A STUDY OF THE COMMUNICATIONS AND TELECOMMUNICATIONS NEEDS OF DEAF-BLIND PERSONS

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CHAPTER 1

INTRODUCTION

1.1 OBJECTIVES

"A Study of the Communications and Telecommunications Needs of Deaf-Blind Persons" was carried out under contract with the Broadcasting and Social Policy Branch of the Department of Communications, Government of Canada. The objectives were:

1. to identify the approximate size and nature of the deaf-blind population in Canada from existing data;

2. to identify the communications handicaps contingent on this disability;

3. to review research and development aimed at addressing these communications handicaps;

4. to conduct a survey of the deaf-blind, their parents and health care professionals to discover perceived needs; and

5. to make recommendations for policy initiatives in this area.

This report is one of a series dealing with recommendations for the Department of Communications on communication needs of handicapped Canadians. Studies on the vision impaired (1) and studies of the hearing impaired (2) did not address the unique yet diverse needs of the deaf-blind. To date little has been done in Canada to address communication and telecommunication needs of deaf-blind individuals. Yet, technology and information processing are developing at an unprecedented rate. The needs and concerns of unique groups like the deaf-blind require special consideration in terms of future planning and direction.

1.2 OVERVIEW OF THE DEPARTMENT OF COMMUNICATIONS

It is important at the outset to briefly examine the mandate of the Department of Communications, how the department is integrated with other federal departments and how it interacts with provincial governments. Also it is essential to consider the department's area of responsibility and its plans for future developments.

The Department of Communications spans a diverse spectrum of operations, among them space programs, broadcasting policy research and management of the airwaves must all be covered by the department (3). The department is divided into six sectors:

1. Policy
2. Space
3. Research
4. Arts and Culture
5. Spectrum Management and Government Telecommunications
6. Financial Management

These sectors interact with the public (viz., radio users, manufacturers, the media, artists and performers) primarily via five regional offices and 47 district and sub offices.

The department is also working with industry in researching and developing information systems, as well as communication and space technology. The technology is being transferred from government laboratories to industry. Canadian equipment and services are being marketed nationally and internationally. "In all these programs whether they relate to information and communications technologies or to cultural industries and heritage, the department's approach is predicated on its recognition that the private sector is the driving force in our society, and that the major role of government is to foster a climate favourable to creative activity and economic growth. " (4)

CHAPTER 2

BACKGROUND

2.1 THE PROBLEM

A person who is both deaf and blind faces problems which are much greater than the combined problems associated with being blind or those of being deaf. We are not only dealing with the actual double disability of the two senses, but in addition we must appreciate that there may be possible complications in the encoding and integration of sensory information along the central pathway from the sensory organ to the brain. For most people, sight and hearing are the two main senses which are responsible for gathering information with respect to other people and with respect to the environment. Vision and hearing are important to this environmental interaction and are often referred to as the distance senses. Many deaf people are able to exploit their vision to gather enough information to allow them to function independently and vice versa for blind people. Since enhancing services which depend on

sight or vision is not necessarily a viable solution for some deaf-blind people, we must also investigate alternate solutions for communication. The importance of such investigations become apparent if we consider the importance and breadth of interaction based on communication or telecommunication services, for individuals without handicaps. The needs of the deaf-blind population in this regard are largely unmet.

2.2 POPULATION CHARACTERISTICS

It was necessary to identify the people who the study addressed. The most recent and extensive report was completed in February 1984. (5) The definition used in this report by Foreningen Sveriges Dovblinda (Swedish Society of Deaf-Blind) was chosen as appropriate for our application.

"A person is considered deaf-blind when he has reduced hearing and vision such that considerable difficulties exist in daily life. More specifically:

1. It is difficult to receive news via radio, television or press; or
2. It is necessary to have a deaf-blind interpreter to maintain satisfactory connection with the outer world; or
3. Special means are nesessary to participate in education for hearing or sight handicapped. " (5)

Inherent in this definition is the obvious importance of communication, not just with other people, but with the environment as well. Radio, television and press are

considered important enough to be specifically mentioned since lack of access will result in considerable difficulties in daily life. We will return to this definition later (Section 5.2).

The needs to be addressed vary greatly within this population. The population according to the Swedish definition includes the group of deaf-blind people who are similar to those included by definition in other countries. However, the Swedish definition uniquely covers a broader group of individuals including many with residual sight, hearing or both. Not only is there a vast range of vision and hearing impairments, but the individuals range from working adults who have university degrees to children who exhibit autistic-like behaviour to elderly people living in a nursing home. The needs of these groups vary considerably.

2.2.1 Degree of Deaf-Blindness

The actual manifestations of the deaf-blindness can be divided into four categories:

1. profoundly deaf and totally blind;
2. totally blind with residual hearing;
3. profoundly deaf with residual sight;
4. residual sight and residual hearing.

Legal blindness is defined as a loss of vision such that the individual can see at a distance of 20 feet what a normally sighted person can see at a distance of 200 feet or to have peripheral vision that is restricted to 20 degrees or less. There is no legal definition of deafness. However a hearing loss of 90 dB HL in the better ear is considered to be profound.

The actual physical disability of those referred to as deaf-blind ranges from profoundly deaf and totally blind to residual hearing and residual sight. In between one finds profoundly deaf with residual sight and totally blind with residual hearing. This diversity is significant when discussing communications. Those with residual sight or hearing may be able to take advantage of adaptations for deaf or print-handicapped. However, many are totally isolated from their environment since they cannot take advantage of any of the communication or telecommunication

devices currently available for those with a single handicap.

The mental handicap is more difficult to understand. For example: A child with congenital cataracts may still have difficulty "seeing" once the cataracts have been removed. The problem is one of learning to interpret the visual input. Probably the most important factor in determining how well a person will be able to function without sight or hearing is the age at which the double disability or the secondary disability has occurred. A child who is born deaf-blind and has had no opportunity for language development prior to the disability, and an elderly person who becomes both deaf and blind and finds it difficult to accept new ideas, are in situations totally different from a deaf teenager who becomes blind. Age of onset becomes a significant factor for perceptual retraining or training and hence rehabilitation or habilitation.

2.2.2 Time of Onset of Deaf-Blindness

For the purpose of discussion and appreciation of the diversity of deaf-blindness, there appear to be three critical age ranges for the acquisition of deaf-blindness:

1. less than 3 years of age - These children are deaf-blind usually due to a viral infection or genetic abnormality;
2. 15 to 20 years of age - Most of these young adults have a genetically transmitted disease;
3. 60 or more years of age - These older adults are usually afflicted with symptoms of old age.

Related to age of onset is the problem of language development. If a child has had an opportunity to hear speech or see sign language before he loses that sense, then it is much easier to teach him about words and the structure of words for communication purposes.

2.2.3 Other Considerations

Another consideration is the residential situation of the individual. The needs of a person in an institution or residence for the elderly are very different from those of a person living on his own in a private dwelling. It is important to assess the situation of the deaf-blind individual so that his/her communication needs can be addressed in the most effective manner.

2.3 PRESENT INFORMATION ACCESS

2.3.1 Intervention

At the present time there appears to be limited access to communication and telecommunication services for deaf-blind people. The most fortunate individuals have intervenors (6) who act as an interface between themselves and the environment or other people. The individuals who have intervenors are few and far between for several reasons. There are very few individuals qualified to be intervenors and those who are qualified earn $5.00 per hour for a forty hour week.

2.3.2 Adaptations Presently in Use

The individuals with residual sight or hearing may be able to take advantage of special services for the deaf or blind. These services include radio reading services, braille tapes, braille books and papers, and closed caption television. The TTY and TDD are adaptive devices for telephones which allow deaf people to send typed messages and receive a written reply on a visual display. Taking advantage of this service would not be particularly easy for people who only have limited residual sight.

For the deaf-blind who are comfortable using braille, there is access to information using tapes, papers and books. Also, there are several versions of a TTY or TDD device which have a braille interface so that the light display is transformed into braille and the messages can be entered using a brailler. Some of these devices are available commercially but the prohibitive cost of $6,500 (7) has effectively prevented handicapped individuals from purchasing them.

There also exist deaf-blind individuals who even with adaptive devices may not be able to take advantage of our present communication and telecommunication systems because of complications due to additional disabilities such as being developmentally or mentally disturbed. The needs of

these people would require special consideration.

2.4 REQUIRED INFORMATION ACCESS

At the present time, the intervenor plays a crucial role in providing information access for the deaf-blind. An intervenor not only translates spoken or written words, but he/she also passes on the only information which the deaf-blind individual has about the environment. For example: A deaf-blind person would have to be told that a new house was being built across the street or that people were laughing at a joke on the other side of the room. Intervenor services could play an important role in facilitating many of the daily interactions which we take for granted.

For many deaf-blind interaction is severely restricted unless an intervenor is present. Few people take the time to learn even one of the forms of interpersonal communication available for a deaf-blind person. A further barrier is that communication can be very slow and tedious even if a person is familiar with an appropriate method of communication. The two-handed manual alphabet involves touching the deaf-blind person's palm and fingers in specified positions to indicate letters. In this way words and sentences are spelled out. An alternative which is useful for those unfamiliar with the two-handed manual

alphabet is printing letters on the deaf-blind person's palm.

The time of onset of the dual handicap plays a very significant role in determining the method of communication used. If a person acquired a hearing loss after he became blind then chances are he would feel more comfortable communicating in braille than would a person who lost his hearing after his sight. It could be very difficult for someone who is used to communication in American Sign Language (ASL), which has its own sentence structure to switch to braille which uses the sentence structure which most of us are accustomed to using. This could become especially significant when considering possible services for elderly individuals.

A recent task force headed by Tom Blue entitled "A Task Force Report on Services to Deaf-Blind Persons in Canada" (6) has made the very strong recommendation that intervention is the key to assisting deaf-blind persons. It may be possible to complement the concept of intervention with some technical support. Improvement in communication and telecommunication services could work together with intervention to provide an individual with the personal contact of intervention plus technical aids which allow a certain amount of independence. This technical support could be valuable in terms of employment, education and

life-style.

Every person should have access to information on services, community resources and programs. At the Second Helen Keller World Conference on Deaf-Blindness held in Hannover, FRG, 21-25 July, 1980 the deaf-blind participants adopted the following as one of the responsibilities of deaf-blind persons: "Deaf-blind people should take personal responsibility in participating in community life, following the daily news and take part as much as possible in fraternal and special interest associations and to work within these associations to promote the betterment of the deaf-blind" (8). It was also resolved by the Committee on Services to the Deaf-Blind: "That special aids, appliances and services be provided to deaf-blind youth and adults, without charge or at an affordable cost, to assist the deaf-blind person in making the most of his other skills in education, employment and social life" (9). The importance of communication and telecommunication are obvious not only to the people who serve the deaf-blind, but also to the deaf-blind themselves.

CHAPTER 3

APPROACH

3.1 GENERAL APPROACH OF THE STUDY

The total time allowed for this investigation was six months. Due to the amount of material which had to be covered, and the time required to aquire pertinent information, three different methods were used. They were:

1. requests by mail to special service agencies;
2. collecting background information and published data;
3. personal interviews and formulation of recommendations.

The first stage was to contact as many people as possible who might have valuable contributions to make to the study. A letter was mailed to Canadian and foreign organizations which might interact with deaf-blind individuals or, which could provide the name of an organization which did provide services. The letter was a

request for information related to the objectives of the study and specific data concerning the organization. Eventually through referals and new contacts, about 150 organizations were contacted. The response rate was about 50%. During the first three months this information was compiled and catalogued using a database information handling system.

The second stage was a background search including demographic and medical information about deaf-blindness. At the same time an investigation was conducted of present technology and possible applications of future technology. Of special interest were developments in the communications and telecommunication industries. This stage involved a search for previously published material and interviews with individuals who were experienced in each of these areas.

The final three months were spent personally interviewing deaf-blind individuals, their parents and people who work closely with them. These interviews were perhaps the most valuable stage of the study.

3.2 DEMOGRAPHY

Canadian demographic information about the deaf-blind proved to be a significant problem. Statistics Canada had no information on deaf-blind Canadians (10). They referred to the CNIB (Canadian National Institute for the Blind). The CNIB figures relate to blind people who are registered as blind before they become deaf. There was no index of the number of deaf-blind who might not have been included in the CNIB group. Compared to statistics from studies in other countries, Canada appears to have a relatively low incidence of deaf-blindness. The present study addressed this difference by investigating enrollment of deaf-blind persons in special schools. Despite the lack of published Canadian demographic information, there are studies presently being conducted which should give us a better indication of who the people are who are referred to as the deaf-blind in Canada.

"A Task Force Report on Services to Deaf-Blind Persons in Canada" (6) by Tom Blue released by Health and Welfare, Canada in November 1984 gives us a better indication of the number of deaf-blind Canadians, and an idea of their actual diversity in the Canadian population. Initially, 623 individuals were identified by the CNIB registry. The final report identified 830. Presently data on deaf-blind children are being collected as part of an investigation by

Dr. Jamie MacDougall and Ms. Janet Jamieson at the Mackay Centre for Deaf and Crippled Children in Montreal.

