Eastern Ontario.

Prior to sending out the first questionnaire packages, each potential participant was contacted by telephone and asked if they had anyone that would meet our criteria as “Deaf-Blind” and if they would be interested in participating. Participants were offered a choice of completing the questionnaire; by fax, email or telephone. Following the distribution of the questionnaire, the researchers contacted each participant by fax, email or telephone to remind them of the due date for data collection completion. Our overall response rate was 72%.

Organisations Contacted

The seven categories that are included in our research along with the number of contacts per category per region are listed below:

Table F-6-2: Organizations Contacted

TYPE OF FACILITY	Cent	East	West	Prov Nat	TOTAL
Association for Community Living	15 /21	1/4	3/5	NA	19
Community	5 /13	NA	1/1	4/6 (N)	10
Disability	14 /15	3/3	1/1	4/5(P) 1/3(N)	23
Educational	19 /29	6/7	5/6	4/4(P)	34
Independent / Supportive Living	4 /7	3/3	1/2	0	8
Medical	4 /4	N/A	N/A	2/2(P) 1/1(N)	6
Seniors Residences	18 /29	3/6	4/6	0	25
TOTAL	79	16	15	16	125

Obstacles Encountered

A few organisations were disinclined to cooperate because they had reservations about the validity of the methodology being employed. This likely had a negative impact on our response rate.

No provision was made to screen out overlap and duplication of persons identified as being Deaf-Blind. A number of those contacted mentioned that the people they were including in their response would also appear on other databases. For example, one person received services from four different agencies that responded to this survey. With the design of the interview guide, it appears that there are four people who are Deaf-Blind when in fact there is only one.

Some organisations felt that they could not meet the deadline for data collection. We encountered problems with our research due to the timing of the project. Our research period overlapped the University Reading Week and the Primary / Secondary Schools' March Break holidays so many potential participants were away from their jobs. We were not subsequently able to make contact with all of our targeted schools. In addition, the end of the budget year on March 31st ensured that many potential participants were too busy to participate in the study.

A number of organisations indicated that it would require considerable effort to gather the necessary data and they did not have the time or resources to participate.

Other organisations said that the request needed to go through their Ethics Committee (which typically meet once a month or even once every three months). There wouldn't be time to complete the survey even if it was approved by the committee.

Research Findings

The response rate from the above-mentioned contacts is as follows:

Table F-6-3: Response Rate From Above Contacts:

TYPE OF FACILITY	Cent	East	West	Prov
Association for Community Living	15/21	38078	38109	N/A
Community	38360	N/A	37986	38141
Disability	14/15	38048	1	4/5(P) 1/3(N)
Educational	19/29	38173	38142	38080
Independent / supportive Living	38171	38048	38017	N/A
Medical	38080	N/A	N/A	2/2(P) 1/1(N)
Seniors Residences	18/29	38141	38140	N/A
TOTAL	83/ 120	18/ 22	14/ 22	16/ 18

Table F-6-4: Response Rate as a Percentage.

TYPE OF FACILITY	CENT	EAST	WEST	PROV
Association for Community Living	71%	50%	60%	N/A
Community	69%	N/A	100%	67%
Disability	93%	100%	100%	80% (P) 33% (N)

Educational	66%	86%	83%	N/A
Independent / supportive Living	57%	100%	50%	N/A
Medical	100%	N/A	N/A	100%
Seniors Residences	62%	67%	50%	N/A
TOTAL	69%	82%	64%	89%

The researchers were unable to determine precisely which areas in each region are considered to be rural since there has been considerable urban and suburban sprawl throughout the Southern Ontario region. Facilities were selected randomly within each region; some were from smaller towns and others from larger municipalities. In total, over 500 telephone and 100 email contacts were made in a geographic region that contains over one-third of Canada's population. Facilities contacted served client bases that ranged in size from approximately fourteen (14) to over three hundred (300+).

Responses to Questions

The following tables contain the actual numbers taken from returned questionnaires and telephone interviews. Not all questionnaires were fully or accurately completed (please see comments section).

Question 1. *Does your organisation have clients, members, consumers, etc. who meet the definition of "Deaf-Blind" outlined in the introduction?*

Question 2. *Does your organisation keep records of, or can you identify the number of your clients, members, consumers, etc. who meet the definition of "Deaf-Blind"?*

Table F-6-5: **Responses to demographic questions 1 and 2**

CATEGORY	DOES NOT TRACK	NO ONE FITS CRITERIA	YES
Assn for Community Living	0	12	7
Community and Government	2	1	1
Disability	5	5	13
Educational	0	17	17
Independent /Supportive Living	2	5	1

Medical	6	0	1
Seniors Residences	2	18	5
TOTAL	17	58	45

Question 3. *How many of your organisation's clients, members, consumers, etc. meet the definition of "Deaf-Blind"?*

Question 4 (a-d) *Are any of these individuals 5 years of age or younger/ between 6 and 20 / between 21 and 60 / age 61 years or older? If known, how many of them are congenitally Deaf-Blind? If known, how many of them have acquired Deaf-Blindness?*

Table F-6-6: Distribution by Age

	Congenital	Acquired	Unknown	Total
0 - 5 years	7	5	3	15
6 - 20 years	154	19	0	173
21 - 60 years	94	185	6	285
61+ years	12	181	2	195
Total	**267**	**390**	**11**	**668**

Table F-6-7: Distribution by type of Deaf-Blindness

Legend Key:
C=Congenital
A=Acquired
?=unknown

CATEGORY	0 – 5	38157	21-60	61+	TOTAL
Association for Community Living	1C	3C	11C 4A 1?		15C 4A 1?
Community			1?	2?	3?
Disability	5C	89C 9A	81C 177A 3?	12C 85A	187C 271A 3?
Educational	1C 3?	62C 9A	1C 4A		64C 13A 3?
Independent/Supportive Living			1?		1?
Medical	0.208	0			0.25
Seniors Residences			1C	96A	1C 96A

TOTAL	7C 5A 3?	154C 19A	94C 185A 6?	12C 181A 2?	203C 377A 8?

In total, we have received 588 Table 26 says there are 6 reports of people who meet the criteria of “Deaf-Blind” as defined by this study. It should be kept in mind that these 588 reports are out of a total Southern Ontario population of approximately 10.7 million people. This would probably work out to significantly less than one percentage point. Because there was no mechanism in place for cross-referencing the data collected, there is a probability of overlap built into these numbers.

Question 5. (a*) How many live in private home (such as houses, apartments, co-ops, etc.)*
5A - How many live with their parents?
5B - How many live with other members of their family of origin (e.g. brother, sister, aunt, uncle, grandparent)
5C - How many live with a spouse / partner / children?
5D How many live alone without support services such as Intervenors/Interpreters, home care services, Meals on Wheels, etc.?
5E - How many live alone with support services such as Intervenors/Interpreters, home care services, Meals on Wheels, etc.?

