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# Stakeholder-driven approach to optimizing access to low vision rehabilitation services in Massachusetts

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BOSTON UNIVERSITY  
SCHOOL OF PUBLIC HEALTH

Dissertation

**STAKEHOLDER-DRIVEN APPROACH TO OPTIMIZING ACCESS TO  
LOW VISION REHABILITATION SERVICES IN MASSACHUSETTS**

by

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Submitted in partial fulfillment of the  
requirements for the degree of  
Doctor of Public Health

2018

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## **DEDICATION**

To my husband, Casey, and children, Tyler, Tristan and Nolan,  
Thank you for all the support, understanding and love.

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**ABSTRACT**

**Background:** Visual impairment impacts over 15% of Americans over the age of 65, roughly 7.3 million people. Currently there is no statewide model for low vision rehabilitation services that serves individuals across the visual impairment continuum. This dissertation sought to examine the existing eye care service delivery models, identify best practices, and explore perceived barriers and facilitators to access low vision rehabilitation services for older adults in order to inform the development of a revised service delivery model. The model will guide practice and policy change for existing and future services.

**Methods:** A mixed methods convergent approach was used to achieve the study's overarching objectives. First, quantitative data from a synthetic estimation, was used to categorize high and low resource communities, which informed the purposeful sampling of focus groups and provided essential data to guide model development. Next, focus groups and one-on-one key stakeholder interviews were held to understand stakeholder perspectives on access to low vision rehabilitation services in both high and low resource communities. Further, one-on-one interviews with focus group participants provided

additional quantitative data on individual prioritized barriers. Taken together, qualitative and quantitative research was conducted concurrently and then merged and expanded to inform a low vision rehabilitation focused care delivery model grounded in the Institute for Health Improvement's Chronic Care Model

**Results:** Key findings indicate the need for a model of service delivery that provides the full continuum of care, beginning with a low vision eye exam, which is coordinated throughout the community and health systems and addresses the chronic nature of visual impairment. Care should be client-centered and provided when the client is ready to accept services. Lastly, ongoing education to health care providers, consumers, and society will facilitate productive interactions and positive health outcomes.

**Conclusion:** The stakeholder-driven low vision rehabilitation focused care delivery model grounded in the Chronic Care Model will provide a structure for service delivery throughout the state. This collaboration with community and health systems, as well as case management, will assist with program sustainability and reach to all adults throughout the state living with VI.

## TABLE OF CONTENTS

DEDICATION .....	iv
ACKNOWLEDGMENTS .....	v
ABSTRACT .....	vi
TABLE OF CONTENTS.....	viii
LIST OF TABLES .....	xii
LIST OF FIGURES .....	xiv
LIST OF ABBREVIATIONS.....	xv
CHAPTER 1: Introduction .....	1
1.1: Overview.....	1
1.2: Current Service Delivery .....	7
1.3: Gaps in Service Delivery .....	12
1.4: Overall Study Design and Methods.....	13
1.5: Dissertation Organization .....	16
1.6: Dissertation Significance .....	16
CHAPTER 2: Theoretical Foundation & Literature Review.....	18
2.1: Theoretical Foundation.....	18
2.2: Literature Review .....	24

CHAPTER 3: Synthetic Estimation.....	43
3.1: Introduction.....	43
3.2: Methods .....	43
3.3: Data Collection .....	44
3.4: Data Analysis.....	45
3.5: Results.....	48
3.6: Discussion.....	49
3.7: Limitations.....	50
3.8: Conclusion.....	51
CHAPTER 4: Perceived Barriers and Facilitators to Accessing LVRS.....	52
4.1: Abstract.....	52
4.2: Introduction.....	54
4.3: Methods .....	57
4.4: Data Analysis.....	61
4.5: Results.....	63
4.6: Discussion.....	74
4.7: Limitations.....	79
4.8: Conclusion.....	80

CHAPTER 5: Stakeholder-Driven Model of LVRS Delivery.....	81
5.1: Introduction .....	81
5.2: Methods .....	87
5.3: Participants.....	88
5.4: Data Analysis.....	89
5.5: Results.....	93
5.6: Recommendations: Proposed Model .....	104
5.7: Feasibility for Implementation.....	110
5.8: Conclusion .....	111
CHAPTER 6: Conclusions, Strengths & Limitations.....	112
6.1: Summary of Results.....	112
6.2: Contributions of the Study.....	112
6.3: Implications for Clinical Practice: Need for Referral to LVRS.....	113
6.4: Implications for Policy.....	113
6.5: Implications for Research .....	115
6.6: Strengths & Limitations .....	116
6.7: Conclusion .....	119
APPENDICES .....	122

APPENDIX A: Prevalance Rate of VI and Number of those Legally Blind in MA	122
APPENDIX B: Rate and Number of Individuals Registered with MCB by Town..	124
APPENDIX C: Visual Health Resources MA .....	136
APPENDIX D: Low Vision Peer Support Groups .....	138
APPENDIX E: Evidence Table .....	140
APPENDIX F: Stakeholder-Driven Model of LVRS Delivery .....	149
APPENDIX G: MCB Report .....	150
APPENDIX H: Demographic Questionnaire.....	200
APPENDIX I: Focus Group Guide.....	201
APPENDIX J: Stakeholder Interview Guide.....	202
REFERENCES .....	203
CURRICULUM VITAE.....	216

## LIST OF TABLES

Table 1-1. Visual Impairment in U.S. Adults.....	3
Table 1-2. Demographics of Visual Impairment.....	6
Table 1-3. Risk Factors and Prevalence of VI by Race and Age.....	6
Table 1-4. Review of Practice Guidelines.....	9
Table 1-5. Aims, Processes, Procedures, Outcomes, & Theory.....	15
Table 2-1. Barriers in Context of the SEM Framework.....	25
Table 2-2. Low Vision Services in Developed and Developing Countries.....	34
Table 2-3. Levels of Low Vision Service Delivery Models.....	35
Table 3-1. National Prevalence Rates Based on Age and Race Estimates.....	46
Table 3-2. Synthetic Estimation of Boston.....	46
Table 3-3. Town Prevalence Rates and Resources.....	48
Table 4-1. Prevalence of Visual Impairment by Race & Age.....	55
Table 4-2. High and Low Resource Communities.....	58
Table 4-3. Descriptive Characteristics of Participants.....	64
Table 4-4. Emerged Themes Organized by Level of the SEM.....	65
Table 4-5. Prioritized Barriers and Facilitators to Accessing LVRS.....	73
Table 4-6. Demographics, Service Characteristics, and Receipt of LVRS.....	74
Table 5-1. Emerged Themes Organized by Level of the Chronic Care Model.....	92

Table 5-2. Demographics, Service Characteristics, and Receipt of LVRS .....	93
Table 5-3. Descriptive Characteristics of Participants .....	94
Table 5-4. Role of Key Team Members .....	98
Table 5-5. Review of Practice Guidelines .....	100
Table 5-6. Outcome Measures .....	109

## LIST OF FIGURES

Figure 2-1. Chronic Care Model for Low .....	20
Figure 2-2. Social Ecological Model .....	24
Figure 2-3. Optimum Low Vision Rehabilitation Service Delivery Model .....	39
Figure 3-1. High and Low Resource Communities in MA.....	49
Figure 5-1. Chronic Care Model.....	86
Figure 5-2. Optimum Low Vision Rehabilitation Service Delivery Model .....	105
Figure 5-3. Stakeholder-Drive LVRS Chronic Care Model .....	106

## LIST OF ABBREVIATIONS

AAO	American Academy of Ophthalmology
ACO	Affordable Care Organization
AER	Association for Education and Rehabilitation for the Blind and Visually Impaired
AMD	Age-related Macular Degeneration
AOA	American Optometric Association
AOTA	American Occupational Therapy Association
CCM	Chronic Care Model
CI	95% Confidence Interval
DR	Diabetic Retinopathy
FTE	Full Time Equivalent
HR	High Resource
LOVRNET	Low Vision Rehabilitation Network
LR	Low Resource
LV	Low Vision Rehabilitation
LVRS	Low Vision Rehabilitation Services
MA	Massachusetts
MCB	Massachusetts Commission for the Blind
MD	Medical Doctor/Ophthalmologist
OD	Doctor of Optometry
OR	Odds Ratio
PCP	Primary Care Physician

SEM ..... Social Ecological Model  
URE.....Uncorrected Refractive Error  
VI ..... Visual Impairment  
VPUS ..... Vision Problems in the United States

## CHAPTER 1: INTRODUCTION

Margaret is an 85-year old who was diagnosed with age-related macular degeneration five years ago. She lives alone in a second-floor walkup in a suburban environment. Over the past year, her vision has declined significantly and she struggles to complete daily activities. She sees her ophthalmologist yearly, but has not received any rehabilitation services to learn how to compensate for her vision loss. Margaret is not alone; visual impairment is a serious public health issue affecting nearly one in five adults 70 years and older in the United States (Campbell, Crews, Moriarty, Zack & Blackman, 1999; Federal Interagency Forum on Aging-Related Statistics, 2012; Lighthouse International, 2014). Visual impairment (VI) refers to a permanent loss of vision that interferes with a person's ability to complete daily activities (National Eye Institute [NEI], 2016).

### **1.1 Overview**

The purpose of this dissertation is three-fold. It will examine the existing eye care service delivery models, identify best practices in low vision rehabilitation (LVR), and explore perceived barriers and facilitators to access LVR services for older adults in order to inform the development of a stakeholder-driven LVR service delivery model. The model will guide practice and policy change for existing and future services.

This chapter includes an overview of VI and blindness as a public health issue, describes the current model of service delivery, and explains the significance of the project.

### **1.1.1 Visual Impairment in the U.S.**

Visual impairment impacts over 15% of Americans over the age of 65, roughly 7.3 million people (Campbell et al., 1999; Federal Interagency Forum on Aging-Related Statistics, 2012; Lighthouse International, 2014). With an aging population, the rate of adults with VI is expected to double by 2030 (Centers for Disease Control and Prevention, n.d.). Visual impairment can impact all aspects of daily life. Campbell, et al. (1999), found individuals with VI were at increased risk for greater functional limitations in daily activities, higher rates of systemic health conditions, increased social isolation, and higher prevalence of depression and increased risk of falls.

Vision impairment falls along a continuum that ranges from low vision to no light perception. When discussing VI, two terms are often used: low vision and blindness. Low vision is a permanent loss of visual acuity, visual field, or visual function that is not correctable through medication, surgery, or optical lenses (National Eye Institute, 2016). This type of vision loss does not meet the legal definition of blindness and excludes those with low vision from receiving services from Commissions for the Blind and other social service agencies. Blindness, as defined by the Social Security Administration (2014), is a central visual acuity of 20/200 or less and/or a visual field of no greater than 20 degrees.

### **1.1.2 Distribution of Visual Impairment**

Differences are found in visual health in adults in the U.S. based on race, age, gender, and socioeconomic factors. Although visual impairments are more common in older adults, there are racial variations (Casten, 2008; Prosner & Shin, 2008). Table 1-1 illustrates health care disparities across visual conditions.

**Table 1-1: Visual Impairment in U.S. Adults by Race, Age, Gender, and Socioeconomic Status**

	Cataract	AMD*	Glaucoma	DR*	URE*
Race					
White					
Hispanic					
Black					
Age & Gender					
Age					
Male					
Female					
Socioeconomic					
Lower Income					
Education					
Disability					

*Note.* \* Age-related Macular Degeneration (AMD); Diabetic Retinopathy (DR); Uncorrected refractive error (URE); **Key:** Dark gray indicates higher prevalence of eye condition; Striped box indicates higher prevalence and increased disability as a result of eye condition  
Adapted from: Chou, Baker, Crews , Primo & Zhang, 2012; Casten, 2008; NEI, 2004; Qui, Wang, Singh & Lin, 2014; Zhang, et al., 2012; Prevent Blindness America, 2005; Reeves, Strine & Pratt, 2011)

The following section provides a brief review of the common causes of VI and blindness, existing racial and gender differences by diagnosis, and health disparities that have been found throughout visual healthcare.

### *Cataracts*

Cataracts are the most common cause of VI and blindness in the US. The primary risk factor for cataracts is age, with slightly higher rates found among women. Other factors that increase risk of cataracts include history of smoking, exposure to UV radiation, and diabetes. Cataracts are surgically correctable; however, it has been found that those who are Black were five times more likely to have inoperable cataracts or experienced delayed medical treatment (Qui et al., 2014; Zhang et al., 2012; Center for Disease Control [CDC], 2009).

*Age-Related Macular Degeneration (AMD):*

The primary risk factor for age related AMD is also age, but it is also more common in White women, and accounts for 54% of all blindness cases (Zambelli-Weiner, 2012). Other factors that influence AMD are light eyes, fair skin, exposure to UV radiation, improper nutrition and physical activity, and family history (Qui et al., 2014; Zhang et al., 2012; CDC, 2009).

*Glaucoma:*

Glaucoma occurs most commonly in older adults; there is a slight higher risk among women. It was also found that half of those with glaucoma were unaware of their condition. The highest prevalence is seen in those who are Black or Hispanic, who were found to have a 3-5 times greater risk of developing glaucoma and 6 times greater risk of developing visual impairment as a result (NEI, 2004). As a result of these identified racial differences, the National Eye Institute's strategic plan seeks to examine the disparities in glaucoma care and outcomes. Existing initiatives are examining biological differences and current treatment regimens (NEI, 2004).

*Diabetic Retinopathy:*

Diabetic retinopathy (DR) can lead to VI and blindness and is seen in 100% of those with type I diabetes and 50% of type II, 20 years after initial diagnosis (Zambelli-Weiner, 2012). It has been found that those who are Hispanic and Black have higher rates of DR (odds ratio among Blacks 1.08 and among Hispanics 1.3) and those who are Black are 6 times more likely to develop visual impairment as a result of diabetic retinopathy compared to those who are white (NEI, 2004; Zambelli-Weiner, 2012; Health and Human

Services, 2014). Initiatives are examining biological differences and current treatment regimens (NEI, 2004).

*Uncorrected Refractive Error:*

The risk of having inadequate refraction or inappropriate glasses increased in those who were Hispanic, Black, below the poverty level, had lower education, and those with no or inadequate health insurance (Qui et al., 2014; Zhang et al., 2012; CDC, 2009). . Uncorrected refractive error could be related to the lack of awareness of the importance of regular eye examinations, those who were of low income, minority and uninsured were found to have a lack of visual health information. Even in those with eye care coverage, less than 50% of Medicare beneficiaries had an eye exam in the last year, many of whom lacked basic eye health information. In those with age related eye disease and visual impairment, annual eye examination rates varied depending upon type of insurance 67% (private), 55% (public), and 42% (none). Those who identified as having inadequate vision coverage also varied by insurance type 58% (private), and 44 % (public) (CDC, 2009).

Data supports disparities in access to visual health services. Although disparities reflect an important aspect of access, they will not be addressed in this study as access issues including identification of ocular disease and medical intervention proceed the focus of this study. In addition, when evaluating structural inequalities within the context of the Massachusetts Commission for the Blind (MCB), they are not reflected in the demographics of those served, refer to Table 1-2. This dissertation will address the identified disparities within the context of the development of a stakeholder-driven model

of low vision rehabilitation services (LVRS).

	65+	Male	White	Hispanic	Black	Other
Pop. Served by MCB, %	66	36	68.3	4.8	18.6	8.3
National, %	69.2	39.2	68.6	11.4	11.4	8.6

American Foundation for the Blind, 2018

### 1.1.3 Visual Impairment in Massachusetts

In MA, there are nearly 60,000 residents 65 and older with a VI and over 28,000 residents registered with the Commission for the Blind (refer to Appendix A). This number will only increase with the aging of the population, as prevalence of VI increases with age. Rates of VI increase from 0.9-2.2% for those 65-69 years, to 10.5-20% for those 80 years and older, depending on race (refer to Table 1-3) (NEI, 2016). In 2015, those 65 and older made up 15.3% of the population; it is estimated that by 2030 this will increase to 21.2% (Dugan, Porell, & Silverstein, 2015).

Eye Condition	Age	White	Black	Hispanic
<b>Cataract</b>	65-69	25.0%	23.6%	24.3%
	70-74	37.4	31.7	34.4
	75-79	51.1	40.1	45.2
	80+	70.4	53.5	60.7
<b>Diabetic Retinopathy</b>	65-74	8.4	7.6	15.9
	75+	7.4	6.9	18.9
<b>Glaucoma</b>	65-69	1.6	5.7	2.4
	70-74	2.3	7.4	3.6
	75-79	3.3	8.9	5.4
	80+	7.42	11.4	10.4
<b>Age-Related Macular Degeneration</b>	65-69	.9	1.0	1.0
	70-74	1.7	1.3	1.2
	75-79	3.6	1.5	1.5
	80+	13.6	2.2	2.1

*Note. 4 Major causes of visual impairment and blindness, risk factors and prevalence rates by age, Adapted from National Eye Institute, 2014.*

## 1.2 Current Service Delivery

In the U.S., there are three levels of services delivery for individuals with visual impairment and blindness. The primary level of care provides primary eye care services and may provide referral to low vision services, including referral to community level self-management programs (Brody et al., 2002). The secondary level of care, LV may be provided within community-based services or as part of traditional eye care services. At this level of care, services include medical management of the eye disease, as well as low vision assessment and device prescription. In a study by Owsley and colleagues (2009), they found nearly half (42.7%) of all low vision services were found in private optometry practices and nearly 90% did not include referral to rehabilitation. Further, they found that 1 in 3 individuals seeking low vision rehabilitation are over the age of 80 with multiple comorbidities that require care to address these chronic conditions. In the tertiary level of care, LV services consist of a multidisciplinary team providing comprehensive low vision rehabilitation. For example, the Veteran's Administrations Low Vision Services is a tertiary care model (Stemlack et al., 2008; Kuyk et al., 2008). Additional examples of U.S. models of service delivery are provided in Chapter 2.

In comparison, services provided in MA for assessment and intervention of VI, are organized within three systems: health care system, blindness system, and social services system. These three systems include the components of the primary and secondary levels of service delivery identified within the U.S.; however, there is limited access to the tertiary level of care throughout the state.

### **1.2.1 Health care system**

Health care services currently available for assessment and intervention of VI primarily include providers from the health care system. Hospitals, private practices, and community health centers offer comprehensive eye examinations and medical management of ocular disease. A limited number of clinics provide low vision examinations and LVRS. Refer to Appendix C for a list of Low Vision Providers within MA.

Ophthalmologists and optometrists provide medical management of ocular conditions. A limited number of these medical providers offer comprehensive low vision services that include assessment of functional vision and training in use of low vision devices to assist individuals in completing daily activities, such as reading. Other specialists, such as occupational therapy, social work, and psychology provide additional rehabilitation and counseling services to individuals with VI under the direction of a prescribing physician. The American Academy of Ophthalmology (2013), the American Optometric Association (2007), and the American Occupational Therapy Association (2013) have established guidelines which are based on a review of the current evidence and provide practitioners with recommendations for evaluation, treatment, and referral. All guidelines have identified the importance of an interdisciplinary team approach to care to improve an individual's ability to maintain independence and quality of life, refer to Table 1-4. These services are provided to individuals across the visual continuum and address the functional complaint of the client.

**Table 1-4. Review of Practice Guidelines**

<b>Guidelines</b>	<b>Summary of information</b>
<b>Vision Rehabilitation Preferred Practice Pattern The American Academy of Ophthalmology (2013)</b>	<ul style="list-style-type: none"> <li>• All providers are encouraged to provide low vision rehabilitation resources to their clients</li> <li>• Encourage all clients with central field loss to use eccentric viewing</li> <li>• Physicians specializing in LVR should address: reading, Activities of Daily Living, safety, participation, and psychosocial status</li> <li>• MDs specializing in LVR should encourage self-management and problem-solving skills</li> </ul>
<b>Care of Patients with Visual Impairment: Low Vision Rehabilitation The American Optometric Association (2007)</b>	<ul style="list-style-type: none"> <li>• Provides clinical practice guidelines for examination and treatment of individuals with VI</li> <li>• Provides tools for the optometrist to: <ul style="list-style-type: none"> <li>• Identify VI</li> <li>• Evaluate visual function</li> <li>• Emphasizes need for comprehensive assessment</li> <li>• Provide education to client</li> <li>• Provide referral to LVR (occupational therapy, psychology, etc.)</li> </ul> </li> </ul>
<b>Occupational Therapy Practice Guidelines for Older Adults with Low Vision The American Occupational Therapy Association (2013)</b>	<ul style="list-style-type: none"> <li>• Based on the results of a series of systematic reviews</li> <li>• Provides occupational therapy providers evidence-based assessment and intervention guidelines</li> <li>• Provides guidance to communicate to external audiences the role of occupational therapist in LVR</li> <li>• Strongest evidence supports a team approach to care that uses a problem-solving strategy approach</li> </ul>

### 1.2.2 Blindness system

In addition to services offered through the health care system, services are also available through the blindness system. These services are complementary to those provided within the healthcare system, but dependent on a referral. The blindness system is a national network of agencies that provide services to the blind and in some states, to

those with low vision. However, in MA, no statewide blindness services are available for those with low vision. An adult with a VI is only eligible for services from the MCB, if they meet the legal definition of blindness (Social Security Administration, 2014) or are currently employed. The blindness system is largely funded by federal funds as a result of the Rehabilitation Act of 1973 (Public Law 93-112) (Equal Employment Opportunity Commission, 1978). Initially, federal funds were provided for vocational rehabilitation, but were expanded to include independent living training for older adults with Title VII, Part B Amendments to the Rehabilitation Act in 1978. Vocational rehabilitation programs remain the primary focus, with limited funding available for older adults (Saner, 2017). In MA, 80% or more of the state and federal funding is earmarked for vocational training programming. As a result, and despite the services available to all ages within the blindness system, older adults are the most underserved population within the existing system (Equal Employment Opportunity Commission, 1978; Saner, 2017).

Once an individual is registered, they are assigned a caseworker and a rehabilitation teacher who provides services in the home or community. If deemed appropriate, the rehabilitation teacher may refer the individual for further assessment, training, or advanced training services from a residential blind rehabilitation program. These programs provide adults who have become near-total to totally blind intensive training in blind techniques to live independent lives.

### **1.2.3 Social Service System**

Community programs provide adjunctive support to the services provided by the healthcare and blindness system. In MA, forty-nine peer-led low vision support groups

are offered throughout MA to deliver support services, (refer to Appendix D).

Individuals with VI are either referred to these support groups through the healthcare system, blindness system, or through word of mouth. These groups meet monthly and serve as a support system, information, and referral hub. They offer an opportunity for attendees to share ideas and experiences with other members, and guest speakers increase the depth of knowledge shared.

Other community services assist those with VI to obtain or borrow the necessary equipment they need or want to maintain or improve their functional ability. An example within the MA context is Easter Seals, which offers a device loan program. Another community resource for low vision adaptive equipment and devices is the Lions Club. District 33Y, which supports the western part of MA, helps the Lions Eye Research Fund and assists in purchasing closed circuit televisions (reading machines) for those in need. The Lions Club, in collaboration with the New England College of Optometry, is also developing a low vision rehabilitation network (LOVRNET). The objective is to: 1) create a self-sustaining network of vision rehabilitation providers accessible to individuals who are visually impaired in Massachusetts, 2) increase the number of trained providers (optometrists, ophthalmologists and occupational therapists) available as service providers, 3) reduce barriers to obtaining care by providing education to the community (and other community health providers), transportation, and other support services, and 4) improve the quality and effectiveness of low-vision services provided through client-reported outcome measures. The Massachusetts Commission for the Blind may serve as a referral source for LOVRNET for individuals not meeting the legal

definition of blindness, or for areas underserved by the MCB.

#### **1.2.4 Interactions between systems**

Although the evidence supports an interdisciplinary approach to care with ongoing communication and follow-up, care is often provided in isolation with little communication between systems. Access to systems varies, dependent upon level of VI and other factors such as income or employment status. In addition, care is often provided episodically which does not address the chronic nature of vision loss or the ongoing functional needs of individuals with VI. Given the complexities of vision loss, coordinated care provided by skilled professionals is essential. Barriers to accessing these systems will be presented in Chapter 2.