3.3 HANDICAPS DUE TO DISABILITY

The actual handicap is contingent on the disability. To understand the extent of a handicap, we must examine the diversity of factors which help to determine the degree of the disability. The population of deaf-blind individuals spans those who exhibit autistic-like behaviour through working adults who have university degrees to elderly people whose sight and hearing have gradually deteriorated. This vast range of functioning of individuals may be partially explained if one examines the actual extent of the manifestations of the disability and the time of life when the disability was acquired. This has been explained in the section 2.2: Population Characteristics.

Perhaps a secondary, but practical consideration is the question of accommodation. The needs of people vary with their environment. An individual living in an institution or special home would have needs different from those of an individual living in a private home with his or her family. For an elderly person living in an old age home who seldom sees his family, the television and telephone assume a more important role. A deaf-blind person in this situation might not enjoy the interaction with the other residents and

staff. Therefore, the resulting handicaps assume varying degrees of importance if one considers the situation of the deaf-blind person in addition to the physical and mental manifestations of the deaf-blindness.

3.4 REVIEW OF RESEARCH AND DEVELOPMENT

A review of research and development included an investigation of current technology and devices as well as an investigation of anticipated future developments in the area of communication and telecommunication.

Publications listing existing devices and technologies from Canada, the United States, Scandanavia and Europe were reviewed. Existing devices were discussed with organizations which have assumed responsibility for interfacing the people they serve with the devices available.

There was some interaction with industry to determine where developments were heading. There were also discussions with different government agencies to gain some insight into where they believed developments were leading.

Since present and future developments in the area of communication and telecommunications were investigated, a relatively accurate background picture was obtained for use

as a reference when discussing possible developments which could assist deaf-blind persons.

3.5 SURVEY AND QUESTIONAIRE

The survey formed the most important portion of the study. This was the method of obtaining information directly from the individuals who would be taking advantage of improved services. It was important to find out what their priorities were and thus what appeared to be their most pressing needs.

As information was collected for the background of the study, the questions for the survey evolved. In addition, previous work in Canada and other countries was studied to ensure that the essential areas were covered. The drafts of the questionaire were discussed with people who worked in the field of deaf-blind services.

We interviewed individuals who had agreed by prior arrangement to participate in the survey. Due to the size and nature of the population of deaf-blind people, it was necessary to interview a cross-section of people representing all sectors of the deaf-blind community. The sample size is necessarily small and does not lend itself to statistical treatment of the information. Nevertheless, it was expected that most of the important issues would be

recorded. We were limited to those few individuals who were physically, geographically and mentally able to contribute. It was felt that their answers would provide a significant stepping stone in representing the needs of those who would directly benefit from improved services.

Questionaires were designed specifically to discover communications and telecommunications needs. A separate questionaire was used for organizations and health care professionals and deaf-blind individuals or their families or helpers. The questions for health care professionals or organizations focused on the perceived needs of the deaf-blind individuals. The questionaire for individuals or parents asked similar questions. In addition, a section was added to collect demographic and etiological data with respect the individual's deaf-blindness. This information is essential to ensure that the interests of deaf-blind individuals who fall into each of the various categories were investigated.

CHAPTER 4

ETIOLOGY OF DEAF-BLINDNESS

4.1 MATERNAL OR CONGENITAL RUBELLA

Maternal Rubella (11) is the main cause of infantile deafness and blindness. There is a classic triad of rubella embryopathy which consists of cardiopathy, cataracts, and deafness. Rubella is transmitted via a virus which causes regular, but small scale epidemics in Europe and large scale, but less frequent (every 6-10 years) epidemics in Canada and the United States. Epidemics usually occur at the end of winter and during the spring. The virulence of the rubella virus increases during the major outbreaks. Some women who have never had any clinical symptoms of the virus have given birth to infants who are carrying the virus.

The frequency and the severity of the foetal infection varies according to the stage of the pregnancy when infection occurs. The virus inhibits cell division which

affects the differentiation of tissue. The virus acts in three ways:

1. it causes malformation;
2. it inhibits development of other tissue;
3. it continues to develop itself.

The resulting malformation first affects the ears, eyes and heart.

The malformations manifest themselves in various ways. Deafness due to cochlea and saccule involvement occur in 30 to 50% of the cases. Disturbed vision is found in 50% of the cases due to bilateral cataracts, microphthalmia or retinopathy.

4.2 USHER'S SYNDROME

This disease is called a syndrome because it includes several hereditary illnesses and degenerative hereditary illnesses which are associated with pigmentary retinitis.

Retinitis Pigmentosa is an autosomal recessive disease which affects nearly all the rods and cones of the retina. It usually becomes apparent in late adolescence or early twenties. It is sometimes characterized by :

1. poor dark adaptation;

2. poor side vision;
3. poor central vision.

At present there is no treatment or cure.

Twenty-five percent of the people with retinitis pigmentosa have a hearing loss. 2 - 6% of congenitally deaf children have Usher's Syndrome (12). The hearing loss is usually apparent near birth or early childhood. This loss can be due to a variety of causes. One person in every 100 or 200 is a carrier for the disease (13).

4.3 OTHER CAUSES

4.3.1 Deaf-Blindness

The following are additional causes of deaf-blindness:

1. measles;
2. chicken pox;
3. shingles;
4. viral hepatitis;
5. mumps;
6. influenza;
7. poliomyelitis;
8. megalocytosis virus (herpes);
9. congenital toxoplasmosis (parasite);

10. congenital syphilis.

4.3.2 Loss of Vision

Loss of vision for an individual who is already deaf can lead to deaf-blindness. The following are causes of loss of vision:

1. cataracts;
2. glaucoma;
3. diabetic retinopaty;
4. macular disease;
5. retinitis pigmentosa;
6. trauma;

4.3.3 Loss of Hearing

Loss of hearing for an individual who is already blind can also lead to deaf-blindness. The following are causes of loss of hearing:

1. spinal meningitis;
2. mumps;
3. reaction to oto-toxic drugs;
4. chemotherapy;
5. diabetes;
6. genetic disorders;

7. trauma;

CHAPTER 5

DEMOGRAPHY

5.1 INTRODUCTION

It is essential to understand the causes of deaf-blindness and to be conscious of the inherent diversity due to these causes. The significance of the various causes becomes important when studying the demographic information.

We can say with some certainty that at least 50% of the deaf-blind in Canada are over 60 years of age (5,14). Next to old age there exist two main causes of deaf-blindness.

1. Rubella which occurs in small or large viral epidemics;

2. Usher's Syndrome which is genetically recessive via autosomal recessive transmission.

Other causes are listed in section 4.3: Other Causes.

5.2 DEFINITION

As mentioned in section 2.2, the Swedish definition used by Foreningen Sveriges Dovblinda in 1984 was found to be the most useful for our study. It emphasizes the functional handicap of the double disability for daily living.

"A person is considered deaf-blind when he has reduced hearing and vision such that considerable difficulty exists in daily life. More specifically:

1. It is difficult to receive news via radio, television or press; or
2. It is necessary to have a deaf-blind interpreter to maintain satisfactory connection with the outer world; or
3. Special means are necessary to participate in education for hearing or sight handicapped. " (5)

This definition includes a consideration of education which is used by Centers and Services for Deaf-Blind Children in the United States: "... children who have auditory and visual handicaps, the combination of which causes such severe communication and other developmental and communication problems that they cannot properly be accommodated in special education programs for the hearing handicapped child or for the visually handicapped child. " (15) The Swedish definition also incorporates the previous Nordic definition. "A person is considered deaf-blind when he has a serious degree of combined hearing and vision deficiency. " (5)

Due to the character of deaf-blindness these definitions are functional. They are based on the effect of the disability not the disability itself. There are several reasons. The most important consideration is that the deaf-blindness is a double disability. Deaf people try to acquire information visually and blind people to acquire information auditorily. A deaf-blind person may not be diagnosed as either legally blind or deaf but he may not be able to use his residual second sense to overcome the barriers that the handicapped first sense presents. In addition, there exist complications. The senses which tend to be the most important in information processing are sight and hearing. If these two pathways are not functioning, what kind of total impression is being created in the brain? If residual sight or hearing exist, were the information pathways developed so that the person was able to take advantage of the information which is acquired? If the pathways did exist at one time, how have they been altered now that the input information of one or more of the senses has been reduced? We have no answers for these questions and they are beyond the scope of this investigation. However it is important to realize the intricacy of the problem of such a double disability.

Since the interactions of areas within the brain and the concept of perception are not well understood, we must be content to evaluate what effect these complications have

on the daily life of deaf-blind individuals. The Swedish definition emphasizes this functional aspect by identifying communication with the rest of the world, access to education and most importantly access to other people as essential components to a person's lifestyle.

5.3 SWEDISH STUDY (5)

One of the objectives of the Swedish study was to search out all deaf-blind individuals in Sweden. This particular report is based on 14 out of 24 counties in Sweden. The original estimate for the number of deaf-blind in these 14 counties was 500. The actual number of deaf-blind in the 14 counties (population: 5.6 million) was 818.

5.3.1 Age

The age distribution is presented in Table 1 (adapted from the Swedish report). Only 0.12% of the deaf-blind population were preschool children. This could be due to difficulties locating very young deaf-blind children. The number of school age deaf-blind is also very small compared to the total number of deaf-blind (7.2%). By far the largest proportion of deaf-blind were the elderly. Fifty percent of the deaf-blind were over 80 years of age and 80% of the deaf-blind were over 50 years of age.

Table 1: Age Distribution

	Age (years)						
Category of Disability	0-6	7-23	24-49	50-65	66-79	=>80	total
deaf and blind	6	27	16	11	16	21	97
deaf with residual sight sight	1	14	40	31	31	32	149
blind with residual hearing	0	3	6	12	38	107	166
residual sight and hearing	2	15	24	23	75	267	406
total	9	59	86	77	160	427	818

Summary statistics according to degree of loss indicated that:

1. 50% had residual sight and hearing;
2. 20% were blind with residual hearing;
3. 18% were deaf with residual sight;
4. 12% were deaf and blind.

It appears that there were the same number of people who are blind with residual hearing as there were deaf with residual sight.

5.3.2 Age of Onset

Table 2 (adapted from the Swedish report) shows the distribution of individuals with respect to age of onset of vision and hearing loss.

Table 2: Age of Onset of Vision and Hearing Loss

Age of Loss of Hearing (years)	Age of Loss of Vision (years) < 3	15-20	60-69	unknown	total
< 3	101	84	57	4	246
15-20	13	38	46	4	101
60-69	13	58	385	6	419
unknown	1	1	12	38	52
total	128	138	500	52	818

The following summarizes the ages of onset in Table 2:

vision impairment

1. less than 3 years of age - 16 %
2. between 15 and 20 years - 17 %
3. 60 years or older - 61 %
4. unknown - 6 %

hearing impairment

1. less than 3 years of age - 30 %
2. between 15 and 20 years - 12 %

3. 60 years or older - 51 %

4. unknown - 6 %

If one examines these percentages related to age it becomes clear that there are twice as many children who are deaf with residual sight than blind with residual hearing. The percentages begin to be similar in the teens with the onset of retinitis pigmentosa in Usher's Syndrome. Among the Swedish population a total of 15% of the deaf-blind have Usher's. These individuals usually show impairment of vision between 15 and 20 years of age. For the elderly, loss of vision is more prevalent than loss of hearing.

Several other results are evident. It should be noted that the 12% of the children who are congenitally deaf-blind are also developmentally disturbed. Also 47% of the deaf-blind actually acquire both these handicaps, mostly, as a complication of the aging process.

5.3.3 Sex

It was found that there were more deaf-blind women than men. This is explained if one realizes that there are more elderly women than men in Sweden. Considering that 80% of the deaf-blind individuals were over 50 years of age, this outcome is not surprising.

5.3.4 Genetic Considerations

A higher prevalence of deaf-blindness occurred in one of the 14 counties. This was explained by a higher incidence of Usher's Syndrome.

5.3.5 Other Complications

Three health categories were created. They are as follows:

1. completely well - The individual is without functional reductions or diseases besides the deaf-blindness.
2. lightly handicapped - The individual is physically well without good psychological balance or the individual has one or two functional handicaps.
3. severely handicapped - The individual is developmentally disturbed, psychologically ill (chronically), severely emotionally retarded, has severe allergies, diabetes, epilepsy, age symptoms or more than two functional reductions or diseases.

The results are summarized in Table 3. Considering that 80% of the individuals are over 50 years of age, it is interesting to note that 29% are completely well.

Table 3: Other Complications

%	deaf and blind	deaf, residual sight	blind, residual hearing	residual sight & hearing	total
completely well	12	48	20	30	29
severely handicapped	78	49	76	67	67
lightly handicapped	10	3	4	3	4
total	100	100	100	100	100

5.3.6 Education

Table 4 contains information about education. The number 523 out of 818 attending primary school does not relate solely to the children without handicap. Included here are many children who were considered retarded. Also, the fact that 47% acquired their deafness and blindness after 60 years of age would have given them the opportunity to go to school.