***Table F-6-8*: Living Arrangements**

Living Arr.	*Total 23*
Private Homes	0
Parents	196
Other Family	14
Spouse	51
Alone without support	6
Alone with support	106
Group Settings	0
Ind. Living Residences	36
Group Home	88
Seniors Complex	16
Personal Care Home	63
Other Living	19

CATEGORY	5A	5B	5C	5D	5E	TOTAL
Association for Community Living	5	1	0	0	1	7
Community	0	0	0	0	3	3
Disability	123	13	51	4	100	291

Educational	63	0	0	2	1	66
Independent / Supportive Living	0	0	0	0	1	1
Medical	5	0	0	0	0	5
Seniors Residences	0	0	0	0	0	0
TOTAL	196	14	51	6	106	373

Question 5. c) *How many live in group settings (such as supportive independent living residences, group homes, seniors' complexes, personal care homes, etc.)?*

5F - How many live in a supported independent living residence?
5G - How many live in a group home?
5H - How many live in a seniors' complex?
5I - How many live in a personal care home?
5J - How many live in other housing arrangements?

CATEGORY	5F	5G	5H	5I	5J	TOTAL
Association for Community Living	1	10	1	0	1	13
Community	0	0	0	0	0	0
Disability	35	64	15	20	9	143
Educational	0	13	0	0	5	18
Independent / Supportive Living	0	0	0	0	0	0
Medical	0	1	0	0	0	1
Seniors Residences	0	0	0	43	4	47
TOTAL	36	88	16	63	19	222

'Other' included:
Long Term Care Facilities (4)
unknown (9)
associate family (1)
children's hospital centre (4)
foster home (1)

Please note that the numbers under Living Arrangements and the overall total of Deaf-Blind persons located cannot be reconciled due to inconsistent and incomplete response patterns.

Summary Comments

We received a variety of comments from participants about the study and questionnaire. We have included a representative sample of these comments below.

There was confusion among some participants with regards to the definition of "Deaf-Blind". This may have been partly due to pre-existing notions or "mind-set" as illustrated by the following quote from one of the Provincial Schools for the Deaf. "The two students we previously mentioned have a vision impairment but do not attend school for persons who are Deaf-Blind". The school returned a questionnaire that stated that they had no Deaf-Blind students.

The definition of "Living Arrangements" also differed from participant to participant. For example, one person referred to the Rotary Cheshire Homes facility in Toronto as a "group setting" while another described it as a "private setting". As well, the was some confusion about whether Long Term Care facilities would be considered a "personal care home" in a group setting or be classified as "other" housing arrangements. Long Term Care facilities were categorised under both labels.

There was another area of confusion surrounding the Living Arrangements section. In one response the total number of people who were identified was 28 although when the numbers under Living Arrangements were added up they totalled 42.

A number of questionnaires were returned incomplete. In the "Living Arrangements" section, some respondents would indicate if people lived in 'private' or 'group' settings but would not provide the additional data requested in question 5(b) or 5(d). This has resulted in inconsistent numbers.

Different terminology used by different organisations made it impossible in some cases to distinguish between supported independent living residences and group homes. This was the case with CNIB who stated, "We combined independent living residences and group homes because we don't differentiate between the two."

Two school boards felt that providing information on Living Arrangements for their students could be used to identify the student. One school board was a large metropolitan board while the other served a smaller rural community. One was public and the other was Catholic.

Respondents had difficulty classifying seniors in some cases due to mental health issues. One facility wrote on their questionnaire, "This may not be accurate as some residents are diagnosed with late stage dementia and it is difficult to tell."

The majority of problems encountered with the Living Arrangements question appeared to centre around the ambiguity of the terms used and the number of options available on the questionnaire.

Appendix F-7 Quebec

Abbréviations :
CHSLD : Centre d'Hébergement et de Soins de Longue Durée (A CHSLD offers home care services for seniors).
CR : Centre de Réadaptation (Readaptation or rehabilitation centre).
CRDI : Centre de Réadaptation en Déficience Intellectuelle (CRDI are readaptation centres for persons with intellectual disabilities).
INLB : Institut Nazareth et Louis-Braille (This is a readaptation centre for persons who are blind located in Longueuil city, in Montérégie, on the south shore of Montreal).
IRD : Institut Raymond-Dewar (This is a readaptation centre for persons who are hearing impaired located in Montreal).
IRDPQ : Institut de Réadaptation en Déficience Physique de Québec (This is a readaptation centre for persons with a variety of disabilities located in Quebec city).

Introduction

The purpose of this study was to determine as precisely as possible how many persons who are Deaf-Blind live in Quebec, their ages, the causes of their disabilities, their living arrangements and their distribution in urban and rural locations. In order to collect this information, contacts were made with readaptation centres of all types, many CHSLD, hospitals, associations for persons with hearing impairments, as well as associations for those who are blind and First Nations organizations.

Since no identifying information about individuals was collected and because many persons who are Deaf-Blind are clients or members of more than one organization, it is impossible to know exactly how many individuals who are Deaf-Blind live in Quebec. The studies published by the Office des Personnes Handicapées du Québec and the Ministère de la Santé et des Services Sociaux are of little benefit since they include persons who are blind or have hearing impairments. There is no information about those who are Deaf-Blind. At best, we can only gather information about the numbers of persons who are Deaf-Blind which is based on estimates.

The majority of those who are Deaf-Blind in Quebec are clients of readaptation centres. This explains why most of the efforts to collect data focused on these centres. It is still possible that the data may inflate the numbers of persons who are Deaf-Blind because many are clients of more than one readaptation centre.

This is why the data from the two readaptation centres with a supra-regional mandate for Deaf-Blindness are of special importance. These centres are the Institut Raymond-Dewar (IRD), a readaptation centre for those with hearing impairments located in Montreal, whose mandate covers the South and West parts of the province, and the Institut de Réadaptation en Déficience Physique de Québec (IRDPQ), whose mandate in Deaf-Blindness covers the rest of the province.

Obstacles encountered
The collaboration of readaptation centres was generally excellent, though some did not respond. The CHSLD participation rate was low, more information from this source could be collected in future research.

In a few instances, organizations requested an internal ethical review through their ethics committees in addition to the successful review already undertaken by CCDS. For example in two readaptation centres, it took several months to complete this review.

