



# **Summary of Findings and Recommendations From The National Survey of People Who Are Blind/Visually Impaired**



GOVERNMENT OF BERMUDA

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**Ministry of Health**

National Office for Seniors and Physically Challenged

Cabinet Office

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**Department of Statistics**

**BERMUDA SOCIETY FOR THE BLIND**

# **Summary of Findings and Recommendations From The National Survey of People Who Are Blind/Visually Impaired**

Published by



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## Executive Summary

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The 2009 National Survey of People who are Blind/Visually Impaired was initiated because of the recognized importance of developing programmes and services to meet the needs of people who are visually impaired. A public-private partnership, under the auspices of the National Office for Seniors and the Physically Challenged (NOSPC), was established between NOSPC, the Bermuda Society for the Blind (BSFB), and the Department of Statistics (DOS) to conduct a survey of the visually impaired population. It was estimated that the number of people in Bermuda who are visually impaired ranged between 107 and 295 as recorded by the 2009 recruitment drive and 1991 census, respectively. The information obtained during the survey will be used to impact policy and ultimately to improve the quality of life of persons of all ages with visual impairment in Bermuda.

In November 2008, the steering committee representing all of the partners and chaired by DOS Social Statistician, Melinda Williams, convened to oversee the survey project. The survey targeted individuals, with visual impairment, in both the community and institutions. Participation was voluntary. Interviews were conducted and all information was self-reported. At the conclusion of the survey implementation, in October 2009, 69 persons had completed the process. Thirteen were living in institutions and 56 persons were living in the community.

The key findings from the National Survey of People who are Blind/Visually Impaired, 2009 are as follows:

- There are three peak periods when people in Bermuda are more likely to lose their vision — between birth and five years of age, during their fifties and during their seventies.
- The five leading causes of visual impairment, as described by respondents to the survey, are: glaucoma, cataracts, macular degeneration, diabetic retinopathy and trauma due to accidents or violence. None of these five causes of visual loss are entirely preventable; however incidence and impact rates can be reduced.
- The profile of the respondent in the Survey indicates that he or she is more likely categorized as impaired or partially blind, and an older black Bermudian living in the community and likely living with someone. More than a third of all of the respondents do not have a high school leaving certificate and although likely to be employed and/or receiving a pension, they are significantly less likely to earn Bermuda's median income of \$58,000 or higher. Although most respondents do not think that their impairment prevents them from working, they believe that they are limited in the kind and amount of work that they can do.

- None of the institutional respondents, and only some of the community based respondents, thought that their visual impairment affected their access to medical services. Almost all of the participants had some kind of insurance with major medical being the most popular. Participants with major medical insurance reported the greatest ability to pay for medical services. Twenty per cent of the survey respondents indicated that they had difficulty paying for medical services and 20% indicated that they had difficulty paying for services related to their visual impairment.
- A significant number of respondents to the survey have multiple disabilities and other health problems like hypertension, diabetes and hearing loss.
- The majority, 64%, of all participants reported that they are prevented or limited in their everyday life activities. Institutional participants mostly reported requiring daily assistance for the majority of the activities of daily living about which the survey inquired. In contrast, most of the community participants indicated that they did not need assistance with most of their daily activities, for most of their activities — with the exception of reading personal correspondence, shopping and transportation — which was also identified by institutional respondents. Educational assistance was also identified by students as a need.
- Most of the respondents thought their visual condition prevented their leaving home alone. Only a minority seem able to utilize public transportation and independent methods of mobility (i.e. white cane or service animal), leaving the majority of the people restricted.
- Community-based participants said the majority of the assistance they received came from family plus friends. Very few reported receiving help from professionals. Neither community nor institutional respondents reported receiving assistance from volunteers.
- Less than half of the participants had received training specifically designed for people with visual impairment. A majority of those persons indicated that the training was not comprehensive. A minority received training in the use of adaptive or assistive technologies and a similar minority reported knowing how to use a computer.
- Very few participants reported having utilized many useful services. However, those who used services from various organizations indicated that, generally, they were satisfied with the services received.
- The top six services that participants identified that they would use were: audio literature, retail outlet, low vision centre, assistive or adaptive technology, Braille, mobility instruction and rehabilitation.<sup>1</sup>

The following recommendations are put forward to further the UN initiative (to eliminate

<sup>1</sup>Since some of these services are provided, this discrepancy needs further exploration.

avoidable blindness and prevent avoidable visual impairment) and reflect the findings of the National Survey of People who are Blind/Visually Impaired, 2009. Bermuda should:

- Identify and implement strategies to promote the independence, including financial, of persons with disabilities.
- Develop and implement prevention and mitigation strategies, according to trends, to reduce the incidence of visual impairments or to reduce the level of severity where it has occurred. Attention should be given to persons with multiple disabilities which compound the impact of their visual impairment. BSFB should coordinate prevention strategies and activities with groups likely to have a vested interest in these efforts.
- Provide a full range of services, including proper assessment and case management, and a continuum of care across the lifespan, for people who are visually impaired. This would begin when people are first identified as being visually impaired and include a service plan. Appropriate services, reflected in the individual service plan, would be available from the initial intensive period of assessment and training and then be adjusted as needed throughout life.
- Continue to provide support, through the Ministry of Education, for the education of children and adolescents with visual impairment by providing a teacher dedicated to meeting the educational needs of students who are visually impaired.
- Mount a PR campaign, including a newsletter, with the help of service providers, to get information out to persons with visual impairment about the availability of resources, services and other supports to impact their visual impairment.
- Provide training tailored to family, friends, employers, teachers, professional caregivers, etc. on a regular or ongoing basis to maximize independence while providing necessary support to the visually impaired.
- Educate, train and promote access to assistive technology for people who are visually impaired in order to promote independence.
- Provide mobility instruction, orientation and assistance with transportation for persons who are visually impaired to promote independence and accessibility.
- Establish a Register for Persons who are Visually Impaired and gather basic information that will assist in policy development and service provision.
- Expand the research done on people with visual impairment and use additional methods of data collection — like the census, a register for the visually impaired and utilization surveys — in order to clarify some of the anomalies identified. Continue to monitor the quality of life of people with visual impairment in Bermuda.

# Introduction

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The National Survey of People who are Blind/Visually Impaired, 2009, was initiated because both public and private segments of the community recognized the importance of developing programmes and services to meet the needs of people with visual impairment. Under the auspices of the National Office for Seniors and the Physically Challenged (NOSPC), a public-private partnership was established between NOSPC, the Bermuda Society for the Blind (BSFB), and the Department of Statistics (DOS) to conduct a survey of the visually impaired population.

The purpose of the survey was to:

- Obtain demographic information on people in Bermuda who are visually impaired.
- Collect information on impairment specifics — **nature, cause, age at onset and impact preventability.**
- Identify the resources (training and assistance) people who are visually impaired are currently using to cope with any impact of their impairment on activities of daily living.
- Get feedback from persons who are visually impaired on their level of satisfaction with the resources they are currently utilizing.
- Identify improvements to resources for persons who are visually impaired.

The information obtained during the survey will be used to impact policy and ultimately to improve the quality of life of persons of all ages with visual impairment in Bermuda.

A survey registration drive was initiated and it identified 107 persons with visual impairment in Bermuda. Based on this information it was estimated that the number of people who are visually impaired ranged from 107 to 295 as identified in the 1991 census.

In November 2008, the steering committee representing all of the partners and chaired by DOS Social Statistician, Melinda Williams, convened to oversee the survey project. Duties and responsibilities of representing members were agreed and the survey project commenced.

Visual Impairment was defined as follows:

**...one of these conditions that has lasted or will last, for more than six months: complete or partial blindness, being legally blind or registered as blind,...even if wearing corrective lenses<sup>2</sup>.**

<sup>2</sup>Definition is adapted from the definition developed by the Washington Group on Disability Statistics.