Table 4: Education

Schooling	Frequency
public school	523
school for deaf	130
hearing classes	2
school at home	7
Ekeskolan (special school)	6
special schools	10
discontinued public school	33
discontinued special school	6
presently in school	56
no school	15
unknown	30
total	818

5.3.7 Living Arrangements

During interviews with individuals, it became apparent that their first objective was that they wanted to live on their own. Most were interested in special homes which would facilitate this.

5.3.8 Employment

In the area of employment 70% of the deaf-blind were work-active at some previous time. Fourteen percent had special job education. Of the 70 out of 818 people capable of working, 38 work and 15 would like a job.

5.3.9 Social Life

The quality of social life was expressed as levels of stimulation. The individual was satisfactorily stimulated, unsatisfactorily stimulated or not stimulated.

1. satisfactorily stimulated - 46 %
2. unsatisfactorily stimulated/passive - 27 %
3. not stimulated at all - 27 %

Satisfaction was evaluated by the interviewers, based on reponses from the individuals.

5.4 AMERICAN DATA

The National Academy of Gallaudet College had identified 10,000 deaf-blind children and adults in the United States. This was reported in 1980. They estimated that 21,000 existed. Of the 10,000, 5,990 children had been identified (16). There is a definite preponderance toward the young in the number of children, corresponding to the rubella epidemic in the 60's. State institutions house 2,124 of these children.

5.5 CANADIAN DATA

In the past few years some Canadian data have been published. Due to the focus on education, much of the data is centred on children. This information is valuable but gives us little information on adults.

The Canadian Survey for Hearing Impaired Children and Youth (1979) indicates that 4.3% of the deaf children or 163 children are legally blind or have uncorrected visual problems (17).

5.5.1 Canadian Task Force

Tom Blue's Report "A Task Force Report on Services to Deaf-Blind Persons in Canada" identified 830 deaf-blind people while travelling accross Canada. (6). All indications lead to the conclusion that there are many unidentified deaf-blind. The report estimates that there are between 1,500 and 2,000 deaf-blind individuals in Canada.

The CNIB data shows that 336 out of 623 deaf-blind are over 65 years of age. Despite incomplete data, the assumption that over 50% of the deaf-blind people are elderly is supported by data from other countries.

5.5.2 The McGill Study

There is work presently in progress by Dr. Jamie MacDougall and Ms. Janet Jamieson at the Mackay Centre for Deaf and Crippled Children in Montreal. They are collecting information on all deaf children in Canada with special emphasis on deaf-blind children and young adults. This will be the first comprehensive study collecting basic demographic data. An attempt has been made to include every deaf child in Canada. Special arrangements have also been made to include the Inuit who are usually omitted from surveys due to problems of accessibility.

This information will be invaluable. However, there is still a need to collect and compile data on Canada's entire population of deaf-blind people. The study on children will give us valuable information on the incidence of deaf-blindness. Also, since Usher's Syndrome is evident before a young adult leaves school, we will have indications of the incidence of this gene in the population.

5.6 EXTRAPOLATION OF DATA AND DISCUSSION

Since the Canadian information is very limited, it is useful to get an approximate idea of the magnitude of the problem with which we are dealing from studies conducted in other countries.

We can gain valuable information from the Swedish study. Geographically Sweden is similar to Canada. Thus the two populations are subjected to similar environmental factors. There is evidence to support the hypothesis that Sweden may have a higher incidence of Usher's Syndrome than that of other countries. In Sweden, Usher's Syndrome is responsible for only 15% of the deaf-blindness. The rubella epidemics tend to be smaller yet more frequent than those in Canada. In Canada the Inuit have a higher incidence of hearing loss due to extreme temperature changes and noise-induced hearing loss from snowmobiles. Probably the most important difference between Canada and Sweden is that of the gene pool.

The American estimates can again offer information on the magnitude of the numbers with which we are dealing in Canada. And again, there are differences in the gene pool which will result in difference in prevalance due to genetic causes of deaf-blindness. The rubella epidemics, however, would be comparable for the two groups.

Based on total population ratios of Canada, Sweden and the United States, the total number of deaf-blind people in Canada was extrapolated.

Table 5: Extrapolated Numbers of Deaf-Blind People

Country	number identified	number estimated	estimated population	estimated number of Canadians*
United States (1982)	10,000	21,000	230.0 mil	2,100
Sweden (1984)	818	**	5.6 mil	3,500

* assuming the population of Canada is 24 million

** in Sweden the number identified is the number estimated as of February 1984.

Residential, education, employment and income information will be specific to Canada. We have no information in these areas.

5.7 CONCLUSIONS

According to Table 5 between 2000 and 3500 individuals are deaf-blind in Canada. Current data indicates that fewer than 1000 are identified as deaf-blind. The greater proportion (at least 50%) of the deaf-blind individuals are over 65 years of age.

We are dealing with a large diversity of individuals. This diversity is based on age of onset of deaf-blindness, actual extent of disability, complications, and possible developmental problems. Despite this diversity, the Swedish data indicated that 30% of the deaf-blind were in good health. These individuals are from a variety of residential situations and backgrounds. Also there is a extreme range of potential for very limited self-care to independent living.

CHAPTER 6

IDENTIFICATION OF HANDICAPS

6.1 EXPLANATION OF CATEGORIES

The divisions were chosen so that the complete diversity of the deaf-blind population could be covered. The degree of deaf-blindness in addition to the age of onset covered the full spectrum.

The degree of deaf-blindness as previously discussed is as follows:

1. totally blind and profoundly deaf;
2. profoundly deaf with residual sight;
3. totally blind with residual hearing;
4. residual sight and residual hearing.

The age of onset has been divided into three categories as follows:

1. acquired before 3 years of age;
2. acquired between 15 and 20 years of age;
3. acquired after the age of 60 years.

The age of onset makes a substantial difference in the potential for learning new strategies for perception and the adaptability of the individual.

It was felt that each of the categories offered their own particular problems which should be investigated.

6.2 DEGREE OF DEAF-BLINDNESS

The Swedish report (5) indicated that 50% of the deaf-blind individuals had both residual sight and residual hearing. This large number is probably due to the high proportion of elderly people who gradually lost both their sight and hearing or gradually lost their second sense. Because they have developed and used both sight and hearing they have the potential to use reduced information in these sensory pathways. However, due to their disposition and age they may not be able to adapt to their new situation.

If a person is not able to take advantage of his residual sight or hearing, he is virtually isolated. For many the only contact with the environment is the limited personal contact which they have.

At the present time a limited number of Telebrailles are on the market. However, due to the price of $6500 (7) they are effectively unavailable. If a person is able to learn braille and use it, then these devices are invaluable because they allow personal interaction via the telephone lines at the rate at which an individual is able to receive or send information.

There is virtually no form of communication with the general environment unless the deaf-blind individual has a personal intervenor.

6.3 TIME OF ONSET

Three very distinct sets of problems are associated with the three general times at which deaf-blindness is acquired.

The children who are under 3 years of age usually have Congenital Rubella. This disease presents specific problems which may be associated with rubella such as mental retardation or cardiopathy. However, most deaf-blind children have developmental problems whether they have congenital rubella or not. When deafness or blindness or both are acquired at such an early age, language development is difficult and at times impossible.

The elderly have specific problems due to their age. Adaptability is often inhibited despite the fact that they have the potential to learn new methods of communication. When deaf-blindness is acquired later in life the ability to interpret sensory information and language development are usually intact.

The group which perhaps is at the greatest advantage in terms of communication are the individuals who acquire their deaf-blindness between 15 and 20 years of age. Most of these people have Usher's Syndrome. If they are lucky they were able to develop some form of communication before they lost the second sense. In addition, their minds are still open to new ideas and new forms of communication.

It is obvious that these people desperately need some form of communication in addition to direct personal contact. They presently only have a part-time intervenor to allow them to interact satisfactorily with their environment.

6.4 SUMMARY

The needs of deaf-blind people whose situation ranges from autistic-like and developmentally retarded children to elderly people accustomed to free interaction with their entire environment are unique, yet diverse. The majority of the deaf-blind appear to be elderly. There is a significant group of people who have the potential to greatly benefit from communication and telecommunication devices.

CHAPTER 7

TECHNOLOGY

7.1 STATUS OF SYSTEMS AND SERVICES

A number of devices appear in the discussion such as trade names and acronyms. These are listed in Appendix B: Glossary.

7.1.1 Broadcasting and Newspapers

The broadcasting services presently available may be divided into two categories: 1) services for those with residual hearing and; 2) services for those with residual sight.

Some individuals with residual hearing who are within the Oakville, Ontario broadcast area can take advantage of radio reading services. Due to limited air space, these services use a modulated signal transmitted at a different

frequency by a regular FM station. A demodulator filters out the conventional radio signal at the destination and demodulates the radio reading service signal. This service of reading news and magazine articles over the air is available to those individuals who have been loaned or have purchased a demodulator. This special service is in addition to any regular news broadcast or commentary which are part of regular radio programming. Publications may be "read" using these services only if an individual can tune into a particular voice.

If a person can hear a particular voice then the Kurzweil Reading Machine may be useful. This machine converts ordinary printed material or typed materials in any size, style or format of print into synthetic speech in seven different languages. This device requires a significant financial investment ($37,000) (18). This device is the key element in many of the combined systems of devices.

When discussing these adaptations for individuals with residual hearing, it is necessary to keep several points in mind. If these people are fortunate enough to have some auditory perception, they probably are making the most of limited auditory functioning. In this case it is necessary to maximize the variation in the parameters of the voice: volume, pitch, rate of forming words and spacing between

words. Since the last of these parameters is not easy to control, replay features would be an asset to any device using a voice for information transmission. This is not possible with broadcasts, but would be possible using the Kurzweil Reading Machine with printed material.

Individuals with residual sight, but profoundly deaf have several alternatives available for access to the environment. Some news broadcasts have the news captions in sign language as part of their regular programming. In addition, news and some additional programs are available with closed captions. Closed caption programs have the words printed under the person who has said them. A special decoder unscrambles the signal for the written words. Again, this decoder involves a financial investment ($350). (19)

Some publications appear in large print and thus they do provide information for a larger number of visually impaired people. Some individuals find that they are able to read regular print publications with the aid of a closed circuit television. This device enlarges characters up to 60 times in size and can produce white characters on a black background. Again, this piece of equipment is very expensive (e.g., Visualtek: $2750). (20)

When dealing with residual sight it is important to consider the variables which are associated with a visual input: contrast of colours, contrast of intensity and magnification. Different devices enhance different variables found in broadcasting and publications.

Finally there are those individuals who have neither residual sight nor residual hearing and must rely on tactile methods of communication. There is no broadcasting service to which these individuals have direct access. The Kurzweil Reading Machine may be used to read publications and reproduce them in braille. The DEST attachment ($17,500) (21) has been used for this purpose but the attachment is severely limited in the type face and quality of type recognized. The VersaBraille ($8000-9000) (18) connected to the Kurzweil Reading Machine has proven to be much more useful. The Optacon ($5600) (21) which is a small camera changes print into raised letters the shape of the letter viewed by the camera. The use of the Optacon has been limited because it is user specific and requires a highly trained user. This may also be used for any printed material.

7.1.2 Telephone and Telecommunications

Use of the telephone relies on auditory perception. For those who are hearing impaired, amplification switches and coils in the receiver can make the difference between being able to use the telephone and not having access to it. However, these devices only aid some of those with residual hearing.

The telephone has been used with a visual display in the form of a TDD. The regular displays which are used with this equipment can be enlarged for people with residual vision. Individuals who are able to use this device are limited to communicating over distances only with other individuals who have a similar device. Many of these devices are limited to communication with those devices transmitting information by the same system (ASCII vs. Baudot). Therefore all TDDs are not capable of communicating with all other TDDs.

Some modifications and recent developments have opened up the telecommunications services to deaf-blind persons who were unable to use them previously. There appear to be three developments which are relatively important: 1) Telebraille developed at Helen Keller National Center and manufactured by Telesensory Systems Inc.; 2) HASICOM coordinated by Breakthrough Trust and funded mainly by the

Department of Trade and Industry in Great Britain; and 3) Commprint-One presently being developed by the Canadian Hearing Society.

The Telebraille is designed for communication over telephone systems or one to one communication between two deaf-blind individuals or a deaf-blind and sighted person. This unit is based on a Superphone which is a TDD with a keyboard, visual display and acoustic coupler. The Superphone is connected to a braille keyboard with a 20-cell braille display. The deaf-blind person places the telephone receiver on the acoustic coupler and encodes or receives messages using the braille unit.

HASICOM stands for Hearing and Sight Impaired Communication. Braille machines are adapted to convert typing from a braille keyboard into code. This code in a digital data form can then be translated into alphabetical script or transmitted over telephone lines to visual display terminals or similarly adapted braille machines. It is hoped that less expensive devices will become available as a result of this work.