#### **1.3 Gaps in Service Delivery**

Throughout the U.S., services to individuals with VI have been underutilized and under supported (Equal Employment Opportunity Commission, 1978; Saner, 2017). Awareness of LVRS among those with VI ranges from 19-71%, while the need for services is high (Casten, Maloney, & Rovner, 2005; Overbury & Wittich, 2011; Lam & Leat, 2013; Pollard, Simpson, Lamoreaux, & Keefe, 2003; Spafford, Rudman, Leipert, Klinger, & Huot, 2010). MA has existing medical and social service resources for adults with VI, poor utilization, variable access in certain communities, and limited integration of service streams inhibits access to services. In addition, within the blindness system, access to services is limited due to staffing and funding shortages resulting in few well-established low vision services offered through the health care system. There is also a

lack of occupational therapists, social workers, and psychologists who are trained to provide comprehensive low vision services or support services to individuals with VI and blindness (Campion, Awang, & Ward, 2010). Lastly, although VI is a progressive condition that requires ongoing care and follow-up, it is not treated as a chronic condition, rather care is provided episodically with poor coordination across the health system.

Historically, health care has been considered a response to an acute event, where the focus was on rapid diagnosis and treatment, remediation, or cure. The client was a passive recipient of the care provided. With an aging population and the complexities of multiple chronic conditions, including VI, there is a need for systems change to focus on management of these chronic conditions. A chronic care model of service delivery for visual impairment should seek to address the complexities of chronic diseases, the symptoms, resulting disability, psychological distress, medical interventions, and the necessary adjustment and self-management skills needed for older adults (Wagner, 2001).

#### **1.4 Overall Study Design and Methods**

The study aims to answer the following questions:

Research Question 1: What are the current models of service delivery of LVRS in MA?

Aim 1: Quantify current service delivery of LVRS in MA, examining variation in services between high and low resource communities.

Research Question 2: What are the perceived barriers and facilitators to accessing LVRS for older adults with visual impairments in high and low resource communities?

Aim 2: Ascertain perceived barriers and facilitators to accessing LVRS for older adults with visual impairments in high and low resource communities.

Research Question 3: Informed by data collected in questions 1 & 2, what are the components of a stakeholder-driven best practice model of LVRS?

Aim 3: Develop a stakeholder-driven best practice model of LVRS.

Aim 1 seeks to identify the current services delivered in MA. Aim 2 seeks to understand the perceived barriers and facilitators to accessing LVRS (both community and health systems) for older adults with VI and key stakeholders. Aim 3 seeks to develop a model of service delivery within the blindness system that addresses the chronic nature of visual impairment in adults. Table 3-1 summarizes aims, processes, procedures and outcomes of the project.

A mixed methods convergent approach was used to achieve the study's overarching objective, which was to develop a stakeholder-driven LVR service delivery model to address the needs of adults with VI living in MA. First, quantitative data (using the 2016 American Community Survey data and the National Eye Institute prevalence rates for visual impairment) from a synthetic estimation, was used to categorize high and low resource communities, which informed the purposeful sampling of focus groups and provided essential data to guide model development. Next, focus groups and one-on-one key stakeholder interviews were held to understand stakeholder perspectives on access to low vision rehabilitation services in both high and low resource communities. Further, one-on-one interviews with focus group participants provided additional quantitative data on individual prioritized barriers. Taken together, qualitative and quantitative research

was conducted concurrently and then merged and expanded to inform a translation of the existing chronic care model to a LVR focused care delivery model for the Massachusetts Commission for the Blind.

**Table 1-5. Aims, Processes, Procedures, Outcomes, & Theory**

<b>Aim</b>	<b>Process</b>	<b>Procedure</b>	<b>Outcome</b>	<b>Model</b>
<b>Aim 1. Quantify current models of service delivery of LVRS in MA</b>	Quantitatively capture current state of LVR services throughout the state	Complete synthetic estimation of prevalence of LV and GIS Mapping	Mapping of prevalence of VI and resources by town	Understanding current Community and Health Systems

**↓**  
**Informs Community & Health Systems Level**

<b>Aim 2. Explore perceived barriers and facilitators to accessing LVRS for older adults with VI</b>	Qualitatively capture perceived barriers and facilitators by key stakeholders	Focus groups of adults with VI 1:1 key stakeholder interviews Triangulate stakeholder themes with follow up 1:1 calls	Identify barriers and facilitators of accessing LVR services	Provides an understanding of the larger influences on health seeking behavior and the interactions between the individual, interpersonal, organizational community, and public policy factors
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**↓**  
**Merge Findings to inform Practice Level and Productive Interactions**

<b>Aim 3. Develop a stakeholder-driven best practice model of LVRS</b>	Analyze and merge findings to inform model development  Meet with MCB to understand resources needed for model development and implementation	Meet with key stakeholders to develop consensus Develop model of care	Disseminate results: Revised model of LVR services	LVRS: Merge findings to inform model development
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### **1.5 Dissertation Organization**

This dissertation is organized in the following manner. Chapter 1, Introduction, will provide a background to the problem, existing services, gaps within MA, and an overview of the overall methods. Chapter 2, Literature Review, will provide a thorough review of the existing literature, and theoretical foundation. Chapters 3 through 5 will be organized by aim and will provide an introduction, methodology used, results, discussion and conclusion for each of the 3 dissertation aims. Chapter 6, Conclusion, Strengths and Limitations, will discuss the implications of this research to the field of low vision rehabilitation, limitations and conclusions.

### **1.6 Dissertation Significance**

Research illustrates the growing need for LVRS with expected increased rates of VI (AMD by 25%, cataracts by 19%, glaucoma by 22%, and diabetic retinopathy by 89%) (Prevent Blindness America, 2013). Although the majority of VI is not curable, there are services that can reduce the societal and economic burden of vision loss. By understanding current models of practice, availability of services, and perceived barriers and facilitators to accessing LVRS, results of this study may facilitate the development of best practices in the state of Massachusetts for both those with VI and those who are legally blind. A new model of service delivery may increase access and utilization of LVRS resulting in increased overall health status and quality of life of older adults with VI.

Evidence supports the use of interdisciplinary and multidisciplinary care to

provide the most comprehensive services to individuals with visual impairment. Despite evidence to support the use of interdisciplinary and multidisciplinary coordinated care, the MCB primarily provides vocational rehabilitation services with limited funding and support available for adults with vision loss. Consideration for resources and capacity of the current model will inform and provide valuable information on the potential reach for MCB's revised stakeholder driven model of care.

In 2010, the total costs of VI and blindness for MA exceeded \$1.7 billion (Prevent Blindness America, 2013). With an aging population, the costs to MA will significantly increase over upcoming years. Access to visual health services, as well as LVRS, can significantly reduce health care costs and improve functional abilities, as well as quality of life (Rein, Wirth, Johnson, & Lee, 2007; Maciosek, Coffield, Flottemesch, Edwards, & Sloberg, 2010). As reimbursement and funding mechanisms are expected to change for MCB, new models of service delivery must be explored. The development of a stakeholder-driven service delivery model can guide transition of MCB for service delivery throughout MA in order to optimize the health of this population. The model may serve an example of best practice that could be replicated in other parts of the country.

## **Chapter 2: Theoretical Foundation & Literature Review**

This chapter includes the theoretical foundation that guides the project's questions, aims, and research design. In addition, a literature review of the barriers to accessing LVRS and models of service delivery will be provided.

### **2.1 Theoretical Foundation**

The Chronic Care Model (CCM) provides a framework for the development of a stakeholder-driven model of LVRS (Wagner, et al., 2001; Wagner, Davis, Schafer, VonKorff, & Austin, 1999). The Social Ecological Model will guide data collection and data analysis to understand personal perspectives of barriers and facilitators to accessing care and the relationship between community resources and health systems for adults living with vision loss. By using the Social Ecological Model to understanding the context to accessing services for adults with VI in MA, I will identify key components of care that will guide the use of the CCM to ground a new model of LVRS.

#### **2.1.1 Chronic Care Model**

The CCM proposes a systematic approach to the coordination of care between the medical system and social services necessary for effective disease management. The CCM model was developed by Wagner and colleagues (2001) with support from the Robert Wood Johnson Foundation to provide a framework for quality improvement in chronic disease management. The CCM focuses on integrated care across the healthcare system and mobilizing community resources in order to foster self-management skills that improve health outcomes. It stresses the importance of an ongoing client centered

approach that is proactive in anticipating individual need. Although the CCM has not been used to address the needs of those with VI, there is an abundance of evidence in its application for management of other chronic diseases, such as diabetes, heart disease, and mental health (Wagner et al., 2001; Wagner et al., 1999). For instance, McCullough and colleagues (2000), evaluated a population-based approach to diabetic management and found a system based on surveillance, best practice guidelines, self-management support, and a team approach to care improved outcomes, client satisfaction, and reduced overall health care costs.

In a systematic review evaluating the effectiveness of interventions to improve diabetic management, they found updated medical records systems improved process outcomes and clearly defined team member roles and a client-centered approach to care showed improved glycemic control (Renders et al., 2000). In addition, systematic follow-up and case management was found to decrease depressive symptoms in adults with depression and other chronic conditions (Simon, VonKorff, Rutter, & Wagner, 2000; Shojania, et al., 2006; Stellefson, Dipnarine, & Stopka, 2013; Katon et al., 1995; Piette, Kraemer, Weinberger, & McPhee, 2001). Further, Katon et al. (2012), found that education, including self-management, goal setting, and problem solving improved medication adherence and improved outcomes. Lastly, Lim and colleagues (2014) reported that acknowledging clients' values and providing client-centered practice was crucial for productive interactions. As the majority of visual impairments are progressive and chronic, the use of the CCM may be an effective model to guide service delivery.

As illustrated in Figure 2-1 and discussed below, the CCM provides a structure

for the coordination of the medical and social systems of care to promote productive interactions and better health outcomes for individuals with VI.

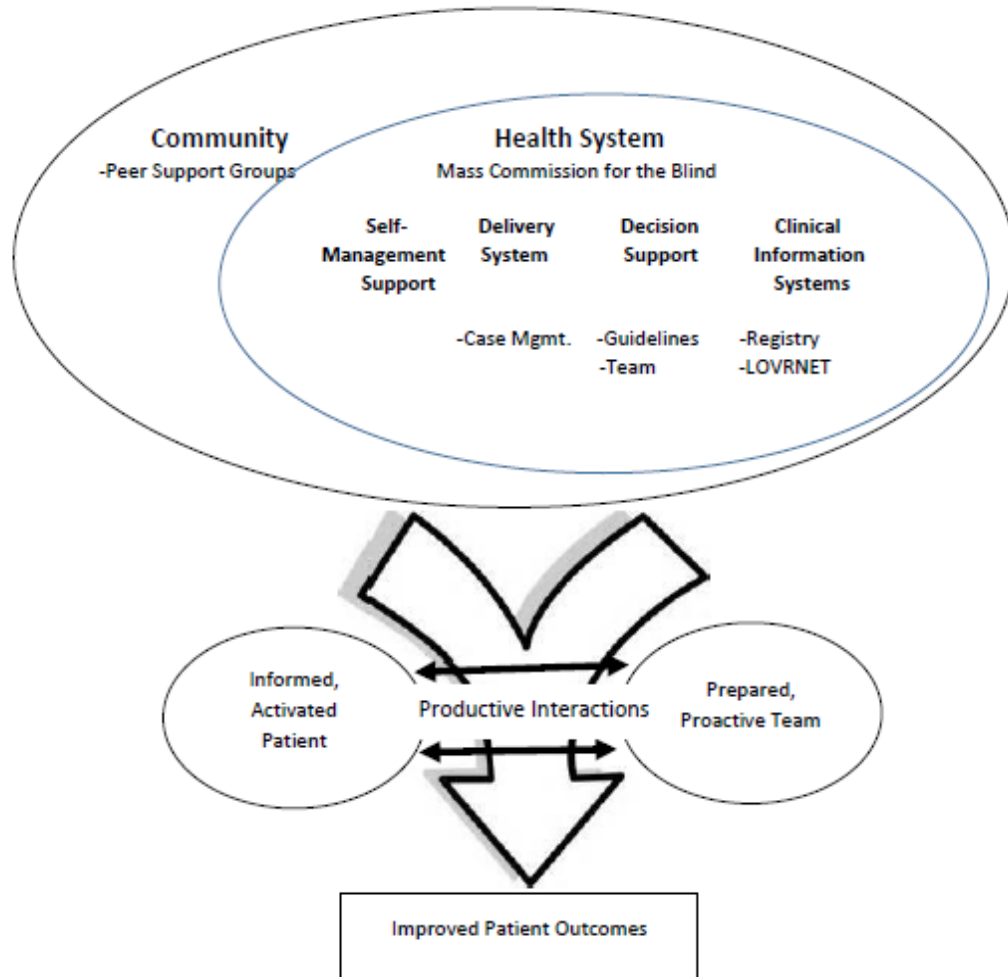


Figure 2-1. Chronic Care Model for Low Vision; Adapted from Wagner, 1998

### *Community and Health Systems Level*

Looking from a top down approach, coordinated health services and community resources are essential to meet an individual's needs and improve health outcomes. Medical services for VI, such as comprehensive medical management of the ocular

disease, low vision examination of visual function, and rehabilitation services from occupational therapy can optimize visual function and provide the individual with the skills to live independently. Community resources, such as peer support groups, senior services, or home meal delivery, can support an individual's independence and safety in their homes. Effective partnerships between health systems and community services can bridge the gaps between service provision and encourage active participation and support self-management skills (Wagner et al., 2001; Wagner et al., 1999).

#### *Practice Level*

According to the CCM, to have effective interactions and well-informed clients, the healthcare system must include self-management support, delivery system redesign, decision support, and clinical information systems.

#### *Self-Management Support*

Chronic disease management requires the system to prepare the individual to manage his/her own care. Self-management emphasizes the need for service delivery to be evidence-based and client-centered, including collaborative goal setting. Ongoing case-coordination and education should be provided to promote client engagement and facilitate effective support strategies. Programs should provide ongoing and effective assessment of client knowledge and behavior (Katon et al., 2010; Stellefson, Dipnarine, Stopka, 2013; Wagner et al., 1999).

#### *Delivery system design*

Effective delivery system design provides clear identification of team members' roles and scope of service delivery. It promotes the provision of evidence-based

interventions for care, with ongoing case management that ensures follow up and coordination of care. Care should be provided in a culturally appropriate manner which is delivered at a level that is accessible to the individual (Katon, et al., 2012; Piette, Kraemer, Weinberger, & McPhee, 2001).

#### *Decision support*

Effective chronic disease management requires well-informed clinicians and integrated care that includes evidence-based interventions or practice guided by practice guidelines that provides integration of care (primary care and specialty eye care). It should also include ongoing education of the practitioner and client (Katon, et al., 1995; Katon et al., 2010; McCulloch, Price, Hindmarsh, & Wagner, 2000).

#### *Clinical Information Systems*

Information that is organized and accessible by all team members can facilitate communication and coordination of care. In the absence of an electronic medical record, databases and case management can be utilized to remind clients of follow up care, improve carryover of information of clients and share information with the low vision team members, improve care planning, and monitor progress (Wagner, et al., 2001; Wagner et al., 1999).

#### *Productive Interaction*

For effective chronic disease management, productive interactions between the client and the practice team must occur. Productive interactions result in informed and activated clients and providers who are evidence-based and proactive. This productive interaction can be supported through ongoing case coordination and communication

among the practice team (Wagner et al., 1999).

### *Outcomes*

Through productive interactions, the CCM results in improved client outcomes, health status, and quality of life. In studies looking at the use of the CCM with chronic health conditions, results show improvements in self- management skills, increased quality of life, decreased depressive symptoms, and cost savings per quality adjusted life year (Wagner, et al., 2001; Wagner et al., 1999). These positive outcomes are the result of ongoing review of client data, collaborative goal setting, application of evidence-based interventions, and ensuring ongoing follow up and case coordination (Wagner, et al., 2001; Wagner et al., 1999).

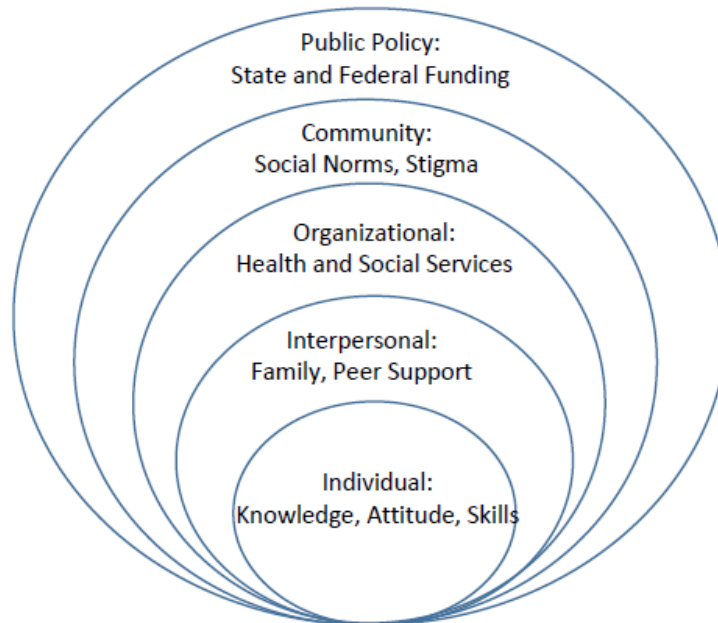
#### **2.1.1.1 CCM for Low Vision Service Provision**

The CCM will serve as the foundation to a proposed model for service delivery. To improve care for adults living with chronic VI, I will align the essential elements to comprehensive LVRS to the levels of the CCM. Currently, LVRS exists within the Community and Health Systems level with little coordination. This limited collaboration between health systems and community services impedes active participation and informed clients, and ultimately health outcomes.

#### **2.1.2 Social Ecological Model**

The Social Ecological Model (SEM) provides a framework for explaining the larger influences on health seeking behavior and the interactions between the individual (knowledge, skills), interpersonal (social environment), organizational (health and social systems), community (family/community supports), and public policy factors

(reimbursement) (Katon et al., 1995; Salihu et al., 2015). This theoretical framework provides a structure to organize key factors to VI care delivery, which will then inform how to translate the CCM model to a VI population (refer to Figure 2-2).



*Figure 2-2.* Social Ecological Model

The SEM provides a framework for examining the barriers and facilitators to productive interactions within the CCM framework for VI. The SEM will guide analysis of key barriers and facilitators to VI services and will inform the development of the model.

## **2.2 Literature Review**

The purpose of this literature review is to investigate the perceived barriers to accessing LVRS and to identify the current models of LVR service delivery. The review will identify gaps and inform key components of the stakeholder driven model of LVRS.

Although many of the studies included in this review occurred outside of the US context, including studies from Canada, England, Australia, India, Belgium, and the Netherlands, many are consistent with findings from US studies. Data gathered were used to inform interview guides in order to understand the US provider and consumer perspectives on barriers and facilitators to accessing LVRS.

### 2.2.1 Barriers to Accessing Care

This literature review investigated the perceived barriers to accessing LVRS for those with VI in the context of the SEM framework, refer to Table 2-1. The literature review was conducted to identify relevant resources published between 2000 and present (refer to Evidence Table Appendix E). Common barriers to accessing low vision rehabilitation services (LVRS) include: lack of awareness of available services and/or need for services, lack of knowledge of low vision services by the older adult, lack of knowledge of available services by the health care provider, transportation, lack of communication between providers and providers and clients, perceived negative social implications, and sociodemographic factors.

<b>SEM Domains</b>	<b>Barriers</b>
<b>Public Policy</b>	<ul style="list-style-type: none"> <li>• Regulations on qualifications for service provision</li> <li>• Lack of state and federal funds</li> <li>• Lack of coverage for prescriptive lenses or devices</li> </ul>
<b>Community</b>	<ul style="list-style-type: none"> <li>• Stigma</li> <li>• Fear to disclose/vulnerability</li> </ul>
<b>Organizational</b>	<ul style="list-style-type: none"> <li>• Lack of education of providers</li> <li>• Transportation</li> </ul>
<b>Interpersonal</b>	<ul style="list-style-type: none"> <li>• Lack of understanding VI by friends and family</li> </ul>
<b>Individual</b>	<ul style="list-style-type: none"> <li>• Income</li> <li>• Education</li> <li>• Lack of awareness of services or efficacy of interventions</li> </ul>

### **2.2.1.1 Public Policy Factors**

Qualifications for services within the blindness system vary, however most are developed based on the Social Security definition of blindness. An adult with a VI is only eligible for services from the MCB, if they meet the legal definition of blindness (Social Security Administration, 2014) or are currently employed. The blindness system is largely funded by federal funds as a result of the Rehabilitation Act of 1973 (Public Law 93-112) (Equal Employment Opportunity Commission, 1978). Initially, federal funds were provided for vocational rehabilitation, but were expanded to include independent living training for older adults with Title VII, Part B Amendments to the Rehabilitation Act in 1978, thus increasing access to adults and older adults with VI and blindness. However, the main component of the blindness system remains vocational rehabilitation, including Massachusetts (Saner, 2017). As a result, despite the services available to all ages within the blindness system, older adults are the most underserved population within the existing system (Geiser, 1992).

In 1990, the Center for Medicare and Medicaid Services approved Medicare coverage for LVRS for individuals with VI as their primary diagnosis when prescribed by a physician (Code of Federal Regulations, 1994). This change in coverage enabled recognized health care providers to provide services when determined to be medically necessary (Warren, 2000). Some professionals within the blindness system, orientation and mobility specialists, low vision therapists, and rehabilitation teachers currently are not currently recognized by Medicare as health care professionals, and therefore not eligible to receive reimbursement through third parties (Warren, 2000).

### **2.2.1.2 Community Factors**

#### *Perceived negative social implications*

Being diagnosed with a VI may have multiple negative social implications. Perceived prejudicial attitudes create psychological barriers to accessing care. Pollard and colleagues (2003), found that individuals with VI did not want to appear blind as an issue of fear and vulnerability. Spafford and colleagues (2010) found that individuals with VI were hesitant to utilize services that threatened their perceived independence or dignity. The perceived negative view of VI and blindness by friends and family, as well as society, can inhibit access of services (Lam & Leat, 2013; Southall, & Wittich, 2012). In addition, many deny having a VI or do not identify functional difficulties as related to their visual problems. Denial can be related to fear associated with stereotype or stigma, a need to appear independent, and lack of understanding of diagnosis and implications of function from friends and family.

Many older adults report that they are unmilling to seek out solutions and/or services until their family and friends accept their VI diagnosis and associated functional limitations (Spafford et al., 2010). For example, in a study of assistive device use, social acceptance was a key factor in device use (Wessels, Soede, Gelderblom, & DeWitte, 2003). Participants also reported that the use of long white canes and being identified or labeled as blind were stigmatizing (Boyce et al., 2014; Matti et al., 2011; Spafford et al., 2010). Matti and colleagues (2011) found that 27% of participants with VI felt they did not need LVRS.

### **2.2.1.3 Organizational Factors**

*Lack of knowledge of the healthcare provider and lack of communication between provider and client*

This barrier directly relates to the practitioner's lack of knowledge of LVRS, requirements for access to services, and the efficacy of these services. For example, many providers and older adults with low vision believe they must meet the criteria for legal blindness in order to receive services. The evidence shows more positive results when vision rehabilitation services are started as soon as the individual identifies a functional problem as a result of their vision loss (Marinoff, 2012). To that end, clients and providers need to be educated on how to qualify for services, the benefits of services (and need for follow-up/long term treatment), how to access services, and when to refer for services.

There is moderate evidence from one Level II, one Level III and nine Level IV studies that lack of referral from the practitioner is a major barrier to access LVRS. Eye care providers were one of the most frequently reported barriers to accessing LVRS (Southall & Wittich, 2012; Wittich, Canuto, & Overbury, 2013). In a study examining the perceived barriers to accessing LVRS of ophthalmologists in India, 82.3% reported a lack of training and 74.7% reported a lack of awareness of services available (Khan, Shamanna, & Nuthethi, 2005). Similarly, MacLennan and colleagues (2014) examined eye care services in Alabama and found only 23.1% of ophthalmologists and optometrists received specialty training in LV. Further they found only 2.7% of ophthalmologists and 15% of optometrists provided LV services to their clients. Spafford and colleagues

(2010) study found that 64.7% of participants blamed their eye doctors for their non-use of LVRS. They reported a lack of information, referral and support of available services. Matti and colleagues (2011) found that referrals to LVRS were often delayed due to a lack of awareness of the provider in terms of when it is appropriate to refer an individual to LVRS. Further, Overbury and Wittich (2011) reported that individuals who were living independently were least likely to receive a referral from their eye care practitioner and had lower rates of acceptance of referrals.