With this criteria, the survey targeted individuals with visual impairment in both households and institutions. Participation in the survey was voluntary and information was obtained through self reporting. Interviews were conducted either via telephone or in person. Ninety-five people responded to general and targeted community-wide recruitment efforts conducted between March and May 2009. Of these, 90 were eligible to participate with 69 having completed the survey by its conclusion in October, 2009. A summary of the results of the survey of these 69 persons are presented in the findings of this report<sup>3</sup>.

<sup>3</sup>The numbering of the tables, in this report, is specific to this report.



## Findings of the Visual Impairment Survey

For ease of reference the summary of the findings, listed below, is presented under six categories — Demographics on Respondents, Impairment Specifics, Impact of Loss of Vision, Coping with Visual Impairment and Promoting Independence, Satisfaction with Services and Needed Improvements to Resources. It should be noted, in order to protect the confidentiality of respondents, that findings of the survey that reflect the answer of less than five respondents are indicated by the less than symbol, “<” , in the charts in this report.

### Demographics on Respondents

A wide range of demographic information was collected by the survey team and 12 characteristics are reported on in this report, including age, racial identity and financial status.

#### Age

The majority, 58%, of participants in this survey were retirement age, 65 years, and older. Thirty, or 75%, of the seniors who participated in the survey were over the age of 75 (sometimes referred to as old-old by sociologists), while 10 (25%) were between 65 and 74 years of age (what sociologists call young-old).

#### Gender and Religious Affiliation

Generally there was no significant difference between the numbers of males and females who participated in this survey or finding related to religious affiliation.

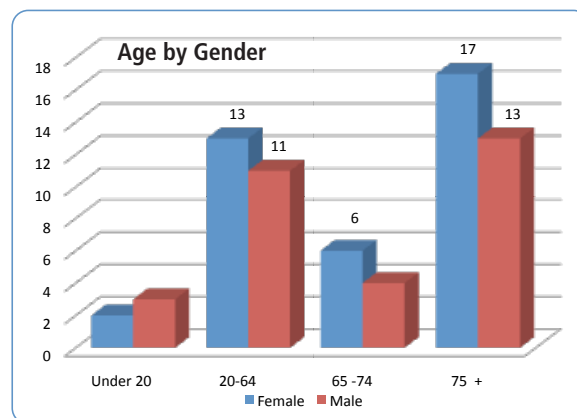
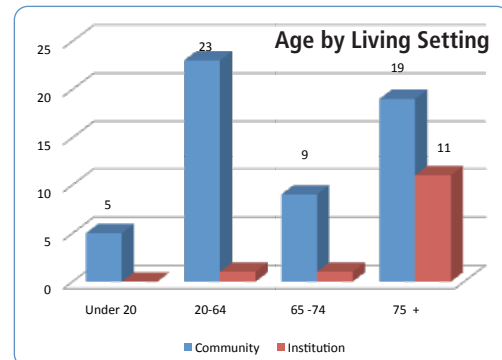
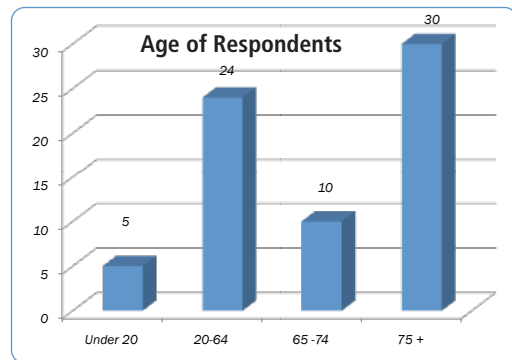
#### Living Setting

Eighty-one per cent of participants, or 56 persons, were living in the community at the time of the survey and 19% of participants or 13 persons were living in institutions.

**Table 1: Age of Respondents by Gender and Living Setting**

	Total	Community	Institution	Female	Male
Respondents	69	56	13	38	31
Under 20	5	5	<	<	<
20-64	24	23	<	13	11
65-74	10	9	<	6	<
75 +	30	19	11	17	13

## Respondents in the National Survey of People who are Blind/Visually Impaired



### Marital Status

At the time of the survey, 70% of the participants (55 persons) were unmarried. It should be noted that the majority, (69% or 44 persons), of the respondents who were 15 years and older were or had been married at some stage of their lives.

### National Origin

Nearly all, 99%, of the participants in the survey were Bermudian.

### Racial Identity

Seventy-four per cent of participants reported a black racial identity, with an additional 5% reporting themselves to be black and white or black and other (totalling 55 persons). Nineteen per cent of participants, 14 persons, reported a white or other racial identity.

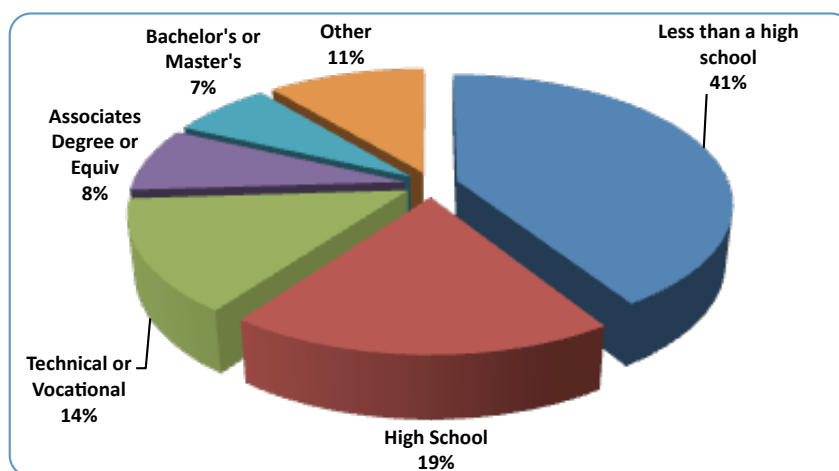
### Education

Fourteen per cent or 10 of the respondents in this survey identified themselves as students currently enrolled in an educational institution. Of the respondents who were 16 years or older:

- 41% have less than a high-school education.
- 19% reported having a high school certificate.

- 14% have a technical or vocational college certificate.
- 8% reported having achieved an associate's degree or Bermuda College diploma or senior matriculation.
- 7% indicated that they had achieved a bachelor's or master's degree.
- 11% have attained other academic qualification for example qualifying certificates.

### Highest Academic Qualification



### Employment

Fifty-one of the community-based respondents, 16 years and older, were asked about their employment status for the week of 31 May through 6 June 2009. Thirty-five per cent of these respondents were retired, 27% were working for pay, 6% were doing voluntary work, and 8% were engaged in home duties. Twelve per cent of the respondents were seeking employment and 11% reported being unable to work.

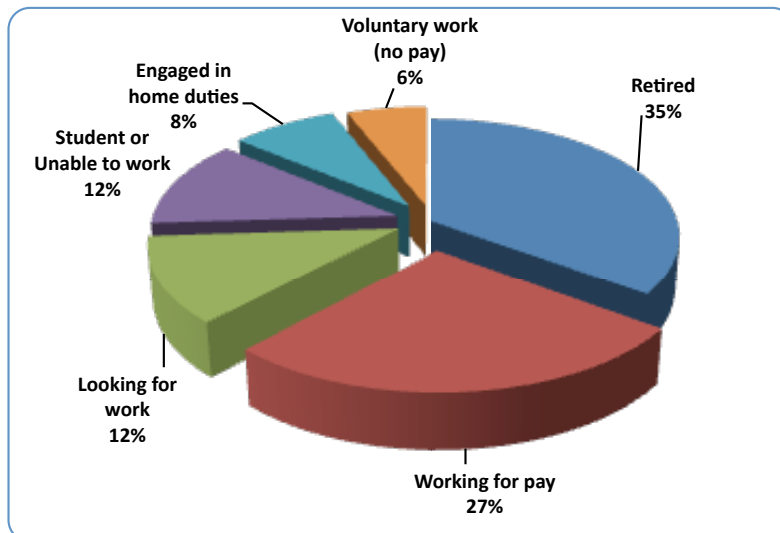
While 16 of the respondents over the retirement age of 65 reported being retired, 38% reported working either for or without pay.