The Commprint-One is a TDD financed by the Canadian Hearing Society. It deserves special mention as a TDD because it has been designed to incorporate maximum flexibility. It would be possible to connect a braille

attachment to turn it into a device which the deaf-blind who read braille could use.

Both the Commprint-One and the Superphone are compatible with ASCII and Baudot modems at the opposite end of the line. More information on the HASICOM system is not presently available.

There are many tactile transducers which are used to indicate sound as a vibro-tactile signal. One of the most versatile devices is the Tactile Speech Indicator (no price available). A deaf-blind person can discriminate by touch whether a person on the other end of the line has replied "yes" or "no". This is assuming that the deaf-blind person could ask questions of the individual he has called. It could also be used to send Morse code over the telephone. The Code Com ($7.50 to install, $5.10 per month) (22) converts sound signals into visual and tactile signals and is easily attached to the base of a telephone. It could be used the same way as the Tactile Speech Indicator. These devices do not require a large investment of capital.

7.1.3 Information Technology

The deaf have recently been able to take advantage of a messaging service ENVOY which is available through Telecom Canada. Using a TDD device individuals can leave messages at rates which are much cheaper than the charges associated with long distance telephone calls, since the system operates on Datapac. Any device with a modem which operates over telephone lines and has a written output and input should be able to be interfaced with a brailler and used on this system. In addition to accessing individuals with TDDs anyone with a computer and modem can hook up to the system.

Along the same lines, there are American newspaper services which can operate over the telephone lines similar to the messaging service. This would allow a person who reads braille to access what has been printed in the newspaper using a braille interface instead of the screen.

7.1.4 Ham Radio

Recently, adjustments have been make to facilitate the use of Ham radios by deaf-blind individuals. Messages are sent and received using Morse code. A Ham Radio Tactile Receiver was developed by the National Research Council of Canada. Also a Morse Key Board and Tactile Receiver are available which consist of a typewriter keyboard transmitting the letters in code to a tactile receiver.

7.2 STATUS OF DEVICES

7.2.1 Communication Technology

Communication technology in relation to broadcasting and telecommunications has already been discussed. However, there are a few additional devices which should be presented.

Individuals with residual sight can use large-character displays and anything which enhances visual input. Some of these people use finger spelling, sign language and printed material to communicate. Amplifiers can be used in various ways to enhance audio input for individuals who have residual hearing. The largest obstacle is the fact that amplifying any input also amplifies the background noise so

that the real signal is difficult to identify. The introduction of FM transmission systems improve the signal by increasing the signal-to-noise ratio so that the actual signal is more readily distinguished. There are also devices which can be placed at the source of a signal and amplified so that the background noise is not affected by the amplification. The Phonic Ear ($500-1100 depending on options) (21) is a stereo wireless FM auditory training unit which is used extensively in some schools. This also serves to amplifly the signal only for the individual who requires the amplification if they have the appropriate receiver (e.g., Telebooster).

For individuals who are profoundly deaf and totally blind, the individual must rely on tactile methods of communication. This usually means using the manual alphabet, print on palm, feeling the other person sign, sign on the body of the deaf-blind person or braille.

The Tellatouch ($420) (20) can be used as a typewriter for a sighted person and a braille keyboard with a single letter braille cell by the deaf-blind person. This device is used for one to one communication.

A variety of devices exist for signalling voices or environmental sounds. The Tactile Communicator (23), Wristcom (23) and Vibralert ($425) (18) all use a radio

signal to activate a vibrator worn by the deaf-blind person. A transmitter is attached to the source of the sound. The advantage of the less flexible Vibralert is the price.

Patterned tactile speech displays take sound and convert it to tactile patterns which have been used on the wrist or chest. Several have been developed but are not commercially available.

7.2.2 Orientation and Mobility

For those individuals with residual sight or residual hearing, there are devices which were designed for the deaf or the blind. A Wide Angle High Power Flashlight (22) can be strapped over the shoulders for individuals with residual sight to aid them in the dark. This device is particularly useful for those with tunnel vision. Several electronic mobility aids like the Nottingham Obstacle Detector (23) and the Trisensor (23) exist to aid individuals with residual hearing. Another one is the Sonicguide ($2100) (18) which uses ultrasound emitted from a pair of glasses. These sound waves are reflected back off the objects. The receiver converts the reflection into an audible signal which gives information about the distance and surface of the object which reflected the signal.

The Lindsay Russell PathSounder (23) is a device similar to the ones just described. However, the auditory signal is converted to a tactile signal by a vibrator on the neck strap. The Mowat Sensor ($700) (18) is a small hand-held vibrating box which emits an ultrasonic beam. This beam is reflected off objects located within six feet. The box vibrates faster as the object gets closer. Finally there is a Laser Cane (about $3000) (24) which has also been adapted to produce a vibrating signal instead of an auditory one. The vibrating signals are produced when the light beams emitted indicate a drop-off or an object straight ahead. These devices with tactile output are particularly suitable for individuals who are completely deaf and totally blind.

7.2.3 Daily Living

As seen, many devices developed for the deaf or the blind can be used by the deaf-blind. Devices with audio or visual output are converted to simple somato-sensory (usually vibrators or fans) signals. This is suitable for doorbells, telephones, alarm clocks, smoke detectors and light detectors. In addition braille labels, watches, scales and thermometers are available.

7.3 RESEARCH

There is already relevant technology which has not been used to its maximum potential as far as deaf-blind adaptations are concerned. However, it is necessary to analyze present research to discover which direction the developments will likely proceed. New technology quickly becomes old technology. Therefore applications of these developments must be designed to incorporate the maximum possible flexibility. In this way benefits will also be maximized.

For individuals using the manual alphabet a mechanical model of a human hand has been developed in Britain. Another mechanical hand was investigated by the Southwest Research Institute (United States). This hand forms a three-dimensional representation of each character when the character to be formed is punched in the keyboard of the control computer.

A new development based on Touch-Tone (TM) telephone allows low-cost, long distance, portable communication via the telephone. At the present time, Frequency Shift Key equipment (e.g., TDD) is required at both the sending and receiving ends of the telephone line. Without this equipment, the person is inaccessible. Also, this equipment is bulky to transport and is not usually handy for emergency

calls (e.g., from a telephone booth). With the new development the keypad of the telephone is coded in two-key sequences to correspond to the alphabet and numbers so that all that is required to send a message is an overlay for the code on the keypad. To receive messages a more sophisticated decoder is required. However one example of a decoder is very portable (about 15 x 10 x 3 cm, 250 g) at a projected cost of only $200. (25) This device can also be used with a standard rotary telephone with a separate Touch-Tone keypad ($15).

The computer applications in aid of communication for the deaf-blind are virtually limitless. At this point in time, if the initial investment is available for the hardware (actual computer) then all that is required is the software (programs), modem and tactile interface. This allows adaptations of computers to suit the specific needs of individuals. Perhaps most significant is the potential for increased flexibility and general availability of personal computers with communication facilities (modems). In this way, deaf-blind individuals could be linked to the same networks available to other individuals. Personal computers may provide easier access to networks and services, and also enhancement of these as new applications are developed. As the deaf-blind have increased accessibility to personal computers and thus an increased understanding of their capacity, individuals will develop

their own software to address specific needs. Already equipment is commercially available which could provide the required access. Triformation Systems, Inc. have a Voice Information Processing (VIP) Computer which can access data audibly and visually depending on the options chosen. (26) Clarke and Smith International Ltd. offer the Brailink personal computer with a Braille display which operates independently. However, blind employees at several large computer companies have used this equipment to hook into the main frame systems. Due to the tactile nature of this equipment, it would be suitable for any deaf-blind individuals familiar with braille. In addition to any personal developments which could be applied to other individuals in similar situations, broader technical developments designed for use with personal computers could significantly improve many aspects of daily living.

The technology is not only available for actual use by the deaf-blind individuals, but could easily be used by health care professionals to monitor problems while the deaf-blind person is on his own. For example, motion detectors could be used and programmed to notify a supervisor if a person is wandering around at an odd time, or if he may have fallen when there should be motion. This is just one small example of the extent of applications which could easily be developed by applying present technology.

The cellular telephone (27) is a portable telephone which is typically hooked up to power supplies in cars and boats. Cellular telephone systems are being installed in major centres in Canada at the present time. It is expected that Motorola Canada Ltd. will make available units with built-in rechargeable batteries, by the summer of 1985. The units will be small enough to fit into a jacket pocket. These portable units could provide immediate access to assistance if a deaf-blind individual found himself in unfamiliar surroundings. (The cost for a cellular phone is $40.00 one-time access fee plus a monthly rate month plus $0.50 per minute).

There is evidence of work done on a "vocoder" which is essentially a patterned tactile speech display. It has not been systematically investigated but shows a great deal of potential for development. It is important, however, that in conjunction with this work research must be conducted on perception associated with the intact sensory pathways of the deaf-blind. This includes not only the sense of touch but also hearing and vision. We can hope to provide information normally acquired by vision and hearing only if we understand the similarities and differences between potential for information from the various senses.

7.4 PLACE OF TECHNOLOGY

Technical aids can provide a degree of independence to supplement or complement the interaction of the deaf-blind individual with an intervenor. Technology may enhance the ability of the individual to be competitively employed by making maximum use of skills which the individual has or could acquire. Basically, the level of functioning in areas affecting daily living could be significantly improved.

CHAPTER 8

SURVEY

8.1 INTRODUCTION AND PURPOSE

A survey in the form of a series of interviews was conducted to evaluate the communication and telecommunication needs of the deaf-blind as perceived by themselves and the professionals who work with them. (Please refer to Appendix C: Questionaires.) The survey questions were designed to instigate and guide discussion in areas which would influence communications and telecommunications needs of the deaf-blind individuals. There were two forms of the survey: 1) one for deaf-blind individuals or their parents and; 2) one for health-care, service, and education professionals. Much of the same information was required from both groups. However, from the deaf-blind individuals we needed specific information regarding the nature and extent of the individual's dual handicap. For most of these people there was a lack of understanding and awareness of current technology.

Therefore questions concerning telecommunications needs had to be asked in an indirect way. From the professionals we asked questions which would take advantage of their experience and knowledge of perceived needs.

When talking with deaf-blind individuals the questions were asked directly to the person unless a French/English intervenor was assisting. In this case the intervenor specifically asked the deaf-blind person the questions. If prompting was necessary or a problem with understanding occurred, then the interviewer (DF) would suggest ideas for possible answers so that it was clear what was being discussed. This direct method of approach was necessary because there was a tendency for people to interpret the responses of the deaf-blind individual. If at all possible, we wanted the opinions directly from the respondent. Due to lack of communication skills and comprehension of several children surveyed we had to rely on the responses of the parents since it was impossible to approach the child directly.

The survey of deaf-blind individuals falls into two very broad categories which were reflected in the answers to the questionaires: 1) congenitally deaf-blind who have not had the opportunity to develop a repertoire of experiences; and 2) deaf-blind who have lost one or both senses adventitiously and thus have a range of intellectual

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functioning and perceptual experience.

8.2 STATISTICAL LIMITATIONS

One of the requirements set down for the survey was to cover all possible backgrounds and living situations of deaf-blind individuals. People were requested to participate based on the suggestions and referals of other participants or interested groups. We attempted to include any person who was willing to participate and who could be described as deaf-blind according to the functional definition chosen. Therefore, we do not have a random sample and as a result no indication of the frequency or indication of causes of deaf-blindness.

Most interviews were conducted by the same individual (DF). The remaining ones involved an intervenor who could also translate English to French. However, in this case, the same investigator conducted the course of the discussion.

8.3 INFORMATION AND ISSUES ADDRESSED

The information collected will briefly be discussed in terms of background information of deaf-blind individuals, their opinions on matters of communication and telecommunication and the opinions of professionals on perceived communication and telecommunication needs.

The initial response to our letters requesting information resulted in 71 replies. Out of the 71, 32 contained relevant information for our study. The 11 professionals personally interviewed consisted of 4 health care professionals, 3 educators and 4 technically oriented individuals. In addition, 8 informal or special interviews were conducted where the questionaire was not complete, but particular questions were covered where appropriate. Therefore a total of 31 contributions were obtained including 10 deaf-blind individuals, 2 families, 11 professionals with questionaires and 8 professionals with incomplete questionaires.

To identify the medical situation of the deaf-blind person the current age, age of onset of visual and hearing impairment, and extent of each impairment were requested in addition to etiology (if known) and other health problems. The living situation was then identified by living arrangements, degree of independence, past and present

education, occupational history, source of income and recreational activity.

Communication obstacles, communication priorities, present awareness of environment and desired awareness of environment were discussed to discover what the deaf-blind individual wanted in terms of communication and telecommunications. Subsequently, devices presently used, or previously used and devices and services desired were discussed to get an understanding of the types of solutions which the deaf-blind individual would find compatible with his/her situation and needs. A general question regarding government policy elicited some comments which were useful for the formulation of recommendations. In general, the comments after the formal questionaire was completed quite often proved to be the most valuable portion of the discussion.