Results of a study by Pollard and colleagues (2003) found a lack of communication between providers and their clients. Participants reported a lack of understanding of the purpose of LVRS, limited information related to coping with vision loss, and a delay in referral until the vision loss had significantly impacted the individual's daily life. Further, participants were often told, "nothing more can be done" (p. 325), which is consistent with findings from Chiang and colleagues (2011) study. Nearly half of ophthalmologists studied found registration of their clients as the perceived final stage of their medical management and they were unclear on their role or the services available to their clients (Boyce et al., 2014). Further, Roelands and colleagues (2012) identified education gaps in terms of awareness of LVRS, for a key community resource for older adults in Belgium, the community nurse.

### *Transportation*

There is evidence from four level IV studies that transportation is a major barrier to accessing LVRS. Even once clients are aware of services and referred by their ophthalmologist or optometrist, barriers exist in getting clients to access services. The

main practical barrier involves transportation needs to and from appointments. Many individuals with low vision are required to retire from driving for safety reasons (Walter, Althouse, Humble, Leys, & Odom, 2004). This leads to a decrease in independence and a need for use of an alternate means of travel. However, many individuals have anxiety or fear using public transportation or taxis and may be uncomfortable asking for help from family members and friends. If individuals are unable to find transportation, distance to appointments can be a barrier, especially in rural areas where there is limited outreach and access to clinics (Spafford et al., 2010; Wittich, Canuto, & Overbury, 2013). In a study of gaps in the provision of eye care, those living within 20 miles or less of an eye care provider was more likely to receive regular eye care (Sloan, Yashkin, & Chen, 2014). The amount of time required to get to and attend doctors' appointments is also a barrier. Many individuals with VI also have comorbidities that require many doctor appointments and complex transportation demands. The importance of vision rehabilitation is often minimized due to the prioritization of addressing other chronic conditions and lack of time for additional appointments and the required transportation.

*Lack of communication between providers and clients*

There is moderate evidence from one level II, one level III, and five level IV studies that lack of communication between the provider and client is a major barrier to accessing LVRS. A disconnect between providers can occur at all levels in many healthcare systems. Persons with VI may receive services from different providers or at different facilities but for best care it is imperative that these providers communicate regularly about treatment, expectations, and client needs (Khan, Shamanna, & Nuthethi,

2005; Wessels, Dijicks, Soede, Gelderblom, & DeWitte, 2003). A reoccurring theme in the literature regarding communication amongst medical providers is lack of provision of information to clients about coping with their VI (Southall & Wittich, 2012). Instead, providers typically offer only medical advice and definitions. Medical providers are not educating clients on why referrals to LVRS are being made or the next steps necessary for accessing services (Spafford et al., 2010). These gaps in service may be the byproduct of (a) the limited time available for providers and patients to engage in such dialogue during appointments and/or (b) providers not understanding LVRS (Pollard, 2003; Wittich, Canuto, & Overbury, 2013). MacLennan and colleagues (2014) illustrate that this ineffective communication may contribute to higher rates of eye disease, increased visually significant eye disease, and poor adherence to recommended medical care especially in African Americans.

#### **2.2.1.4 Individual & Interpersonal Factors**

##### *Lack of Awareness of available services and/or need for services*

Individuals with low vision may be unaware of services available to improve their quality of life, improve and/or maintain their level of independence in completion of daily tasks, and help slow the progression of vision loss. This can be attributed to a lack of community outreach or lack of communication between health care providers and their clients.

There is moderate evidence from two level II and five level IV institutionally-based studies that lack of awareness of services is as a key barrier to accessing LVRS. Siemsen and colleagues (2015) examined the use of an education program to improve

access and use of LVRS. They found that many older adults lacked information on the efficacy of LVRS and lacked awareness of services within their communities. A study conducted in India examining effective models of LVR service delivery found awareness of services and their efficacy was a major challenge in program implementation (Rao, Khanna, Athota, Rajshekar, & Rani, 2012). Further, the researchers recommended outreach programs to improve awareness and availability of services. Pollard and colleagues (2003) examined characteristics of clients seen within a large ophthalmology clinic in Australia. A lack of awareness of services and their efficacy was the most commonly identified barriers to accessing LVRS.

Three studies (one level II and two level IV), conducted as part of the Montreal Barriers Study, found that participants were ill-informed about available services or the need for services. Further, in many cases, the gradual loss of vision decreased the perceived need for LVRS (Wittich, Canuto, & Overbury, 2013; Overbury & Wittich, 2011; Southall & Wittich, 2012). Lastly, two studies looked at disparities in terms of access and use of LVRS. It was found that those with higher levels of education were more likely to be aware of services; those with less severe vision loss were less likely to be aware of and use services and those who were black were significantly less aware of services available than any other race (Overbury & Wittich, 2011; Mwilambwe, Wittich, & Freeman, 2009).

In four community-based level IV studies, lack of awareness of availability and efficacy of LVRS was found to be a key barrier to access. In a survey of adults with vision loss in West Virginia, only 17% of individuals with VI were aware of LVRS in

their communities (Walter, Athouse, Humble, Leys, & Odom, 2004). Roelands and colleagues (2002) examined the awareness of community dwelling older adults of assistive devices that could assist in maintaining independence and participation in valued activities. They found that although older adults held positive attitudes towards assistive devices that would assist with daily tasks, they were unaware of their availability. In a study conducted in Tanzania, a major barrier to LVRS and eye care in general was a lack of awareness of treatments or interventions available, where they were provided, or the costs associated (Nkumbe, 2008). Further, in a study of 34 community dwelling older adults who had received eye care services in Canada, 73.5% reported that they were unaware of LVRS or how to access them (Spafford et al., 2010).

#### *Sociodemographic factors*

There is evidence from three level IV studies that sociodemographic factors influence access to LVRS. Sociodemographic factors resulting in barriers to access care differ depending on location and the population being considered. General factors that are typically associated with lack of access to care for VI include, age, socioeconomic status, location (urban vs rural), comorbidities, and low literacy levels. Chiang and colleagues (2011) reported that those living in rural areas, lower incomes, and a history of a disability had greater limitations in access to services. Several studies found that individuals with lower incomes were more likely to report having a vision impairment (Walter et al., 2004; Gold & Simson, 2005; Chiang, Xie, & Keeffe, 2011). Further, several studies identified the cost of low vision devices as a barrier to care (Gold & Simpson, 2005). In order to maximize service provision and client outcomes, these

factors need to be considered when an individual is assessed for low vision rehabilitation services.

## 2.2.2 Models of Service Delivery

The purpose of this section of the literature review is to investigate the current models of LVR service delivery in order to inform model development.

### 2.2.2.1 Current Models of Service Delivery throughout the World

Chiang and colleagues (2011) completed a worldwide survey of LV service delivery and coverage of service provision, refer to Table 2-2. Definition of LV services varied from community workers providing counseling and community support to comprehensive clinic based LVRS. Services were reported in 103 of 178 countries who responded. Coverage of services varied, 34% of countries reported less than 10% coverage, 19% reported 11-50% coverage, and 41% of countries did not report coverage data. The majority of developed and developing countries included low vision in their national health plan and included referral guidelines. There were significant differences in funding sources between developed and developing countries, with increased governmental support in developed countries (Chiang, O'Connor, LeMusurier, & Keefe, 2011).

	Developed Countries	Developing Countries
Part of the national health plan	75%	80%
National referral guidelines	45%	32%
Existing standards of practice	48%	36%
Fully funded by government	32%	12%

Many countries provide multiple levels of LVRS, refer to Table 2-3. The

majority of comprehensive LVRS, identified in the tertiary level of care in Table 2-3 include a similar care process, which includes: comprehensive low vision assessment, diagnosis, treatment, referral to multidisciplinary LVRS and education (Teutsch, McCoy, Woodbury, & Welp, 2016). Teutsch and colleagues (2016) found that models differed significantly by setting, cost, duration of intervention, LVRS team members, and scope of services provided. Outcomes of select service delivery models are provided in Table 2-3.

Country/ Region	Primary	Secondary	Tertiary
Australia <sup>3</sup>	<ul style="list-style-type: none"> <li>- Community services through Vision Australia</li> </ul>	<ul style="list-style-type: none"> <li>- Community based LV services</li> <li>- LV as part of eye care services</li> <li>- Provided by eye doctor</li> <li>- Treatment of eye condition</li> <li>- Referral for low vision assessment and device prescription</li> </ul>	<ul style="list-style-type: none"> <li>- Multidisciplinary team</li> <li>- Clinical assessment by eye doctor</li> <li>- Rehabilitation services</li> <li>- Referrals to counseling and additional support services</li> </ul> <p><b>Outcomes:</b></p> <ul style="list-style-type: none"> <li>- Significant improvements in QOL and reading performance 3-6 mo. post rehabilitation</li> <li>- Significant improvements in visual function and reading 30 days post rehabilitation (LV device, training, O&amp;M, and ADL training)<sup>3</sup></li> </ul>
Canada <sup>10-13</sup>	<ul style="list-style-type: none"> <li>- Community services (CNIB)</li> <li>- SmartSight program eye care practitioners “recognize and respond”<sup>12</sup></li> </ul>	<ul style="list-style-type: none"> <li>- Clinic based eye care services</li> <li>- Referral to LV as part of ophthalmology and optometry services</li> <li>- Provided by eye doctor</li> <li>- Treatment of eye condition</li> <li>- Referral for low vision assessment and device prescription</li> </ul>	<ul style="list-style-type: none"> <li>- Multidisciplinary team</li> <li>- Rehabilitation services</li> <li>- Free standing or collaborations between eye care and vision rehabilitation specialists</li> </ul> <p><b>Outcomes:</b></p> <ul style="list-style-type: none"> <li>- Improvements in ADL and reading performance post rehabilitation</li> <li>- Improved use of LV devices, self-perceived ability to perform ADLs, and QOL<sup>13</sup></li> </ul>

		- SmartSight program “record, refract, prescribe and report” <sup>12</sup>	
Pacific Region <sup>9</sup>	<ul style="list-style-type: none"> <li>- Community Health Centers and outreach</li> <li>- Vision screening</li> <li>- Assessment of functional vision</li> <li>- Referral to low vision</li> <li>- Prescription of low vision devices</li> <li>- LV services in the community</li> </ul> <p><b>Example:</b> Christian Blind Mission</p>	<ul style="list-style-type: none"> <li>- Center based model</li> <li>- Provided by eye doctor</li> <li>- Treatment of eye condition</li> <li>- Low vision assessment and device prescription</li> </ul> <p><b>Example:</b> Malaysian Association for the Blind</p>	<ul style="list-style-type: none"> <li>- Multidisciplinary model</li> <li>- Orientation &amp; Mobility (O&amp;M), Occupational Therapy (OT)</li> <li>- Clinical assessment by eye doctor</li> <li>- Rehabilitation services</li> </ul> <p><b>Example:</b> Singapore Association of the Visually Handicapped</p>
South Africa <sup>4</sup>	<ul style="list-style-type: none"> <li>- Primary healthcare workers and primary eye care workers provide education</li> <li>- Identification of need and referral to LV</li> <li>- Home based services</li> </ul>	<ul style="list-style-type: none"> <li>- Ophthalmic nurses provide assessment</li> <li>- Assess need for LV devices</li> <li>- Provide counseling and education</li> </ul>	<ul style="list-style-type: none"> <li>- Multidisciplinary team</li> <li>- Train and support eye care providers</li> <li>- Rehabilitation services</li> <li>- Prescription of LV devices</li> </ul>
United Kingdom	<ul style="list-style-type: none"> <li>- Community services through Royal National Institute for the Blind (RNIB)</li> </ul>	<ul style="list-style-type: none"> <li>- Community based eye doctor provides LVRS in primary care setting</li> </ul> <p><b>Example:</b> Welsh Low Vision Service</p> <p><b>Outcomes:</b></p> <ul style="list-style-type: none"> <li>- Improved access to low vision services (+51.7%)</li> </ul>	<ul style="list-style-type: none"> <li>- Multidisciplinary team</li> <li>- Work out of a general hospital</li> <li>- Provides comprehensive exam, diagnosis, LV devices, and training</li> <li>- Home visit LVRS (OT &amp; O&amp;M)</li> </ul> <p><b>Example:</b> Interdisciplinary LV Service (ILVS)*</p> <p><b>Outcomes:</b></p> <ul style="list-style-type: none"> <li>- Significant change in depressive symptoms,</li> </ul>

		- Improved disability scores in 97.4% of patients	safety, and reading 6 months post rehabilitation <sup>1</sup>
United States <sup>5,7,8</sup>	<ul style="list-style-type: none"> <li>- Community based self-management programs</li> <li>- Primary eye care providers</li> <li>- Assessment of functional vision</li> <li>- Referral to low vision</li> </ul> <p>Outcomes:</p> <ul style="list-style-type: none"> <li>- Improvements in QOL, self-efficacy, and self-reported function 6 months post self-management group<sup>5</sup></li> </ul>	<ul style="list-style-type: none"> <li>- Community based LV services</li> <li>- LV as part of eye care services</li> <li>- Provided by eye doctor</li> <li>- Treatment of eye condition</li> <li>- Low vision assessment and device prescription</li> </ul>	<ul style="list-style-type: none"> <li>- Multidisciplinary team</li> <li>- Rehabilitation services</li> <li>- Free standing or collaborations between eye care and vision rehabilitation specialists</li> </ul> <p><b>Example:</b> Veterans Administration*</p> <p><b>Outcomes:</b></p> <ul style="list-style-type: none"> <li>- LOVIT study should significant improvement in QOL, mobility, reading skills, and visual abilities 4 months post rehabilitation<sup>7,8</sup></li> </ul>
<p><i>Note.</i> Data for low vision service delivery models from <sup>1</sup>Hinds, Sinclair, Park, Suttie, Paterson, &amp; MacDonald, 2003; <sup>2</sup>Kammer, Jamara, Kollbaum, Matchinski, &amp; Flom (2010); <sup>3</sup>Lamoureux et al., 2007; <sup>4</sup>Simon, 2008; <sup>5</sup>Brody et al., 2002; <sup>6</sup>Larizza, 2011; <sup>7</sup>Stelmack et al., (2008); <sup>8</sup>Kuyk et al., 2008; <sup>9</sup>Lim, Vukicevic, Kokl, &amp; Boyle, 2014; <sup>10</sup>Gold, Zuvella, &amp; Hodge, 2006; <sup>11</sup>Teichman &amp; Markowitz, 2008; <sup>12</sup>Jackson, 2006; <sup>13</sup>Hooper, Jutai, Strong, &amp; Russell-Minda, 2008; *model programs that are discussed below</p>			

### 2.2.3 Models of Service Delivery that align with the CCM

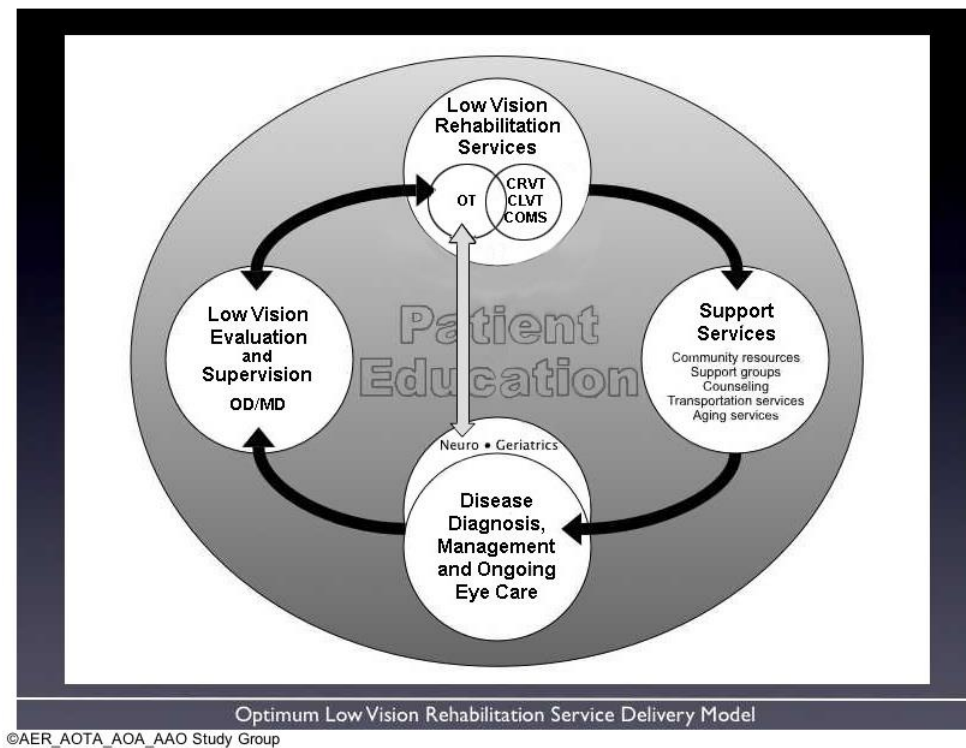
This section of the literature review investigates the current models of service delivery that align with the CCM. There are several models of low vision care that may be used to inform components of the stakeholder-driven model of service delivery. These include models from the health systems and practice levels of the CCM. All models

emphasize the need for interdisciplinary care to provide the most comprehensive services to individuals with VI (Pizzimenti, 2003; Ryan, 2014).

### **2.2.3.1 Health Systems Level**

In 2007, the Association for Education and Rehabilitation of the Blind and Visually Impaired (AER), the American Occupational Therapy Association (AOTA), the American Optometric Association (AOA), and the American Academy of Ophthalmology (AAO) facilitated a study group to collaborate and develop an optimum low vision rehabilitation service delivery model within the medical system (refer to Figure 2-3). The model is a guide to best practice for provision of comprehensive low vision rehabilitation within a medical model (American Academy of Ophthalmology, 2013; American Optometric Association, 2007; Kaldenberg & Smallfield, 2013). The group identified four major providers that serve as the low vision rehabilitation team: ophthalmology, low vision optometry, occupational therapy, and individuals from the blindness system (e.g., certified orientation and mobility specialists and rehabilitation teachers). Key components of care include medical management of the eye disease, low vision evaluation to identify needs and to prescribe low vision devices, low vision rehabilitation services, and support services. The model emphasizes that throughout an individual's care, collaboration and communication between all team members and the individual with low vision is imperative. As most eye conditions in older adults are progressive, ongoing follow up must also be provided to ensure carryover of training and adaptation to further visual changes. This model contains key components that will inform the practice and productive interaction levels of the CCM for vision rehabilitation.

Since its introduction in 2007, the Optimum Low Vision Rehabilitation Service Delivery Model has not been implemented at either an institutional or state level. Although this medical model for LVRS has not been implemented into the U.S., it will serve to inform a new model of service delivery that bridges the medical and blindness systems for LVRS.



*Figure 2-3.* Optimum Low Vision Rehabilitation Service Delivery Model

The Department of Veterans Administration (VA) is an example of a national program that provides comprehensive, interdisciplinary vision rehabilitation programming, which is targeted to veterans with visual impairment. There are 13 inpatient Blind Rehabilitation VA centers throughout the U.S. (serving 12 states) and 56 outpatient centers (serving 35 states) that provide programming (Petzel, 2011). The

programs provide intensive services to support adjustment to vision loss and rehabilitation services to assist in the development of skills to support independent living. The VA program follows a similar model as the medical model discussed above, but veteran follow up and coordination of care in the program has been found to be poor (Agency for Health Research and Quality, 2002).

### **2.2.3.2 Practice Level**

#### *Self-Management Support*

As identified in the CCM model, chronic disease management requires the system to prepare the individual to manage his/her own care. Self-management is a key component of the practice level. Evidence supports the use of client centered care, which includes education and a problem-solving approach. Self-management education programs, individual or group, can increase functional independence, improve self-efficacy, and decrease depressive symptoms in individuals with VI (Teutsch et al., 2016; Lee, Packer, Tang & Girdler, 2008; Dahlin Ivanoff, Sonn & Svensson, 2002; Brody, Roch-Levecq, Kaplan, Moutier, & Brown, 2006). Dahlin Ivanoff and colleagues (2002) found that health education programs improved participant's perceived security in their ability to complete daily activities. Further, a systematic review of 12 randomized control and quasi-experimental studies found support for the use of self-management to improve functional independence, self-efficacy and decrease emotional distress in adults with AMD (Stellefson, Dipnarine, & Stopka, 2013). Brody and colleagues (2002) evaluated the effectiveness of a self-management program, consisting of health education and problem solving to improve quality of life for adults with AMD. They found

significant improvement in mood ( $p=0.02$ ), decreased emotional distress ( $p=0.001$ ), improved function ( $p=0.04$ ), and improved self-efficacy ( $p=0.02$ ). The outcomes were sustained at six month post-intervention (Brody, Roch-Levecq, Thomas, Kaplan, & Brown, 2002). In addition to functional improvements, self-management programs for adults with AMD have shown to have clinically significant reductions in depressive symptoms ( $p=0.03$ ) (Brody, Roch-Levecq, Kaplan, Moutier, & Brown, 2002). Self-management will help to facilitate effective interactions and well-informed clients.

#### *Delivery System & Clinical Information Systems*

As a result of the U.S. Rehabilitation Act of 1973, all states are funded to provide services to those who meet the legal definition of blindness. These state social service systems vary in scope and capacity of services. National, state, and private agencies provide varying levels of care to those with VI and blindness. Due in large part to budget constraints, the scope of these services is often limited.

Most states include a Commission for the Blind, which provides surveillance, referral and resources. Some also provide direct vision rehabilitation services. The scope and duration of these services varies dramatically and is often dependent on state and federal funding. Ophthalmology and optometry practitioners often refer clients to a Commission for the Blind when they meet designated visual functional deficits; in most cases legal blindness (Overbury & Collin, 2000). Some states, including Massachusetts, have begun to broaden the service delivery. However, these services are often offered only to a select group of people who meet service requirements, such as working adults (Saner, 2017).

#### **2.2.4 Summary of Literature Review**

The majority of studies addressing barriers and facilitators to accessing care occurred outside of the United States (US), including studies conducted in the United Kingdom, Canada, Australia, and India. Given differences in health systems between the U.S. and that of other countries, it will be important to understand the U.S. consumer perspective to guide effective intervention and policy change. In addition, many of the studies included were completed in large eye care practices or addressed only those who met particular categories of VI, which may not reflect the access barriers of the general population. Other limitations included small sample sizes, outcome measures that were not sensitive enough to determine change, sampling bias, and poor response rates.

Although there are a variety of models of LVR practice, there is limited evidence on the most effective model of service delivery. The majority of literature is on the efficacy of interventions or particular aspects of care versus models of care. Although there are studies that support the use of interdisciplinary and multidisciplinary care to provide the most comprehensive services to individuals with VI, there are no examples within the U.S. of an effective integrative medical and social system model of LVRS. Despite evidence to support coordinated care, the MCB primarily provides vocational rehabilitation services with limited funding and support available for adults with vision loss. The models identified in the literature review can serve as a reference to guide the development of a revised stakeholder driven model of care.

## CHAPTER 3: SYNTHETIC ESTIMATION

### 3.1 Introduction

In the U.S., VI impacts over 7 million adults over the age of 65 (Lighthouse International, 2014; Centers for Disease Control and Prevention, n.d.). This number is expected to rise with the aging of the population, as prevalence of VI increases with age (Centers for Disease Control and Prevention, n.d.). Rates of VI increase from 0.9-2.2% for those 65-69 years, and to 10.5-20% for those 80 years and older, depending on race (National Eye Institute, 2016). In MA in 2015, those 65 and older made up 15.3% of the population; it is estimated that by 2030 this will increase to 21.2% (Dugan, Porell, & Silverstein, 2015).

Although there are population estimates of the number of adults with VI, most studies provide data at the state or country level. To understand the current needs of those with VI within the context of MA or other localities, it will be important to understand the prevalence rate of VI at a town or community level. This study aims to characterize the existing low vision service delivery system and calculate the prevalence rate of VI by town throughout MA and presents a methodology that could be applied to others states. This data will be used to inform a new model of LVRS delivery.

### 3.2 Methods

Quantitative methods were used to calculate the prevalence of VI and number of individuals registered as legally blind by town, and to identify the existing services within MA. Existing services provided throughout MA were identified through literature review

and ongoing communication with low vision stakeholders. Services were categorized as low vision services, community and social services, and peer support groups. Synthetic estimation was used to make estimates of the prevalence of VI of the 351 towns in MA, using national estimates of VI and town level census data. These data were used to identify geographic areas for which to draw focus groups to identify perceived barriers and facilitators to accessing LVRS for older adults with VI in both high and low resourced communities and provide quantitative data to inform the development of a new model of service delivery. Prior to data collection, approval for the study was obtained through the Boston University Institutional Review Board.