**Table 2: Employment Status of Participants 16 Years and Older**

Employment Status	Total Community Respondents 16+ years
Total <sup>4</sup>	100%
Retired	35%
Working for pay	27%
Looking for work	12%
Student or Unable to work	12%
Engaged in home duties	8%
Voluntary work without pay	6%

<sup>4</sup> Percentages in this and other tables are always rounded off to the nearest whole number.

## Employment Status of Participants 16 Years and Over



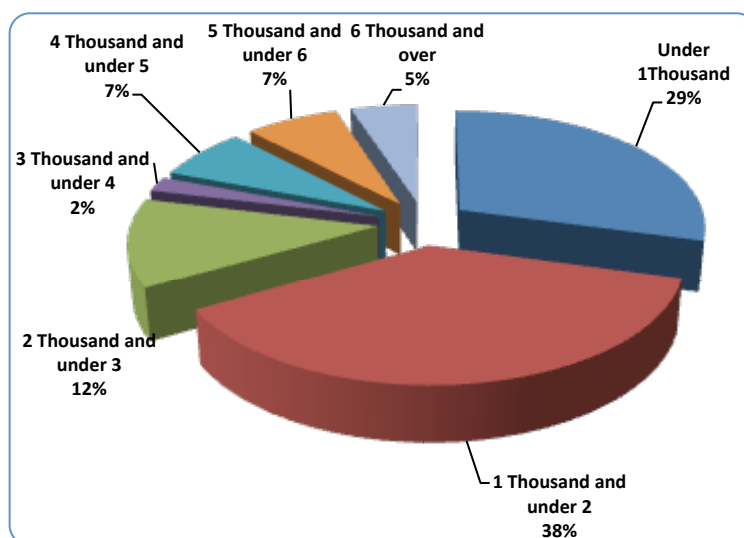
## Financial Status and Health Care Services

Eighty-eight per cent of the participants who are visually impaired and who reside in the community earn less than \$58,000 per annum, the median individual income earned from a main job in Bermuda. Twenty-nine per cent earn less than \$12,000 per annum (\$1,000 per month); 66% earn less than \$24,000 per annum (\$2,000 per month) and 78% earn less than \$36,000 per annum (\$3,000 per month). Twelve per cent reported an income of \$60,000 and above per annum (\$6,000 or more per month).

**Table 3: Amount of Income**

Amount in Thousands \$/per month	Total
Total	100%
Under \$1,000	29%
\$1,000 and under \$2,000	37%
\$2,000 and under \$3,000	12%
\$3,000 and under \$4,000	2%
\$4,000 and under \$5,000	7%
\$5,000 and under \$6,000	7%
\$6,000 and over	5%

## Monthly Income in Thousands



It should be noted that 66% of the respondents to this question have a monthly income of less than \$2,000.

## Sources of Income

A majority, 55%, of respondents reported receiving income from a Government pension, while 10% reported income from an occupational pension. Twenty per cent of participants received income from a principal occupation and 19% confirmed income from financial and/or disability assistance. Twelve per cent of respondents reported that they receive rental income. Other sources of income included relatives, religious organizations, trust funds and war veteran benefits.

**Table 4: Sources of Income\***

Sources	% of Responses	Total Responses
Total	138%	99
Government pension	55%	38
Principal occupation	20%	14
Other **	22%	15
Rent	12%	9
Occupational pension	10%	7
Financial /Disability assistance	19%	13
None	<	<

\* This is a multiple response question so the total is higher than the total number of respondents

\*\*Other — trust funds, veteran benefits, relatives, charitable source

## Insurance and Ability to Pay for Health Care Services

Respondents were asked about the type of health insurance they had and whether they had difficulty paying for medical services or services related to their visual impairment..

Fifty-four per cent of the participants reported having major medical insurance and 26% reported having FutureCare. Fourteen per cent of the respondents indicated that they had basic health insurance coverage, while 6% either had no health insurance coverage at all or did not state if they had health insurance.

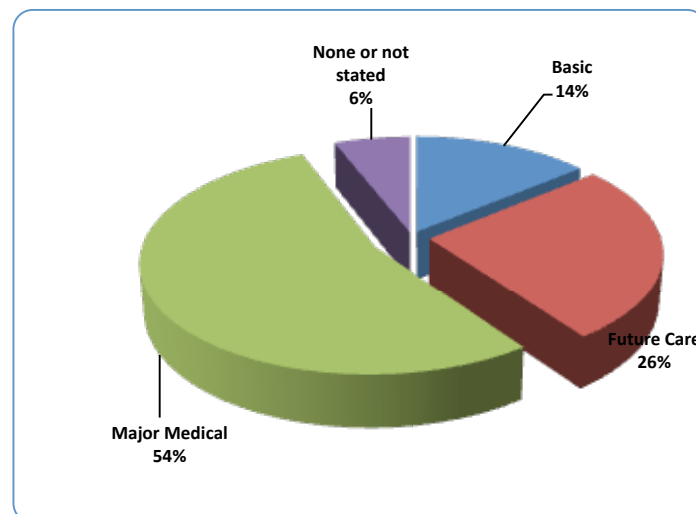
**Table 5: Type of Health Insurance**

Type of Health Insurance	Total
Totals	100%
Basic	14%
Future Care	26%
Major Medical	54%
None or not stated	6%

Twenty per cent of the survey respondents indicated that they had difficulty paying for medical services and 20% indicated that they had difficulty paying for services related to their visual impairment.

Participants with major medical insurance reported the greatest ability to pay for medical services. Fifty per cent of community respondents with basic health insurance reported difficulty paying for services related to their visual impairment. This compared with 31% of respondents with FutureCare, 12% of those with major medical, and 67% of those with no health insurance who reported difficulty paying for services related to their visual impairment.

## Type of Health Insurance



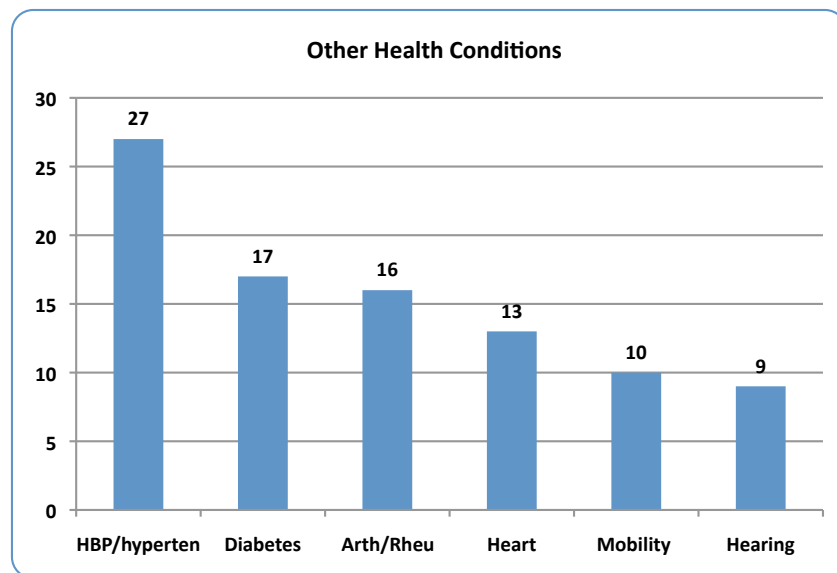
### Other Health Conditions

Overall, 53, or 73%, of respondents reported having other health conditions. This reflects the average between 71% of the community respondents and 100% of the institutional respondents. The top six additional health conditions faced by respondents include HBP/hypertension, diabetes, arthritis/rheumatism, heart conditions, moving/mobility difficulties, and hearing difficulties and deafness. The incidence for each of these conditions is represented in Table 6 below.