The professionals were asked questions which would establish how they interacted with deaf-blind people. Handicaps contingent on the disability and the effect of different etiologies were discussed with respect to the potential to communicate. Specific aids already available and their impact were also analyzed in terms of overcoming obstacles and satisfying priorities. Deaf-blind individuals were questioned about their awareness of government policy, relative to their own particular situation and of the

environment in general. In particular we discussed previous initiatives such as closed captions and radio reading.

8.4 CASES:

To provide a more complete understanding of the diversity and implication of the handicaps, six case studies are presented.

8.4.1 Case 1

1. present age: 21 years
2. sex: male
3. visual acuity: totally blind in one eye but reads large print with the other eye
   - optical aids: eye glasses
   - age of onset: birth
   - etiology: congenital rubella
4. degree of deafness: profoundly deaf
   - special hearing devices: none
   - age of onset: birth
   - etiology: congenital rubella
5. other health problems: none
6. means of communication by deaf-blind individual: speech, print, manual alphabet, sign language
7. means of communication by associates: print, manual alphabet, sign language

8. education: grade 12 at a school for the deaf

9. employment: worked in an institution for the mentally retarded in the communications department and as a ward counsellor

10. living arrangements: with parents in a private home

11. devices in use: closed caption decoder

12. degree of independence: does everything for himself

13. recreational activity: correspondence, crafts, games, travelling independently

- can see enough to take advantage of many adaptations for the deaf, however at school he had many problems because he couldn't see when teachers expected that he should
- has never tried a TDD because they are too expensive
- his mother explains what is going on around him so that he is aware of things including news items
- at work he taught 30 minute lessons on signing to other employees
- he feels that friends and acquaintances are fairly knowledgeable in communicating with him
- he is very patient when explaining to people how to communicate with him
- would like a device which would enable him to attend regular classes at a community college so that he could become certified to work in an institution for the mentally retarded

8.4.2 Case 2

1. present age: 49 years
2. sex: female
3. visual acuity: has great difficulty seeing hand movements
   - optical aids: eye glasses and magnifying glass
   - age of onset: very gradual
   - etiology: retinitis pigmentosa
4. degree of deafness: profoundly deaf
   - special hearing devices: none
   - age of onset: birth
   - etiology: unknown
5. other health problems: none
6. means of communication by deaf-blind individual: braille, feels manual alphabet and sign language
7. means of communication by associates: some large print, manual alphabet, sign language
8. education: grade 6 at a school for the deaf
9. employment: used to volunteer at an institution, used to help at home
10. living arrangements: residence for deaf and deaf-blind seniors
11. devices in use: Visualtek once a week for an hour
12. degree of independence: self care, cleans own room, goes for walks with a guide
13. recreational activity: knitting, cards, bowling and swimming

- she now finds it too difficult to read
- would like news regularly in braille
- needs election and candidate information in braille
- would like to be more active, but needs a volunteer to take her shopping, to a restaurant or just for a walk since she would be lost completely if people didn't know sign language

8.4.3 Case 3

1. present age: 17 years
2. sex: male
3. visual acuity: completely blind
   - optical aids: none
   - age of onset: prelingual
   - etiology: meningitis
4. degree of deafness: severely deaf - must be familiar with voice of person speaking
   - special hearing devices: Phonic Ear
   - age of onset: prelingual
   - etiology: meningitis
5. other health problems: developmentally disturbed
6. means of communication by deaf-blind individual: body language or interactive sign language
7. means of communication by associates: manipulation of deaf-blind person's hands into sign language
8. education: presently at school for the deaf-blind
9. employment: not applicable
10. living arrangements: lives in a private home with family but attends a residential school
11. devices in use: Phonic Ear
12. degree of independence: guided self care with appropriate stimulation
13. recreational activity: roller skating, ice skating, horseback riding, swimming, cross-country skiing

- his mother and sister answered the questions since it was not possible to communicate directly with him
- anticipates outings and walks
- family is worried about what might happen in an emergency situation (fire) or if he were lost
- family feels that there should be more general public awareness of what is available for parents who find themselves in a situation where they need some guidance or access to resources
- medical profession should be educated about what resources are available since they are the first people parents usually contact

8.4.4 Case 4

1. present age: 31 years
2. sex: male
3. visual acuity: can read large print
   - optical aids: glasses and contact lenses
   - age of onset: birth
   - etiology: cataracts and lesions from bilateral acoustic neuromas
4. degree of deafness
   - special hearing devices: none
   - age of onset: 27 years
   - etiology: bilateral acoustic neruomas
5. other health problems: balance difficulties due to lesions from tumor
6. means of communication by deaf-blind individual: speech, print
7. means of communication by associates: large print, enlarged computer print, cued speech
8. education: working on post-graduate degree
9. employment: worked on vibrotactile research
10. living arrangements: university residence
11. devices in use: Apple computer, vibrotactile indicator
12. degree of independence: totally independent
13. recreational activity: reading

o feels interpersonal communication most important

- concerned because associates hesitate to use alternate communication modes
- reads papers and watches captioned news
- wants stereotypes broken down
- wants more captioned programs
- wants a better access to telecommunication via DTMF devices

8.4.5 Case 5

1. present age: 69 years
2. sex: male
3. visual acuity: totally blind
   - optical aids: none
   - age of onset: 54 years
   - etiology: glaucoma
4. degree of deafness: profoundly deaf
   - special hearing devices: none
   - age of onset: 62 years
   - etiology: unknown
5. other health problems: deficiency of bone
6. means of communication by deaf-blind individual: speech
7. means of communication by associates: braille
8. education: university degree (possibly post graduate degrees)
9. employment: probably a professor
10. living arrangements: residence for deaf and deaf-blind seniors
11. devices in use: none
12. degree of independence: needs help with self care
13. recreational activity: none

- will only communicate by reading braille and replying vocally
- refuses to learn any sign

- doesn't read his braille periodicals
- communication is difficult because each sentence must be put in braille for him to read

8.4.6 Case 6

1. present age: 85 years
2. sex: female
3. visual acuity: completely blind in one eye and can read magnified print with the other
   - optical aid: eye glasses
   - age of onset: about 55 years
   - etiology: a congenital disease of the lens, cataracts removed
4. degree of deafness: moderately deaf, attend to one voice at a time
   - special hearing device: none
   - age of onset: gradual
   - etiology: loss due to aging
5. other health problems: none
6. means of communication by deaf-blind individual: speech, print
7. means of communication by associates: very slow, articulated speech, writing
8. education: completed high school
9. employment: did volunteer work before auditory and visual losses
10. living arrangements: lives alone in own apartment
11. devices in use: extra loud telephone bell, magnifying glass
12. degree of independence: completely independent
13. recreational activity: outings, limited reading, correspondence

- travels on her own, with special assistance from airlines
- has difficulty keeping things clean because she cannot see the dirt
- has difficulty going out in winter since she cannot see the ice or shadows from stairs

8.5 SURVEY OF PROFESSIONALS

8.5.1 Health Care Professionals and Service Organizations

A number of contacts were made with professionals who have direct contact with deaf-blind individuals. Intervention was the overwhelming concern. The largest obstacle for most deaf-blind individuals is interpersonal communication. If this need is not met, then complications such as withdrawl are likely to arise. Children are of particular concern. If the deaf-blindness is not recognized and intervention started immediately, then the child's prognosis is not promising.

In all discussions the age of onset was perceived to be the most significant factor for assessing the needs of deaf-blind individuals. Deaf individuals who become vision impaired are at a disadvantage because most have learned a sentence structure for sign language which does not correspond to written or spoken sentences. Braille material and finger spelling tend to correspond directly to written or spoken sentence structure. Therefore, in many situations communication for deaf individuals whose vision subsequently is impaired, involves a process of relearning.

Subsequent to access to an intervenor, one individual suggested that there were three priorities for the deaf-blind. He or she should be assisted to gain the skills required to

1. do something useful
2. live on his or her own; and to
3. gain independence from the intervenor.

Technology could facilitate development in each of these areas. This is addressed in more detail in Chapter 9: Discussion.

Generally, the awareness of deaf-blind individuals is poor. Many do not have access to the news. One individual suggested that more volunteers could reduce the burden for intervenors, because passing on news information is very time consuming. Respondents specifically listed Visualtek, Telebraille and TDDs as useful in addressing the communication and telecommunication needs of their clients. However, cost restricts the availablity of these types of equipment which in turn restricts access to information and other individuals. For example, individuals may typically have access to a Visualtek for only one hour each week.

Due to the unique nature of deaf-blindness, group homes and senior citizens' homes specifically for deaf-blind individuals are strongly suggested by the professionals. The group home is essential to facilitate the difficult

transition to independent living. Also for those individuals who can function outside an institution but will not be totally independent, a group home provides a satisfactory alternative. For senior citizens it is essential that they be placed in an environment where the support staff can communicate with them and understand the problems associated with the dual disability.

The last major area of concern is awareness by the public and the government. The public needs to recognize deaf-blindness as a double disability and know where to seek assistance. Health care professionals need to understand what assistance their profession can provide deaf-blind individuals and to know where to refer these individuals. Also, government policy makers need to understand the uniqueness and diversity of this double disability so that these factors can be considered when making decisions which will subsequently affect deaf-blind individuals.

8.5.2 Education Professionals

There are two major concerns which are interelated:

1. The learning process for deaf-blind individuals tends to be stretched over many more years than that for most individuals.

2. The future of the deaf-blind individual after they finish their formal education is uncertain.

Below we are considering individuals who are considered deaf-blind as children.

The learning process for deaf-blind children extends over a much longer period of time than for most children. One simplistic explanation is that a longer period of time is necessary to assimilate via other senses what is usually visual and auditory information. However, age restrictions on public education limit the time available for formal education. Many students in the process of developing skills for independence are required to withdraw from school and rely on vocational and rehabilitation services. The switch in responsibility results in a discontinuity which potentially has serious effects for the deaf-blind individual.

In the special school setting many devices are available such as computers. The emphasis is on examining the needs and goals of the individual and focusing on the abilities rather than attempting to make up for the disabilities. Some provinces have funding programs which assist the purchase of devices for school age children.

8.5.3 Technical Professionals

The information obtained is discussed in Chapter 7: Technology. However, there are a few additional comments.

The use of American technical devices in Canada is extensive. However, there are many problems related to servicing broken equipment, shipping charges for servicing, reliability of equipment, companies discontinuing products and support of products, companies closing, and imported products undercutting Canadian goods. Concern was expressed about lack of commitment for the development of Canadian products. Also, there was confusion about the responsibility of CSA (Canadian Standards Association) and DOC (Department of Communications) for approving devices.

There have been several commendable considerations by the business sector. For example: Several telephone companies charge half price for long distance calls for the hearing impaired and the connect charge for ENVOY has been

waived for the hearing impaired. There has been a definite move in some provinces to financially assist individuals who need special technical devices.

8.5.4 Special Interviews

These interviews consisted of personal discussions, telephone interviews and extensive written correspondence. Individuals from the United States, United Kingdom, Scandinavia and Canada were included in this group. These individuals tended to have a specific area of expertise with respect to deaf-blindness. The topics included plans for future technical work, demography, technical devices and a general understanding of some of the implications of deaf-blindness. The information from these interviews is dispersed throughout the report.

8.6 A MORE PERSONAL PERSPECTIVE

It is difficult to generate a uniform perspective because deaf-blindness does not lend itself to stereotyping. However, there are several points which are important when considering the situation of the deaf-blind.

For those of us with vision and hearing intact it is difficult to imagine what it would be like without them. The magnitude of the isolation is not easily appreciated. Also, the length of time required by the deaf-blind to obtain information and learn new skills is greatly increased. Individuals who lack residual vision or hearing must rely on their sense of touch. Sensory information must be used but there are sometimes problems with respect to overloading the sense of touch. Often a balance needs to be established between desired information and how much people can take in at one time.

Many situations arise in day to day living which become obstacles if there is no auditory or visual input. Think for a moment about meal preparation; For example, making a cup of coffee. If you are preparing your own coffee how would you know when the kettle was boiling. If you were blind, you could hear the kettle boiling and if you were deaf you could see the kettle boiling. A completely deaf and totally blind individual cannot take advantage of either

of the auditory or visual clues. Another example of every day difficulties encoutered by the deaf-blind is in the use of alarm clocks. If you accidently set the alarm for p.m. instead of a.m., how do you know? You would not perceive the visual or auditory clues which deaf or blind individuals would be able to take advantage of to allow them to recognize the mistake. Personal hygiene could also present several problems. This is one area in which people resent needing assistance. What do you do in case of emergency? If you have access to a telephone and you have speech, how do you know if the telephone has been answered at the other end? If you are in an unfamiliar area, how do you find out where you are? How do you locate a telephone booth? These seem to be trivial problems, but they are just a smattering of the difficulties which pile up.