### **3.3 Data Collection**

In order to synthetically estimate the prevalence of VI across MA, three data sources were used: 1) the 2016 American Community Survey (ACS); 2) the National Eye Institute national prevalence rates; and 3) MCB counts of legally blind by town. The ACS is a cross sectional sample of all counties and county-equivalents throughout the U.S. (U.S. Census Bureau, 2016). The ACS uses a continuous measurement approach, collecting monthly samples to produce multiyear updated estimates, using four modes of data collection: internet, mailings, telephone interviews, and personal interviews. The data collected is then weighted using a ranking ratio estimation procedure to obtain estimates of U.S. residents' social, economic and demographic data (U.S. Census Bureau, 2016). Data from the 2016 ACS was used to collect town-level data for all towns in MA. The descriptive data collected, including number of residence by race and age bracket, were then organized by town zip code into an Excel spreadsheet. The national

prevalence rates for VI, stratified by age, gender, and race were then collected from the National Eye Institute (NEI, 2016). Total number of individuals registered as legally blind by town were provided by the MCB. Lastly, published resources, MCB, and other service providers were consulted to obtain a comprehensive list of medical, rehabilitative, and social services within MA in order to characterize existing services. Consultations were continued until no new services were identified. Providers of LV services, as identified by the MA Optometric Association, were identified as any service provider that self-identified as providing direct service to individuals who are blind or VI.

### **3.4 Data Analysis**

A quantitative descriptive approach was used to understand the prevalence of VI and the existing services within MA for adults with vision loss. Synthetic estimation using Census data and Geographic Information Systems (GIS) mapping were used.

#### *Synthetic Estimation*

Prevalence of visual impairment by town was estimated using ACS data for age bracket and racial group and established national prevalence rates of VI by age and race, refer to Table 3-2 (United States Census Bureau, 2018; NEI, 2016). Stratified estimates of adults by age (65-74; 75-84; 85+) and race (White, Black, Hispanic, Asian) were gathered and recorded for each town. National prevalence rate data was then applied to the population age and race categories in order to calculate the overall prevalence rate of visual impairment for each town in MA.

*Table 3-1: National prevalence rates based on age and race estimates*

	<b>65-74</b>	<b>75-84</b>	<b>85+</b>
<b>White</b>	1.3%	3.7%	18.71%
<b>Black</b>	2.3%	3.2%	10.35%
<b>Hispanic</b>	2.9%	6.6%	17.22%
<b>Asian</b>	2.2%	5.3%	14.97%

*Note.* Data for national prevalence rates from NEI, 2016

An example of the synthetic estimation can be found in Table 3-3 for the city of Boston. Each age bracket was broken down by race and national prevalence data was applied to calculate the estimated number of adults with VI in each category. A complete list of prevalence rate by town can be found in Appendix B.

*Table 3-2: Synthetic Estimation of Boston*

<b>Age</b>	<b>Race</b>	<b>Population</b>	<b>National Prevalence Rate</b>	<b>Est. Number</b>
<b>65-74 years of age</b>				
	White	19,833	1.3%	257.8
	Black	9,430	2.3%	216.9
	Hispanic	7,035	2.9%	204.0
	Asian	3,480	2.2%	76.6
<b>75-84 years of age</b>				
	White	10,943	3.7%	404.9
	Black	5,203	3.2%	166.5
	Hispanic	3,882	6.6%	256.2
	Asian	1,920	5.3%	101.8
<b>85+ years of age</b>				
	White	5,347	18.71%	1000.4
	Black	2,542	10.35%	263.1
	Hispanic	1,897	17.22%	326.7
	Asian	938	14.97%	140.4
<b>Total Population</b>				
<b>Total Est # of Individuals with VI</b>				3,415.3
<b>Total Population 65+</b>				72,450
<b>Prevalence Rate per 1000</b>				47.14

*Geographic Information Systems (GIS) Mapping*

GIS mapping was performed using ArcGIS 10.3. A database was created, which included zip code as the unit of analysis. Variables for each geographic region included estimated prevalence rates for VI, numbers of individuals registered as being legally blind, and the identified LV services. Once prevalence rates and numbers of adults who were identified as legally blind were calculated and existing services for individuals with VI were identified by zipcode, GIS mapping was carried out. Prevalence by town was mapped using the Massachusetts Community Boundary Layer obtained from MassGIS (2014). Available services were geocoded using ArcGIS Pro World Geocoding Service, and symbols were used to identify the different LV services.

GIS mapping was completed for both prevalence of VI and number of residents registered as legally blind. Each map contained 4 sets of data: 1) prevalence rate of VI or number of those registered as legally blind (gradient), 2) peer support groups (white dot), 3) community & social services (gray dot), and 4) low vision services (MD or OD) (black dot), refer to Appendix A. Low vision medical services were identified in 38 towns. A total of forty-nine low vision support groups and twenty-five social services were identified. The maps provide a visualization of the services within the state and the areas of highest prevalence.

Communities were then categorized as high or low resourced. High resource communities were defined as towns with high prevalence of VI or number of individuals registered as legally blind and include existing social services for individuals with VI and at least one low vision rehabilitation center or clinic. Low resource communities were

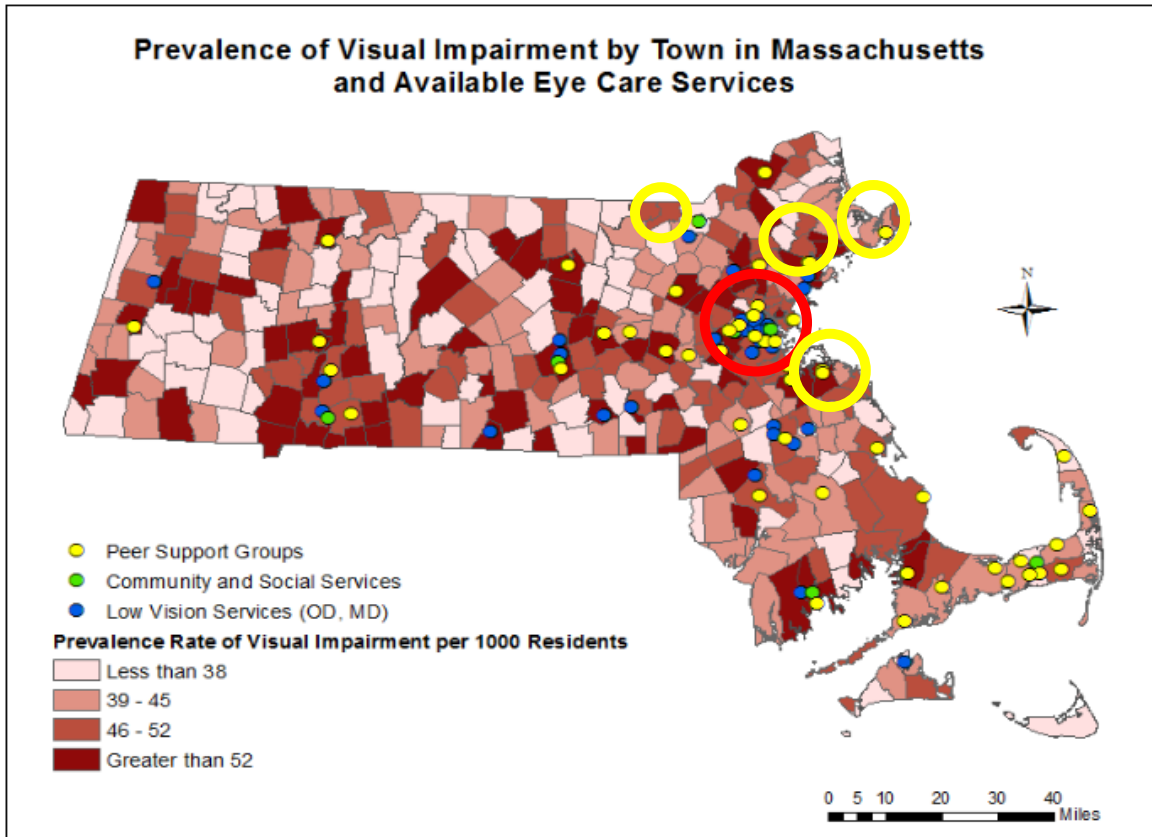
defined as towns with high prevalence of VI or number of individuals registered as legally blind and having no low vision rehabilitation centers or clinics.

### 3.5 Results

GIS maps were created to visualize the prevalence rate of visual impairment or the number of individuals registered with the MCB and the services available by town. The analysis shows the prevalence rate of VI and the distribution of services throughout the state. Town data can be found in Table 3-4. The maps also clearly illustrate the gaps in services available within towns throughout MA. These maps were then used to identify high and low resource communities for focus groups, refer to Figure 3-1. Towns identified as potential focus groups locations include: high resource communities (identified by a black circle), and low resource communities (identified by white circles).

***Table 3-3: Town Prevalence Rates and Resources***

<b>Prevalence Rate</b>	<b>% of towns</b>
Less than 38 per 1000	25%
39-45 per 1000	32%
46-52 per 1000	23%
Greater than 52 per 1000	20%
<b>Resource</b>	
High Resource Communities	9%
Low Resource Communities	91%



*Figure 3-1. High and Low Resource Communities in MA*

### 3.6. Discussion

Overall, communities with aging populations have the highest prevalence of VI and are found in suburban or rural areas. Conversely, the greatest number of resources are found in larger urban communities. This is consistent with previous findings, which found rural communities had increased barriers to basic and specialty eye care services (MacLennan et al., 2014; Overbury & Wittich, 2011). However, it is important to note that service reach was not evaluated within this study. It is possible that some services provide outreach to more rural communities.

Previous research has provided population estimates of VI and blindness at a state

or country level. The current study provides a comprehensive view of the current state of LV services for adults with VI in Massachusetts, as well as an estimate of the prevalence rate of VI and number of individuals registered as legally blind by town. High and low resources communities were identified and clear gaps in services throughout MA are highlighted.

### **3.7 Limitations**

The data in the ACS are population estimates and are at risk for sampling variation and error. However, due to the large sample size, these errors are minimized. This study also created a synthetic estimation using these population estimates and may not represent the true population. Prevalence rates were extrapolated from national averages and may not be representative of MA (NEI, 2016). Older adults in MA may differ from the national sample, however efforts were made to stratify the data by age and race to decrease potential bias. In addition, services were identified through literature review and communication with key stakeholder. However, some services may have not been reflected in this analysis, such as those provided within housing communities which may not have been known to stakeholders. In addition, communities may have been identified as having low vision services, yet, these services, while present, may or may not be provided on a regular basis. Finally, there was no analysis of service effectiveness with respect to how they meet the needs of the community (e.g. language, cultural appropriateness).

### **3.8 Conclusion**

As the majority of visual impairments are progressive and chronic, the data provided in this study can inform resource allocation and program development in order to address the ongoing needs of individuals with VI. The GIS maps can be used to prioritize efforts for new service provision, outreach to underserved populations, and education campaigns to improve awareness of LVRS throughout the state. Key findings indicate high and low resourced communities and the need to prioritize service provision in low resources communities throughout Massachusetts.

Areas for continued research and evaluation include analysis of the services provided within the communities, their effectiveness, sustainability, and reach. Access to services in identified high resourced communities was not taken into consideration for this study. Future research could explore transportation and other barriers which may influence LVRS use. With the aging of the population, both prevalence rates and available services will be important factors to consider when identifying future health care resources. The results of this study can be used to inform the development of a new model of service delivery.

## CHAPTER 4:

### PERCEIVED BARRIERS AND FACILITATORS TO ACCESSING LVRS

#### 4.1 Abstract

**Purpose:** To describe the barriers and facilitators to accessing low vision rehabilitation services (LVRS), determine if there were differences between high and low resource communities, and identify the demographic and service predictors of LVRS provision. This study was part of a larger project focused on developing a new model for low vision service delivery.

**Methods:** Utilizing a mixed methods approach, a purposive sample of adults with visual impairment (n=64) representing high and low resource communities engaged in focus groups and follow-up interviews. Barriers and facilitators to accessing LVRS were initially explored through focus groups. The resulting data were then coded and grouped into themes, guided by the Social Ecological Model (SEM). Following focus groups, participants were asked in one-on-one interviews to prioritize the themes that emerged from the focus groups and complete a questionnaire to collect additional data on demographics and service utilization. The resulting data were explored in bivariate analysis which examined reported barriers and facilitators to accessing services stratified by low vs. high resource communities. Multivariate logistic regression analysis was used to determine predictors of access to LVRS.

**Results:** Twelve themes emerged which were organized into the five levels of the SEM: (a) bureaucracy & funding (public policy), (b) public awareness and stigma (community), (c) services available, knowledge of providers, care coordination, transportation

(organizational), (d) people and lack of awareness of family/friends (interpersonal) and (e) income, health status, knowledge, self-advocacy, time (individual). Many of the identified themes were viewed as both a barrier and facilitator. In the bivariate analysis, only financial resources within high resource communities were found to be statistically different as compared to low resource communities ( $p=.001$ ). Differences in demographic and service utilization variables were examined for the entire sample ( $n=64$ ), comparing those who received LVRS and those who did not. A sequential multivariate logistic regression was used to examine the predictor variables that were found to be significant in the bivariate analysis as improving access to LVRS (Male gender, having a low vision examination, and being registered as legally blind). Only having a low vision exam was found to have a significant correlation with increased likelihood of accessing LVRS (OR 2.57, 95% CI 3.16, 53.53).

**Conclusion:** Key findings from the qualitative analysis indicate the need for: 1) coordinated services that address both medical and social services and the chronic nature of VI; 2) increased education to health care providers, consumers, and society; 3) client-centered care that is provided when the client is ready to accept services; and 4) service provision that takes into consideration sociodemographic factors. Each of these aspects needs to be considered when providing or planning low vision rehabilitation services. However, as suggested in the quantitative analysis, improving referral and access to low vision examinations are the most important predictor of accessing LVRS for adults with VI.

## 4.2 Introduction

Visual impairment (VI) impacts nearly 20% of Americans over the age of 65, roughly 7.3 million people (Crews & Campbell, 2004; Federal Interagency Forum on Aging-Related Statistics, 2012; Lighthouse International, 2014). Four of the five major causes of VI and blindness are age-related: age-related macular degeneration (AMD), glaucoma, cataracts, and diabetic retinopathy. With an aging population, the rate of adults with VI is expected to double by 2030 (Centers for Disease Control and Prevention [CDC], n.d.).

Visual impairment can impact all aspects of daily life. Crews & Campbell (2004), found individuals with VI were at an increased risk for greater functional limitations in daily activities, higher rates of systemic health conditions, increased social isolation and higher prevalence of depression, and increased risk of falls.

The rates of ocular disease and risk factors vary by race and age, refer to Table 4-1. Visual impairment has been identified as one of the top ten leading causes of disability in the U.S. (CDC, 2009). Chou and colleagues (2012), report that at least 50% of VI and blindness could be prevented with early detection and proper treatment. Vision rehabilitation services may assist individuals with VI to use compensatory strategies such as using tactile cues, electronic magnification, or organizational strategies to maintain health and independence. Despite service capacities, lack of access to vision rehabilitation services has been identified for all races and visual impairment categories. Lack of referral, knowledge of visual health, and awareness of rehabilitation services all impact utilization and visual outcomes (Casten, Maloney & Rovner, 2005; Proser & Shin,

2008). To that end, Healthy People 2020's vision goals included increasing access to vision rehabilitation services and the devices and strategies that have been found to be effective in reducing the functional implication of vision loss (Office of Disease and Health Promotion, 2018).

***Table 4-1: Prevalence of Visual Impairment by Race & Age***

<b>Eye Condition</b>	<b>Age</b>	<b>White</b>	<b>Black</b>	<b>Hispanic</b>
	65-69	25.0%	23.6%	24.3%
<b>Cataract</b>	70-74	37.4	31.7	34.4
	75-79	51.1	40.1	45.2
	80+	70.4	53.5	60.7
<b>Diabetic</b>	65-74	8.4	7.6	15.9
<b>Retinopathy</b>	75+	7.4	6.9	18.9
<b>Glaucoma</b>	65-69	1.6	5.7	2.4
	70-74	2.3	7.4	3.6
	75-79	3.3	8.9	5.4
	80+	7.42	11.4	10.4
<b>Age-Related Macular Degeneration</b>	65-69	.9	1.0	1.0
	70-74	1.7	1.3	1.2
	75-79	3.6	1.5	1.5
	80+	13.6	2.2	2.1

*Note.* Data for visual impairment from National Eye Institute, 2014.

A review of the literature was conducted to investigate the perceived barriers and facilitators to accessing LVRS for those with VI. The following common barriers to accessing low vision rehabilitation services (LVRS) were identified: a) public policy factors (lack of state and federal funding, and lack of coverage for prescriptive lenses or devices), b) community factors (perceived negative social implications, stigma), c) organizational factors (lack of awareness of available services and/or need for services by providers, education of providers, transportation, lack of communication between providers), d) interpersonal factors (lack of understanding of VI by friends and family),

and e) individual factors (socioeconomic status, education, lack of awareness of services, or efficacy of interventions) (Boyce et al., 2014; Matti, Pesudovs, Brown, & Chen, 2011; Overbury & Wittich, 2011; Overbury, Wittich, & Ferraresi, 2008; Pollard et al., 2003; Sloan, Yashkin, & Chen, 2014; Southall & Wittich, 2012; Spafford et al., 2010; Walter et al., 2004).

Services to individuals with VI have been underutilized by those who would benefit from service provision and are under supported by state and federal government (Equal Employment Opportunity Commission, 1978; Saner, 2017). One reason for this lack of utilization may be a lack of awareness of LVRS. Awareness of LVRS among those with VI ranges from 19-71%, while the demand for services is high (Casten, Maloney, & Rovner, 2005; Overbury & Wittich, 2011; Lam & Leat, 2013; Pollard, Simpson, Lamoreaux, & Keefe, 2003; Spafford et al., 2010). Although medical and social service resources exist for adults with VI, poor utilization, variable access in certain communities, and limited integration of service streams inhibits access to services. Given these challenges, this research aimed to answer the following research questions: What are the perceived barriers and facilitators to accessing LVRS for older adults with VI in high and low resource communities? I hypothesized that these barriers differ between high and low resources communities which impacts access to LVRS? The results of this study will be used to inform a stakeholder driven model of service delivery for those with VI and blindness.

### **4.3 Methods**

#### ***Participants***

Using stratified purposeful sampling, older adults with VI who resided in low and high resource communities were recruited for the study. High resource communities were defined as towns with high prevalence of visual impairment (moderate to high prevalence rate as identified in GIS mapping, >46/1000) or number of individuals registered as legally blind, existing social services for individuals with VI, and at least one low vision rehabilitation center or clinic. Low resource communities were defined as towns with high prevalence of VI or number of individuals registered as legally blind and having no low vision rehabilitation centers or clinics. Low vision support groups located in high and low resource communities were invited to participate, refer to Table 4-2. Contact information for each low vision support group was obtained through a social service agency coordinating peer led support groups. Low vision support group leaders communicated details of the study with members and identified individuals who were interested in participating. The primary investigator then spoke with interested individuals over the phone or in person, and invited them to participate. Study participation criteria included self-identification of having a VI, being a member of a low vision support group, and being at least 50 years of age. Written informed consent for participation in the research study was obtained by the researcher from each individual. Prior to the start of the focus group session, consent forms were provided in large print and verbally read or explained, as appropriate.

**Table 4-2: High and Low Resource Communities**

Town (high resource, HR; low resource, LR)	Number of participants	Estimated Prevalence of Visual Impairment per 1,000 adults 65+	Number of residents registered as legally blind
HR #1	8	47.46	241
HR #2	8	56.64	271
HR #3	7	44.50	211
HR #4	7	47.14	483
LR #1	7	51.77	463
LR #2	11	49.33	458
LR #3	9	57.21	81
LR #4	7	46.18	150

Estimated prevalence rates were calculated using a synthetic estimation; Number of residents registered as legally blind was provided by the Massachusetts Commission for the Blind, 2018

### ***Data Collection Strategies***

This study used a mixed methods sequential design approach, with the quantitative results building from the qualitative (Cameron, 2009; Fetters, Curry, & Creswell, 2013). Four focus groups consisting of 30 participants with VI from high resource communities and four focus groups of 34 participants with VI from low resource communities were facilitated. First, qualitative barriers and facilitators were defined through focus groups for adults with VI. Focus groups allowed for multiple perspectives and understanding the lived experience in accessing LVRS for individuals with VI living in both high and low resource communities. Second, those involved in the focus groups were asked to participate in a follow-up one-on-one interview, in which they prioritized key barriers and facilitators to accessing LVRS that had emerged from larger focus groups. They were also asked to identify any additional items not included on the list, which they felt were important to include. In addition, demographic and service utilization data was collected. This prioritization quantified and characterized the key barriers and facilitators at the individual level and allowed for identification of

differences on these between high and low resource communities. Demographic and service utilization data were analyzed to examine the relationship between these variables and access to LVRS. Prior to data collection, approval for the study was obtained through the Boston University Institutional Review Board.

### *Qualitative Methods*

Focus groups were conducted in conjunction with a scheduled low vision support groups in both low and high resource communities to facilitate optimal engagement. Each focus group included 7-11 people and was guided by a semi-structured interview guide which aimed to explore perceptions of barriers and facilitators to accessing LVRS. A focus group guide, created by the researcher and informed by a thorough literature review and the study's theoretical foundation, was used to ensure procedural consistency among the focus groups. The discussion questions for the focus groups were designed to explore the influences on health seeking behavior and the perceived influences on access to low vision rehabilitation services. Focus groups were facilitated at peer led support groups, and were audiotaped with permission and transcribed. Field notes were written during and immediately following each focus group and interview. Audio-recorded interviews were transcribed verbatim for analysis and data was analyzed through content and thematic analysis using line-by-line coding to identify themes.

In an effort to ensure rigor of qualitative methods, each member of the focus group was contacted via phone to schedule a follow-up one-on-one interview. This provided an opportunity for member checking, to verify accuracy and truthfulness of interpretation of focus groups and explore emergent themes in greater detail (Birt, Scott,

Cavers, Campbell, & Walter, 2016). Specifically, each participant was asked to clarify questions that arose from initial focus groups analysis and confirm key themes.

### *Quantitative Methods*

Follow-up interviews were conducted and demographic questionnaires were administered to collect demographic and service utilization data, and to prioritize the barriers and facilitators that emerged from the data. As previously discussed, the literature indicates sociodemographic (e.g. age, race) and lack of service utilization (e.g. having regular and specialty eye care) as factors associated with barriers to access LVRS. Given this, the quantitative analysis was driven by these variables. Data collected included the primary outcome variable of receiving LVRS (yes/no), and predictor variables: age (under 65 and 65 and older), gender (male/female), race (White and Non-White), education level (high school; some college; college graduate), marital status (married, lives alone), visual diagnosis (age-related or congenital VI), registration with the Massachusetts Commission for the Blind (yes/no), and having a low vision exam (yes/no). These data were collected to examine differences between respondents from high and low resource communities and to determine the relationship between access to LVRS and sociodemographic factors.

All participants were then given a list of themes that emerged from the focus groups related to barriers and facilitators to care. Each participant was then asked to prioritize the top three to five key barriers and facilitators detailed on the list according to their own experiences with accessing LVRS. These responses were used to further

examine key barriers and facilitators and permitted comparison between low and high resourced communities.

#### **4.4 Data Analysis**

##### ***Qualitative Data***

Qualitative descriptive inquiry was used to explore the perceived barriers and facilitators to accessing LVRS in adults with VI that were discussed in the focus groups (Colorafi & Evans, 2016). Qualitative descriptive inquiry is a methodology used, in this case, to describe the perceived barriers and facilitators of adults living with VI. In this method, the interpretation of the data is less transformed (Sandelowski, 2000; Sandelowski, 2010). Open coding was completed and organized using QSR International NVivo qualitative data analysis software (Version 11). Each transcript was read twice by the researcher prior to initial coding of the data. Each focus group transcript was coded individually; the researcher took written notes and created memos throughout the coding process to help clarify thoughts or questions which arose during the data analysis phase. As additional interviews were coded, a codebook with definitions was created; new codes were added throughout the coding process, and some codes which shared definitions were collapsed into one. Data collection continued and new codes were added as they emerged until no new codes were identified. Once final codes were established, these were then grouped into themes. Themes were confirmed with a second reader, a research assistant. The assistant reviewed two randomly selected transcripts from each category (high and low resource community) using the same line-by-line coding method and took written notes and memos of codes as they emerged. The Principal Investigator and

research assistant then met to discuss findings and any discrepancies were discussed and resolved. Codes were reviewed and codes with similar ideas were grouped, and defined. These codes were confirmed and then grouped into themes which were organized by the levels of the Social Ecological Model (SEM). Lastly, analysis was compared to the existing literature.