**Table 6: Top Six Other Health Conditions**

Incidence in Participants		% of Participants
Totals	92	134%
HBP/hypertension	27	39%
Diabetes	17	25%
Arthritis/Rheumatism	16	23%
Heart conditions	13	19%
Moving/mobility difficulties	10	15%
Hearing difficulties/Deafness	9	13%

### Top Six Other Health Conditions



It is noteworthy that hypertension and diabetes, the top two most frequently reported “other health conditions” in our survey, are both linked to eye problems in the form of hypertensive retinopathy and diabetic retinopathy, respectively.

Fifteen of the workforce age respondents reported other health conditions, with the onset of these conditions mostly occurring during the fifties. Twenty-two of the retirement aged respondents reported the occurrence of other health conditions. This is consistent with the reality that as people get older they will experience more health problems.

### Multiple Disabilities

Significantly, 38% of all respondents (26 respondents) indicated that they had other conditions which limited their activities of daily living in some way other than the impact of their visual impairment. It is noteworthy, that 17% identified hearing difficulties or deafness as one of these conditions. This is particularly challenging because of the higher complexity involved in rehabilitation services and support for people with both visual and hearing loss, depending on the extent of each.

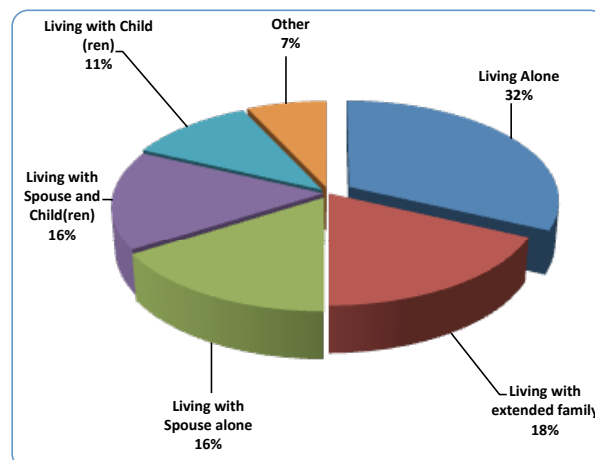
Given the above, persons with multiple disabilities will need special support in coping with these conditions as well as their visual impairment.

### Living Arrangements and Housing

A majority of the community-based respondents, 61%, reported living with other people; including 32% who reported living with their spouse and or children. An equal amount, 32%, reported living alone in the community.

**Table 7: Living Arrangements in Community**

Living arrangement	Total
Total	100%
Living Alone	32%
Living with extended family	18%
Living with Spouse alone	16%
Living with Spouse and Child(ren)	16%
Living with Child(ren)	11%
Other	7%





## Living Arrangement in Community

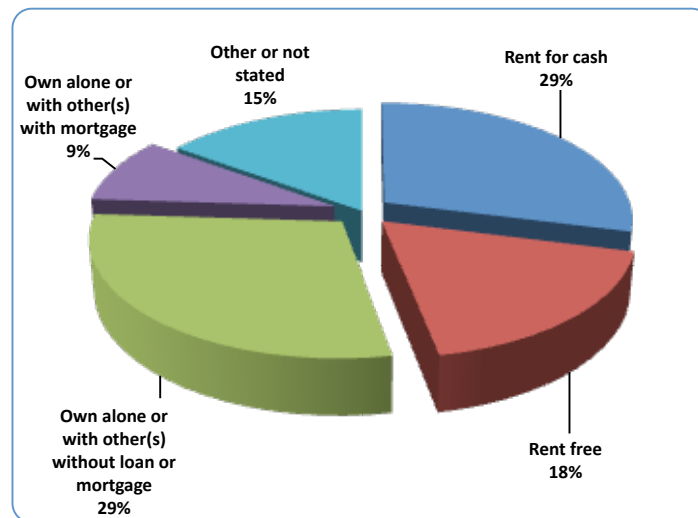
Forty-seven per cent of the respondents based in the community rent the accommodations in which they live, while 38% reported owning the premises they reside in either alone or with others.

Twenty-nine per cent reported no mortgage or loan and 9% of home owners in this survey reported owning with a mortgage or loan.

**Table 8: Housing Status**

Ownership/Renter	Total
Total	100%
Rent for cash	29%
Rent free	18%
Own alone or with other(s) without loan or mortgage	29%
Own alone or with other(s) with mortgage	9%
Other or not stated	15%

## Housing Status



## Impairment Specifics

Survey participants were asked questions about impairment specifics, which cover the nature, age at onset, cause and impact of impairment. The findings for these specifics follow.

## Nature of Visual Condition

Most participants, 57%, reported being impaired or partially blind<sup>5</sup>. Twenty-three per cent reported being legally or registered blind. Seventeen per cent of the respondents in this study reported being completely blind. Nine per cent reported colour blindness and seven per cent reported night blindness. There was no discernible pattern between difficulty seeing with the right eye versus the left eye.

**Table 9: Type of Visual Impairment(s) \***

Type of Visual Impairment	Total
Visually impaired/partially blind	39
Legally/registered blind	16
Complete blindness	12
Other **	8
Colour blindness	6
Night blindness	5

\* Multiple response items so total number of responses is higher than sample size because respondents could have had more than one of the listed options.

\*\*Other responses included 'unsure', 'only have sight in one eye', and 'see flashes of light'.

## Age at Onset of Visual Impairment

Data from this survey related to the age of onset of visual impairment indicates that there are three peak periods when people are more likely to lose their vision — during their seventies (19%), between birth and five years of age (17%), and during their fifties (13%). It should be noted that:

- 54% of the participants lost their vision after the age of 50
- 23% became impaired by the age of 10
- 26% were impaired by the age of 20

This data highlights the importance of providing support during education years and as persons approach their senior years.

## Cause of Visual Impairment

The five leading causes of visual impairment, as described by respondents, are: glaucoma 35%, cataracts 27%, macular degeneration and diabetic retinopathy 13%, and trauma due to accidents or violence 10%. Of the remaining conditions, 19% were congenital or hereditary conditions.

<sup>5</sup>See the Glossary attached for the definition for the various visual conditions.

Cataracts, which are treatable, are the leading cause of visual impairment worldwide and the second leading cause in this Bermuda sample. The other identified causes are either preventable or their impact can be significantly decreased with early detection, treatment/management and lifestyle changes.

**Table 10: Causes of Visual Impairment**

<b>Diagnosis</b>	<b>Total</b>
Total Responses	85
Glaucoma	24
Cataracts	18
Diabetic retinopathy	9
Macular degeneration	9
Accidents, violence, trauma	7
Congenital conditions of the retina	6
Corneal scarring	5
Congenital conditions of the cornea	<
Hereditary conditions of the retina	<
Other hereditary conditions	<

### **Impact of loss of vision on Activities of Daily Living (ADL)**

Sixty-four per cent of participants indicated that they were prevented or limited in their activities of daily living as a result of visual impairment. Eighty-four per cent of the respondents reported that they required assistance of some type for their visual condition. Sadly, a small number of participants, living as dependent shut-ins, reported that the loss of their vision impacts “everything”.

In addition to these global responses, participants provided information regarding specific areas of life functioning and activities of daily living as follows:

#### **Health**

Most of respondents, (89%), indicated that their visual impairment did not affect their access to medical services.

#### **Education**

Thirty-eight per cent of the respondents indicated they required educational assistance because of their visual impairment and most of these said they needed this assistance daily. Seventy per cent of student participants reported that they required educational assistance on a daily basis.

## **Employment**

Of the 56 community respondents, 54% did not think their visual condition prevented them from working. However, 52% of the respondents, reported limitations to the kind or amount of work in which they could engage.

## **Mobility and Transportation**

Survey participants were asked whether their visual condition limited or prevented them from leaving home alone.