Study Findings

Numbers of persons who are Deaf-Blind in Quebec

This study has located 1059 Deaf-Blind persons in Quebec. The analysis of data indicates that the population of Deaf-Blind persons in Lanaudière, Laurentides and Montérégie is larger than our figures indicate. If the percentage of individuals who are Deaf-Blind in these three regions was similar to that of the neighbouring regions of Laval and Montréal, and if we apply Montreal’s rate of 17 Deaf-Blind persons per 100 000 inhabitants to only three other regions whose data is incomplete, Mauricie-Centre-du-Québec, Saguenay-Lac-Saint-Jean and Estrie, then there would be 1523 individuals who are Deaf-Blind in Quebec, for a rate of 21,04 Deaf-Blind persons per 100 000 residents. Since it is probable that many seniors who became Deaf and blind when they were older are not clients of readaptation centers, the researcher believes that this estimation is still lower than reality.

Regional distribution of persons who are Deaf-Blind, their ages and causes of disabilities

Table F-7-1: Bas-Saint-Laurent
Data given by CR L’Interaction. L’Association du Québec pour Enfants avec Problèmes Auditifs (AQEPA), section of Bas-St-Laurent, does not have any Deaf-Blind persons.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	0	0	0	0

6-20	1	0	0	1
21-60	9	1	1	7
61 +	83	0	2	81
total	93	1	3	89

Table F-7-2: Saguenay-Lac-Saint-Jean

The Centre Hospitalier Jonquière has 1 Deaf-Blind client.

age	No. of persons who are Deaf-Blind.	congenital	acquired	unknown
0-5	0	0	0	0
6-20	0	0	0	0
21-60	0	0	0	0
61 +	0	0	0	0
unknown	1	0	0	1
total	1	0	0	1

Table F-7-3: Québec

Data given by IRDPQ. The CRDI de Québec and the Centre Hospitalier de Charlevoix advised the researcher that their information system contained no information about persons who are Deaf-Blind. The Association du Québec pour Enfants avec Problèmes Auditifs (AQEPA), section Québec, has no persons who are Deaf-Blind.

age	No. of persons who are Deaf-Blind.	congenital	acquired	unknown
0-5	1	1	0	0
6-20	5	5	0	0
21-60	47	27	15	5
61 +	122	8	114	0
total	175	41	129	5

Table F-7-4: Mauricie et Centre-du-Québec

Data given by IRDPQ. The Association des Personnes Malentendantes de la Mauricie and the Regroupement des Personnes Sourdes de la Mauricie have no persons who are Deaf-Blind.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	1	1	0	0
6-20	0	0	0	0
21-60	4	3	0	1
61 +	5	4	1	0
total	10	8	1	1

Table F-7-5: Estrie

Data given by IRDPQ. The CR Estrie has no data. The Association du Québec pour Enfants avec Problèmes Auditifs (AQEPA), section Estrie, and the Regroupement CNDE/Dixville Retirement Homes have no Deaf-Blind clients.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	0	0	0	0
6-20	0	0	0	0
21-60	0	0	0	0
61 +	1	0	1	0
total	1	0	1	0

Table F-7-6: Montréal-Centre

The CR Constance-Lethbridge, the CRDI Gabriel Major, the Centre Miriam and the Hôpital Douglass have no Deaf-Blind clients.

Data provided by: the Rassemblement des Aveugles et Amblyopes du Montréal Métropolitain (46 members who are Deaf-Blind), the Foyer Rousselot (6 clients), IRDPQ (4 clients), the Mackay center (39 clients), the Institut Nazareth et Louis-Braille (INLB) (343 clients) and IRD (515 clients, including 267 on Montreal's island).

The numbers of persons who are Deaf-Blind living on Montreal's island were obtained by the addition of IRD and Mackay center clients. The distribution among age groups of IRD clients was evaluated in accordance with the proportion of the figures of all its clients.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	5	5	0	0
6-20	16	10	6	0

21-60	129	13	116	0
61 +	156	1	155	0
total	306	29	277	0

Table F-7-7: Outaouais

Data given by the CR La Ressource. The Pavillon du Parc and the Résidence La Pietà have no Deaf-Blind clients.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	2	2	0	0
6-20	5	4	1	0
21-60	18	2	16	0
61 +	72	3	69	0
total	97	11	86	0

Table F-7-8: Abitibi-Témiscamingue

Data given by the CR La Maison. The Clair Foyer residence has no Deaf-Blind clients, the Association des Sourds et des Malentendants de Rouyn-Noranda will soon have 3 recognized members who are Deaf-Blind.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	0	0	0	0
6-20	0	0	0	0
21-60	10	7	3	0
61 +	49	3	46	0
total	59	10	49	0

Table F-7-9: Côte-Nord

Data given by IRDPQ. The Centre de Protection et de Réadaptation de la Côte-Nord has no Deaf-Blind clients.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	0	0	0	0
6-20	0	0	0	0
21-60	5	4	0	1
61 +	2	0	2	0

total	7	4	2	1

Table F-7-10: Nord-du-Québec

The Centre Régional de Santé et de Services Sociaux de la Baie-James has no persons who are Deaf-Blind in the region. Since there are only about 30 000 residents in the region and an urban population rate of 51%, the researcher believes there are likely no persons who are Deaf-Blind living there.

Table F-7-11: Gaspésie-Îles-de-la-Madeleine

Data given by IRDPQ.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	0	0	0	0
6-20	0	0	0	0
21-60	9	6	2	1
61 +	2	0	2	0
total	11	6	4	1

Table F-7-12: Chaudière-Appalaches

Data given by IRDPQ. The CRDI Chaudière-Appalaches has 1 or 2 Deaf-Blind clients.

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	1	1	0	0
6-20	0	0	0	0
21-60	14	5	9	0
61 +	68	2	66	0
total	83	8	75	0

Table F-7-13: Laval

The CRDI Normand-Laramée has 2 Deaf-Blind clients. The Association des Personnes Vivant avec une Surdité de Laval has one senior Deaf-Blind member. IRD has 3 clients aged less than 21 years, INLB has 9 of 21-60 years of age and 3 older. Now, IRD has a total of 54 clients in Laval. Following the general distribution of age of IRD clients, we get this chart :

age	No. of persons who are Deaf-	congenital	acquired	unknown

	Blind			
0-5	1	0	0	1
6-20	2	0	0	2
21-60	23	0	0	23
61 +	28	0	1	27
total	54	0	1	53

Table F-7-14: Lanaudière

The CR Le Bouclier has 30 clients in Lanaudière, while IRD has 38. Combining the data of both readaptation centers and following (as far as is possible) the general distribution of age of IRD clients, we get this chart**:**

age	No. of persons who are Deaf-Blind	congenitally	acquired	unknown
0-5	1	1	0	0
6-20	4	4	0	0
21-60	15	9	0	6
61 +	18	3	13	2
total	38	17	13	8

Table F-7-15: Laurentides

The CRDI du Florès has no Deaf-Blind clients. IRD has 17 Deaf-Blind clients, including 3 between 0-20 years of age. The following chart shows the general age distribution of IRD clients:

age	No. of persons who are Deaf-Blind	congenitally	acquired	unknown
0-5	1	0	0	1
6-20	2	0	0	2
21-60	6	0	0	6
61 +	8	0	0	8
total	17	0	0	17