### ***Quantitative Data***

Descriptive analysis was conducted to characterize the distribution of the independent variables for both the high and low resource communities. Means and standard deviations were used for continuous variables and proportions were used for categorical indicators. Bivariate analysis, using t-tests and chi-square analysis, were then used to determine differences between high and low resource communities on perceived barriers and facilitators and ascertain if further analyses required stratification.

Among the key barriers and facilitators presented to the participants, frequencies were calculated for each barrier and facilitator prioritized. The barriers and facilitators were ranked according to prevalence rate of response from participants. These were then compared between high and low resourced communities.

Because there was no difference in perceived barriers between high and low resourced communities, the entire sample was used for further data analysis. The relationship between each independent variable (i.e., demographics, service utilization) and dependent variable (i.e., access to LVRS) was examined using bivariate analysis. Each demographic and service utilization variable and its relationship to the outcome variable, LVRS, was examined, refer to Table 4-3. Initially, all independent and outcome

variables were analyzed separately. To determine which variables were independently associated with access to LVRS, sequential multivariate logistic regression was used.

#### **4.5 Results**

Sixty-four adults (high resource (HR) = 30, low resource (LR) = 34) with self-reported VI participated in the focus groups, refer to Table 4-3. The age range of the 64 participants was 50-98 years of age, with a mean age of 74.70 (1.71) years. The majority of participants identified as female, White, living alone, and registered with the Massachusetts Commission for the Blind. Visual diagnoses varied and included age related macular degeneration, glaucoma, diabetic retinopathy, corneal disorders, and a combination of visual conditions. The majority of participants received regular eye care, but few reported receiving comprehensive low vision rehabilitation services.

**Table 4-3: Descriptive Characteristics of Participants stratified by Low and High Resourced Communities**

	low resource (n=34)	high resource (n=30)	Between group differences p-value	total (n=64)
<b>Demographic</b>				
<b>Age, mean (SD)</b>	74.29 (2.46)	75.17 (2.40)	0.42	74.70 (1.71)
<b>Gender, %</b>				
<b>Female</b>	79	70	0.78	75
<b>Male</b>	21	30	0.62	25
<b>Race</b>				
<b>White</b>	88.20	70	0.83	79.70
<b>Non-White</b>	11.8	30	0.18	20.3
<b>Marital Status, %</b>				
<b>Married</b>	34.71	26.67	0.33	31.25
<b>Not married</b>	65.29	73.33	0.33	68.75
<b>Education, %</b>				
<b>High School</b>	52.90	46.67	0.72	50
<b>Some College</b>	17.65	16.67	0.92	17.60
<b>College or higher</b>	29.45	36.66	0.61	32.40
<b>Congenital Dx**</b>	8.80	16.67	0.38	17.19
<b>Age-related Dx</b>	91.20	83.33	0.31	82.81
<b>Service Utilization</b>				
<b>Legally Blind, %</b>	79.41	50	0.15	65.63
<b>LV Eye Exam, %</b>	38.24	40	0.91	39.06
<b>LVRS, %</b>	26.47	23.33	0.80	25
** excluded from final analysis				

**Focus Group Results**

Twelve themes emerged which were organized into the five levels of the SEM:

- (a) bureaucracy and funding (public policy), (b) public awareness and stigma (community), (c) services available, knowledge of providers, care coordination, and transportation (organizational), (d) people and lack of awareness of family/friends

(interpersonal) and (e) income, health status, knowledge, self-advocacy, and time (individual), refer to Table 4-4.

***Table 4-4: Emerged Themes Organized by Level of the Social Ecological Model***

<b>Level</b>	<b>Themes</b>
Public Policy	Bureaucracy/Policy
Community	Lack of knowledge and stigma
Organizational	Lack of services Lack of knowledge-provider Lack of coordination of care Transportation Lack of individualized care
Interpersonal	Lack of support & lack of knowledge- others
Individual	Lack of knowledge-self Time Cost Readiness to accept services

#### *Public Policy*

When discussing barriers to accessing LVRS, several participants described the influences of public policy on accessing care. Specifically, this included challenges created by the VI continuum, financial, or age restrictions on service provision, and the lack of funding for service provision for older adults. When discussing the continuum of VI, one participant responded, “You have access or don’t have access based on where you fall along some arbitrary continuum (HR).” Many participants discussed the bureaucracy of policy restrictions or qualifications required for obtaining services. One participant stated, “You can fall through the cracks of not meeting the right criteria for getting services...there’s qualifiers as far as income or age (HR).” Another participant discussed the policy and funding challenges of service delivery within the Commission for the Blind, “Unless you’re in a working situation, the commission isn’t with you as

much as they are in a working situation. It's like we're lower class citizens. And it's like you said, they only have so many resources (LR).”

### *Community*

Many participants discussed the lack of public awareness surrounding VI and the stigma associated with vision loss. Many participants identified a lack of public awareness of VI. One participant stated, “I was at my doctor's office yesterday, and I am supposed to follow a nurse. Where's the nurse?...That happens a lot (LR).” Another participant stated, “There is just not enough awareness for that. Even within the disabled community there is not enough awareness. And I've been actively engaged in several different organizations now to get them to realize (LR).” Others discussed the associated social stigma with VI. One participant reported, “There is a stigma in our society about blindness. There are a lot of stereotypes about blindness, what blindness looks like, who is blind and who isn't (LR).”

### *Organizational*

Nearly all focus groups identified organizational factors that influence access to LVRS and reported a lack of services available in their community as a significant barrier. One participant stated,

“Services for the blind are probably understaffed, there are too many clients. They take a cookie cutter approach because they don't have time to do it all individually. It costs a lot of money to help us adapt. And the administration is trying to cut money everywhere. And society goes in waves of helping those in distress (LR).”

Focus groups participants discussed significant barriers regarding the lack of understanding of available services and of referrals provided by their healthcare provider.

One participant reported,

“I haven’t been to my eye doctor in several years. I like him very much, but every time I would go, every 6 months, he would say your eyes are healthy. There’s nothing wrong with them. Everything is wonderful, except you’re blind and there’s nothing I can do (LR).”

Many reported hearing, “There is nothing more I can do” from their eye care practitioner while seeking support and services to assist with adjustment and improving functional abilities. Another participant reported,

“Knowledge is a huge thing.... providers should know what’s available. There can be a disconnect between when people go to see their doctor and they say I have vision problems and they’re like ok well go figure it out versus when you’re declared legally blind then they might take more of a role in making the connections (HR).”

Further, all focus groups reported a lack of care coordination in relation to their vision loss. One participant reported, “All the agencies that are so important to us don’t talk to each other (HR).”

Similarly, all focus groups identified transportation as either a barrier or facilitator and an important piece of coordinated care. Many discussed access to public transportation, community ride programs, or other paid services. One participant stated, “Taxis are expensive. And so it makes it difficult. But I do the best I can, but it’s not

great (HR).” Another participant reported that he participated in a pilot transportation program. He stated, “It was excellent. I say it was excellent because it suited me to a tee. And I think I’m the average consumer (HR).” A transportation system providing an appropriate level of support was identified as a key factor. For example, a door-to-door system was found to be more beneficial than a curb-to-curb service. Some communities offered their own transportation systems, some had set limitations, such as to doctors’ appointments, while others were more flexible to the individual’s transportation needs. One participant stated, “I will never move out of my community because of the transportation (LR).” Many discussed the challenges of time, as some systems required advanced planning, “I call maybe a week ahead and then you have to call two days before they’re supposed to pick you up (LR)” or were shared rides that required additional time due to frequent pickups and drop offs. One participant stated, “A thirty-minute eye doctor appointment can take all day (LR).”

### *Interpersonal*

All focus groups reported interpersonal factors as both a barrier and facilitator in accessing care. People, most often friends and family, were identified as an influence in accessing low vision services. People could act as a facilitator in providing assistance and support. One participant stated,

“My daughter makes my doctor’s appointments, she’ll call them and assign somebody to come and meet me at my place and we go and we go together in the car and they stay with me through the appointment and it is strictly volunteer (HR).”

However, many participants verbalized fears of being a burden in asking friends and family for frequent assistance. In other instances, people's lack of awareness created a barrier to understanding the individual's needs. In terms of understanding, one participant reported, "If I don't have my cane then people will look at me like I'm crazy and tell me "No, you're not blind" (LR)." Another participant noted that her family overcompensates and limited her independence, "You know when in social situations...they feel obligated to say like "Oh, there's a curb here." or "Watch out for that." They don't want me to fall when I'm with them (LR)."

Many participants identified access to peer support groups as a facilitator to accessing care or understanding services available within their community. Participants discussed how they were referred to the peer support groups. For some, their eye care provider provided the referral, some were referred from the Commission for the Blind, while others were referred by friends or family. One participant discussed the importance of the peer support group, "We learn from each other more than anything else (LR)."

### *Individual*

All focus groups identified individual factors that inhibited or facilitated access to care. Seven of eight focus groups identified financial factors impacting access. Many noted services required out of pocket expenses, which created an access barrier. Participants noted, "There are devices and those kinds of things that can help you," "They are really expensive, (HR)" and "Money is the bottom line (LR)." Others reported that having financial resources was a facilitator in accessing services or technology. One participant stated, "There are so many advancements and technologies that are available

if you can afford them (LR).”

Many participants discussed the impact of other chronic conditions on access to LVRS. One participant stated, “There are all of these things that have an impact on my life as someone who has encountered and daily encounters increasing VI as well as hearing impairment and other health challenges (HR).” Addressing multiple chronic health conditions created barriers for everyday tasks, as well as managing multiple appointments and medication regimens. Others discussed the challenges of maintaining confidentiality when assistance is needed with reading forms or health information. One participant stated,

“What about medical confidentiality, that’s the thing that drives me crazy.

Everybody wants to send me letters and stuff but then I got to have somebody read. I don’t want people knowing about my medical stuff, that’s my stuff (LR).”

Many participants discussed the technology divide that impacted their health literacy and medical management. One participant stated, “Technology is overwhelming (HR).” Others discussed needing to be connected to technology for health information or communication with health providers or community services. One participant commented, “It is assumed that people communicate via email, but I don’t have access. Here is a newsletter from the center, if it wasn’t for something like this [peer support group] or my friends I wouldn’t hear anything (HR).” Another stated, “There is a need for more accessible information, so you feel informed (HR).”

All focus groups discussed the limitations of their own awareness of services available within their communities. One participant stated, “I’m very lucky I think

because I don't know anything, he [my doctor] doesn't tell me anything, so I don't know anything (HR)." Many discussed the challenges of the VI continuum and how that impacted access to services. One participant stated, "There's lacking in that [services]. Everybody's puts you in a different bracket... you have access or don't have access based on where you fall (HR)."

Many participants discussed acceptance of the vision loss or readiness for services as a barrier to the delivery of care. Participants discussed how services are provided episodically and did not meet the chronic nature of their visual condition. One participant stated, "When you're first referred they have everybody descend on you (HR)." Many reported feeling unready or unable to identify their needs when first diagnosed, "I don't know what I need!" (LR). They felt that they needed time to adjust to their loss and slowly be introduced to strategies to assist in daily tasks. Another participant stated, "They only offer it when you're too new to deal with it, and there's no way you're going to want to talk to someone about it. It's about the timing and repeat (HR)." Many participants discussed the ongoing needs and progressive nature of vision loss, "There are continual changes that get worse and worse. It doesn't get better. And every time it changes, there's something new to adjust to (LR)."

Being a self-advocate was identified by all focus groups as a facilitator in accessing care. Many participants voiced the importance of speaking up and asking for help, "You can't be shy about asking people (LR)." One participant stated, people need to "be individually proactive according to his or her lifestyle and get yourself informed about what is available (LR)."

Lastly, time was identified as a barrier for many focus group participants. Some discussed the delays in terms of accessing services and the impact of managing multiple chronic conditions on time and access. Because many relied on others or public transportation, the time it took to go to appointments was significant. Many discussed the frustration of time and how long it takes to do everyday tasks. One participant stated, “I used to do my checkbook in 20 minutes, now it takes me an hour and a half (LR),” and another stated, “It’s exhausting being in our world (LR).”

### ***Quantitative Results***

There were no statistically significant differences found in identified barriers between high and low resource communities in terms of perceived barriers to accessing LVRS, refer to Table 4-5. However, financial resources as a facilitator was found to be significantly different ( $p=.001$ ) between high and low resource communities. As the initial hypothesis was that there would be differences in perceived barriers between communities was disproved, an alternative hypothesis that having a low vision examination would increase the likelihood of accessing LVRS was examined.

**Table 4-5: Prioritized Barriers and Facilitators to Accessing LVRS by High and Low Resource Community**

	HR Communities (N=30)	LR Communities (N=34)	Chi-square p-value
<b>Barriers</b>			
Knowledge-provider	77%	91%	0.56
Knowledge-consumer	90%	76%	0.56
Lack of coordination of care	53%	44%	0.75
Transportation	27%	35%	0.85
Readiness	20%	15%	0.86
Lack of individualized care	10%	12%	0.83
<b>Facilitators</b>			
People	97%	100%	0.53
Peer Support Groups	67%	76%	0.38
Self-advocacy	43%	62%	0.17
Resources/Financial*	40%	0%	0.00
Transportation	30%	15%	0.29
* statistically significant difference between high and low resourced communities, p value <0.05; variables with response rates <10% were omitted from this table			

### ***Predictors of Access to LVRS***

To examine the relationship between demographic and service utilization variables and accessing LVRS, bivariate analysis (t-test or chi-squared) was completed. Three variables were found to be statistically significant, gender ( $p=0.05$ ), registration with MCB ( $p=0.02$ ) and having received a low vision eye exam in the last year ( $p=0.01$ ). These three variables were entered into the sequential multiple logistic regression model. Given the small sample size and aim to create the most parsimonious model, each variable was entered individually. First, given the hypothesis that having a LV examination was the key variable in accessing LVRS, the base model included only having a LV exam (Model 1). Because those registered with the MCB should have received LVRS as part of regular service delivery, this was entered next into the model (Model 2). Registration with MCB was not significant in Model 2 (OR 21.24, 95% CI

0.54, 48.59), therefore, it was not included in Model 3. In Model 3, gender (i.e. Male) was introduced to the model along with LV exam. Gender was not significant (OR .8, 95% CI 0.57, 13.06). The most parsimonious model, the original Model 1, which only included having a low vision exam as a predictor of accessing LVRS, showed OR 2.57 and 95% CI of 3.16, 53.53.

**Table 4-6: Relationship between demographic and service characteristics and receipt of LVRS**

Logistic Regression Model	Model 1		Model 2		Model 3	
	OR	COI	OR	COI	OR	COI
LV Exam*	2.57	3.16, 53.53	1.94	1.57, 30.56	1.70	1.19, 25.40
Registration with MCB			21.24	0.54, 48.59		
Male					.80	.57, 13.06

#### 4.6 Discussion

Previous research identified barriers and facilitators to accessing care for adults with visual impairment, however, none within the context of high and low resourced communities. Many of the key themes that emerged from the data are consistent with previous studies, including knowledge of provider, transportation, restrictions created by policy, people, and financial resources. However, additional themes emerged from the data that are less clearly identified in previous research. These include: lack of care coordination within the medical and social services systems, readiness to receive services, lack of individualized care, influence of peer support groups, and the importance of self-advocacy.

The lack of practitioner's knowledge of available LVRS, requirements for access to these services, and the efficacy of interventions were identified as primary barriers in

both high and low resource communities, which is consistent with previous findings (Southall & Wittich, 2012; Wittich, Canuto, & Overbury, 2013; Spafford et al., 2010). Given the results of this study and the correlation between having a LV eye exam and accessing LVRS, it is essential that eye care practitioners understand the importance of and provide referral to LVRS.

Likewise, the challenges of transportation systems identified within focus groups were similar to previous studies (Spafford et al., 2010; Wittich, Canuto, & Overbury, 2013). Although there were differences between high and low resource communities in terms of what types of transportation systems were available, both communities identified accessible transportation as a barrier. Cost, time, and type of service were all significant barriers to access. Future research should explore effective models of transportation for high and low resources communities. Transportation should be considered when scheduling LVRS and coordinating care for adults with VI.

Restrictions created by policy for access to service provision have been discussed in previous studies as a lack of provider awareness of qualifying factors for referral to services (Matti, 2011). Continued education for eye care, primary care, as well as rehabilitation service provider education could improve awareness of available services and qualifying criteria for service provision.

All focus groups discussed the influence of people, most often family and friends, on access to LVRS. Lack of awareness of VI was often discussed as a limiting factor for access, which is consistent with previous studies (Spafford, 2010). Others discussed the positive influence of social support in attaining access, when there was awareness of the

functional implications of VI. Family and caregiver education should be considered an important piece of comprehensive LVRS.

Consistent with the evidence, financial resources were identified as a factor in accessing LVRS (Spafford, 2010; Gold & Simpson, 2005). Participants identified the cost of glasses and low vision devices as a barrier to care. Several studies reported that individuals with lower socioeconomic status were less likely to access LVRS or the devices necessary to improve functional independence and quality of life (Walter et al., 2004; Gold & Simpson, 2005; Chiang, Xie, & Keeffe, 2011). In order to maximize service provision and client outcomes, cost and financial resources need to be considered when an individual is assessed for LVRS.

### *New Themes*

Care coordination was identified as a primary barrier for participants in high and low resource communities. Previous literature discussed the limitations created by a lack of communication, which delayed referral to services (Southall & Wittich, 2012; Wittich, Canuto, & Overbury, 2013). Studies reported that nearly half of eye care providers found registration of their clients as the final stage of their medical management of their client with VI and they were unclear on their role in referral or the services available to their clients (Boyce et al., 2014; Chiang, Xie, & Keeffe, 2011). In this study, only 16 participants (25%) reported receiving LVRS and 100% reported need for additional services. This perception of difficulty of referral and lack of information delayed connection to social and rehabilitation services. Participants discussed the need for coordinated services and the importance of a referral from the eye care practitioner.

Connection between providers should occur at all levels throughout the healthcare and social service systems with regular communication about treatment, expectations, and client needs.

An individual's readiness to receive LVRS emerged as a theme. Many verbalized the difficulties in adjusting to vision loss and the challenges of services being provided when first diagnosed. About 10-30% of individuals with VI have been found to have clinically significant depression (Casten & Rovner, 2013; Horowitz, Reinhardt, & Kennedy, 2005). Rovner and colleagues (2011) found that LVRS decreased incidence of depressive disorders by 50%. Service provision should consider the readiness of the individual to accept LVRS and be provided at the appropriate time to meet the individuals identified needs. In addition, many participants receiving care from the Massachusetts Commission for the Blind discussed the lack of individualization. Awareness of the individual's readiness to receive services, including factors that facilitate or inhibit willingness to participate should be considered (Mohler, Neufeld & Perlmutter, 2015). Service provision must include client-centered, evidenced-based interventions that integrate the individual's priorities for care and readiness to receive services.

Lastly, participants identified the influence of peer support groups and the importance of self-advocacy as facilitators in accessing services. Previous literature discussed the psychological barriers of fear, perceived vulnerability and stigma in accessing LVRS (Pollard, 2003; Spafford et al., 2010; Lam & Leat, 2013; Southall & Wittich, 2012). Participants reported peer support groups as a source for information,

social network, and a safe space to discuss fears and frustrations related to vision loss. Many participants identified peer support groups as the only source of information regarding services. In addition, all focus groups identified the importance of self-advocacy in obtaining services to support independence. However, the majority of participants were unaware of LVRS making self-advocacy difficult. These findings highlight the importance of education to consumers and practitioners on the efficacy and availability of LVRS.

### ***Implications for Practice***

As the majority of visual impairments are progressive and chronic, LVRS should be provided to address the ongoing needs of the individual. Currently, most services are provided as episodic care (Saner, 2017). Integration of vision care into primary care could increase access to services and potential funding for service provision and continuity of care. Primary care should consider screenings for any adult with diabetes, and for all adults over 65, with appropriate referral as needed (U.S. Preventive Services Task Force, 2016). Continued research is needed on effective models of practice, program outcomes, and efficacy of interventions. In addition, as VI is expected to increase in prevalence over the next decade, continued surveillance is needed.

### ***Implications for Provider Education***

Due to the aging of the population, there is a need for an increased number of trained practitioners to provide LVRS. The lack of adequately trained practitioners to address the growing need of adults within Massachusetts has been previously identified (Saner, 2017). Academic programs should use established practice guidelines to direct

curricula and provide practitioners with evidence-based recommendations for screening, evaluation, treatment, and referral. Increased provider awareness of services and the efficacy of LVRS for their clients will improve referrals to services and ultimately improve client outcomes and quality of life.

#### **4.7 Limitations**

Although the research has been designed to minimize bias, there are limitations to this study. First, sampling was limited to the context of the Commonwealth of Massachusetts. As a result, this study only reflects the perceived barriers and facilitators of adults in the context of the Commonwealth of Massachusetts. In addition, the sample size is small (n=64), analysis is likely underpowered to detect differences. Secondly, focus groups conducted at low vision support groups in low and high resource communities were used to collect initial data. Responses from focus group participants may be influenced by other members of the group or the researcher's questions. Further, use of peer support groups, because members have been successful in seeking social supports, may not be reflective of all adults living with VI. As a result, this may not be generalizable, as resources and constraints may vary significantly in different parts of Massachusetts, or the U.S. Third, due to the nature of the focus groups, individuals with congenital VI were included in the study. Those with congenital VI may experience LVRS differently than those with acquired VI. Regression analysis was completed without inclusion of those with congenital diagnoses in order to account for this potential difference, n=60. Lastly, although attempts were made to minimize researcher bias through careful development of interview guides and data analysis methods, the

researcher's clinical experience, personal beliefs, and knowledge may have introduced bias to the research. The researcher is an occupational therapist who works with adults with VI and has heard personal stories of individuals who have struggled to access the appropriate levels of LVR care or who have lived with unnecessary levels of disability due to lack of referral. This professional experience may influence interpretations. The researcher practiced reflexivity to reduce this potential bias including using field notes written during and immediately following each focus group allowing for ongoing reflection and use of a second reader for theme development. Given these limitations, this study should be considered exploratory but provides preliminary data to inform service delivery.

#### **4.8 Conclusion**

This study provides insights into the perceived barriers and facilitators of accessing LVRS for adults with VI living in Massachusetts. The results of this study can be used to inform the development of a new model of service delivery. Key findings indicate the need for: 1) coordinated services that address both medical and social services and the chronic nature of VI; 2) increased education to health care providers, consumers, and society; 3) client-centered care that is provided when the client is ready to accept services; and 4) service provision that takes into consideration sociodemographic factors. Each of these aspects need to be considered when providing or planning LVRS.

## **CHAPTER 5: STAKEHOLDER-DRIVEN MODEL OF LOW VISION REHABILITATION SERVICE DELIVERY**

### **5.1 Introduction**

For those with uncorrectable visual impairment (VI), there is much that can be done to support independence and quality of life (Rein, Wirth, Johnson, & Lee, 2007; Maciosek, Coffield, Flottemesch, Edwards, & Sloberg, 2010). Low vision rehabilitation services (LVRS) teach individuals with VI compensatory strategies, including visual skills training, assistive technology, and environmental modifications to participate in activities of daily living. In the U.S., there are currently no statewide comprehensive LVRS that serve both individuals who are blind and those with low vision. Services are often provided in a limited capacity and are often dependent upon financial resources, eligibility, and referral practices (Chiang, Xie, & Keeffe, 2011; Chiang et al., 2011; Wittich, Canuto, & Overbury, 2013).