- 21% of respondents reported navigating without assistance.
- 53% of all respondents thought their visual condition **prevented their leaving home alone.**
- 85% of institutional participants and 63% of community-based participants said that they required **transportation assistance**

## **Recreation**

Sixty-one per cent of the survey participants indicated that they were prevented or limited in their recreational activities. Interestingly, this area of living was the one that the highest number of participants reported difficulty.

## **Comparisons of Impact between Home/Community and Institution Living**

The impact of loss of vision on activities of daily living will differ for those living at home, in the community, and those living in an institution. Comparisons related to community and institutional living are presented below.

### ***Community Living***

The data from community participants indicated that the top three areas where visual impairment limits or prevents activities of daily living are:

- The kind/amount of work (66%).
- Every day life activities (55%).
- Recreational activities (55%).

Only 7% noted the impact of their visual impairment on their personal hygiene and getting around their home alone. This was the least reported area of impact.

### ***Institutional***

By far the majority of institutional participants indicated that their visual impairment limits or prevents activities of daily living in most areas, ranging from 77% to 100% in everyday life activities, kind/amount of activities at home and being able to leave home alone (see Table 11). The area least impacted is their ability to take care of their personal needs and get around in the area that they live (46%).

**Table 11: Visual Impairment Limits or Prevents Activities of Daily Living**

Limits/prevents Activities of Daily Living	Total		Community		Institution	
	Yes	No	Yes	No	Yes	No
Everyday life activities	64%	36%	55%	45%	100%	0%
Recreation activity	61%	39%	55%	45%	85%	15%
Limit kind/amount work	52%	26%	64%	32%	NA	NA
Prevent leaving home alone	52%	48%	41%	59%	100%	0%
Other limits*	51%	49%	45%	55%	77%	23%
Kind/amount activity at home	51%	49%	39%	61%	100%	0%
Prevent work	33%	44%	41%	54%	NA	NA
Caring personal needs/get around in home	14%	86%	7%	93%	46%	54%

## **Coping with Visual Impairment and Promoting Independence**

Participants were asked about assistance (human and technological), training and service utilization to cope with visual impairment and to promote independence.

### **Assistance to Cope with Visual Impairment**

For the purposes of this survey assistance was broadly defined to encompass human assistance as well as assistance from adaptive devices

- 84% of the respondents reported requiring assistance of some type.
- 31% of the community respondents and 85% of those in institutions said they were receiving the necessary assistance.

### **Human Assistance**

Of the 45 community participants who indicated that they required assistance (see Table 12), 78% indicated that they needed assistance with transportation. Additionally, 51% identified the need for assistance with reading personal correspondence and shopping. For those who reported requiring assistance (other than transportation), most needed it more than once a week or daily for most activities. Community-based participants indicated that the majority of the assistance they received came from family or friends. Very few reported receiving help from professionals. None of the respondents reported assistance from volunteers.

- 74% of the respondents stated that family, friends or paid professionals assisted them to get around in the community.
- 32% reported using public transportation.
- 21% reported navigating without assistance.

All of the institutional participants indicated that they required assistance. Most of the institutional participants reported requiring daily assistance for the majority of the identified activities of daily living. Institutional respondents reported primarily receiving the assistance they required from professional health care workers and family, while friends assisted especially with transportation.

**Table 12: Respondents Requiring Assistance (Person/Technology)**

Assistance required	Total	Community	Institution
Yes	58	45	13
No	11	11	<

### **Technological Assistance**

Technological assistance was defined broadly in the survey to mean a wide range of technology including talking watches, talking calculators, talking scales, closed circuit televisions with magnifiers built in, computer screen enhancers and screen reader programs (see glossary for examples of technology).

- 41% of all participants had received training in the use of adaptive or assistive technologies.
- 39% of respondents reported knowing how to use a computer, but only 15% reported having access to an adaptive computer (i.e. with screen enlargers or readers).
- Audio literature is being used by 54% of institutional respondents and 29% of community respondents.
- Institutional respondents used no other reading aids, but 54% of community respondents used large print or other aids (low vision glasses, CCTV and the KNFB<sup>6</sup> reader). Adaptive computer equipment is being used by 14% of the community respondents.
- Only one respondent reported using Braille.

Interestingly, only 20% of community respondents reported requiring assistance from adaptive or assistive technology which does not match the higher number who reported needing help reading personal correspondence. This is a discrepancy that merits further investigation.

### **Training to Cope with Visual Impairment**

To investigate the matter of training to promote independence, participants were asked whether they had received training that is specifically designed for people with

<sup>6</sup>KNFB — refers to the Kurzweil National Federation for the Blind (see Annex I).

visual impairment. Specifically designed training would include teaching in adaptive technologies, rehabilitation services, mobility instruction, job training and instruction in Braille.

- Less than half of the participants had received any of this training (41%):
  - o 30% reported training in the use of adaptive technologies (the most frequently).
  - o 13% reported receiving mobility instruction.
  - o 12% reported having received rehabilitation services and training in Braille.
  - o 7% reported receiving job training.

In reviewing the data on the use of technological assistance, it was noted that there was no technology for which training was provided to a majority of the participants in order to mitigate their visual impairment. Further, only a very few participants had received a full range of training to promote independence. Comprehensive training, which means a full range of training for persons with visual impairment, is not available here in Bermuda. Given this, therefore, persons with visual impairment are more dependent than need be on help from others, like family, friends and professionals, most notably for mobility (using cane, service animal, etc) and reading.

**Table 13: Training to Cope With Visual Impairment**

Total Respondents	69
No training	41
Received Training	28
<b>Type of Training Received*</b>	
Total Responses	Less than 56
	Totals
Braille	8
Assistive/adaptive technology	21
Mobility instruction	9
Rehabilitation services	8
Job training	5
Other	<

\*Multiple response question and response totals could equal number of participants if everyone received at least one training

## **Organizational Services to Cope with Visual Impairment**

Aspects of habilitation and rehabilitation services, have been provided inconsistently over the years either through Government or charity services. These services are critical

since they provide, among other things, life skills training and promote independence.

The majority of participants, 59%, reported that they had not received training to cope with their visual impairment. Most of those who had received training had not received a full range of training that could lead to near or full independence and self sufficiency.

**Table 14: Received Services From Local Organizations**

Organization	Community		Institution		Not Stated
	Yes	No	Yes	No	
Total of Responses	41	253	6	60	<
Society for the Blind/Beacon House	5	51	<	12	<
NOSPC	<	53	<	13	<
Teacher for the Visually Impaired	8	48	<	13	<
LCCA	<	52	<	11	<
Lions Club Sight Conservation Fund	7	48	<	11	<
Other	15	<	<	<	<

### **Satisfaction with Services Received and Needed Improvements**

Overall, there was a noticeable difference between institutional and community-based participants in the levels of satisfaction with the services received. Sixty nine per cent of the community-based participants and 15% of institutional reported that they did not receive the required assistance.

Generally, when services were received the institutional recipients had positive satisfaction level. For the most part, community recipients reported a positive or neutral or above level of satisfaction for services received.

Participants were asked to indicate what services they would use from a list of services typically considered to foster independence in people with visual impairments. The results follow:

- The most endorsed service by all respondents was audio literature, with 77% of both institutional and community-based respondents stating they would use **audio literature**.
- The second most endorsed item was a **retail outlet** with products useful to people who are blind and visually impaired. While no institutional respondents said they would use such an outlet, 71% of the community-based respondents said they would.



- The third most requested service was a **low vision centre**, which was endorsed by 46% of institutional respondents; and 73% of community respondents, or 68% of all respondents.
- 70% of community respondents and 8% of institutional respondents expressed an interest in using **assistive or adaptive technology** (see Annex for examples of this technology).
- 32% of community respondents and 8% of institutional respondents expressed an interest in learning **Braille**.
- 29% of community and 15% of institutional respondents indicated an interest in **mobility instruction**.
- 25% of community and 8% of institutional respondents expressed an interest in using **rehabilitation services** if they were offered.
- The other services that participants mainly expressed an interest in include:
  - o transportation for the blind.
  - o services that would build confidence levels in children with visual impairment.
  - o employment and other rehabilitation services.