A secondary problem which is related to lack of visual and auditory confirmation is that of misconceptions. If an individual with vision and hearing initially makes a mistake in his/her conception of what has been said, then the subsequent visual and auditory clues will not make sense, and the misconception can be cleared up. This process of clearing up a misconception is usually initiated by the individual who has the misconception. People are not in the habit of checking to make sure that you understood completely everything that has been said. For example, in our survey one respondent mentioned an instance when birth

control was explained to a deaf-blind individual: the youth thought that taking any pill would prevent conception. The consequences of such a misunderstanding could be serious. Therefore the process of learning needs constant feedback from the deaf-blind individual to make sure that he has grasped the concepts because he may not realize that there has been a misunderstanding.

Despite the problems encountered, there are individuals who still want to be independent. Many are willing to find ways to overcome some of these set-backs. Individuals who have acquired their deaf-blindness have to cope with an additional problem. They may have to examine their aspirations and set different goals. Living independently may have been assumed prior to the onset of the double disability. This process of re-evaluation becomes more significant if we consider individuals with degenerative causes of deaf-blindness.

Jobs are also an important concern. Many individuals want to do something constructive. Jobs also have their financial rewards. Considering the price of equipment, devices and aids, the income from a job could potentially affect the lifestyle of the individual by providing him/her with the resources to purchase devices. However, there is a very low level of employment among the deaf-blind, so most are on government pensions or assistance. Therefore, the

relative cost of devices is much greater considering limited financial resources.

The deaf-blind individual has access to several service organizations: CDBRA (Canadian Deaf-Blind and Rubella Association), CHS (Canadian Hearing Society) and CNIB (Canadian National Institute for the Blind). Each organization functions in its own way, but they do provide resources, information, counselling and support. An individual is free to get involved in a number of ways because of professional or personal interests. There are other organizations which are involved in various ways with different groups of deaf-blind individuals but these are the most important.

8.7 DISCUSSION

The primary concern of the deaf-blind is overwhelmingly the desire to communicate especially with non-handicapped individuals in social settings, essential communication situations and job settings.

Access to the currently available devices is severely limited usually due to cost. It is important to keep in mind that many of these people are on pensions, have relatively low paying jobs or depend on relatives or institutions. Therefore the prices are extremely high with respect to the buying power of these individuals.

Most of the individuals rely on a friend or relative to take the time to inform them about what is going on in the news, their community or around their home. Because of the time involved, these friends or relatives are likely to be selective in the news that they pass on.

Out of all the discussions, the topic of general public awareness of causes of deaf-blindness, available services, education of the medical profession and awareness of policy makers surfaced as the primary problems.

The results of the survey will be discussed in more detail under the heading of recommendations.

CHAPTER 9

DISCUSSION

Although these recommendations are technologically oriented, the reader should note one general observation. The importance of intervention for deaf-blind individuals is obvious. An intervenor performs two important functions. The first is personal contact for which no piece of equipment can be a substitute. The second function of transferring information to the deaf-blind individual can be complemented by many recent innovations and advances in modern technology. It is this latter function which we are addressing.

Flexibility of services and devices is essential if they are to address the needs of the deaf-blind. This theme is supported by the survey data and the technical information.

9.1 TELECOMMUNICATIONS

A previous report by the Department of Communications (28) defines telecommunication as "interpersonal communication by means of an electric or electronic system transmitted over wires or fibre optic filaments or through air via electromagnetic waves or beams of light. The stress is on interpersonal communication at a distance." Telecommunications may also be seen as a tool that could provide an alternative to or substitute for transportation to various locations.

At the present time several systems on the market are capable of handling telecommunications for deaf-blind individuals. (e.g. Telebraille, Commprint-One, HASICOM, Brailink, Versabraille, Microbrailler etc.). All these devices vary with respect to capabilities, flexibility, reliability and cost. These devices should be studied to evaluate cost effectiveness and the potential to meet the telecommunication needs of the deaf-blind individuals. Initial investigations should include evaluation by deaf-blind individuals with some familiarity with technology. Field evaluations by other deaf-blind individuals should conclude the initial investigation. A group home would be an ideal situation in which to test the telecommunication devices since there is adequate backup if unexpected circumstances require the devices to be altered

to suit the required applications. However, due to the variation in needs especially among the deaf-blind, it is important to continue to evaluate and modify the equipment. This is most easily accomplished if the design of the initial device has incorporated maximum flexibility.

Recommendation 1: The Minister of Communications encourage an appropriate agency to evaluate the telecommunication devices for use by deaf-blind individuals.

Due to the financial situation of many deaf-blind individuals, it is imperative not only to find ways to provide the best technical assistance for telecommunication but a means to provide this assistance at a reasonable cost. One way to approach this problem is to support a single flexible system which could be acquired at a reduced rate due the quantities purchased. A single flexible system could consist of a micro computer with several input/output ports to connect up the required peripheral devices that an individual requires. Since many deaf-blind have residual sight or hearing, it is possible that the device could be used by the deaf, blind and deaf-blind.

Recommendation 2: That the feasibility of supporting a single system for deaf-blind individuals be investigated.

The use of Touch-Tone (TM) coding is accomplished by assigning the letters of the alphabet a two-key sequence using the keys on a push button phone pad. An individual can send a coded message by keying in the appropriate letters similar to typing a message on a TDD. A more sophisticated decoder is required to read the messages sent in this manner. A visual display will be available shortly at a projected cost of $200. This amount will necessarily increase if a tactile display is added. However as noted before, the decoder is small, convenient, and portable. Messages can be sent by the deaf-blind individual from any phone equipped with Touch-Tone lines.

Recommendation 3: The Department of Communications encourage the development and subsequent use of Touch-Tone (TM) coding as an inexpensive, portable means of telecommunication for use by deaf-blind and hearing-impaired individuals.

Due to the possible impact that a Touch-Tone communication system may have on the lives of deaf and deaf-blind individuals, it follows that the transition to Touch-Tone should be encouraged.

Recommendation 4: The Minister of Communications encourage the telephone companies to switch to Touch-Tone (TM) as soon as possible since this method of transmission facilitates

the application of improved telecommunication devices.

Electronic bulletin boards and messaging services are presently being used extensively by some businesses, but private individuals are also finding them useful. It is anticipated that use by private individuals will increase dramatically. (29) Several bulletin boards are in full operation and the Canadian Hearing Society has found Envoy 100 very useful. Envoy can operate without a computer. Small screens provided by Telecom Canada may be used by those with residual vision. Again, a tactile display could be used by individuals without residual vision.

Rcommendaion 5: The use of messaging in addition to, or instead of, long distance telephone communication for deaf-blind individuals should be encouraged.

Preprogrammed emergency numbers on a telephone could be used in cases of emergency if the deaf-blind individual is living independently. Prerecorded messages could be used for various situations. If one of the emergency numbers was an answering service or call forwarding, then it would be possible for a relative or friend to be contacted by phone to ask them to check the deaf-blind individual.

Recommendation 6: Federal and provincial regulatory agencies should encourage telephone companies to provide

leased telephone equipment with programmed emergency numbers and recorded messages for use by deaf-blind individuals who are living independently.

The mobile cellular telephone system could promote independence and mobility for the deaf-blind individual. The person could carry a small mobile telephone on his/her belt so that if lost, he/she could contact someone for help. One often fails to consider that the deaf-blind individual who is unfamiliar with his/her environment would not have easy access to a telephone and would be unable to communicate his needs to individuals within easy reach. The cellular telephone system allows the use of a greater number of channels by means of computer controlled nodes as one moves from cell to cell.

Recommendation 7: The use of cellular telephones for use by deaf-blind individuals in case of emergency, while away from specially adapted equipment should be publicized by businesses providing mobile communications.

9.2 BROADCASTING

Most individuals are informed of international and national news via programs which are broadcast on radio and television, or written in daily newspapers. These media facilitate Canadians identifying with a culture in addition to providing factual information. Most deaf-blind individuals do not have access to any of these resources. Since the adaptations to the present broadcasting system would have difficulty addressing many of these needs for deaf-blind individuals, it is necessary to turn to alternate means of providing the same information, culture and entertainment. The use of computer messaging services and bulletin boards which could provide some of the information which other Canadians are capable of receiving via broadcast services should be encouraged.

Recommendation 8: The Minister of Communications encourage the use of computer messaging services which deliver the same news and community information which sighted and hearing individuals can obtain from broadcast programs.

Individuals with residual vision or hearing may be able to take advantage of special programming. This would be particularly useful for coverage of events of interest especially to the deaf-blind. Background noise can act as interference for an individual with residual hearing. Also

for many deaf-blind individuals with residual hearing, it is possible to tune into a single voice at a time to hear what is being said. Lack of contrast can blur the image for an individual with residual sight. Since broadcasting is by definition a mass medium, and since the broadcasting needs of deaf-blind individuals can rarely be met using conventional broadcasting methods it is necessary to examine how broadcast programs can be adapted at the receiving end of the broadcast. This is an approach which does not require a new method, such as computer bulletin boards, of information transmission. The receiving end could be adapted to vary the appropriate parameters such as volume, pitch, rate of voice, colour, intensity and magnification of picture. For example: A program could be recorded on a VCR and played later with adjustment of the rate (speed), mode (intensity of picture or frequency range of voice), and amplification or magnification. Ultimately these personalized modifications would allow the maximum possible advantage to be taken of existing broadcasting systems.

Recommendation 9: The Minister of Communications encourage research into and development of equipment which would allow the viewer or listener to vary appropriate parameters of broadcast programs.

Due to the lack of knowledge among the general public, some deaf-blind children do not receive special assistance

until they are close to school age. This is particularly dangerous since the chances of fundamentally helping these children are very small after they are three years of age. Therefore it is essential that if deaf-blind children are to become responsible adults and be able to take advantage of telecommunication and communication services, they must receive early attention. This involves informing the public. Many elderly individuals accept the isolation that deaf-blindness brings because they are not aware of what is available to help them. Telecommunication could help remove some of the loneliness since many of these individuals find travelling difficult. Again, broadcast programs could address some of these needs and at the same time provide information and assist understanding of family members and friends. These programs could address vision, hearing, mental and perceptual impairments as well as medical problems faced by the elderly.

At the present time we receive programs from other countries. Some countries in Europe and Scandinavia are making advances in the areas of deaf-blindness. It is conceivable that we could share some mutually beneficial programming. The Department of Communications could play a role in facilitating the use of foreign programs which address issues, events and interests of deaf-blind individuals.

Recommendation 10: Broadcasters should be encouraged to produce programming dedicated to rehabilitation or preventative medicine including programming produced in other countries.

9.3 COMPUTERS AND DEVICES

"It is not enough for the handicapped individual to be able to use his own computer and its specially prepared programs. The employer needs workers who can operate the company's computers and its programs. If a disabled person cannot do that, then he cannot carry out the job. The issue is to equip disabled people to use standard hardware and standard software that is in place, at the office or at the school or wherever it is that the disabled individual is expected to perform. If we cannot do this then computers will become a new "barrier" for disabled people." (30) Computers are capable of playing an assistive role such that physical reliance on machines rather than people does not lead to hostility due to dependence.

It is important to keep in mind that applications of computers and devices are of limited use unless they can be provided at reasonable cost.

The development of a versatile tactile interface is essential to the developments of most devices for individuals without the use of residual sight. This tactile interface could be used with a computer or with a telecommunications device. If one device were supported for all applications by most deaf-blind and blind individuals then the price would likely decrease. It is important to note that some deaf-blind individuals do not use braille. It would then be possible to develop a tactile interface which uses raised letters rather than braille.

Recommendation 11: The Minister of Communications encourage research and development into applications of a versatile, standardized, compatible tactile interface for use with telecommunication and communication equipment for deaf-blind individuals.

A single versatile personal computer (PC) with variable peripherals could substantially change the quality of life for many deaf-blind individuals.

Access to banking and shopping using a PC is now a reality in several cities in the United States. A PC is connected to the bank or store using a modem and standard telephone. As the software is developed for Canadian banks and stores, the flexibility for use by the deaf-blind should be built into the programs. Eventually, deaf-blind

individuals may themselves be able to develop the software which they would find useful. Much of the software available today has evolved as individuals decided they needed it for particular applications. Environmental sensing (visual and auditory) could be fed into a PC for processing and presentation. This would facilitate individuals living on their own and would be inexpensive if connected to a PC which had other applications as well. The elderly will feel more comfortable as people age who are accustomed to using computers.

Children in schools for the deaf-blind are presently exposed to some of the wonders of the computer. Due to the sensory deprivation some children experience great anxiety when their sense of touch is overloaded. Because the computer is impersonal, it can alleviate some of the problems experienced by touching other people. The child can also be encouraged to initiate human contact if required information to use the computer is withheld. The child must then ask for the necessary information to continue. Some families find that the computer facilitates communication with their children. Also computer aided instruction is being used a great deal especially in schools where the program out of necessity is individualized for each child. Therefore much of the resistance to using computers will disappear.