Given these challenges, this research aimed to develop a new model of low vision rehabilitation service delivery for adults with VI. The research sought to understand the perceived barriers and facilitators to accessing care for older adults with VI, as well as other key stakeholders. These identified barriers need to be considered when developing the new model of service delivery. In addition, the research sought to explore if the Chronic Care Model (CCM) could be used as a framework to guide a new model of LVRS delivery. Results from focus groups, key stakeholder interviews, as well as literature reviews were used to inform model development.

### *Current Service Delivery*

In the United States, medical low vision (LV) services are provided at three levels of care. At the primary level of care, basic LV may be provided by a primary eye care provider. This level of care typically consists of assessment of functional vision and may include a referral for a comprehensive LV evaluation provided by an optometrist or ophthalmologist specialized in LV. In addition, there are community self-management programs that may provide some instruction of compensatory strategies to help the individual with VI adjust to vision loss (Brody et al., 2002). Providers may refer to these community services or individuals may find them on their own. At the secondary level, a LV exam is part of comprehensive eye care services. These services may be provided by an optometrist or ophthalmologist and include medical management, a functional assessment of vision, device prescription, and referral to LV rehabilitation services (LVRS) (Kammer, Jamara, Kollbaum, Matchinski, & Flom, 2010). At the tertiary level of care, LVRS consist of a multidisciplinary team providing comprehensive LV services (Kuyk et al., 2008; Stelmack et al., 2008). These services can be provided within a free-standing clinic or in collaboration between eye care and vision rehabilitation specialists.

In addition to services offered through the health care system, services are also available through the blindness system. These services are complementary to those provided within the health care system, but dependent on a referral from a medical or eye care provider. The blindness system is a national network of agencies that provide services to the blind and in some states, to those with LV. However, in Massachusetts (MA), no statewide blindness services are available for those with LV. An adult with a

VI is only eligible for services from the Massachusetts Commission for the Blind (MCB) if they meet the legal definition of blindness (Social Security Administration, 2014) or are currently employed. This system is largely funded by federal funds as a result of the Rehabilitation Act of 1973 (Public Law 93-112) (Equal Employment Opportunity Commission, 1978). Initially, federal funds were provided for vocational rehabilitation, but were expanded to include independent living training for older adults with Title VII, known as Part B Amendments to the Rehabilitation Act in 1978. Vocational rehabilitation programs remain the primary focus, with limited funding available for nonworking older adults (Saner, 2017). In MA, 80% or more of the state and federal funding is earmarked for vocational training programming. As a result, and despite the services available to all ages within the blindness system, older adults are the most underserved population within the existing system (Equal Employment Opportunity Commission, 1978; Saner, 2017). There are also a small number of community programs that provide adjunctive support to the health care and blindness system, such as peer-led LV support groups, device loan programs, and reading programs for the blind and visually impaired. Currently there is limited collaboration between these three systems to provide the necessary services for those with VI.

### ***Chronic Nature of Visual Impairment***

Despite the evidence supporting an interdisciplinary approach to care with ongoing communication and follow up, LV services are often provided in isolation with little communication between systems. Access to systems vary dependent upon the level of VI and other factors such as income or employment status. In addition, care is often

provided episodically which does not address the chronic nature of vision loss or the ongoing functional needs of individuals with VI.

Like other chronic conditions, VI can have a significant impact on an individual's daily function and quality of life. In a study examining conditions included in multimorbidity indices, VI was included in a third of all indices measured (Diederichs, Berger, & Bartels, 2011). Individuals with VI were found to be at increased risk for greater functional limitations in daily activities, higher rates of other chronic health conditions, increased social isolation, higher prevalence of depression, and increased risk of falls (Campbell et al., 1999; Sibley, Voth, Munce, Straus, & Jaglal, 2014; Chang-Quan, Bi-Rong, Zhen-Chan, Ji-Rong, & Qing-Xiu, 2010). Compared to the general population, those with VI had greater limitation in mobility, self-care, daily activity, increased reports of pain, anxiety, and depression (Langelaan et al., 2007). Further, when compared to other chronic conditions, VI was only surpassed in severity by stroke and chronic fatigue syndrome. As such, intervention for VI should address the chronic nature of the condition.

To address the chronic nature of VI, the Chronic Care Model (CCM) provides a framework for the development of a stakeholder-driven model of LVRS for the Massachusetts Commission for the Blind (MCB) (Wagner, et al., 2001; Wagner et al., 1999). The CCM uses a systematic approach to the coordination of care between the medical system and community services necessary for effective disease management. The CCM model was developed by Wagner and colleagues (2001) with support from the Robert Wood Johnson Foundation to provide a framework for quality improvement in

chronic disease management. They stress the importance of an ongoing client centered approach that is proactive in anticipating individual needs. Although the CCM has not been used to address the needs of those with VI, there is an abundance of evidence in its application for management of other chronic diseases which align with identified best practices in LVRS, such as diabetes, heart disease, and mental health (Wagner et al., 2001; Wagner et al., 1999).

Many studies illustrate how the domains of the CCM can be used to address the challenges of chronic disease. For instance, McCullough and colleagues (2000), evaluated a population-based approach to diabetic management and found a system based on surveillance, best practice guidelines, self-management support, and a team approach to care improved outcomes, client satisfaction, and reduced overall health care costs. In a systematic review evaluating the effectiveness of interventions to improve diabetic management, Renders and colleagues (2000) found updated medical records systems improved process outcomes and clearly defined team member roles and a client-centered approach to care showed improved glycemic control. In addition, systematic follow-up and case management was found to decrease depressive symptoms in adults with depression and other chronic conditions (Simon et al., 2000; Shojania et al., 2006; Stollefson, Dipnarine, & Stopka, 2013; Katon et al., 1995; Piette et al., 2001). Further, Katon et al. (2012), found that education, including self-management, goal setting, and problem solving improved medication adherence and improved outcomes. Lastly, Lim and colleagues (2017) reported that acknowledging clients' values and providing client-centered practice was crucial for productive interactions. As the majority of VIs are

progressive and chronic, the use of the CCM may be an effective model for service delivery. As illustrated in Figure 5-1 and discussed below, the CCM provides a structure for the coordination of the medical and social systems of care to promote productive interactions and better health outcomes for adults with VI.

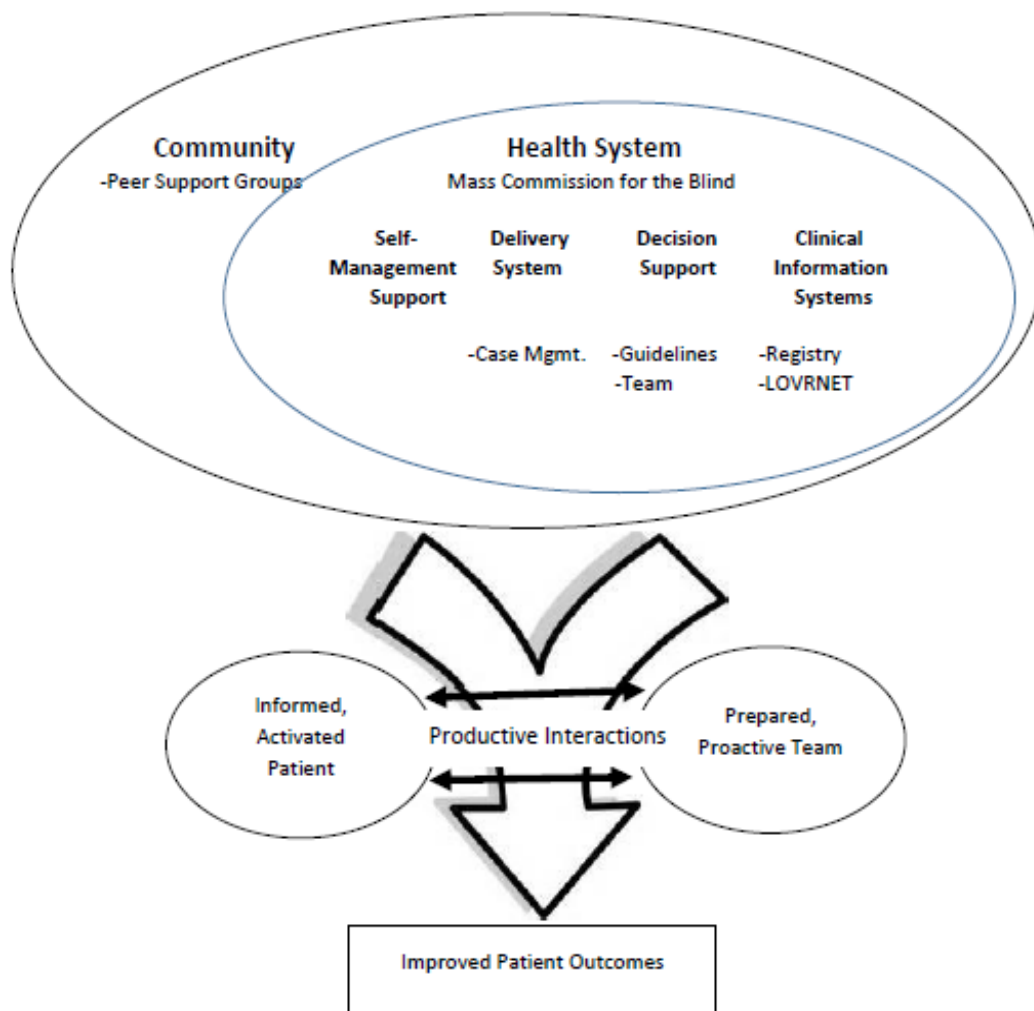


Figure 5-1. Chronic Care Model; Adapted from Wagner, 1998

## 5.2 Methods

This study used a mixed method, convergent design approach. Using the convergent design, the qualitative and quantitative data were collected in a similar timeframe. An iterative process allowed for concurrent data collection and analysis (Fetters, Curry, & Creswell, 2013). Focus groups were conducted to understand consumer perspectives of barriers and facilitators in accessing LVRS. Focus groups were conducted with individuals with VI living in high and low resource communities. Those involved in the focus groups received a follow-up interview in which demographic data was collected, and participants were asked to identify and prioritize key barriers and facilitators to accessing LVRS. These prioritized barriers were used to identify differences between high and low resource communities. Demographic data were also analyzed to examine the relationship between demographic and service utilization factors and improved access to LVRS.

Key stakeholder interviews (n=5) were conducted to understand additional perspectives on barriers and facilitators to accessing care. Each interview was guided by a semi-structured interview guide which aimed to explore perceptions of barriers and facilitators to accessing LVRS. The interview guide, created by the researcher and informed by a thorough literature review and the study's theoretical foundation, was used to ensure procedural consistency among the interviews. The discussion questions for the interviews were designed to explore the influences of policy, health systems, and provider practices on access to low vision rehabilitation services. Interviews were audiotaped with permission and transcribed. Field notes were written during and

immediately following each interview. Audio-recorded interviews were transcribed verbatim for analysis and data was analyzed through content and thematic analysis using line-by-line coding to identify themes. In an effort to ensure rigor of qualitative methods, each interviewee (focus group participants and stakeholder interviewees) was contacted via phone to conduct a follow-up interview. This provided an opportunity for member checking, to verify accuracy and truthfulness of interpretation of themes that emerged and explore the themes in greater detail (Birt, Scott, Cavers, Campbell, & Walter, 2016). Data from focus groups and interviews were collected, themes were organized and merged, and integrated to inform model development. Prior to data collection, approval for the study was obtained through the Boston University Institutional Review Board.

### **5.3 Participants**

Stratified purposeful sampling was used for focus groups to include a sample from both low and high-resource communities. High resource communities were defined as towns with high prevalence of visual impairment or number of individuals registered as legally blind; existing social services for individuals with VI; and at least one low vision rehabilitation center or clinic. Low resource communities were defined as towns with high prevalence of VI or number of individuals registered as legally blind and having no low vision rehabilitation centers or clinics. Study participation criteria included: self-identification as having a VI, being a member of a LV support group, and being at least 50 years of age. LV support groups located in high and low resource communities were invited to participate. Contact information for LV support groups was obtained through a social service agency coordinating peer led support groups. LV

support group leaders communicated with members and identified interest in participation. Participants were invited to participate either in person or via telephone. Consent was obtained by the Principal Investigator. Prior to the start of the focus group session, consent forms were provided in large print and verbally read/ explained, as appropriate. Consent was obtained individually and the consent form was read to the participant if requested. Each focus group included between 7-11 participants. The semi-structured questionnaire was guided by the Social Ecological Model (SEM). The SEM provided an understanding of the larger influences on health seeking behavior and the interactions between the individual, interpersonal, organizational, community, and public policy factors on access to LVRS.

Convenience sampling was used for key stakeholder interviews. Study participation criteria for key stakeholder interviews included being an individual categorized in the literature as a key stakeholder in LVRS and who provided direct service or support to people with VI living in MA. Key stakeholders included: two LV eye care providers, high ranking state official who is involved in LVRS policy and provision of services, a primary care provider in an Affordable Care Organization, and a caregiver. Interviews took place in person in the individual's office or over the phone. Consent was obtained by the researcher prior to the interview.

## **5.4 Data Analysis**

### **5.4.1 Qualitative analysis**

Qualitative descriptive inquiry was used to explore perceived barriers and facilitators to accessing LVRS in adults with VI and key stakeholders (Colorafi & Evans,

2016). Descriptive inquiry attempts to understand a phenomenon where the interpretation remains close to the data (Sandelowski, 2000). A total of eight focus groups of individuals with VI and five one-on-one key stakeholder interviews were completed. Open coding was completed and organized using QSR International NVivo qualitative data analysis software (Version 11). Each transcript was read twice by the researcher prior to initial coding of the data. Each focus group and interview transcript was coded individually; the researcher took written notes and created memos throughout the coding process to help clarify thoughts or questions which arose during the data analysis phase. As additional interviews were coded, a codebook with definitions was created; new codes were added throughout the coding process, and some codes which shared definitions were collapsed into one. Data collection continued and new codes were added as they emerged until no new codes were identified. Once final codes were established, these were then grouped into themes. Themes were confirmed with a second reader, a research assistant. The assistant reviewed two randomly selected transcripts from each category (high and low resource community) and from two key stakeholders using the same line-by-line coding method and took written notes and memos of codes as they emerged. The Principal Investigator and research assistant then met to discuss findings and any discrepancies were discussed and resolved. Codes were reviewed and codes with similar ideas were grouped, and defined. These codes were confirmed and then grouped into themes. As described in Chapter 4, the focus group themes were organized by the levels of the SEM. For this study, themes from focus groups and key stakeholder interviews were organized by the level of the CCM.

### 5.4.2 Quantitative Analysis

Descriptive analysis was conducted to characterize the distribution of the independent variables (age, gender, race, education level, marital status, visual diagnosis, registration with the Massachusetts Commission for the Blind, and having a low vision exam), among focus group participants stratified by high and low resource communities. Means and standard deviations were used for continuous variables and proportions were used for categorical indicators. Bivariate analysis, using t-tests and chi square analysis, were then used to assess differences between members in report of perceived barriers and access to LVRS (high and low resources communities) and ascertain if analyses needed to be stratified by community resources or as a collective sample. Among the key barriers and facilitators presented to the participants, frequencies were calculated for each barrier and facilitator. The barriers and facilitators were ranked according to prevalence rate of response from participants. The rankings were then compared between high and low resourced communities.

Because there was no difference in perceived barriers between high and low resourced communities, the entire unstratified sample was used for further data analysis. The relationship between each independent variable (i.e., demographics, service utilization) and the dependent variable (i.e., access to LVRS) was examined in bivariate analysis, refer to Table 4-3. To determine which variables were independently associated with access to LVRS, sequential multivariate logistic regression was used.

### 5.4.3 Convergence of Data

Qualitative and quantitative data were then merged. Themes identified by focus groups and key stakeholder interviews were organized by aspects of the CCM, refer to Table 5-1.

<b>Level</b>	<b>Themes</b>
<b>Health Systems Level</b>	Bureaucracy/Policy Lack of knowledge and stigma from society Lack of coordination of care across health system Reimbursement/Cost Lack of services
<b>Practice Level</b>	Lack of knowledge-provider Lack of coordination of care Transportation Lack of individualized care Readiness to accept services
<b>Productive Interactions</b>	Communication between provider and consumer Lack of support & knowledge of self & others Lack of care coordination Time Readiness to accept services

Quantitative data, examined the relationship between demographic and service utilization variables and accessing LVRS, bivariate analysis (t-test or chi-squared) was completed. Three variables were found to be statistically significant, gender ( $p=0.05$ ), registration with MCB ( $p=0.02$ ) and having received a low vision eye exam in the last year ( $p=0.01$ ). These three variables were entered into the sequential multiple logistic regression model. Given the small sample size and aim to create the most parsimonious model, each variable was entered individually, refer to Table 5-2. First, the base model included only having a LV exam (Model 1). Given that LVRS are part of the services delivered after an individual is registered as being legally blind, registration as legally

blind was entered next into the model (Model 2). Registration was not found to be significant in Model 2 (OR 21.24, 95% CI 0.54, 48.59), therefore, it was not included in Model 3. In Model 3, gender (i.e. Male) was introduced to the model along with LV exam. Gender was not significant (OR .8, 95% CI 0.57, 13.06). The most parsimonious model, the base model (Model 1), including only having a low vision exam as a predictor of accessing LVRS, showed OR 2.57 and 95% CI of 3.16, 53.53. This multi-faceted approach allowed for more robust data to inform a translation of the existing chronic care model to a LVR focused care delivery model.

**Table 5-2: Relationship between demographic and service characteristics and receipt of LVRS**

Logistic Regression Model	Model 1		Model 2		Model 3	
	OR	COI	OR	COI	OR	COI
LV Exam*	2.57	3.16, 53.53	1.94	1.57, 30.56	1.70	1.19, 25.40
Registration with MCB			21.24	0.54, 48.59		
Male					.80	.57, 13.06

## 5.5 Results

Sixty-four adults (high resource (HR) = 30, low resource (LR) = 34) with self-reported VI participated in the focus groups (refer to Table 5-2). All focus group participants also participated in one-on-one follow-up interviews. In addition, five key stakeholders who work directly with individuals with VI participated in one-on-one interviews. The fourteen themes which emerged were organized to inform levels of the CCM as adapted for LVRS. Data from focus groups and key stakeholder interviews, as well as previous literature and established best practice guidelines were merged and applied to the CCM model. Themes related to public policy, community, and

organizational levels were applied to the community and health systems level, as well as practice level of the CCM. Interpersonal and individual factors were applied to the practice level and productive interactions levels. Because VI is a chronic condition that requires ongoing service delivery, the Chronic Care Model was used as the new model's framework, applying the existing Chronic Care Model to develop a LVR focused care delivery model, refer to Appendix F.

**Table 5-3: Descriptive Characteristics of Participants stratified by Low and High Resourced Communities**

	low (n=34)	high resource (n=30)	Between group differences	total (n=64)
<b>Demographic</b>			p-value	
<b>Age, mean (SD)</b>	74.29 (2.46)	75.17 (2.40)	0.42	74.70 (1.71)
<b>Gender, %</b>				
<b>Female</b>	79	70	0.78	75
<b>Male</b>	21	30	0.62	25
<b>Race</b>				
<b>White</b>	88.20	70	0.83	79.70
<b>Non-White</b>	11.8	30	0.18	20.3
<b>Marital Status, %</b>				
<b>Married</b>	34.71	26.67	0.33	31.25
<b>Not married</b>	65.29	73.33	0.33	68.75
<b>Education, %</b>				
<b>High School</b>	52.90	46.67	0.72	50
<b>Some College</b>	17.65	16.67	0.92	17.60
<b>College or higher</b>	29.45	36.66	0.61	32.40
<b>Congenital Dx**</b>	8.80	16.67	0.38	17.19
<b>Age-related Dx</b>	91.20	83.33	0.31	82.81
<b>Service Utilization</b>				
<b>Legally Blind, %</b>	79.41	50	0.15	65.63
<b>LV Eye Exam, %</b>	38.24	40	0.91	39.06
<b>LVRS, %</b>	26.47	23.33	0.80	25

**Note. OR: Odds Ratio; COI: 95% Confidence Intervals, \*\* excluded from model**

### **5.5.1 Community and Health Systems Level**

Data from focus groups and key stakeholder interviews identify the need for coordination between the community and health systems in order to provide the necessary care to individuals with VI. A new model of LVRS delivery must coordinate with community-based social services, as well as medical services. One key stakeholder stated that: “Coordination of care is a problem across the board.” Prevent Blindness America (2005) found no statewide coordinated systems of LVRS and have made recommendations for state health departments to coordinate partnerships within community and health services in order to meet the needs of this growing population. Further, they identified the need for comprehensive services that address the barriers in access and the individual needs of the person and their community.

Access to community and health services was also discussed by all focus groups and key stakeholders. Many discussed the criteria for inclusion, one focus group participant stated: “You can fall through the cracks of not meeting the right criteria for getting services...there’s qualifiers as far as income or age [or visual status].” Additionally, one key stakeholder discussed how she determined who was referred to LVRS: “I go by the criteria that they have set out, so, legal blindness. Otherwise, I go by an objective visual measurement that would qualify from an insurance standpoint, in addition to a functional goal.” Access to services should be considered regardless of where an individual falls along the VI continuum, from “normal” vision to complete blindness.

The healthcare system, specifically reimbursement of services, can play a major

role in both access and participation in the rehabilitation process. Healthcare coverage of all aspects of LVRS, including examination and recommended devices is a facilitator to access. However, care that is recommended but not fully covered is a significant barrier.

One key stakeholder stated:

“It ends up being the resources the patient has, you know the insurance will cover the assessment and the exam but not necessarily the devices or rehabilitation. So, you have to be cognizant about that and how do you maneuver around these obstacles and barriers.”

Effective partnerships between health systems and community services may bridge the reimbursement gaps between service provision and encourage active participation and support self-management skills (Wagner et al., 2001; Wagner et al., 1999).

### **5.5.2 Practice Level**

According to the CCM and supported in the data collected, the healthcare system should include self-management support, delivery system redesign, decision support, and clinical information systems in order to have effective interactions and well-informed clients.

#### *Self-Management Support*

Chronic disease management requires the system to prepare the individual to manage their own care. For those with VI, chronic disease management requires the system to help individuals develop the skills and strategies to be able to manage their own care and maintain independence in daily activities and social participation. A self-management approach emphasizing client-centered, evidence-based interventions with

ongoing education and coordinated care was consistent across participants and consistent with the literature (Katon, et al., 2010; Stellefson, Dipnarine, Stopka, 2013; Wagner et al., 1999).

The literature supports a problem-solving approach to increase activities of daily living (ADL) performance, social participation, quality of life, and self-management (Brody et al., 2002; Eklund & Dahlin-Ivanoff, 2007; Girdler, Packer, & Boldly, 2008; Birk et al., 2004; Rovner & Casten, 2008). Rovner and Casten (2008) describe problem solving strategy as a collaborative process between the client and practitioner in identifying the problem, establishing a realistic goal (collaborative goal setting), generating potential solutions, implementing strategies (evidence-based interventions), and assessing the outcomes. An effective problem-solving approach can result in increased participation in valued activities and improved overall health outcomes (Rovner & Casten, 2008; Girdler, et al., 2010). One provider stated: “You have to give the individual strategies which in many ways instills hope..... Determining a treatment plan that gets the patient there and for after.” A problem-solving approach can provide the skills and strategies to address the individual’s immediate needs but also helps with adaptation as visual function changes. Further, another provider stated, “[Providing the] patient with the devices or additional services and helping them train and learn to use the device in their particular thing they want to do in the setting that they're in.” It is essential to provide services that meet the client needs and in their own context.

#### *Delivery System Design*

Effective delivery system design provides clear identification of team members

and their roles within LVRS (refer to Table 5-3), and evidence-based interventions that are client-centered and coordinated across the system (Katon, et al., 2012; Piette et al., 2001).

<b>Provider</b>	<b>Role</b>
<b>Primary Care Physician</b>	Provides overall management of the individuals general health care
<b>Ophthalmologist / Optometrist</b>	Provides overall medical management of ocular disease; some specialize in LV
<b>LV Ophthalmologist / Optometrist</b>	Specialization in LV assessment and rehabilitation; provides referrals to other LV service providers
<b>Occupational Therapist</b>	Supports individuals with VI in developing new skills or strategies to function at the highest level possible
<b>Orientation &amp; Mobility Specialist</b>	Provides instruction in safe and effective mobility within their environment
<b>Case Manager</b>	Coordinates services within community and health systems to support the individual's overall health and well being
<b>Social Services</b>	Adjunctive services that provide ongoing support to individuals with VI

The goal of LVRS is to provide client centered and evidence-based interventions that are culturally appropriate and provided at the right time and level appropriate for the individual. However, current services are often provided episodically and, as reported by focus groups and key stakeholders, they are often not client-centered or evidence-based. One focus group participant described her challenge in receiving services when she was not ready.