Table F-7-16: Montérégie

The CRDI Montérégie-Est has no data about Deaf-Blind clients. The Centre Montérégien de Réadaptation has 5 clients between 0-5 years of age, IRD has 7 between 0-20 years of age, INLB has 47 between 21-60 years of age (this number may be too high because of the criteria for Deaf-Blindness that were used) and 3 over 60 years of age. Moreover, IRD has a total of 107 clients in Montérégie. The best possible age distribution of these clients is as follows:

age	No. of persons who are Deaf-Blind	congenital	acquired	unknown
0-5	5	3	2	0
6-20	5	0	0	5
21-60	44	1	1	42
61 +	53	0	0	53
total	107	4	3	100

Table F-7-17: Nunavik

The Makivik Organization has no data about persons who are Deaf-Blind in Nunavik. According to the Régie Régionale de la Santé et des Services Sociaux du Nunavik (which published a study in 2002), among the 7 communities of the Hudson coast, there are 6 children and 5 adults with hearing impairments and 3 children and 1 adult with vision problems. On the Ungava coast, 10 children and 3 adults have hearing impairments, while 1 child and 1 adult have vision problems. No individuals who are Deaf-Blind are living in the territory.

Table F-7-18: Terres-Cries-de-la-Baie-James

The Conseil CRI de la Santé et des Services sociaux made contact with all clinics of the nine Cree communities, and found no Deaf-Blind clients.

Other First Nations organizations

The Association des Femmes Autochtones du Québec and the Conseil Tribal de la Nation Huronne-Wendat from Wendake (north of Quebec city) have no data about persons who are Deaf-Blind. The Service de Santé de la Nation Huronne-Wendat knows of some hearing impaired persons, but is unaware of any persons who are blind or Deaf-Blind.

Provincial associations

The Association des Malentendants du Québec and the Association des Implantés Cochléaires du Québec have no members who are Deaf-Blind. The head office of the Association du Québec pour Enfants avec Problèmes Auditifs (AQEPA) presented the study to its regional sections but, unfortunately, this organization could not provide data.

Table F-7-19: Total for Quebec province

age	No. of persons	congenital	acquired	unknown

	who are Deaf-Blind			
0-5	18	14	2	2
6-20	40	23	7	10
21-60	333	78	163	92
61 +	667	24	472	171
age unknown	1	0	0	1
total of known d-b p.	1059	139	644	276
lacking data (estim.)	approx. 464			

Table F-7-20: Living arrangements in Quebec

		IRD	CR Montérégien	SR-SOR	Bouclier	La Ressource	Maison Rouyn	Foyer Rous-selot	IN-LB	IR-DPQ
private homes	total	?	5	0	26	67	39	0	91[c]	136
	with parents	beaucoup	5		5	7	1			10
	with other members of family					13	7		3[d]	57[e]
	with partner and/or children				21	24	15			41
	alone without support services					2	7			28[f]
	alone with support services					21	9			
group settings	total	95	0	2	4	26	24	6	28	61
	supported ind. living resid.					0	16			
	group home	8		2	1	1				
	seniors' complex	82			3	13	8	6	24	57

	personal care home	5[a]				6			4	4[g]
Other housing arrange m.						6[b]				
unknown						4			20	93

a: Five individuals are living in a psychiatric hospital.
b: Two are in family type resources (it is impossible to define "family-type resources" more specifically, as the label is very general) and 3 are in pension. This means that these young people need to live close to their schools and that their natural parents are paying foster families to provide shelter. 1 Deaf-Blind client is waiting for placement in a hospital.
c: All data from INLB exclude those for young people below 21 years of age. Most of these data are visibly not related to Deaf-Blind people as defined by the current study. Of the 91 persons living in private homes, one lives in a family-type resource and 87 live in personal homes (the label for “personal home” is not specific).
d: All are placed with foster families.
e: Four are placed with foster families.
f: With or without services.
g: 2 are in a hospital, two are in a readaptation center.

C) Analysis of results

1. Regional distribution of persons who are Deaf-Blind in Quebec

Here is a map of Quebec’s regions and the data of a population census done in 2001 (both are taken from the web site of the Institut de Statistiques du Québec; for the chart: http://www.stat.gouv.qc.ca/regions/lequebec/population_que/occupter20_an.htm

It should be noted that in the health system, region 10 Nord-du-Québec, has been divided to form regions 10 Nord-du-Québec (in the south), 17 Nunavik (in the extreme north) and 18 Terres-Cries-de-la-Baie-James (in between). Region 17 of the map, Centre-du-Québec, has been joined to region 4 Mauricie. The chart has been modified accordingly, using data from Statistics Canada, http://www12.statcan.ca/francais/census01/home/Index.cfm

Table F-7-21: Population and land occupation, Québec administrative regions, 2001

Administrative region	Land Area Km2	Percentage of Regional Area (%)	Population (n)	Population Density (inhab./km2)	Urban Population Rate (%)
01 Bas-Saint-Laurent	22 628,1	1,5	200 630	8,9	52,4
02 Saguenay–Lac-Saint-Jean	104 051,7	6,8	278 279	2,7	71,8
03 Québec	19 312,5	1,3	638 917	33,1	87,7
04 Mauricie et Centre-du-Québec	46 703,0	3,1	473 770	10,1	72,6
05 Estrie	10 196,8	0,7	285 613	28,0	63,9
06 Montréal	502,0	0,03	1 812 723	3 610,7	100,0
07 Outaouais	32 972,7	2,2	315 546	9,6	74,2
08 Abitibi-Témiscamingue	65 143,5	4,3	146 097	2,2	54,8
09 Côte-Nord	298 469,2	19,6	97 766	0,3	68,8
10 Nord-du-Québec	390 816,0	25,7	16 314	0,04	?
11 Gaspésie–Îles-de-la-Madeleine	20 744,6	1,4	96 924	4,7	27,8
12 Chaudière-Appalaches	15 211,9	1,0	383 376	25,2	58,1
13 Laval	245,4	0,02	343 005	1 397,7	100,0
14 Lanaudière	13 090,1	0,9	388 495	29,7	71,9
15 Laurentides	21 459,6	1,4	461 366	21,5	69,4
16 Montérégie	11 226,4	0,7	1 276 397	113,7	81,7
17 Nunavik	443 293,8	29,13	9 632	0	?
18 Terres-Cries-de-la-Baie-James	5 586,3	0,4	12 629	2,3	?
All Québec	**1521 653,8**	**100,0**	**7 237 479**	**4,8**	**80,4**

Table F-7-22: Chart of Deaf-Blind population distribution among Quebec's regions.