Recommendation 12: The use of a flexlible personal computer with various peripherals and standard software should be encouraged so that the deaf-blind can make maximum use of the present and future communication and telecommunication systems.

The development of devices which facilitate the integration of deaf-blind individuals with respect to communication should be continued. There exists an inherent interaction between telecommunication and communication devices which can be maximized if developments are pursued in each area.

Recommendation 13: The Minister of Communications encourage research into and development of devices for interpersonal communication by deaf-blind.

Financial assistance in the form of service contracts, rental equipment and low interest loans should be set up. This would allow individuals to gain experience with devices and could possibly provide a means of employment and recreation. It is unlikely that individuals will have the skills to acquire employment or the desire to become proficient using a computer if a computer is not financially feasible. Most handicapped individuals are in a lower income bracket so the financial assistance becomes even more necessary. At the present time Workers Compensation,

Vocational and Rehabilitation Training and some special schools provide some training in this area.

Recommendation 14: Federal and provincial governments should consider the introduction of financial assistance programs in the form of service contracts, rental equipment and low interest loans for the deaf-blind.

9.4 SOCIAL AND MEDICAL AWARENESS

A database should be instigated or an existing database should be adapted to provide information for professionals on communication, telecommunication, other devices and information which relate to deaf-blindness. Professionals interacting with the deaf-blind in any capacity should have access to this database. In this way the available information could be kept current.

Recommendation 15: The establishment and use by professionals of a database which lists communication and telecommunication devices for deaf-blind individuals should be encouraged.

A brochure explaining where to obtain information on deaf-blindness should be mailed to all family physicians. This could be mailed along with the hospital insurance plan mailings, for example. Otolaryngologists, Opthalmologists,

Audiologists, Speech Pathologists, Psychologists, Neurologists and Rehabilitation Medicine Specialists all require more detailed information regarding deaf-blindness due to the special hardships imposed by the double disability and the importance of early intervention. Consultants should be named for referral purposes (For example: Canadian Deaf-Blind and Rubella Association may wish to take this on.) In this way members of the deaf-blind community, their families, caretakers, and hospital personnel could be referred to the appropriate individuals who could address funding possibilities, education programs, devices, retraining and rehabilitation programs.

Recommendation 16: The Minister of Health and Welfare should encourage provinces to include information on deaf-blind services and communication systems and devices to family physicians and specialists in Canada.

Due to a lack of public knowledge of available communication devices, telecommunication devices, information and services, the Department of Communications might wish to participate in the dissemination of this information in the form of a lecture series aimed at providing professional information about the deaf-blind.

Recommendation 17: The Minister of Communications in conjunction with the Minister of Health and Welfare may wish

to sponsor a "travelling" lecture series to disseminate information on telecommunications and deaf-blindness.

Service groups should be encouraged to support group homes and the purchase of special equipment required for use by the relatively small population of deaf-blind individuals. These groups would be able to see the immediate effect of their support on the quality of life for the individual who they were able to assist. Much of the equipment necessary for deaf-blind individuals to participate in some of the suggested programs could be costly on an individual basis. However, it may be possible to provide these for common use by small groups. As an example, the Brantford Lions Club is financially assisting the group home in that city for the deaf-blind.

Recommendation 18: Service groups should be encouraged to support the purchase of special communication and telecommunication equipment for deaf-blind individuals.

9.5 RESEARCH

This section does not include recommendations for research in the area of computers and devices since that has previously been covered in section 9.3: Computers and Devices.

Individuals with residual or no sight and hearing depend heavily on touch -- the somato-sensory information channel. Strategies should be developed to investigate acceptable information rates when providing somato-sensory information both in normal individuals and in those with either reduced sight and/or hearing or those profoundly deaf and totally blind. Some work has been done in the somato-sensory area (31). However, future work in terms of telecommunication and communication would be very useful. Computer translation of speech to somato-sensory signals for speech recognition, or speech processing of sounds should be supported due to the telecommunication applications of such work.

Recommendation 19: The Minister of Communications encourage the development of strategies to investigate somato-sensory information processing in particular for the deaf-blind as a mode of communication and telecommunication.

Reliable Canadian demographic data is essential to assess the needs of deaf-blind individuals so that the available resources may be used most effectively. The needs vary considerably according to such variables as the extent of visual and auditory impairment, age, and place of residence. Such information will be particularly useful for addressing the needs of the increasing number of individuals over the age of 60 with an acquired dual handicap. Vehicles such as the Canadian census or Canadian Health Survey could address some of the more important questions relevant to deaf-blindness as part of the regular census.

Recommendation 20: The federal government should develop detailed, reliable Canadian demographic data on deaf-blind individuals.

Investigations are also necessary to explore the human factors aspects of technology. A mechanism should be established for testing devices which special consideration given to the individuals who will use them. This includes consumer acceptability of equipment features relating to portability, simplicity of operation, adaptability, applicability (over a wide range of ages and educational backgrounds), versatility, speed of communication, feedback provision, correctability, provision for hard copy, ease of maintenance and serviceability.

Recommendation 21: The Minister of Communications encourage the development of a mechanism for testing telecommunication devices for the deaf-blind with respect to human factors.

9.6 POLICY

A national centre should co-ordinate questions relating to communications and telecommunications for the deaf-blind. This centre could serve to distribute information and provide consultation regarding deaf-blindness. The federal government should encourage the establishment of provincial centres as sources of professional expertise and state-of-the-art technical aids. Provincial centres would be in a position to assess community needs for future investigations. Currently, several areas of government are concerned with the needs of the deaf-blind as part of some larger program. As a result no one agency deals with the specific problems of this group of individuals. There is a need for a specially designated co-ordinator who is in a position to make recommendations about funding of projects and who is informed of all work pertaining to the deaf-blind.

Recommendation 22: The Minister of Communications encourage the development of a national centre which addresses the telecommunication and communication needs of deaf-blind individuals.

Consideration of communication expenses incurred should be continued and encouraged. Some Canadian telephone companies charge 50% of the long distance telephone rates if a person is hearing impaired. Long distance charges for individuals who can only talk to others with the same equipment and who are typing messages rather than speaking them incur larger long distance bills. Some programs exist for tax credit on devices. However there are no federal guidelines, and there is currently no particular way to access funding and subsidies for services and aids (eg. information service charges).

Recommendation 23: The Minister of Communications encourage telephone companies to provide special services for the deaf-blind, and recognize those telephone companies who already provide special services.

The federal government should encourage standardization and improvement of provincial funding programs for communications and telecommunications devices. Communication aids should be evaluated at the federal level and should be considered essential devices for deaf-blind individuals.

Recommendation 24: The federal government should encourage standardization and improvement of provincial funding programs for provision of communications and

telecommunications devices for the deaf-blind.

Rehabilitation centres, hospitals, chronic care institutions and other health care institutions should have a telecommunication centre which individuals can access from home or use when they are in the centre. A single number with access to special communication equipment could be used to relay messages in case of emergency.

Recommendation 25: The Minister of Communications encourage the establishment of telecommunication centres geared to both vision and hearing impaired in rehabilitation centres, hospitals, chronic care institutions and other health care institutions.

Provincial and local agencies should establish an interpretation bureau to be used by hospitals, courts, police departments and for emergency needs of the deaf-blind. This bureau could be equipped with special telecommunication equipment and have communication equipment which could be used for emergency needs.

Recommendation 26: The establishment of interpretation/ intervention bureaux which might be used by hospitals, courts, and police departments for emergency needs of the deaf-blind should be encouraged.

Production and purchase of Canadian-made telecommunication products for the deaf-blind should be encouraged and supported if their quality is comparable with products from outside Canada. This would support especially small manufacturing businesses and could provide a marketable export product.

Recommendation 27: The Minister of Communications encourage the production and purchase of Canadian telecommunication products for use by deaf-blind individuals.

CHAPTER 10

SUMMARY OF RECOMMENDATIONS

10.1 TELECOMMUNICATIONS

1. The Minister of Communications encourage an appropriate agency to evaluate the telecommunication devices for use by deaf-blind individuals.

2. That the feasibility of supporting a single system for deaf-blind individuals be investigated.

3. The Department of Communications encourage the development and subsequent use of Touch-Tone (TM) coding as an inexpensive, portable means of telecommunication for use by deaf-blind and hearing-impaired individuals.

4. The Minister of Communications encourage the telephone companies to switch to Touch-Tone (TM) as soon as possible since this method of transmission facilitates the application of improved telecommunication devices.

5. The use of messaging in addition to, or instead of, long distance telephone communication for deaf-blind individuals should be encouraged.

6. Federal and provincial regulatory agencies should encourage telephone companies to provide leased telephone equipment with programmed emergency numbers and recorded messages for use by deaf-blind individuals who are living independently.

7. The use of cellular telephones for use by deaf-blind individuals in case of emergency, while away from specially adapted equipment should be publicized by businesses providing mobile communications.

10.2 BROADCASTING

8. The Minister of Communications encourage the use of computer messaging services which deliver the same news and community information which sighted and hearing individuals can obtain from broadcast programs.

9. The Minister of Communications encourage research into and development of equipment which would allow the viewer or listener to vary appropriate parameters of broadcast programs.

10. Broadcasters should be encouraged to produce programming dedicated to rehabilitation or preventative medicine including programming produced in other countries.

10.3 COMPUTERS AND DEVICES

11. The Minister of Communications encourage research and development into applications of a versatile, standardized, compatible tactile interface for use with telecommunication and communication equipment for deaf-blind individuals.

12. The use of a flexlible personal computer with various peripherals and standard software should be encouraged so that the deaf-blind can make maximum use of the present and future communication and telecommunication systems.

13. The Minister of Communications encourage research into and development of devices for interpersonal communication by deaf-blind.

14. Federal and provincial governments should consider the introduction of financial assistance programs in the form of service contracts, rental equipment and low interest loans for the deaf-blind.

10.4 SOCIAL AND MEDICAL AWARENESS

15. The establishment and use by professionals of a database which lists communication and telecommunication devices for deaf-blind individuals should be encouraged.

16. The Minister of Health and Welfare should encourage provinces to include information on deaf-blind services and communication systems and devices to family physicians and specialists in Canada.

17. The Minister of Communications in conjunction with the Minister of Health and Welfare may wish to sponsor a "travelling" lecture series to disseminate information on telecommunications and deaf-blindness.

18. Service groups should be encouraged to support the purchase of special communication and telecommunication equipment for deaf-blind individuals.

10.5 RESEARCH

19. The Minister of Communications encourage the development of strategies to investigate somato-sensory information processing in particular for the deaf-blind as a mode of communication and telecommunication.

20. The federal government should develop detailed, reliable Canadian demographic data on deaf-blind individuals.

21. The Minister of Communications encourage the development of a mechanism for testing telecommunication devices for the deaf-blind with respect to human factors.

10.6 POLICY

22. The Minister of Communications encourage the development of a national centre which addresses the telecommunication and communication needs of deaf-blind individuals.

23. The Minister of Communications encourage telephone companies to provide special services for the deaf-blind, and recognize those telephone companies who already provide special services.

24. The federal government should encourage standardization and improvement of provincial funding programs for provision of communications and telecommunications devices for the deaf-blind.

25. The Minister of Communications encourage the establishment of telecommunication centres geared to both vision and hearing impaired in rehabilitation centres, hospitals, chronic care institutions and other health care institutions.

26. The establishment of interpretation/ intervention bureaux which might be used by hospitals, courts, and police departments for emergency needs of the deaf-blind should be encouraged.

27. The Minister of Communications encourage the production and purchase of Canadian telecommunication products for use by deaf-blind individuals.

APPENDIX A

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APPENDIX B

GLOSSARY

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and

product information form manufacturers and distributors.

- adventitious: aquired, not congenital.
- American Sign Language (ASL): a language using hand positions to represent words. The grammar uses spatial relations to indicate grammatical relations.
- ASCII: American Standard Code for Information Interchange, a code which is used to form each number and letter in the alphabet in electronic communication.
- autistic: state of mind characterized by daydreaming, hallucinations and disregard of external reality.
- Auto-Dialer: automatic telephone dialer with braille or large print coded labels next to push-buttons that enable contact with emergency numbers. It may be combined with pre-recorded taped messages.
- autosomal recessive: genetically inhereted form of trait transmission which is independent of sex. The trait is evident if both chromosome are inherited from both parents.
- Baud: Information transmission rate in bits per second. Related to the number of characters per second which are transmitted.
- Baudot: a code which is used to form each letter and number in the alphabet in electronic communication.
- bilateral: involving both sides.
- bit: binary digit, the smallest unit of information in computers.
- Brailink: a paperless braille micro-computer.
- cardiopathy: abnormal state with respect to the heart.
- cataract: clouding of the crystalline lens of the eye or its capsule.
- cell: an area containing a transmitter for use with cellular telephone operation, about 21 kilometers in diameter.

- cellular telephone: a mobile telephone using radio frequencies rather than telephone wires to transmit messages to various cells (see cells). A computer switches calls to the nearest cell as individual moves from area to area.