**Table 15: Would Use Service If Offered**

Service	Respondents	% Participants
Total Respondents	69	100%
Audio literature	53	77%
Low vision centre	47	68%
Retail outlet for assist/adapt tech & other equipment	40	58%
Assistive/adaptive technology	40	58%
Braille lessons	19	28%
Mobility instruction	18	26%
Rehabilitation services	17	25%
None	6	9%
Other	6	9%

## Synopsis of the Findings

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There are three peak periods when people in Bermuda are more likely to lose their vision — between birth and five years of age, during their fifties and during their seventies. The five leading causes of visual impairment, as described by respondents to the survey, are: glaucoma, cataracts, macular degeneration, diabetic retinopathy and trauma due to accidents or violence. None of these five causes of visual loss are entirely preventable. However incidence rates can be reduced through:

- routine eye examinations, early detection and treatment for glaucoma.
- effective protection of the eyes from harmful ultraviolet rays for cataracts and macular degeneration by:
  - prevention programmes and lifestyle change for diabetic retinopathy,
  - prevention strategies —directed at averting accidental eye injuries and promoting the use of eye protection in high risk recreational activity and occupations — and anti violence strategies to address eye trauma resulting from violence.

The profile of the respondent in the Survey indicates that he or she is more likely impaired or partially blind, and an older black Bermudian living in the community and possibly living with someone. More than a third of the respondents do not have a high school leaving certificate and although likely to be employed and/or receiving a pension, they are significantly less likely to earn a median income of \$58,000 or higher, per year. Although most respondents do not think that their impairment prevents them from working, they believe that they are limited in the kind and amount of work that they can do.

**Effective targeted public health strategies focusing on the peak periods of the onset of visual impairment could reduce both the frequency and severity of visual impairment in Bermuda**

**Financial independence is linked to both educational achievement and income. This therefore must be one of the goals of policies and interventions directed to persons with visual impairment.**

None of the institutional respondents, and only some of the community-based respondents, thought that their visual impairment affected their access to medical services. Almost all of the participants had some kind of insurance with major medical being the most popular. Participants with major medical insurance reported the greatest ability to pay for medical services. Twenty per cent of the survey respondents indicated that they had difficulty paying for medical services and 20% indicated that they had

difficulty paying for services related to their visual impairment.

Proper assessments and strategies to meet the individual needs, including recreation and transportation, would insure appropriate service and use of professionals, friends and family as well as volunteers.

A significant number of respondents to the survey have multiple disabilities and other health problems like hypertension, diabetes and hearing loss. This is particularly challenging because of the higher complexity involved in rehabilitation services and support for people with both visual and hearing loss, depending on the extent of each.

**Adequate insurance and a continuum of services should be available for persons with visual impairment to ensure quality of care regardless of complexity of need.**

People with visual impairment can benefit from three types of assistance (human, technological and organizational) in order to help them cope with their impairment. Most visually impaired respondents require various types of assistance in their daily living depending on:

- the level of their impairment;
- the amount of training received to cope with their impairment;
- their living conditions;
- the presence of other health conditions; and
- their age and stage of life.

The Survey found that the majority, 64%, of all participants reported that they are prevented or limited in their everyday life activities. Institutional participants mostly reported requiring daily assistance for the majority of the activities of daily living about which the survey inquired. This may reflect the criteria for admission to the institution. In contrast, most of the community participants indicated that they did not need assistance with their daily activities, with the exception of reading personal correspondence, shopping and transportation, which was also identified by institutional respondents. Educational assistance was also identified by students as a need.

Most of the respondents thought their visual condition prevented their leaving home alone. Only a minority seem able to utilize public transportation and independent methods of mobility (i.e. white cane or service animal) leaving the majority of the people with visual impairments dependent with respect to mobility and transportation.

Community-based participants said the majority of the assistance they received came from family plus friends. Very few reported receiving help from professionals. Neither community nor institutional respondents reported receiving assistance from volunteers.

**Proper assessments and strategies to meet the individual needs, including recreation**

**and transportation, would promote independence and ensure appropriate service and use of professionals, friends, family and volunteers.**

Less than half of the participants had received training specifically designed for people with visual impairment. A majority of those persons indicated that the training was not comprehensive. A minority received training in the use of adaptive or assistive technologies and a similar minority reported knowing how to use a computer. Survey data leads to the conclusion that even the minority of people with visual impairments who receive training, do not appear to be receiving a full range of training.

**Persons with visual impairment should have access to full range of services — habilitation/rehabilitation services, rehabilitation, counselling; mobility instruction and orientation. These services would include training to maximize independence and the use of technology and human assistance for functions that cannot be accomplished independently.**

Aspects of habilitation and rehabilitation services have been provided inconsistently over the years either through Government or charity services. Training and access to assistance is generally provided by organizations with expertise in working with people who are visually impaired. Very few participants reported having utilized any of these services. That notwithstanding, those who reported using the services cited the Lions Club Sight Conservation Fund, the Ministry of Education, LCCA<sup>7</sup> and BSFB as the most frequently used. It should be noted that many useful services were not accessed by persons with visual impairments. However those who used services from various organizations indicated that, generally, they were satisfied with the services received.

**Individual service plans would identify service needs, promote coordination and monitor the impact of service intervention for persons with visual impairment. This policy could not only promote the use of available service but also could be used to identify corrective actions required to ensure the effectiveness of service to persons with impairments.**

When questioned, the top six services that participants said that they would use relate to audio literature, retail outlet, low vision centre, assistive or adaptive technology, Braille, mobility instruction and rehabilitation. Interestingly, the Bermuda Public Library provides audio literature as part of its lending libraries. Additionally, the Bermuda International Eye Institute, in conjunction with Lighthouse International has offered a low vision centre for five years.<sup>8</sup> Given that both of these can greatly enhance independence, we must encourage persons with visual impairment to take advantage of all of the resources at their disposal and resolve any issues that prevent the use of the services.

**A public awareness campaign could alert the impaired to the scope of services offered and associated benefits, help to foster use and minimize any miscommunication and misunderstanding that may exist.**

<sup>7</sup>LCCA is the acronym for the Lady Cubitt Compassionate Association.

<sup>8</sup>This finding and others related to income need further exploration.

## Why Improve Response to Persons with Visual Impairment?

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The World Health Organization (WHO) indicates that 100 years ago, people with visual impairment were condemned to a life of confinement and institutionalisation. It was rare for visually impaired people to become educated, employed or live an independent life. They were seen as helpless and a burden.

Over the years the battles to achieve equality and non-discrimination led in 1999 to a global initiative known as 'VISION 2020: the Right to Sight'<sup>9</sup>. This initiative established a partnership between the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB). The specific aims of Vision 2020 are to eliminate avoidable blindness and prevent the projected increase in avoidable visual impairment by the year 2020. In the WHO Action Plan, 2009–2013, which focuses on the prevention of avoidable blindness and visual impairment, five objectives were identified. Countries of the world were asked to adopt this plan and to take steps to:

1. Strengthen advocacy to increase political, financial and technical commitment in order to eliminate avoidable blindness and visual impairment.
2. Develop and strengthen national policies, plans and programmes for eye health and prevention of blindness and visual impairment.
3. Increase and expand research for the prevention of blindness and visual impairment.
4. Improve coordination between partnerships and stakeholders at national and international levels for the prevention of blindness and visual impairment.
5. Monitor progress in the elimination of avoidable blindness.

These objectives can serve as a guide for the development of strategies to address visual impairment here in Bermuda.

As Baby Boomers continue to age, the problem of visual impairment among older people will increase dramatically. Currently, Canada is experiencing an unprecedented surge in age-related blindness with one in four Canadians over the age of 75 developing irreversible vision loss.