Region	% of Quebec population	nb of d-b persons	% of Quebec's d-b living in region	d-b pop. per 100 000 inhab.
01 Bas-St-Laurent	2,77	93	8,78	46,35
02 Saguenay-Lac-Saint-Jean	3,84	1	0,1	0,36
03 Québec	8,83	175	16,53	27,39
04 Mauricie-Centre-du-Québec	6,55	10	0,94	2,11
05 Estrie	3,95	1	0,1	0,35
06 Montréal	25,05	306	28,90	16,88
07 Outaouais	4,36	97	9,16	30,07
08 Abitibi-Témiscamingue	2,02	59	5,57	40,38
09 Côte-Nord	1,35	7	0,66	7,16
10 Nord-du-Québec	0,23	0	0	0
11 Gaspésie-Îles-de-la-Madeleine	1,34	11	1,04	11,35
12 Chaudière-Appalaches	5,30	83	7,84	21,65
13 Laval	4,74	54	5,10	15,74
14 Lanaudière	5,37	38	3,59	9,78
15 Laurentides	6,37	17	1,61	3,68
16 Montérégie	17,64	107	10,10	8,38
17 Nunavik	0,13	0	0	0
18 Terres-Cries-de-la-Baie-James	0,17	0	0	0
Québec (total)	100	1059	100	14,63
Québec (estimation)	100	1523	100	21,04

Quebec city's region is the home of 8,83% of the province's population and of 16,53% of Deaf-Blind Quebecers. Deaf-Blind persons are heavily represented there. Chaudière-Appalaches (a southern suburb of Quebec) has a lower rate of Deaf-Blind residents, but they are also overrepresented in the region. The situation is different on Montreal's island, the home of 25% of Quebec's population and of roughly the same percentage of Deaf-Blind Quebecers. Persons who are Deaf-Blind, then, are not over represented despite the number and quality of available services. Laval (a close suburb of Montreal) has the same demographic profile. This is quite surprising since the researcher expected Deaf-Blind persons to be proportionally more numerous in Montreal than anywhere else, except Quebec city.

Table F-7-23: Distribution of Deaf-Blind persons in age groups and regions

The following chart shows the proportion of Deaf-Blind persons for all age groups, in regions for which data is significant.

age region	0-5	6-20	21-60	61 +	No. of Persons who are Deaf-Blind	No./ 100 000
01 Bas-St-Laurent	0	1,08	9,68	89,25	93	46,35
03 Québec	0,57	2,86	26,86	69,71	175	27,39
06 Montréal	1,63	5,22	42,16	50,98	306	16,88
07 Outaouais	2,06	5,15	18,56	74,23	97	30,07
08 Abitibi-Témiscamingue	0	0	16,95	83,05	59	40,38
09 Côte-Nord	0	0	71,43	28,57	7	7,16
11 Gaspésie-Îles-de-la-Madeleine	0	0	81,82	18,18	11	11,35
12 Chaudière-Appalaches	1,20	0	16,87	81,93	83	21,65
13 Laval	1,85	3,70	42,59	51,85	54	15,74
14 Lanaudière	3,33	13,33	30	53,33	30	9,78
15 Laurentides	5,88	11,76	35,29	47,06	17	3,68
16 Montérégie	4,67	4,67	41,12	49,53	107	8,38

Regions with the highest proportion of persons who are Deaf-Blind also have the highest rate of Deaf-Blind seniors. In round figures, Bas-St-Laurent, with 46 Deaf-Blind persons per 100 000 residents, has only 1% of Deaf-Blind persons under 21 years of age. Abitibi-Témiscamingue, with 40 Deaf-Blind persons per 100 000 residents, has none less than 21 years of age. Chaudière-Appalaches, with 22 Deaf-Blind persons per 100 000 residents, has only 1% of Deaf-Blind persons under 21 years of age. Data from Côte-Nord and Gaspésie-Îles-de-la-Madeleine are too partial to be compared with others, but it should be noted that these two regions located very far from Montreal and Quebec city has reported no Deaf-Blind persons under 21 years of age.

Outaouais, with 30 persons who are Deaf-Blind per 100 000 residents, has 7% less than 21 years of age. Montréal, with 17 persons who are Deaf-Blind per 100 000 residents, has also 7% under 21 years of age. Laval’s demographic profile is similar to Montreal’s. It is likely that the researcher did not count all Deaf-Blind residents of Lanaudière. It would appear that the numbers of persons who are Deaf-Blind has been under-estimated for those between 21-60 years of age. Otherwise, the distribution among age groups is quite similar to Montreal’s (possibly because Lanaudière is the northern suburb of Montreal). The same is true for Laurentides (an other northern suburb of Montreal) where there would seem to be an under-estimation in the numbers of both adults and seniors in the region, and Montérégie (a southern suburb of Montreal) where the numbers of seniors in the region would seem to be under-estimated. In the region of Quebec, there are 3,4% of Deaf-Blind persons under 21 years of age, which is intermediate between the high rate observed in Outaouais and Montreal, and the low rate observed in distant regions.

This chart suggests that young Deaf-Blind persons may be moving to Montreal to receive more services, except for Outaouais where Gatineau and Ottawa are also very attractive. If the concentration of Deaf-Blind persons in Montreal is nevertheless lower than that in distant regions, it could be explained by the migration of young people towards major centres. A majority of older persons with acquired Deaf-Blindness would thus remain in distant regions. However, data from the Institut de Statistiques du Québec indicate that the population of Bas-St-Laurent is no older than the population of Montreal and that of Abitibi-Temiscamingue is younger. The age of the latter population is very similar to that of the suburbs of Montreal and Outaouais. The peculiarity of Abitibi-Temiscamingue is that its migratory balance is very negative while in Bas-St-Laurent, it is even. In Outaouais and the greater Montreal, the migratory flux is highly positive. It is possible then, that there are more Deaf-Blind persons in Abitibi-Témiscamingue and Bas-St-Laurent because seniors who are Deaf-Blind are less mobile and remain in the region.

In Quebec city, the rate of young Deaf-Blind persons is not as high as our model would predict. The data for this region appears to be quite complete and the region's population is increasing slightly more rapidly than the provincial average. It is also well equipped in readaptation and an important urban center for the North, the Center and the East of the province, this explains why it would be expected to drain much of their population of Deaf-Blind children. But this is not the case. These Deaf-Blind children appear to be moving to Outaouais and Montreal rather than to Quebec city.

If the data for distant regions confirmed that there are more people who are Deaf-Blind than in major cities, this does not support the need to advocate for a decentralization of services. If an adult becomes Deaf-Blind at 60, he requires different services than a child who is Deaf-Blind. This could justify, though, a difference between the services offered in regions and in major cities.