- closed caption TV: Programs which have the spoken words printed under the individuals who say them.

- closed circuit TV: print is magnified by placing it under a camera which uses a zoom lens. The image is displayed on the screen where brightness, contrast and negative image can be controlled.

- cochlea: essential organ of hearing containing the membranous cochlear duct in which the spiral organ of Corti with its nerve endings is located.

- Code-Com: device which converts sound signals to visual and tactile signals, attached to the base of a telephone, and a sending key which controls an audio oscillator.

- Commprint-One: a portable TDD with printer.

- communication: act of imparting or transmitting information either interpersonally or via telephone, telegraph, radio, or electronically.

- cone: visual receptor, one of flask-shaped cells, which, with the rods form one of the eight layers of the retina.

- congenital: present at birth.

- database: information stored electronically in a computer. May also be a special program that allows sorting through these lists for information.

- deaf-blind: vision and hearing impaired, see Chapter 5.2: Definition.

- decoder: device which recovers original message from a coded form of message.

- demodulator: device which processes a wave resulting from previous modulation to derive a wave having substantially the characteristics of the original wave.

- DEST attachment: device which can be attached to the Kurzweil Reading Machine to obtain tactile rather than auditory output.

- developmentally disturbed: retarded development due to perceptual, mental, or other handicap.

- disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

- elctromagnetic waves: wave characterized by variations of electric and magnetic fields, e.g. radio waves.

- electronic bulletin board: an announcement board on a computer system, accessed by individual terminals or computers.

- electronic mail: all the ways of sending and receiving messages using computers. Hooking a computer into the telephone network gives access to special news services, word processing, databases, stock market quotations, etc. which are provided by electronic mail companies.

- electronic messaging service: ways of sending messages using computers, see electronic mail.

- embryopathy: abnormal state with respect to foetus.

- ENVOY: Canadian electronic messaging service.

- fibre optics: the technology that combines tiny infrafed lasers with glass fibres made up of the purest silica sand to transmit information.

- finger spelling: method of forming the letters A-Z by manipulating fingers of one hand into specific positions. The deaf-blind person may place his/her hand over the speaker's hand to feel the position of the fingers.

- FM: frequency modulation of a signal, e.g. radio signal.

- Frequency Shift Key: form of frequency modulation in which the modulating signal shifts the output frequency between predetermined values.

- glaucoma: disease of eye, marked by high intraocular pressure, resulting in hardness of the globe, cupping of optic disk and eventual blindness.

- HAM radio, HAM Tactile Receiver: amateur radio for sending and receiving messages, tactile receiver converts messages to Morse Code.

- handicap: a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, social and cultural factors) for that individual.

- hardware: a computer, 'smart' telephone, word processor or other electronic device.

- HASICOM: Hearing and Sight Impaired Communication system presently being developed in Britain for use over telephone lines.

- impairment: any loss or abnormality of psychological, physiolbgical, or anatomical structure or function.

- information technology: technology relating to the communication of information.

- intervention: an interaction with another individual where one person mediates between a deaf-blind person and his environment to enable him to communicate effectively with and receive non-distorted information from that environment.

- Kurzweil Reading Machine: device which detects lines of print on a page by using a small computer-controlled camera; uses grammar and pronunciation stored in memory; can attach embosser or paperless braille equipment.

- Laser Cane: cane capable of emitting three light beams which are reflected when they bounce off an object. It can be fitted with a vibrator rather than an auditory signal.

- lesion: any morbid change in the structure or function of tissues due to injury or disease.

- main frame system: computer system which can support several terminals.

- manual alphabet: letters which are represented using one hand or two.

- meningitis: inflamation of the membranes of the brain or spinal chord.

- microphthalmia: abnormal smallness of the eyeballs.
- Microbrailler: consists of a text editor, printer (braille) micro computer.
- modem: short for modulator/demodulator, used to attach a computer to the telephone network. It converts computer digital signals to analog for sending and reconverts the analog signal at the other end so the receiving computer can understand it.
- modulated signal: a variation in the amplitude, or phase of a carrier wave in accordance with another wave.
- Morse Code: system of short and long signals which represent letters of the alphabet used for electronic or optical communication.
- motion detector: device which signals when there is motion, e.g. a light beam which has been broken.
- Mowat Sensor: hand-held vibrating box whose frequency increases as an object is approached, box radiates a high-frequency sound which is reflected off objects and causes the box to vibrate.
- newspaper service: a service which allows newspaper articles to be accessed by a terminal.
- neuroma: tumor formed chiefly of nerve cells or fibrous tissue developing from the connective tissue of a nerve trunk.
- Nottingham Obstacle Detector: mobility aid.
- one-hand manual alphabet: see finger spelling.
- Optacon: portable electronic device which reproduces print in a tactile representation, allowing immediate access to all printed material.
- paperless braille: device which allows electronic communication in braille, usually a micro-computer or word processor with a tactile display.
- patterned tactile speech display: a device which converts sound to a tactile pattern on wrist or chest.

- perception: the learned ability to register and give meaning to sensory stimuli.

- peripherals: devices which can be connected to a computer, e.g. printer, tactile display.

- personal computer (PC); a small computer, which operates as an independent unit.

- Phonic Ear: stereo wireless auditory training system, speaker wears microphone/FM transmitter, student wears hearing aid/FM receiver.

- print on palm: a method of printing the alphabet in the palm, form of communication with deaf-blind individuals.

- prognosis: the probable course and outcome of a disease.

- radio-reading service: a radio program where printed items are read, e.g. sale items and community news.

- residual vision/hearing: the remaining vision or hearing which a deaf-blind individual may potentially be taught to utilize

- retina: lining of the interior of the posterior two thirds of the eyeball.

- Retinitis Pigmentosa: hereditary degeneration and atrophy of the retina, usually misplaced pigment associated with Usher's Syndrome.

- retinopaty: abnormal state of the eye.

- rods: cells of the retina which contain visual purple and form with the cones the visual receptor layer of the retina.

- Rubella Syndrome: congenital syndrome caused by intra-uterine rubella infection, characterized by cataracts, cardiac anomalies, deafness, and other neurological impairments.

- Russel Pathsounder: box which hangs in front of the chest by a neck strap. An ultrasound beam reflects off objects; a tactile stimulator can be attached to neck strap. It can also be head mounted.

- sacculе: one of the two sacs of the membranous labyrinth of the vestibule of the internal ear.

- See-Tone: telephone device for deaf or hearing-impaired persons with voice. A red LED display prints messages sent from a Touch-tone phone or keypad.

- sign language: a language using hand signs to represent words.

- signal-to-noise ratio: ratio of the amplitude of the signal to that of the noise (interference).

- software: instructions to the computer to enable specific functions to be performed.

- somato-sensory: information received by cutaneous receptors.

- Sonicguide: uses ultrasound to provide information about distance, position and surface characteristics of objects. A transmitter is located in eye glasses, the reflected signal is converted into audible sound in ear-plugs.

- Superphone: a TDD with keyboard and acoustic coupler.

- tactile: pertaining to the sense of touch.

- Tactile Communicator: stationary wireless signal transmission system for deaf-blind persons. FM transmitter signals doorbell, telephone or smoke alarm with battery operated body vibrator.

- Tactile Speech Indicator: coupled to a telephone handset, this device amplifies signals received and converts them into vibrations. It can also be used to receive Morse code.

- TDD: telephone device for the deaf, usually with LED or paper print-out displays.

- tele-: pertaining to telecommunications.

- Telebooster: device which amplifies sound from radio or TV, attached to a hearing-aid.

- Telebraille: braille telephone for the deaf-blind, can also be used as a conversation aid, consists of a TDD (Superphone) and a braille display unit,

- telecommunications: interpersonal communication by means of electric or electronic systems. It is transmitted over wires or fibre optic filaments or through air via electromagnetic waves or beams of

light.

- Teletext: one-way videotex system that transmits text and graphics as part of the television signal over the air or via cable.

- Telidon: Canadian teletext system.

- Tellatouch: technological aid used in communication between a braille-using deaf-blind person and the sighted world. The non handicapped person types, and the Tellatouch reproduces each letter as raised dots of a braille cell.

- terminal: device connected to a computer, and used to send and receive information.

- Touch-Tone: Bell System version of DTMF (dual-tone multifrequency pulsing). Each digit or character is represented by a simultaneous combination of two frequencies.

- Trisensor: a mobility aid.

- TTY: a teletype which can be used as a TDD.

- two handed manual alphabet: speaker uses one hand to form signs representing A-Z in the deaf-blind receivers hand.

- Usher's Syndrome; disease transmitted genetically by an autosomal recessive gene which involves a profound congenital hearing loss and a progressive loss of vision due to retinitis pigmentosa.

- VersaBraille: a portable paperless braille micro computer, can be used as a braille telephone if connected to a modem.

- Vibralert: a vibrator activated by radio signals.

- vibro-tactile: vibraions used to pass on information using the sense of touch.

- videotex: a generic term for a system that transmits text and graphics for display on a television screen.

- vocoder: a device for patterned tactile speech display.

- Voice Information Processing Computer (VIP): mini computer which accesses data audibly and visually.

- Wide Angle High Power Flashlight: a flashlight held on chest by neck or shoulder strap, especially good for tunnel vision.

- Wristcom: a vibrator activated by radio signals.

APPENDIX C

QUESTIONAIRES

Individual Questionnaire

Part I

Date:

Name of deaf-blind person:

Name of person spoken to:
relationship:

Sex:

Date of Birth:

Date registered deaf: with whom:
" " blind: with whom:
" " deaf/blind: with whom:

Age at onset of deafness: prelingual: postlingual:
" " " " blindness: prelingual: postlingual:

Education Status:

Education History:
- Special Program
- Nursery
- Elementary
- Secondary
- Technical
- University
- School for Blind
- School for Deaf
- Hospital School
- Correspondence Course
- Community College
- Other

Other health problems:
- epilepsy
- speech
- manual co-ordination
- balance & gait
- mental retardation
- paralysis
- amputations
- senility
- emotionally disturbed
- developmentally disturbed
- Other

Etiology for deaf-blindess:
- encephalitis
- meningitis
- prematurity
- congenital rubella
- brain tumors
- cerebral palsy
- multiple schelorsis
- diabetes
- heart disease
- Usher's syndrome
- Von Rechinghausen's Disease
- Retinitis pigmentosa
- other

Living arrangements:
- parents
- siblings
- spouse
- children
- alone

special home:
- deaf-blind
- blind
- deaf
- integrated
- old age
- institution
- specify other

single or multiple dwelling:

degree of independence:
- clean own room
- make light meals
- go for walks
- self care
- work outside home; specify
- no meaningful activity
- transportation

means of communication:

a) by deaf-blind person:
- speech
- print
- large print (close circuit television)
- braille or other raised print
- typewriter
- tella touch
- manual alphabet
- sign language
- concrete clues
- pantomime
- push & pull
- no means
- other

b) by families & associates:
speech
vibration speech
print
large print
typewriter
tella touch
manual alphabet
sign language
no means
other

visual acuity: totally blind
hand movements
guiding vision
large print

if not totally blind: % sight:
blurry & blotchy
tunnel
peripheral

optical aids - specify:

degree of deafness: profoundly deaf
severe
moderate
mild

special hearing devices - specify:

recreational activity: reading
correspondence
crafts
games
sports
clubs
organized holidays

occupational history:

source of income: family
government benefits
old age pension
employment
independent means
other

Name of respondent:

What is the largest obstace in terms of communication?

Is there anything which you feel medically separates you from the rest of the deaf-blind people?

What is most valuable (priorities) in terms of communication?

Is there any device which you have used which has improved the quality or degree of communication for you?

If you could have something invented for you, what would it be?

Do you feel that you are aware of what is happening outside your immediate environment? i.e., services, news, clubs, etc.

If so, how do you find out about these things?

If not, do you want to know?

Do you feel encouraged to be independent? How?

Are you interested in learning more? i.e., courses, etc.

Do you feel that your friends and relatives should be more knowledgeable about communication with deaf blind persons? i.e., courses.

If you could change or make up new government policy, what would you do?

If you could tell the rest of the world something, what would it be?

invention question: which interest you most?
things for perception
rooms
buildings
cities
closed circuit TV - letters
gadgets vs. people

Date:

Name:

Association/Profession:

How does your organization interact with the deaf-blind?

How do deaf-blind people come in contact with you?
- referrals by medical professionals
- referrals by social services
- pushed by relatives
- independently
- other

What is the degree and type of deaf-blind that you see:
- blind - going deaf
- deaf - going blind
- totally blind deaf
- acquired
- congenital
- children
- adults
- seniors

What portion of the deaf-blind population do you see?

What would you expect the total population to be?

What do you feel are the communication handicaps contingent on this disability?

How do the causes of deaf-blind and related medical aspects affect potential communication?

Is there any technical aid which you feel has made a significant improvement in the quality of communication for the deaf-blind?