Vision loss is a major cause of frailty and resultant risk in the elderly. "Recent research in Australia shows that elderly people with vision loss are admitted to nursing homes on average three years earlier than those without vision loss. Their risk of falls is twice as high, their risk of depression three times as high, and their risk of hip fracture — a

<sup>9</sup> <http://vision2020.org/main.cfm>

leading cause of death in the elderly — is four times as high. Worst of all, their risk of death is twice as high.”<sup>10</sup>

From the point of human rights and the assurance of the quality of life for people who are visually impaired, it is incumbent on Bermuda to establish both prevention and intervention programmes. These programmes will improve the education and employment options for persons with visual impairment and positively impact their health and health costs at earlier years.

Individuals and the community as a whole will reap the benefit of prevention and intervention strategies focused on persons with visual impairment.

<sup>10</sup>Impact of vision loss higher than you think - <http://www.costofblindness.org/media/media2.asp>

## **Recommendations from the Survey of Persons who are Blind/Visually Impaired**

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The following recommendations are put forward to further the UN initiative (to eliminate avoidable blindness and prevent avoidable visual impairment) and reflect the findings of the National Survey of People who are Blind/Visually Impaired, 2009. Bermuda should:

- Identify and implement strategies to promote the independence, including financial, of persons with disabilities.
- Develop and implement prevention and mitigation strategies, according to trends, to reduce incidence of visual impairments or to reduce the level of severity where it has occurred. Attention should be given to persons with multiple disabilities which compound the impact of their visual impairment. BSFB should coordinate prevention strategies and activities with groups likely to have a vested interest in these efforts.
- Provide a full range of services, including proper assessment and case management, and a continuum of care across the lifespan, for people who are visually impaired. This would begin when people are first identified as being visually impaired and include a service plan. Appropriate services, reflected in the individual service plan, would be available from the initial intensive period of assessment and training and then be adjusted as needed throughout life.
- Continue to provide support, through the Ministry of Education, for the education of children and adolescents with visual impairment by providing a teacher dedicated to meeting the educational needs of students who are visually impaired.
- Mount a PR campaign, including a newsletter, with the help of service providers to get information out to persons with visual impairment about the availability of resources, services and other supports to impact their visual impairment.
- Provide training tailored to family, friends, employers, teachers, professional caregivers, etc. on a regular or on-going basis to maximize independence while providing necessary support.
- Educate, train and promote access to assistive technology for people who are visually impaired in order to promote independence.
- Provide mobility instruction, orientation and assistance with transportation for persons who are visually impaired to promote independence and accessibility.
- Establish a Register for Persons who are Visually Impaired and gather basic

information that will assist in policy development and service provision.

- Expand the research done on people with visual impairment and use additional methods of data collection like the census, a register for the visually impaired and utilization surveys in order to clarify some of the anomalies identified and continue to monitor the quality of life of people with visual impairment in Bermuda.



# ANNEX I

## Terminology and Information Related to Visual Impairment

### VISUAL IMPAIRMENT

As indicated by the World Health Organization (WHO), the term visual impairment comprises mild or no visual impairment, moderate visual impairment, severe visual impairment, blindness and a category for unqualified visual impairment. The term “low vision” has been incorporated under moderate and severe visual impairment in order to avoid confusion with those requiring low vision care.

An explanation of the categories of visual impairment and charts to explain the visual impairment range is presented below.

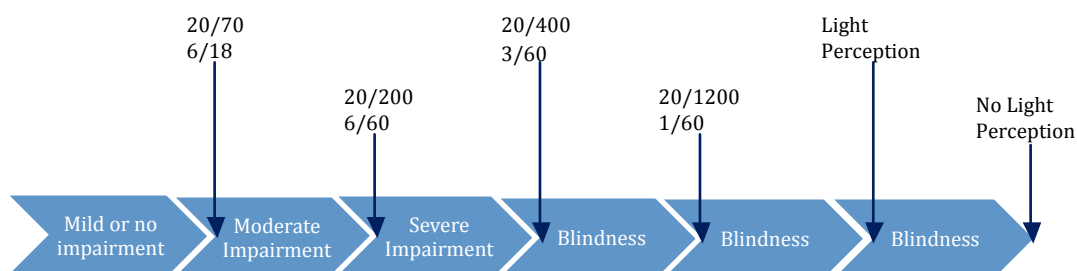
### World Health Organization – Categories of Visual Impairment ICD<sup>11</sup> 10 Version 2010

Presenting Distance Visual Acuity		
Category	Worse than:	Equal to or better than:
Mild or no visual impairment 0		6/18 3/10 (0.3) 20/70
Moderate visual impairment 1	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.1) 20/200
Severe visual impairment 2	6/60 1/10 (0.1) 20/200	3/60 1/20 (0.05) 20/400
Blindness 3	3/60 1/20 (0.05) 20/400	1/60* 1/50 (0.02) 5/300 (20/1200)
Blindness 4	1/60* 1/50 (0.02) 5/300 (20/1200)	Light perception
Blindness 5	No light perception	
9	Undetermined or unspecified	

\* or counts fingers (cf) at 1 metre.

<sup>11</sup>Acronym for International Statistical Classification of Diseases Injuries and Causes of Death

## Categories of Visual Impairment



**MILD VISUAL IMPAIRMENT** – Visual acuity equal to or better than 20/70 (6/18)<sup>12</sup>.

**MODERATE VISUAL IMPAIRMENT** – Visual acuity worse than 20/70 but equal to or better than 20/200 (6/18 and 6/60).

**SEVERE VISUAL IMPAIRMENT** – Visual acuity worse than 20/200 but equal to or better than 20/400 (6/60 and 3/60)

## BLINDNESS

1. **BLIND** – This means sightless or unable to see and represents Category 3 or higher in the WHO chart above.
2. **LEGALLY BLIND** – This is defined as a visual acuity (vision) of 20/200 (6/60) or less in the better eye with the best correction possible. This means that a legally blind individual would have to stand 20 feet from an object to see it with corrective lenses with the same degree of clarity as a normally sighted person could from 200 feet. An alternative definition of legal blindness is visual field restriction to 20 degrees diameter or less (tunnel vision) in the better eye.
3. **PARTIALLY BLIND** – This is not a specific category and generally denotes persons with severe visual impairment.
4. **REGISTERED BLIND** – This is a person who has been assessed and given documentation to the effect that their level of visual acuity falls within the legally blind category.
5. **COLOUR BLINDNESS** – Colour blindness occurs when a person has a problem with identifying colours normally. This condition is usually inherited, but it may also occur because of brain or nerve damage or due to chemical poisoning. There are two major types of colour blindness. The most common type of colour

<sup>12</sup>20/70 means that the visually impaired person must stand 20 feet away in order to see what a person with normal eyesight would see from 70 feet away. In metres this would be expressed 6/18.

blindness results in difficulty in telling the difference between red and green. Blue and yellow colour deficiency is another type. In rare cases, a person may not be able to identify any colour. This is called achromatopsia.

- 6. NIGHT BLINDNESS** – This condition is due to impaired vision in dim light and in the dark due to a problem with the function of specific vision cells in the retina called rods. This abnormality may result from vitamin A deficiency.

**LOW VISION** – A person with low vision is one who has an impairment of visual functioning even after treatment and/or standard refractive correction (correction with glasses) and has a visual acuity of less than 6/18 to light perception or a visual field of less than 10 degrees from the point of fixation but who uses or is potentially able to use vision for planning and/or execution of a task.