C) First Nations

The researcher attempted to determine if there were individuals who are Deaf-Blind among Quebec's First Nations communities. He could not locate any. More precisely, the Inuits of Nunavik, the Crees of James-Bay Territory and the Huronne-Wendat Nation of Wendake (near Quebec city) indicated there are no persons who are Deaf-Blind in these communities. For the other Nations, data are too scarce to draw conclusions.

D) Persons Who are Deaf-Blind and Social Organizations

The researcher contacted many organizations of those with hearing impairments and few had members who are Deaf-Blind. The Rassemblement des Aveugles et

Amblyopes du Montréal Métropolitain, an organization for blind and amblyopic persons have 46 members who are Deaf-Blind.

The presence of individuals who are Deaf-Blind in organizations for those who are blind rather than organizations for citizens with hearing impairments is not surprising. Persons who are hearing impaired have a special culture largely conveyed by Quebec sign language (LSQ or Langue Des Signes Quebecoise). Relatively few persons who are Deaf-Blind know this language or are part of this culture.

Acknowledgement

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Appendix F-8 Atlantic Canada

Organizations Contacted

It was determined that the following agencies and related organizations be established as resources to obtain the required information:

The Canadian Deafblind and Rubella Association
The Canadian National Institute for the Blind
Deaf and Hard of Hearing Organizations
Atlantic Provinces Special Education Authority
Health Canada
First Nations and Inuit Health Branch - Canada
Provincial Government Agencies
Family and Community Services
Health & Wellness
Selected Group & Special Care Facilities
Regional Healthcare Administrations
Nova Scotia Commission on Disabilities

Sources of data collection varied depending upon the province in which the information was being collected.

Due to the fact that not all responses to questionnaires were complete, it is not possible to balance total numbers with components that comprise the data. This becomes evident with respect to information provided by government agencies. In these cases, the information was included in the findings even though it did not fully address the questions contained on the interview guide. It should also be noted that there was some reluctance from government departments to sign consent forms or to complete the interview guide. However, research was compiled from faxes or emails that simply offered the numbers of Deaf-Blind persons within their regions of responsibility.

The researcher also attempted to obtain more specific information related to seniors. In Nova Scotia in particular, random telephone contacts were attempted in five regions of the province to obtain information from seniors' residences, nursing homes and special care facilities. In only one case was a Deaf-Blind person identified.

As outlined in the final paragraph in the New Brunswick report, more than two-dozen people of presumed Acadian descent were described as Deaf-Blind. It is known that persons with Acadian ancestry have a tendency to Usher Syndrome, a condition that results in late onset Deaf-Blindness. Although the information was not available from the Provincial Department of Family and Community Services, it is presumed that many of these people live in either nursing or special care homes.

Another factor that deserves consideration is the possible duplication of reported incidences of Deaf-Blindness. Although it is recognized that this is quite possibly the case, it was estimated by the Executive Directors and officials of the organizations that represent Deaf-Blind services, that such duplication could well be offset by the fact that there are many other cases of which we are unaware and that have never been reported.

It is noted that the urban Deaf-Blind population in New Brunswick is 60% compared to 40% rural. In Nova Scotia, it is estimated that 60% to 75% live in the Halifax/Dartmouth area in that the population in this metro area is more than 50% of the total population for the entire province. In the other two Atlantic Provinces, there is probably a 50/50 split.

New Brunswick

The New Brunswick chapter of the Canadian Deafblind and Rubella Association (CDBRA) is the most active in Atlantic Canada. The chapter also includes responsibility for Prince Edward Island in its mandate. This organization provided the most complete data.

The Canadian National Institute for the Blind (CNIB) was an excellent source of information in New Brunswick, as were the Deaf and Hard of Hearing organizations in regions of New Brunswick.

The Atlantic Provinces Special Education Authority (APSEA) was responsible for supplying information in the three Maritime Provinces (NB, NS, & PEI), and provided the Deaf-Blind school age numbers for these provinces.

Although information obtained from the Family and Community Services and Health departments of the Provincial Government offered some information that was already available from the above mentioned agencies, in the Northeast part of the province (a primarily French speaking region), there were significantly larger numbers of Deaf-Blind persons than had been anticipated. Those numbers will be indicated in the data summaries for the Province of New Brunswick.

Table F-8-1: Distribution by Age New Brunswick

	Congenital	Acquired	Unknown	Total
0 - 5 years	2	0	0	2
6 - 20 years	11	10	0	21
21 - 60 years	21	15	0	36
61+ years	4	10	0	14
Total	**38**	**35**	**0**	**73**

Table F-8-2: Living Arrangements

Living Arr.	*Total 188*
Private Homes	74
Parents	57
Other Family	7
Spouse	13
Alone without support	6
Alone with support	3
Group Settings	14
Ind. Living Residences	5
Group Home	5
Seniors Complex	1
Personal Care Home	3
Other Living	0

Table F-8-3: Reponses to Questions - New Brunswick

Question	CNIB	APSEA	CDBRA	SJD&HH	SE NB D & HH	North NB	Total
Deaf-Blind Numbers	24	12	58	6	11	29	140
Age 5 and under			2				2
Congenital			2				2
Acquired							
Ages 6 to 20	1	12	30				43
Congenital			11				11
Acquired			10				10
Ages 21 to 60	16		22	5	10	27	80
Congenital		8	13				21
Acquired		4	11				15

Ages 61 and over	7		4	1	1	2	15
Congenital							
Acquired			4		10		14
Live in Private Homes			54	4	10	6	74
Parents			48			9	57
Other Family Members						7	7
Spouse/Partner			3		10		13
Alone w/o Support						6	6
Alone With Support			3				3
Group Settings			14				14
Ind Living Supported			5				5
Group Home			5				5
Seniors Complex			1				1
Personal Care Home			3				3
Other							

<u>Legend:</u>

CNIB	Canadian National Institute for the Blind
APSEA	Atlantic Provinces Special Education Authority
CDBRA	Canadian Deafblind and Rubella Association
SJD&HH	Saint John Deaf and Hard of Hearing Association
SE NB D & HH	South East New Brunswick Deaf and Hard of Hearing Association
North NB	Northern New Brunswick

It is significant to note that Northern and Eastern New Brunswick contain relatively high occurrences of Deaf-Blindness. These areas are primarily French speaking and are of Acadian ancestry. It has been reported that the Acadian population is particularly susceptible to Usher Syndrome that results in late onset Deaf-Blindness, as evidenced in New Brunswick, somewhat in Quebec, and in Louisiana in the United States.

Nova Scotia

This province presented more of a challenge in obtaining information. The Nova Scotia Chapter of the CDBRA has been dormant for several years and was being recreated at the time of the research. Although some information was forthcoming from our CDBRA contacts, the most significant data was obtained from the CNIB and from APSEA. There were contacts made with major group homes and regional related associations in five geographic regions of that province, however, these contacts yielded only one incidence of Deaf-Blindness in Central Nova Scotia.