“Every person is an individual. Not every person is ready to see a counselor the day after they get diagnosed. Sometimes you get offered something but then it's never ever offered again. And it shouldn't be like that. Like I said earlier, things come in waves and it changes and you're ready at different times to deal with it.

They only offer it when you're too new to deal with it, and there's no way you're gonna want to talk to someone about it. The timing. And repeat."

Participants reported care should be ongoing and provide the individual the ability to adjust as vision changes overtime.

The literature supports service provision that is informed by the evidence. The American Academy of Ophthalmology (2013), the American Optometric Association (2007), and the American Occupational Therapy Association (Kaldenberg & Smallfield, 2013) all have practice guidelines which are concordant and informs service provision. Providers should follow recommendations within their practice in order to provide the individual with the best available interventions to maximize visual function, safety, independence in daily tasks, and quality of life. A summary of practice guidelines is provided in Table 5-4. Through discussion with focus group participants and key stakeholders it was identified that these key recommendations are not consistently followed. Only 39% of focus groups participants reported having a LV exam and 25% reported receiving comprehensive LVRS. As recommended, anyone who identifies as having an uncorrectable VI that impacts their ability to complete daily activities should be referred to LVRS.

Finally, all participants reported the need for coordinated services to ensure proper follow-up and potentially improve compliance and overall health outcomes. One provider stated,

"I think a team approach so the patient doesn't have to seek out the next step, the next step is organized and scheduled for the patient. This will ensure that it is

coordinated for the patient. So case management or care coordination is key.”

Individuals with VI also agreed with the need for coordinated services. One participant commented, “...all the agencies that are so important to us they don’t talk to each other”. While another stated, “the connection is never given, making those connections is essential”.

<b>Table 5-5. Review of Practice Guidelines</b>	
<b>Guidelines</b>	<b>Summary of information</b>
<i>Vision Rehabilitation Preferred Practice Pattern The American Academy of Ophthalmology (2013)</i>	<ul style="list-style-type: none"> <li>• All providers are encouraged to provide LV rehabilitation resources to their clients</li> <li>• Encourage all clients with central field loss to use eccentric viewing</li> <li>• Physicians specializing in LVR should address: reading, Activities of Daily Living, safety, participation, and psychosocial status</li> <li>• MDs specializing in LVR should encourage self-management and problem-solving skills</li> </ul>
<i>Care of Patients with VI: LV Rehabilitation The American Optometric Association (2007)</i>	<ul style="list-style-type: none"> <li>• Provides clinical practice guidelines for examination and treatment of individuals with VI</li> <li>• Provides tools for the optometrist to:               <ul style="list-style-type: none"> <li>• Identify VI</li> <li>• Evaluate visual function</li> <li>• Emphasizes need for comprehensive assessment</li> <li>• Provide education to client</li> <li>• Provide referral to LVR (occupational therapy, psychology, etc.)</li> </ul> </li> </ul>
<i>Occupational Therapy Practice Guidelines for Older Adults with LV The American Occupational Therapy Association (2013)</i>	<ul style="list-style-type: none"> <li>• Based on the results of a series of systematic reviews</li> <li>• Provides occupational therapy providers evidence-based assessment and intervention guidelines</li> <li>• Provides guidance to communicate to external audiences the role of occupational therapist in LVR</li> <li>• Strongest evidence supports a team approach to care that uses a problem-solving strategy approach</li> </ul>

### *Decision support*

Effective chronic disease management requires well-informed clinicians and integrated care that includes evidence-based interventions and integrated care (primary

care and specialty eye care), that provides ongoing education for the practitioner and client (Katon et al., 1995; Katon et al., 2010; McCulloch et al., 2000).

Established guidelines to support clinical practice exist for providers within the LVRS team (refer to Table 5-2). However, there is a need for increased education and wide scale role out of these recommendations as there is an identified lack of trained LV rehabilitation service providers (Saner, 2017). One provider commented, “From the practitioner standpoint it all comes down to knowledge of the service and taking the time to educate the patient appropriately.” Another provider stated,

“Lack of knowledge at least that is part of it. I think they [other practitioners] just don’t spend the time to educate their patient. And a lack of understanding of the services that the patient should receive.”

One focus group participant commented, “Knowledge is a huge thing even of providers or social service agencies or those kinds of knowing what’s available.”

#### *Clinical Information Systems*

Information that is organized and accessible by all team members can facilitate communication and coordination of care. In the absence of a shared electronic medical record, database surveillance systems and documentation and ongoing communication from case management can be utilized. Clinical information systems can be used to remind clients of follow up care, to improve carryover of information of clients and share information with the LV team members, and to improve care planning, and monitor progress (Wagner et al., 2001; Wagner et al., 1999).

MCB and Low Vision Resource Network (LOVRNET) have the capacity to

maintain registries or databases. MCB currently uses the registry for surveillance and tracking. LOVRNET, a referral network for individuals with VI, is currently developing their registry that will allow for referral and care coordination for adults with VI. It will be important to explore the use of the registries to assist case management in providing carryover, follow-up, and ongoing communication between individuals and the LV team members.

### **5.5.3 Productive Interaction**

For effective chronic disease management, productive interactions between the client and the practice team must occur. Productive interactions result in informed and activated clients and providers who are evidence-based and proactive. This productive interaction can be supported through ongoing case coordination and communication among the practice team (Wagner et al., 1999).

All participants identified the need for case management to provide carryover, follow-up, and ongoing communication between team members. One key stakeholder stated,

“Care for chronic disease requires complex care management and advocacy to break down barriers to access and ensure compliance”. Further, she reported “connections between systems and engagement are key.”

Further, a focus group participant commented,

“Between that physician who is managing the eye disease or whatever is going on. [They] need to use some sort of system if it’s a case manager, whatever communication system it is to connect, make that connection early on and I think

all of you had agreed sort of when that first diagnosis when things are starting to impact your daily lives to make that connection or coordinate the care so you get referred into a system of services.”

#### **5.5.4 Improved Patient Outcomes**

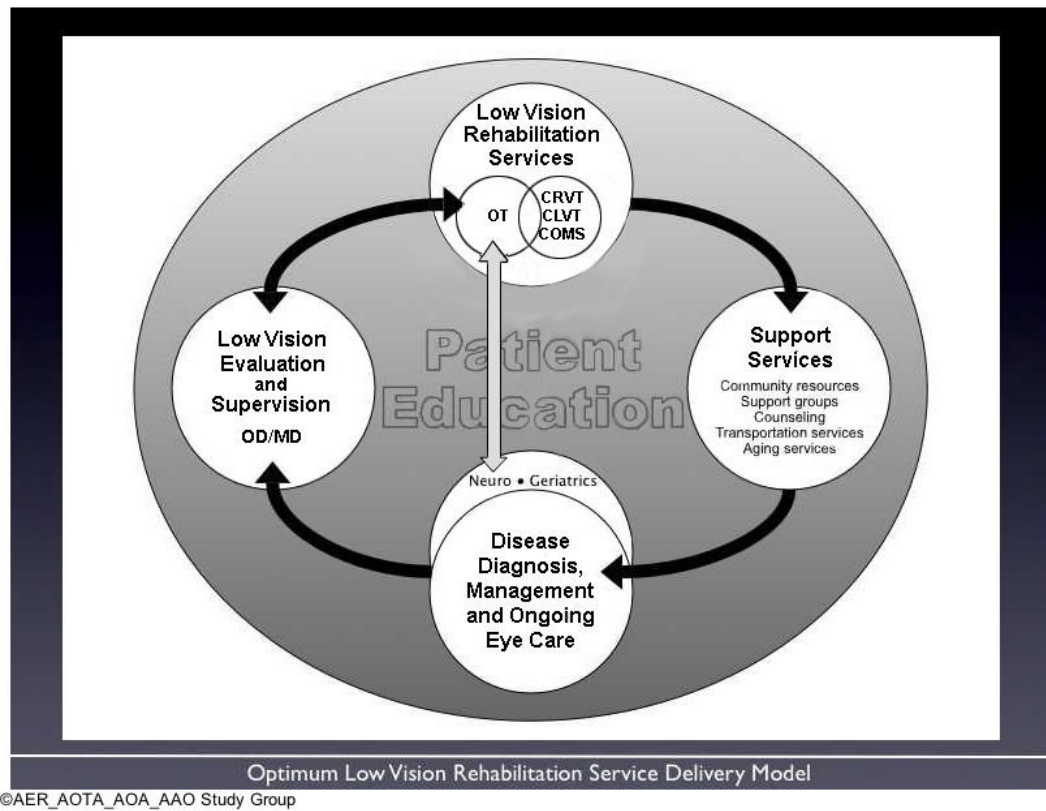
The CCM posits that, through productive interactions, there will be improvement in client outcomes, health status, and quality of life. In studies looking at the use of the CCM with chronic health conditions, results show improvements in self-management skills, increased quality of life, decreased depressive symptoms, and cost savings per quality adjusted life year (Wagner, et al., 2001; Wagner et al., 1999). These positive outcomes are the result of: 1) ongoing review of client data, 2) collaborative goal setting, 3) application of evidence-based interventions, and 4) ensuring ongoing follow-up and case coordination (Wagner, et al., 2001; Wagner et al., 1999).

One provider commented on the importance of productive interactions between members of the LVRS team, “[I] explain to people that we are all working towards the same goal so the more we can work together the better it can be for the client.” Another commented on the need for the inclusion of LV into primary care and to focus on health outcomes,

“[With the advent of] accountable care organizations because you talk about the attribution of care for each individual there is focus on patient centered care which focuses on the individual’s health outcomes. You’re focused on providing the best care that maximizes outcomes but also the money spent for the care for that individual.”

## **5.6 Recommendations: Proposed Model**

In 2007, the Association for Education and Rehabilitation of the Blind and Visually Impaired (AER), the American Occupational Therapy Association (AOTA), the American Optometric Association (AOA), and the American Academy of Ophthalmology (AAO) developed an “optimum low vision rehabilitation service delivery model” within the medical system (refer to Figure 5-2). The model was considered a guide to best practice for provision of comprehensive low vision rehabilitation within a medical model (American Academy of Ophthalmology, 2013; American Optometric Association, 2007; Kaldenberg & Smallfield, 2013). Key components of care include medical management of the eye disease, low vision evaluation to identify needs and to prescribe low vision devices, low vision rehabilitation services, and support services. As a model of practice within the medical system it has significant limitations. It does not account for the need for case management to coordinate interactions between the community and health systems, as well as the need for productive interactions between the individual and the team in order to promote the best possible outcomes. Current systems often do not include case management, connection to community resources, or provide coordination within the greater health care system, specifically the primary care physician. With health care reform and the passage of the Affordable Care Act, greater emphasis needs to be placed on outcomes. As such, it will be important to include the Primary Care Physician (PCP) as part of the LV rehabilitation team.



*Figure 5-2.* Optimum Low Vision Rehabilitation Service Delivery Model

The proposed model, see Figure 5-3, integrates key components of previous best practice models, practice guidelines, and results from focus groups and key stakeholder interviews. The data were merged and applied to the CCM framework.

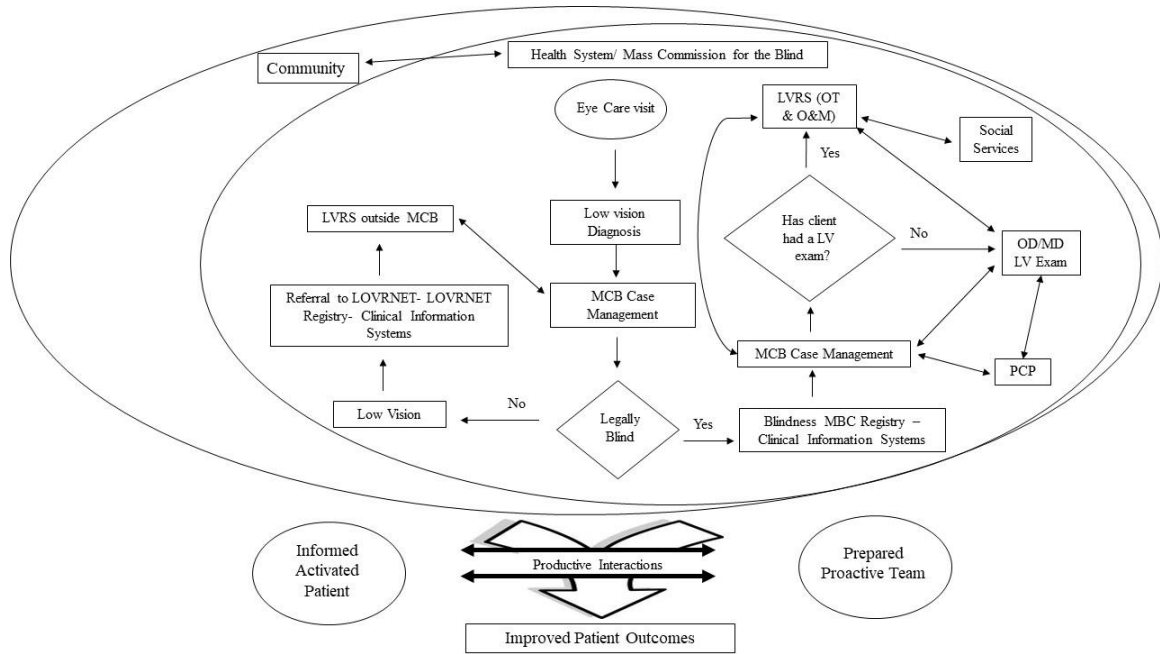


Figure 5-3. Stakeholder-driven LVRS Chronic Care Model; Adapted from Wagner, 1998

**5.6.1 Practice Level Work Flow**

Figure 5.3 illustrates the proposed practice level of the CCM model for LVRS. Once an individual is seen by an eye care provider and is identified as having a VI, they are referred to case management through the registration system. The case manager then determines the individual’s eligibility for either LV services or MCB services. If the individual has LV, but does not meet requirements for legal blindness, they will be referred to the LV Resource Network (LOVRNET) where they are referred on for LVRS. LOVRNET assists the individual in making an appointment and any needed transportation or social service support. Comprehensive LVRS will utilize a self-management approach emphasizing client-centered, evidence-based interventions with ongoing education and coordination of care. Ongoing case management will follow the individual and their ongoing needs. If visual function changes over time, the individual

re-enters the system for further evaluation and service provision.

If the client meets the requirements for legal blindness, they are then entered in the MCB system. Case management then determines if the client has had a LV examination. Existing MCB staff members will be utilized for case management positions. These professionals are the most appropriate as they are familiar with community level services and understand the importance of comprehensive LVRS. As found in the analysis of themes from focus group interviews and participant demographics, having a LV exam was the only factor found to increase the likelihood of accessing LVRS. Recommendation for LV exam prior to LVRS is also consistent with best practice guidelines for optometry, ophthalmology, and occupational therapy (The American Academy of Ophthalmology, 2013; the American Optometric Association, 2007; Kaldenberg & Smallfield, 2013). If an individual has not had a LV exam, the case manager will provide the referral, assist in scheduling the appointment, and coordinate transportation, as needed. A comprehensive LV exam provided by a LV optometrist or ophthalmologist should adhere to best practice recommendations, refer to Table 5-5.

After receiving the LV exam, the optometrist or ophthalmologist refers the client to LVRS with a recommendation for intervention. As identified by both focus groups and key stakeholders, referral to LVRS is key. Case management should provide follow up after the LV exam to ensure that referrals have been made. One focus group participant stated, "I would go [to the eye doctor] every 6 months, he would say your eyes are healthy there's nothing wrong with them, everything is wonderful, except you're blind and there's nothing I can do." There is much that can be done to assist the

individual in maintaining safety and functional independence; a referral to LVRS is the first step. LVRS should adhere to best practice recommendations, refer to Table 5-5. This includes connection to community and social services.

As illustrated in Figure 5-3, communication between the multidisciplinary LV team should be ongoing and include coordination with the primary care provider. The system is a loop, so as vision or needs change, the individual can re-enter the system for additional evaluation or service provision.

### **5.6.2 Productive Interactions between Consumers and the Healthcare Team**

Study findings support a need for education at both the individual consumer level and the health practitioner level to establish productive interactions. All LVRS team members should be providing ongoing education to the individual with VI and their caregivers/ support system. This ongoing education can help facilitate improved awareness of visual health and rehabilitation services and decrease the potential for misinformation or misinterpretation. Consumer education has been found to improve access, adherence, use of LVRS and productive interactions between the individual and their health care team (Siemens, Bergstrom, & Hathaway, 2005; Jose, Thomas, Bhakat, & Krithica, 2016).

Saner (2017), reported a lack of adequately trained service providers in Massachusetts to address the needs of those living with VI. Support for continuing education for all providers is essential for an effective model of service delivery. MCB can work with local universities to continue to develop and support professionals entering the field of LVRS. In addition, ongoing outreach to existing practitioners can help to

improve awareness of the need for and effectiveness of LVRS.

### 5.6.3 Outcomes Measures & Reimbursement Challenges/Opportunities

Key stakeholders identified current changes in healthcare reimbursement that have created challenges and unique opportunities. With reimbursement tied to individual health outcomes, service delivery models need to incorporate outcome measures into documentation. This will allow for greater communication between the community and health systems, as well as provide effective program evaluation. Documentation of improved patient outcome will help position LVRS for potential inclusion within an Affordable Care Organization (ACO). Collaboration with existing ACOs throughout the state should be explored to increase sustainability. Table 5-6 provides a list of potential outcome measures to be included in the revised model of service delivery. These outcome measures have been used extensively in the literature and also capture data on associated risk factors of VI. Considerations were made with recommendations for ease of administration and efficacy of the tool.

<b>Screening Tool</b>	<b>Description</b>
<b>Self-report Assessment of Visual Function Performance (SRAVFP), Velvo, et al., 2013</b>	39 item self-report instrument: assessment of ADL and IADL performance, components can also be assessed objectively
<b>Visual Function Questionnaire (VFQ- 25), Mangione, et al., 2001</b>	25 item self-report survey, assessing influence of visual disability and visual symptoms on general health, well-being, and QOL
<b>Falls Efficacy Scale (FES-I), Yardley, et al., 2005</b>	16 item scale that measures the level of concern about falling during social and physical activities indoors and outdoors
<b>Geriatric Depression Screening (GDS), Yesavage, et al., 1983</b>	30 item self-report, assessing feelings during the past week
<i>Note.</i> ADL-activities of daily living; IADL-instrumental activities of daily living; QOL-quality of life	

## **5.7 Feasibility for Implementation**

When considering the feasibility of implementation of this new model of LVRS, it will be important to consider the existing resources within the health or social service system including: staff, referral resources, and administrative support. The MCB will be the lead agency for managing model implementation.

Within the context of MCB, existing staff (rehabilitation teachers) can be trained to take on the new role as case manager. Rehabilitation teachers have extensive knowledge of resources within the community. Training would need to be completed on referral processes, and model process flow, including requirements for communication and data collection methods. Case managers will coordinate referral resources, ensure collaboration and ongoing communication between team members, and assist in program data collection.

MCB administration will need to provide ongoing support to case managers, ensure staff have the proper knowledge and skills to implement the model, and collect data for ongoing quality and program evaluation. Data collection will allow for improved surveillance on visual impairment across the continuum, and program outcome analysis will help with evaluating program sustainability and reach.

### *Funding*

MCB is looking to modify existing service delivery due to changes in funding. Currently, adult services are not sustainable given the lack of federal and state funding. The limited service provision for non-working adults is currently subsidized by vocational rehabilitation funds. In order to implement the new model of service delivery,

the 28 staff members currently providing services to adults can take on the role of case manager throughout the state. Several of these staff members are also visually impaired and currently need drivers to provide direct service. With the change in role to case management, drivers will no longer be needed. This would be a cost savings of an estimated \$195,000 for the 3.2 full-time equivalent drivers. In addition, due to the savings in travel time for client visits, it is estimated that the current staff would increase client interactions from 1,800 per year to 35,000 (estimating 5 client interactions/day per staff member).

## **5.8 Conclusion**

The new model of LVRS was guided by a thorough literature review, established best practice guidelines, data collected from key stakeholders, and the CCM (Simon et al., 2000). The CCM helped to provide an understanding of the larger influences on care delivery between community services and the larger health system. Data from key stakeholders including individual factors (knowledge, skills), interpersonal (social environment), community (family/community supports), organizational (health and social systems), and public policy factors (reimbursement) were applied to the CCM model. The stakeholder-driven best practice model of LVRS will provide the Massachusetts Commission for the Blind a structure for service delivery throughout the state. This collaboration with community and health systems, as well as case management, will assist MCB in their sustainability and reach to all adults throughout the state living with VI. A report to the MCB can be found in Appendix G.

## **CHAPTER 6: CONCLUSION, STRENGTHS & LIMITATIONS**

### **6.1 Summary of Results**

This study explored barriers and facilitators to accessing LVRS in order to develop a stakeholder-driven model of LV service delivery. Results showed barriers in both high and low resourced communities are similar, including lack of knowledge, lack of coordination of care, transportation, readiness to receive services, lack of individualized care, policy, lack of social support, cost, physical access, lack of services, and time. There was no statistical difference in any of the barriers between communities. An effective model of LVRS must address these barriers in order to optimize health outcomes. Individuals interviewed provided vital information for model development. The stakeholder-driven LVRS model focuses on a coordinated system of care informed by established best practices and includes connection to primary healthcare. New workflows are integral to the model, case managers are used to coordinate care across systems and help individuals navigate the VI system. This new model of service delivery utilizes existing staff within MCB and referral to the greater healthcare system.

### **6.2 Contributions of the Study**

As the number of individuals with VI is expected to increase and funding for services has decreased, an effective model of LVRS that takes into account new realities is essential. Through the contribution of the sixty-nine participants, the study provides an understanding of the perceived barriers and facilitators to accessing LVRS. The data collected helped to inform a new model of service delivery. Understanding the barriers

to access helped inform key aspects of the new model. LV service providers should be aware of these barriers in order to enable equal access and improve health outcomes. Contributions of this study focus on a proposed model of service delivery that translates the existing CCM to a LVR focused care delivery model.

### **6.3 Implications for Clinical Practice: Need for Referral to LVRS**

The majority of participants interviewed received services from a variety of medical and community service providers. Yet, the majority reported that they had never received LVRS. Enabling adults with VI access to the needed LVRS can have a significant impact on their ability to engage in meaningful activities, improve functional independence and safety, improve QOL, and overall health outcomes (Campbell et al., 1999). Improved education and awareness of available services and appropriate referral procedures for all service providers can increase access for those with VI.

### **6.4 Implications for Policy**

Study results provide support for needed policy changes within the health and community services systems. These include improving reimbursement for care coordination, improved accessibility of services across payers, and payment for wrap around services to improve access, i.e. transportation.

#### *Coordination of Care*

Lack of coordination emerged as a major barrier by all study participants and limited access to LVRS. The current system of service delivery is provided with limited coordination between medical and community services. The proposed model emphasizes

the vital role of case management and the need for connection and coordination between all levels of care and services provided.

*Usability and Accessibility of Services*

Transportation emerged as either a barrier or facilitator by all participants highlighting the importance for it to be addressed. Many described transportation as the leading barrier to accessing care. Focus group participants identified limitations with the transportation options. Once adults no longer meet the legal requirement for driving, they are left with public or private transportation options. Many of these options have limitations. Public options, such as para-transit, which was identified as the most commonly used system among study participants, also had the most reported limitations. Although para-transit was often an affordable option for many, it was reported to be time consuming and offered a “curb-to-curb” service. If an individual was unable to navigate independently from the curb to the doctor’s office, para-transit was a significant barrier. Use of family or friends was an option for some, but fear of being a burden was a significant limiting factor. Other transportation options that offered services that were more tailored to the individual’s needs were often at a greater cost and inaccessible to some. Considerations should be made for alternative transportation options for individuals with VI that are both affordable and meet the individual’s needs, such as “door-to-door” or “arm-in arm” services or new models using Uber or Lyft (National Aging and Disability Transportation Center, 2018).