## **TRAINING SERVICES FOR PERSONS WITH IMPAIRMENT**

- 1. MOBILITY TRAINING AND ORIENTATION** — When persons with vision loss receive orientation and mobility training, they are given the adaptive skills to move independently around their homes, neighbourhoods, and communities safely. They are also given the devices to further their mobile achievements. This includes cane training and safety skills needed for moving around the community and home. In addition, they are given the training to orientate themselves to living with vision loss.
- 2. REHAB COUNSELLING** — Rehab counselling is one of the major aspects of coping with vision loss. Persons with vision loss will be given the support needed to continue living independently and also discuss issues that arise while adapting to their daily living. Some forms of counselling include Supportive Family Counselling and self-help and support groups.
- 3. REHAB SERVICES** — Rehab Services are services that are provided to help persons with vision loss to adapt daily living skills and live independently. The rehab services spectrum is broad. Below is some of the services provided in this category.
  - A) ASSISTIVE TECHNOLOGY** — technological aids to assist those with vision impairments. These include magnifiers, talking devices, daily living aids, etc.
    - i. Talking Devices:** Talking devices are designed for people who are blind or with low vision. These talking devices ‘talk out loud’ and help people with limited sight. The latest low vision products including talking calculators, talking watches, and talking scales.

- ii. **CCTV:** A video magnifier or closed-circuit television (CCTV) system uses a stand-mounted or handheld video camera to project a magnified image onto a video monitor, a television (TV) screen, or a computer monitor.
  - iii. **Screen Reader Programs:** A screen reader is a software application that attempts to identify and interpret what is being displayed on the screen (or, more accurately, sent to standard output, whether a video monitor is present or not). This interpretation is then re-presented to the user with text-to-speech, sound icons, or a Braille output device.
  - iv. **Braille:** The Braille system is a method that is widely used by blind people to read and write, and was the first digital form of writing Braille was devised in 1825 by Louis Braille, a blind Frenchman. Each Braille character, or cell, is made up of six dot positions, arranged in a rectangle containing two columns of three dots each.
  - v. **KNFB Reader<sup>13</sup>:** This is a handheld electronic reading device for persons with visual impairment. It was developed in a partnership between Ray Kurzweil and the National Federation of the Blind. The original version of the reader was composed of a digital camera and a mobile personal information manager (PDA), which contained specialized optical character recognition software and speech synthesizers to read the scanned material aloud. The software was later ported to the Symbian operating system, to be used on Nokia N82 camera phones.
- B) CAREER AND EMPLOYMENT SERVICES** — gives persons with vision loss the vocational training and assistance needed to successfully find employment.
  - C) CHILD AND FAMILY SERVICES** — provides support for family members and caregivers of school-aged children who have vision loss.
  - D) COMPUTER TRAINING** — provides basic computer skills training, to persons with visual impairment, as well as training in the use of current computer software so that they can communicate independently..
  - E) INDEPENDENT LIVING TRAINING** — provides training in daily living skills like safe cooking and completing laundry tasks, in order to foster independent living.

<sup>13</sup>Definition of KNFB provided by Wikipedia [http://en.wikipedia.org/wiki/K-NFB\\_Reader](http://en.wikipedia.org/wiki/K-NFB_Reader)

## **DIFFERENCE BETWEEN HABILITATION AND REHABILITATION<sup>14</sup>**

There is an important difference between rehabilitation and habilitation services and devices.

**Habilitation Services**, which frequently relate to child/adolescent services, are provided in order for a person to attain, maintain or prevent deterioration of a skill or function never learned or acquired due to a disabling condition.

**Rehabilitation Services** and devices, on the other hand, are provided to help a person regain, maintain or prevent deterioration of a skill that has been acquired, but then lost or impaired due to illness, injury, or disabling condition.

<sup>14</sup>From the “Habitation White Paper” Habilitation Benefits Coalition <http://www.aapmr.org/advocacy/health-policy/federal-reform/Pages/define-rehab-services-devices-health-benefits-under-affordable-care-act.aspx>

## ACKNOWLEDGEMENTS

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Many people have assisted with this survey and we offer our sincere gratitude for all of their commitment and effort. First and foremost, we thank all of the participants and their families or friends, who called to register for the survey, for their participation and support. The keen interest expressed by all those who called was indicative of the enthusiasm with which people who are Visually Impaired (VI) and their loved ones desire support to cope with their visual impairment and remain included in the everyday life of our community.

We thank the former Minister of Culture and Social Rehabilitation, the Hon. Dale Butler, JP, MP for his assistance and sporting spirit by experiencing various forms of visual impairment in order to publicize the launch of the survey. We also thank his successor The Hon. Neletha Butterfield, MBE, JP, MP. Further, we are appreciative of the former Minister of Health, Walter Roban, JP, MP for his strong interest and support when the project moved to his Ministry. Thanks to The Hon. Zane De Silva JP, MP, Minister of Health, and to Kevin Monkman, Permanent Secretary of Ministry of Health, for their on-going commitment to this project

We also gratefully acknowledge the support of the former Director of Human Affairs, Dr. Myra Virgil and her successors, as well as Warren Jones, former Permanent Secretary for the Ministry of Health who ensured continuing support for this project when it transferred to his Ministry.

The staff of the National Office for Seniors and the Physically Challenged (NOSPC) Dr. Melvin Dickinson; former Manager of NOSPC; his successor, John Payne, Acting Manager; Ann Lindroth, Coordinator for Disabled Persons; Keith Simmons, Accessibility Officer; and Ciara Woolridge have been unflagging in their work towards the completion of this survey and are gratefully acknowledged for all of their efforts.

We are especially grateful for the technical support offered by the Department of Statistics staff —Valerie Robinson-James, Chief Statistician; Melinda Williams, Social Statistician; Vincent Williams-Savery, Assistant Statistician; Stephanie Corday, Assistant Statistician; and Andrew Robinson, Statistical Officer. We also appreciate the initial assistance of Crispin Boney, Research Statistician and assistance in editing, coding and keying the data from Jeanna-Dawn Trott and Kitwana Mendoza, Statistical Officers. Thank you to Craig Simmons, economics lecturer at the Bermuda College for his input regarding the financial status information.

We thank the previous Bermuda Society for the Blind (BSFB) Board, Brian Billings, Chair; Dudley Cottingham, Secretary; Jean Howes, Abuwi Rasool, Walter Stevens, Albert Thompson, Sherman Thompson and BSFB staff person, Lois Astwood for their initiative in pursuing this survey and their input throughout.

For reviewing early drafts of the questionnaire, the summary report and offering invaluable technical assistance we thank Marty Davis, Special Educator and former Teacher for the VI at the Ministry of Education; Dr. C. Julie Dunstan, Research & Evaluation Solutions, Bermuda; Dr. Leonard Teye-Botchway, Bermuda International Eye Institute; Ellen Mark and Benoit Allard, Statistics Canada; and members of the Washington Group on Disability Statistics.

We are grateful to Cindy Smith, President of the Bermuda Counsellors Association. Dr. Mellisa Gibbons-Tankard, past President of the Bermuda Psychological Association; and Miriam Shaya for publicizing our request for interviewers. We are very grateful to the dedicated group of interviewers who conducted the survey interviews, namely, Daneika Bean, Gwen Bean, Verdelle Dill, Dr. Mellisa Gibbons-Tankard, Charmaine Richardson, Lynn Wade and Dr. Amanda Marshall.

We thank the staff at the Department of Communication and Information, especially Jamie McDowell, for their assistance in publicizing the survey. We also thank the publicity assistance received from Jean Howes, Sherman Thompson, Pauleter Stevens, Phyllis Harshaw, Douglas Gilfether, Bermuda Optical Company; Maureen Marshall, Hamilton Lions Club; Brian Henschel, Teacher for the VI at the Ministry of Education; and Stephen Davis and Miss. Cooper's P7 Class at West End Primary School.

Thanks to the Ministry of Education, Director of Student Services, Joanne Smith; to the Health Officer at the Department of Corrections; and to Debbie Cottingham; Hamilton Lions' Pre-school Sight Screening, Lady Cubit Compassionate Association (LCCA), Lions Club Sight Conservation Fund, for providing useful information from their programmes.

We thank Dr. Mellisa Gibbons-Tankard, Kristina Bean, Siobhan Brennan and Maureen Marshall for their invaluable assistance with completing the survey report. We especially thank consultant Luelle Todd for completing the Summary of Findings.