Table F-8-4*: Age*

	Congenital	Acquired	Unknown	Total
0 - 5 years	4	0	0	4
6 - 20 years	9	5	0	14
21 - 60 years	0	0	40	40
61+ years	0	4	1	5
Total	**13**	**9**	**41**	**63**

Table F-8-5: Living Arrangements

Living Arr.	*Total 82*
Private Homes	14
Parents	2
Other Family	2
Spouse	8
Alone without support	
Alone with support	4
Group Settings	26
Ind. Living Residences	6
Group Home	4
Seniors Complex	12
Personal Care Home	4
Other Living	0

Table F-8-6: Reponses to Questions - Nova Scotia

Question	CNIB	APSEA	CDBRA	Total
Deaf-Blind Numbers	40	16	7	63
Ages 5 and Under		4		4
Congenital		4		4
Acquired				
Ages 6 to 20	2	12		14
Congenital		9		9
Acquired	2	3		5
Ages 21 to 60	34		6	40
Congenital				
Acquired				
Ages 61 and Over	4		1	5
Congenital				
Acquired	4			4
Private Homes	14			14
Parents	2			2

Other Family Members	2			2
Spouse/Partner	8			8
Alone w/o Support				
Alone with Support	4			4
Group Settings	26			26
Ind Living Supported	6		6	6
Group Home	4			4
Seniors Complex	12			12
Personal Care Home	4			4
Other				

Prince Edward Island

Information was provided by the NB/PEI Chapter of the CDBRA and from APSEA. Representatives of various government agencies indicated that information related to Deaf-Blindness was available from the above-mentioned sources. These government departments stated they had no direct records of Deaf-Blind persons.

Table F-8-7: Distribution by Age

	Congenital	Acquired	Unknown	Total
0 - 5 years	5	0		5
6 - 20 years	8	2		10
21 - 60 years	0	0		0
61+ years	0	0		0
Total	**13**	**2**		**15**

Table F-8-8: Living Arrangements

Living Arr.	*Total 15*
Private Homes	0
Parents	15
Other Family	0
Spouse	0
Alone without support	0
Alone with support	0
Group Settings	0
Ind. Living Residences	0
Group Home	0
Seniors Complex	0
Personal Care Home	0
Other Living	0

Table F-8-9: Reponses to Questions - Prince Edward Island

Prince Edward Island			
Question	APSEA	CDBRA	Total
Deaf-Blind Numbers	5	10	15
Ages 5 and Under	1	4	5
Congenital	1	4	5
Acquired			
Ages 6 to 20	4	6	10
Congenital	3	5	8
Acquired	1	1	2
Ages 21 to 60			
Congenital			
Acquired			
Ages 61 and Over			
Congenital			
Acquired			
Private Homes			
Parents	5	10	15
Other Family Members			
Spouse/Partner			
Alone w/o Support			
Alone with Support			
Group Settings			
Ind Living Supported			
Group Home			
Seniors Complex			
Personal Care Home			
Other			

Newfoundland and Labrador

Information was provided by the CNIB in St. Johns.

Table F-8-10: Distribution by Age

	Congenital	Acquired	Unknown	Total
0 - 5 years	0	0	0	0
6 - 20 years	0	0	1	1
21 - 60 years	0	0	11	11
61+ years	0	0	8	8
Total	**0**	**0**	**20**	**20**

Table F-8-11: Living Arrangements

	Total 27
Private Homes	19
Parents	4
Other Family	1
Spouse/partners	1
Alone without support	0
Alone with support	0
Group Settings	1
Ind. Living Residences	0
Group Home	0
Seniors Complex	0
Personal Care Home	0
Other Living	1

Table F-8-12: Reponses to Questions - Newfoundland and Labrador

Question	CNIB	Total
Deaf-Blind Numbers	20	20
Ages 5 and Under		
Congenital		
Acquired		
Ages 6 to 20	1	1
Congenital		
Acquired		
Ages 21 to 60	11	11
Congenital		
Acquired		
Ages 61 and Over	8	8
Congenital		
Acquired		
Private Homes	19	11

Parents	4	4
Other Family Members	1	1
Spouse/Partners	2	2
Alone w/o Support		
Alone with Support		
Group Settings	1	1
Ind Living Supported		
Group Home		
Seniors Complex		
Personal Care Home		
Other – Adult Foster	1	1
Care Home		

First Nations

There was a concerted effort to obtain information from First Nation Band Offices, Health Canada and from the Canadian Government's First Nations and Inuit Health Branch from their Eastern Canadian office in Halifax. The Nova Scotia Commission on Disabilities was also contacted. After extensive efforts were made, there was a negative result. Referrals to StatsCan from this agency resulted in our being advised that records are not produced that would yield information about Deaf-Blindness.

Atlantic Canada Summary

Table F-8-13: Distribution by Age

	Congenital	Acquired	Unknown	Total
0 - 5 years	11	0	0	11
6 - 20 years	28	17	23	68
21 - 60 years	21	15	95	131
61+ years	0	18	10	28

Table F-8-14: Living Arrangements

Living Arr.	*Total 305*
Private Homes	99
Parents	78
Other Family	10
Spouse	23
Alone without support	6
Alone with support	7
Group Settings	41
Ind. Living Residences	11

Group Home	9
Seniors Complex	13
Personal Care Home	7
Other Living	1

Table F-8-15: Distribution by Age and Living Arrangements

Question	NB	NS	PEI	NFLD	Total
Deaf-Blind Numbers	140	63	15	20	238
Ages 5 or Under	2	4	5		11
Congenital	2	4	5		11
Acquired					
Ages 6 to 20	43	14	10	1	68
Congenital	11	9	8		28
Acquired	10	5	2		17
Ages 21 to 60	80	40		11	131
Congenital	21				21
Acquired	15				15
Ages 61 and Over	15	5		8	28
Congenital					
Acquired	14	4			18
Private Homes	74	14		11	99
Parents	57	2	15	4	78
Other Family Members	7	2		1	10
Spouse/Partner	13	8		2	23
Alone w/o Support	6				6
Alone with Support	3	4			7
Group Home Settings	14	26		1	41
Ind. Living Supported	5	6			11
Group Home	5	4			9
Seniors Complex	1	12			13
Personal Care Home	3	4			7
Other				1	1

Appendix G
Discussion of Canadian Council on Social Development Statistics

To complement the demographic data, The Canadian Council on Social Development (CCSD) gathered statistics on the numbers of persons in Canada over the age of 12 from the Canadian Community Health Survey (2000/2001). The original plan was to utilize statistics from the 2001 Participation and Activity Limitation Survey (PALS). The research team learned that data on persons with both hearing and seeing disabilities were not collected during this post-censal survey, and data sets to enable the creation of statistical profiles of persons with both these disabilities were not publicly available. The research plan was revised to include the gathering of the statistics from the Canadian Community Health Survey (CCHS) which will be discussed below.

The CCHS contains health-related data on persons aged 12 and older in all provinces and territories, except those living on Indian reserves, Canadian Forces Bases, and some remote areas. With a survey response rate of 84.7%, the responding sample size was 131,535. Data collection began in September 2000 and continued over a 14-month period.

According to the CCHS, there were approximately 19,600 individuals aged 12 and over with some degree of both vision and hearing loss, but not complete loss of either sense. An additional 34,700 individuals reported partial loss of one of these senses and a total loss of the other, and 15,500 reported a total loss of both vision and hearing.

Of the approximately 69,700 Canadians (aged 12 and older) with combined hearing and vision loss, 56% were women and 44% were men. The majority (70%) were seniors, with about 15% under age 45 and 15% aged 45 to 64.

Ontario had the largest number of persons with combined vision and hearing loss (about 44%), about 21% lived in Quebec, 8% in the Maritimes, 13% in the Prairies and 13% in BC. Data from the Territories could not be included due to the small sample size.

Appendix H
Advisory Committee Process

The Project Management Committee consisted of the Presidents of both the CDBRA and CNSDB. This Committee created the advisory Committee for the Deaf-Blind Demographics and Services project. This is the first time that CNSDB (an organization representing persons with acquired Deaf-Blindness) and CDBRA (an association primarily but not exclusively representing those who are congenitally Deaf-Blind) agreed to work together for the benefit of all Deaf-Blind

Canadians.

A Project Manager was hired to manage the overall process. Requests for a project manager were sent across the country. An individual who was well known to both groups was hired through consensus.

The Advisory Committee for the Demographic Study was purposefully structured to ensure equal and effective participation by individuals who are Deaf-Blind. Historically, many "good intentioned" individuals had done the talking for Deaf-Blind persons.

To facilitate effective communication by persons who are Deaf-Blind, every means of communication assistance was provided to committee members. This included documents in large print text and Intervenors and notetakers at all meetings.

Establishing Trust among individuals representing CDBRA and CNSDB was paramount to the success of the project. Historically, the CNSDB (which represents persons with acquired Deaf-Blindness) and CDBRA (which primarily but not exclusively meets the needs of individuals with congenital Deaf-Blindness) had worked on their own projects and initiatives. In discussing the current project and the realization that the population of Deaf-Blind Canadians was relatively small, the CNSDB and CDBRA decided it would be more effective to collaborate on the venture to locate the number of Deaf-Blind persons across the country. The Advisory Committee worked together to get to know one another, establish a sense of trust and build an equal partnership.

Members of the Advisory Committee agree that the success of the project was based on the establishment of this trust and equality of participation. Persons who are Deaf-Blind participated at all phases of the project from initial planning to review and implementation.

Appendix I
CNSDB and CDBRA Description

CNSDB is a consumer/advocacy group representing individuals who are Deaf-Blind. CNDSB’s mission is to advocate for new and improved services for persons who are Deaf-Blind; promote public awareness of issues affecting persons who are Deaf-Blind, and gather and distribute information that will assist persons who are Deaf-Blind to become full participants in society.

CDBRA is an advocacy/service organization primarily representing people with congenital Deaf-Blindness. CDBRA is committed to helping all people who are Deaf-Blind to achieve, with intervention, the best quality of life. CDBRA supports the development and understanding of the philosophy of Intervention; a wide range of advocacy efforts, and programs to meet the needs of individuals who are Deaf-Blind, their families and professionals in the field of Deaf-Blindness.

Together, these two organizations make up the Canadian Deaf-Blind Council (CDBC). The objective of the Canadian Deaf-Blind Council is to operate as a resource centre for information relating to Canadians who are Deaf-Blind.

Appendix J
Executive Summary
"Developing a National Volunteer Registry of Persons with Deafblindness in Canada: Results from the study, 1999-2001"

Executive Summary

Fifty (50) organizations throughout Canada were involved in locating persons with Deaf-Blindness to participate in this study.

- Seven hundred and seventy-seven (777) individuals volunteered to be part of the Registry, 370 males and 407 females. The oldest person reporting their age was born in January, 1900, while the youngest was born in June, 1998. Twenty persons or 2.6% of the sample were of pre-school age; 121 or 15.7% were school aged (6 to 21 years); 463 or 60.1% were aged 22-64 and 166 or 21.6% were aged 65+.
- The vast majority (86.4%) of these individuals had been previously identified as having the disability and were receiving some level of service from an organization.
- In the sample of 777 individuals, 44.7% of the respondents had congenital Deaf-Blindness, while 55.3% reported their Deaf-Blindness as acquired.
- Causes of Deaf-Blindness for all respondents are summarized in the following categories: inherited rare disorders (35%); intra-uterine infections (19.5%); congenital brain damage (8%); aging (8%); non-inherited chromosomal abnormalities (6.5%); post natal/early childhood infections (5.4%); acquired brain injury (5.2%); prematurity (3.6%); metabolic conditions (2.7%); birth trauma (2.3%); Sexually Transmitted Diseases (1%) and others (2.5%).
- Usher Syndrome and Congenital Rubella Syndrome are the primary reported causes of Deaf-Blindness, accounting for 29.9% and 18.7%, respectively.
- Fifty-five percent (55%) of the respondents reported receiving the services of an Intervenor
- Almost 26% reported completing some form of education. Just over 19% of respondents are currently in an education program.
- Eighty-one (81) persons or 10.4% of the total respondents indicated they were working, 51 working in competitive employment and 30 working in sheltered programs. The majority (74.5%) working competitively had

acquired Deaf-Blindness; the majority (86.7%) working in sheltered programs had congenital Deaf-Blindness.

- Persons with acquired Deaf-Blindness tend to have a higher rate of use of such modes of communication as writing/printing, sign language (American Sign Language and Signed English), manual alphabet, and speech, than those with congenital Deaf-Blindness.
- The living arrangements of the respondents were reported as follows: lives independently (34.3%); lives with birth family (23.3%); lives in Provincial facility (15.5%); lives in supported living facility (8.6%); lives in retirement home (8.5%); lives in supervised living facility (5.5%); lives with adoptive parents or in foster care (3.7%) and lives in nursing home (0.6%).
- Of those respondents born before 1980, 72% reported their marital status as single; 18% married; 9% widowed and 1% divorced.
- A safe estimate of the Deaf-Blindness ratio in Canada is 10 to 15/100,000, or a population of 3,100 to 4,650 persons.
- The findings of this report show significant distinctions between congenital and acquired Deaf-Blindness in almost every category where comparisons were available. In addition, one major distinction exists; the wide variance between the two groups in terms of the type and extent of services available to each.