### *Reimbursement*

Concerns related to cost and affordability of services emerged from all key stakeholders. Although reimbursement of services is not addressed as part of this study, it will be important to address as an outcome in the new model of service delivery. Advocating for clients to obtain the necessary services and devices should be considered an essential aspect of the case manager's role. Medicare, Medicaid and private insurers cover eye care and vision rehabilitation services. With some exceptions, health insurers do not cover the recommended optical devices that can maintain the individuals' independence and safety in the home.

### **6.5 Implications for Research**

Using the results of this study and understanding the barriers and facilitators to LVRS, it would be helpful to explore how individual factors within the identified barriers and facilitators influence participation and access to LVRS. Specifically, this includes factors that influence care coordination, usability and accessibility of services, and reimbursement.

Although there is literature that explores provider knowledge and barriers to referral, further research is suggested to explore provider knowledge within the MA context in order to inform education campaigns that meet the needs of local practitioners. This should include awareness of resources and perceptions related to efficacy of LVRS. The results of the study showed that having a low vision exam was found to be the only statistically significant predictor of increased likelihood of accessing LVRS ( $p=.029$ ). Further research should explore why certain providers refer while others do not,

specifically looking at patterns of referral based on visual diagnosis, visual severity, or state mandates (legal blindness).

One of the primary barriers to accessing services from the perspective of the individual with VI was transportation. Further research is recommended to explore the perceptions of “accessible” transportation for individuals with VI. Research should include transportation systems in both rural and urban communities and identify the key factors that enable access to LVRS. In addition, exploration of how these key factors can be integrated into existing services provided in MA.

Lastly, perceived cost was a significant barrier to accessing LVRS. Further research should explore cost benefit of low vision devices as part of comprehensive LVRS. Cost savings may facilitate changes to policy to include those devices which increase independence, functional safety, and overall health outcomes.

## **6.6 Strengths & Limitations**

Qualitative research validity and reliability is achieved through rigorous research methods and design. Although the research has been designed to minimize bias, there are limitations that need to be discussed.

### **6.6.1 Selection bias**

Stratified purposeful sampling was used to include a sample from both low- and high-resource communities and include key stakeholders that have been identified within the literature, sampling will be limited to the context of Massachusetts. As a result, this study only reflects the perceived barriers and facilitators of adults in the context of MA. Focus groups were conducted at low vision support groups in both low and high resource

communities. Focus groups were completed until saturation of data was reached. Peer support groups were selected as the site for focus groups as those who attend have self-identified as having a VI and in need of social support. Use of peer support groups, because members have been successful in seeking social supports, may not be reflective of all adults with VI. Those not included, individuals who may be unaware of their vision loss or have no knowledge of LVRS, may have different perceived barriers to accessing services. It was anticipated that saturation will be achieved within 6-8 focus groups. As a result, this may not be generalizable, as resources and constraints may vary significantly in different parts of MA. However, multiple stakeholder groups will be used until data saturation to ensure multiple perspectives. In addition, member checking will be used to ensure accuracy of the data.

### **6.6.2 Researcher bias**

Though attempts were made to minimize researcher bias through careful development of interview guides and data analysis methods, the researcher's clinical experience, personal beliefs, and knowledge may introduce bias to the research. As an occupational therapist who has worked with adults with VI, I have heard many stories of individuals who have struggled to access the appropriate levels of LVR care or who have lived with unnecessary levels of disability due to lack of referral. Reflexivity was practiced to reduce this potential bias. As described by Creswell (2007), reflexivity refers to the researcher's awareness of personal biases, values and experiences that are brought into the research and may affect data analytics. Throughout this dissertation, reflexivity was practiced through: 1) research design; 2) focus group and interview guide

development; 3) participant selection; 4) field notes written during and immediately following each focus group and interview allowing for ongoing reflection; and 5) communication with colleagues and use of a second reader for theme development.

### **6.6.3 Voluntary Participation**

Participants did not have to participate in this research. Participants were informed that they could stop participation at any time. Participants were informed that they were able to refuse to participate or choose to discontinue participation at any time. Participants did not have to answer any questions they did not want to answer.

### **6.6.4 Risks**

There were no expected risks involved in participating in this study other than would normally be experienced in daily life or in sharing life stories. It was possible that the participant might experience psychological discomfort or be uncomfortable sharing information about his or her experience with accessing low vision rehabilitation services. No such circumstances were identified in the study. Due to the group nature of the focus groups, participants answered questions about their experiences in accessing LVRS. All participants were informed about the purpose of the study prior to the start. First names were used during discussions to decrease risk of loss of confidentiality. During data collection, the participant only needed to answer questions that they were comfortable in answering. If a participant expresses discomfort, the researcher responded with a supportive comment such as "I hear you are frustrated", allowing the participant to talk. If more than a typical amount of discomfort was expressed, the researcher would encourage the participant to see his/her physician for potential referral for counseling. No

such incidences occurred in this study. If the participant became fatigued during the session, they were allowed to rest and either resume the session when ready or end the session early. The researcher minimized the potential for fatigue by working at a slow pace and taking rest breaks as needed throughout each session.

During recruitment, name and phone contact information was obtained, as well as demographic data. This information was kept separate (in a locked file cabinet in a locked, private office) from interview data and was shredded once the study was completed. Transcription of the focus groups were deidentified, no personal identifiers were used, and qualitative interviews were stored in a separate locked file from the rest of the data. Participants were assigned a randomly generated 3-digit number which only the researcher had access. This number was linked to the participant's name in a separate document from the research data obtained. All research data collected only contains the participant's research number. The link between the person's name and the research code number was temporarily stored in a locked file cabinet in the researcher's locked office. Only the researcher had access to the link between the participant and their randomly assigned 3-digit research number.

## **6.7 Conclusion**

This dissertation explored the perceived barriers and facilitators to accessing LVRS of 64 older adults living with low vision and 5 key stakeholders (two low vision service provider, a high-ranking state official who is involved in LVRS policy, a primary care provider in an Affordable Care Organization, and a caregiver). These individuals shared their lived experiences and perceptions of LVR service delivery. Key findings

included: 1) the need for a model of service delivery that provides the full continuum of care, beginning with a low vision eye exam, which is coordinated throughout the community and health systems and addresses the chronic nature of visual impairment; 2) care that is client-centered and provided when the client is ready to accept services; 3) the need for ongoing education to health care providers, consumers, and society in order to facilitate productive interactions and positive health outcomes. These key findings were used to develop a stakeholder-driven low vision rehabilitation focused care delivery model grounded in the Chronic Care Model. Collaboration with community and health systems, as well as case management, will assist with program sustainability and reach to all adults throughout the state living with VI.

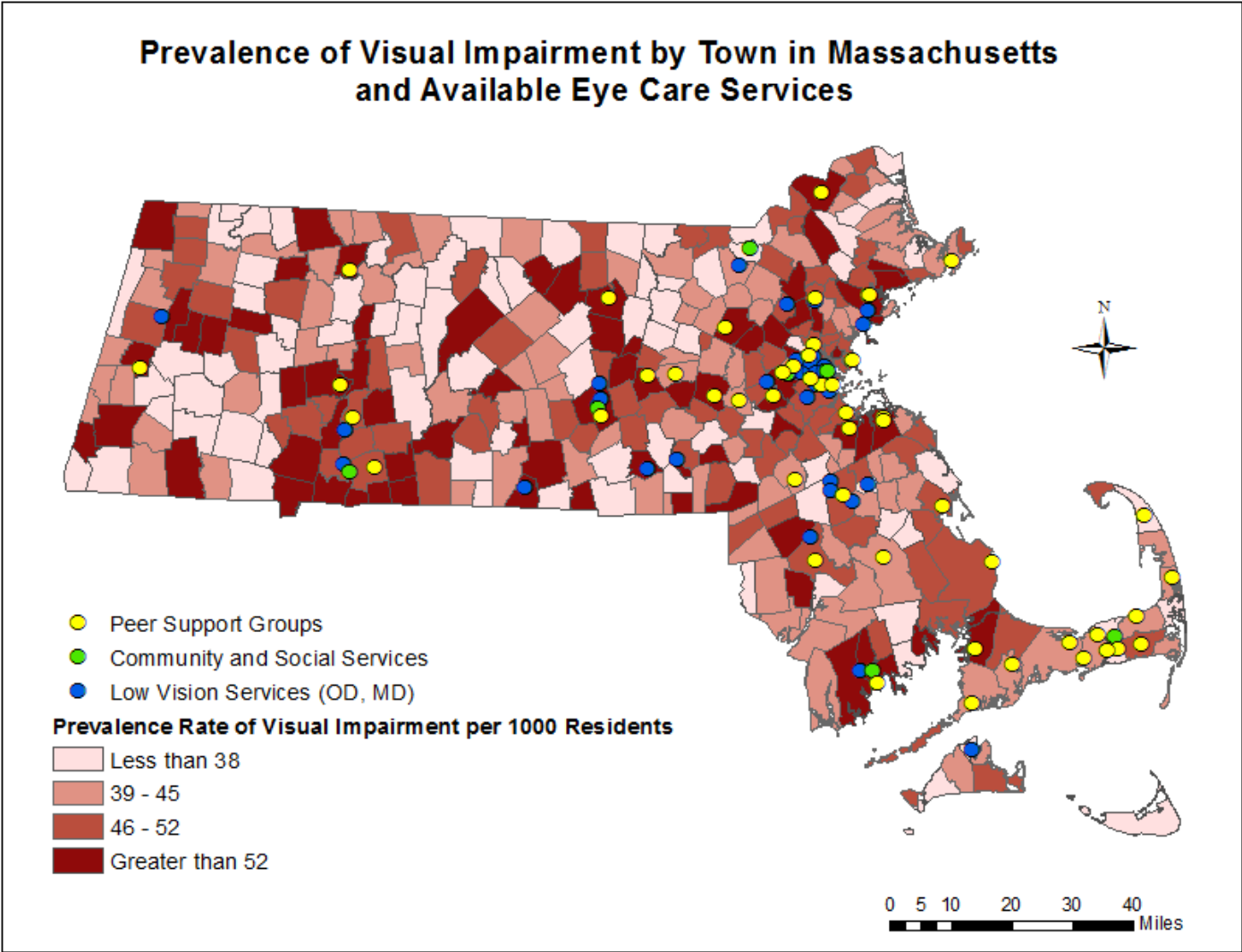
### **6.7.1 Future Steps**

The results of this dissertation will be presented to the Massachusetts Commission for the Blind. Future steps include assisting in the implementation and evaluation of the proposed model and may include: education support, training in proposed workflows, development of documentation and outcome measurement, and program evaluation. Provision of education support to case managers would be completed to ensure staff have the proper knowledge and skills to implement the model and collect the appropriate data for ongoing quality improvement and program evaluation. Training would focus on the referral processes, and model process flow, including requirements for communication and data collection methods. Lastly, with changes in reimbursement and greater emphasis on health outcomes it will be important to incorporate and evaluate outcomes for the proposed model. Data collection will allow for improved surveillance on visual

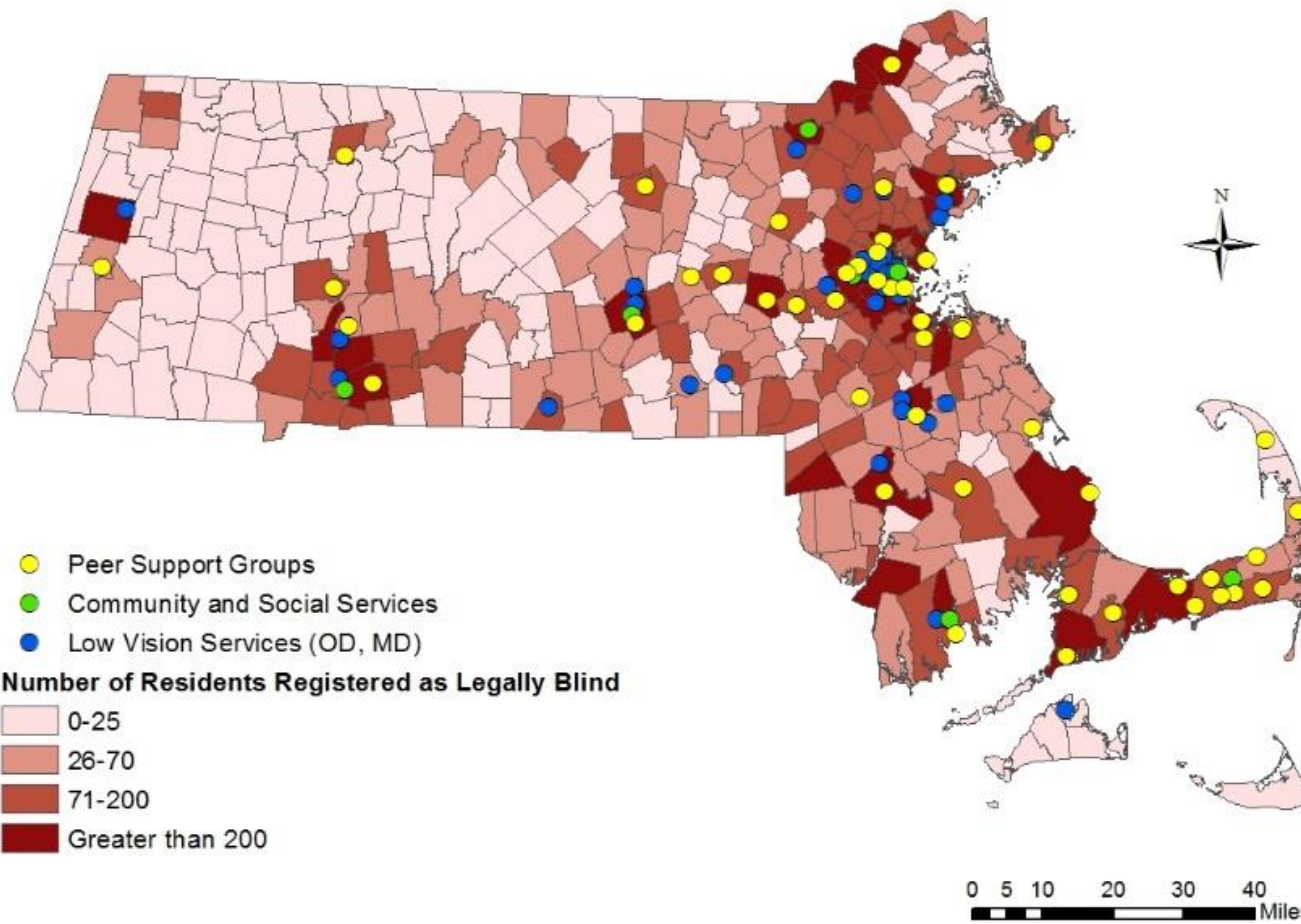
impairment across the continuum, and program outcome analysis will help with evaluating program sustainability and reach. In addition, documentation of improved patient outcome will help position LVRS for potential inclusion within an Affordable Care Organization (ACO) which should be explored.

Future research is suggested to explore provider referral patterns, specifically identify why some providers refer to LVRS while others do not. Exploration of factors that influence referral patterns such as: eye condition, age, race, functional status, or other chronic health conditions, may provide valuable data on barriers to accessing services. In addition, because there are existing best practices in optometry and ophthalmology, it would be helpful to understand the barriers to implementation. Findings from this study also identified readiness as a barrier to accessing services, it may be beneficial to explore the appropriateness of timing and dosage of services for older adults with VI.

**Appendix A: Prevalence Rate of VI and Number of those Legally Blind in MA by Town**



## Number of Blind by Town in Massachusetts and Available Eye Care Services



<b>Appendix B: Prevalence Rate and Number of Individuals Registered with MCB by Town</b>		
<b>TOWN</b>	<b>Prevalence Rate of VI</b>	<b># of Blindness</b>
Abington	39.37	49
Acton	45.18	61
Acushnet	50.09	41
Adams	46.66	46
Agawam	62.64	151
Alford	34.05	2
Allston	47.85	66
Amesbury	45.39	73
Amherst	45.91	76
Andover	44.76	125
Aquinnah	34.06	1
Arlington	58.88	192
Ashburnham	28.45	12
Ashby	46.01	10
Ashfield	38.69	0
Ashland	40.71	2
Ashley Falls	28.18	41
Athol	49.91	0
Attleboro	43.77	71
Auburn	50.15	218
Auburndale	42.54	70
Avon	44.87	0
Ayer	37.55	22
Baldwinville	69.76	51
Barnstable	50.10	0
Barre	56.93	237
Becket	31.74	19
Bedford	59.26	6
Belchertown	36.01	56
Bellingham	45.95	50
Belmont	51.27	50
Berkley	23.56	97
Berlin	45.59	18
Bernardston	46.29	9
Beverly	52.92	4

Billerica	44.20	190
Blackstone	45.98	135
Blandford	35.78	42
Bolton	35.51	2
Bondsville	37.98	13
Boston	47.14	483
Bourne	49.09	85
Boxborough	35.62	10
Boxford	37.76	14
Boylston	62.73	5
Braintree	59.04	176
Brewster	47.21	59
Bridgewater	46.01	66
Brighton	58.60	233
Brimfield	29.92	15
Bristol	32.80	0
Brockton	46.08	486
Brookfield	35.04	20
Brookline	47.46	241
Buckland	39.54	0
Burlington	46.01	101
Buzzards Bay	49.90	0
Byfield	30.70	0
Cambridge	44.45	366
Canton	50.62	97
Carlisle	39.79	10
Carver	43.66	44
Centerville	40.26	0
Charlemont	39.74	1
Charlestown	44.98	55
Charlton	56.94	47
Chatham	44.20	45
Chelmsford	42.70	150
Chelsea	55.60	194
Cherry Valley	25.68	0
Cheshire	35.36	9
Chester	39.63	8
Chesterfield	47.84	0
Chestnut Hill	53.98	0

Chicopee	50.20	317
Chilmark	35.63	0
Clarksburg	41.31	9
Clinton	52.54	38
Cohasset	37.17	34
Colrain	48.58	5
Concord	52.65	72
Conway	40.02	4
Cotuit	43.61	0
Cummington	60.81	4
Dalton	55.73	24
Danvers	57.70	162
Dartmouth	55.71	0
Dedham	59.16	114
Deerfield	39.12	12
Dennis	38.89	104
Dennisport	25.68	0
Devens	23.43	0
Dighton	45.58	26
Dorchester	44.19	710
Douglas	23.85	15
Dover	39.83	12
Dracut	39.97	104
Drury	47.75	0
Dudley	45.05	41
Dunstable	47.94	4
Duxbury	49.96	40
East Boston	62.44	133
East Bridgewater	39.63	43
East Brookfield	45.04	6
East Dennis	48.45	0
East Falmouth	34.60	0
East Freetown	55.87	0
East Hampton	47.39	61
East Longmeadow	57.28	87
East Orleans	187.10*	0
East Otis	35.80	0
East Sandwich	28.89	0
East Taunton	26.26	0

East Templeton	32.64	0
East Walpole	38.32	0
East Weymouth	41.09	0
Eastham	42.87	30
Easton	35.53	65
Easthampton	44.56	61
Edgartown	51.86	15
Egremont	52.48	0
Erving	44.51	10
Essex	33.24	9
Everett	44.62	145
Fairhaven	55.01	87
Fall River	49.99	539
Falmouth	45.05	211
Fayville	39.43	0
Feeding Hills	40.08	0
Fiskdale	51.73	0
Fitchburg	50.35	199
Florence	36.12	1
Forestdale	21.46	0
Foxborough	54.15	51
Framingham	55.52	318
Franklin	47.67	86
Freetown	44.39	42
Gardner	53.54	111
Georgetown	35.04	35
Gilbertville	35.77	0
Gill	42.81	35
Glendale	79.04	0
Gloucester	46.18	150
Goshen	43.63	1
Gosnold	35.81	0
Grafton	41.48	71
Granby	51.93	32
Granville, Granville Center	33.56	5
Great Barrington	56.66	45
Green Harbor	56.12	0
Greenfield	56.10	86
Groton	44.89	69

Groveland	37.97	29
Hadley	62.87	29
Halifax	35.55	25
Hamilton	45.76	0
Hampden	44.80	15
Hancock	35.90	0
Hanover	41.98	27
Hanson	25.91	39
Hardwick	29.79	0
Harvard	32.90	14
Harwich	43.36	0
Harwichport	37.53	0
Hatfield	31.11	5
Haverhill	57.34	302
Hawley	28.20	0
Haydenville	63.80	0
Heath	30.26	0
Hingham	60.32	111
Hinsdale	46.33	6
Holbrook	44.46	57
Holden	47.62	50
Holland	25.84	5
Holliston	46.64	30
Holyoke	65.57	311
Hopedale	77.43	17
Hopkinton	44.74	27
Housatonic	34.96	0
Hubbardston	41.20	15
Hudson	36.79	68
Hull	34.78	45
Huntington	28.43	10
Hyannis	46.88	0
Hyde Park	49.91	179
Indian Orchard	58.36	0
Ipswich	47.75	47
Jamaica Plain	55.33	178
Jefferson	47.19	0
Kingston	57.41	50
Lakeville	40.58	29

Lancaster	40.64	26
Lanesborough	39.75	11
Lawrence	56.78	434
Lee	45.27	29
Leeds	56.69	0
Leicester	37.32	41
Lenox	73.95	44
Leominster	53.99	184
Leverett	31.19	0
Lexington	55.21	151
Leyden	38.60	4
Lincoln	70.14	12
Littleton	47.09	31
Longmeadow	64.44	78
Lowell	51.77	463
Ludlow	51.98	106
Lunenburg	50.88	27
Lynn	51.57	423
Lynnfield	53.74	40
Malden	48.06	279
Manchester	47.45	13
Mansfield	44.28	79
Marblehead	45.71	67
Marion	52.70	26
Marlborough	46.86	147
Marshfield	35.98	70
Mashpee	39.48	71
Mattapan	37.49	175
Mattapoisett	34.25	22
Maynard	46.20	29
Medfield	45.85	26
Medford	49.49	252
Medway	56.17	32
Melrose	45.97	134
Mendon	34.31	15
Merrimac	33.65	27
Methuen	48.51	217
Middleborough	39.38	88
Middlefield	19.57	3

Middleton	41.25	29
Milford	48.64	123
Millbury	41.06	64
Millers Falls	98.68	0
Millis	35.03	21
Millville	41.23	11
Milton	52.65	126
Monroe	32.76	0
Monson	35.74	28
Montague	51.36	9
Montgomery	40.68	1
Mount Washington	28.38	0
Nahant	62.19	11
Nantucket	39.80	21
Natick	41.85	145
Needham	59.07	110
Needham Heights	61.44	0
New Ashford	43.54	0
New Bedford	58.84	533
New Braintree	45.01	0
New Marlborough	36.20	4
New Salem	36.39	4
Newbury	27.28	18
Newburyport	42.74	78
Newton	50.58	0
Newton Center	43.90	0
Newton Highlands	39.15	0
Newton Lower Falls	78.74	0
Newton Upper Falls	70.81	0
Newtonville	36.34	271
Norfolk	35.92	34
North Adams	54.33	113
North Andover	56.04	105
North Attleboro	48.50	95
North Billerica	45.12	0
North Brookfield	40.81	22
North Chatham	50.66	0
North Chelmsford	44.95	0
North Dartmouth	62.61	0

North Dighton	47.96	0
North Easton	37.75	0
North Falmouth	78.43	0
North Grafton	41.50	0
North Hatfield	37.00	0
North Oxford	36.14	0
North Reading	35.43	44
North Weymouth	46.78	0
Northampton	56.78	132
Northborough	45.78	38
Northbridge	47.89	56
Northfield	55.95	0
Norton	42.50	65
Norwell	48.93	34
Norwood	51.18	130
Oak Bluffs	41.79	16
Oakham	43.27	3
Orange	37.84	26
Orleans	40.71	54
Osterville	44.83	0
Otis	32.57	4
Oxford	42.30	50
Palmer	53.78	78
Paxton	42.38	13
Peabody	60.14	325
Pelham	45.13	0
Pembroke	37.32	55
Pepperell	36.05	33
Peru	50.95	0
Petersham	54.54	2
Phillipston	34.17	6
Pittsfield	50.01	270
Plainfield	40.38	1
Plainville	45.38	20
Plymouth	37.97	219
Plympton	29.29	11
Princeton	25.58	4
Provincetown	43.17	16
Quincy	49.33	458

Randolph	45.95	151
Raynham	40.35	47
Reading	57.21	81
Rehoboth	45.32	30
Revere	49.11	245
Richmond	39.65	5
Rochester	52.46	18
Rockland	41.85	79
Rockport	48.16	36
Roslindale	51.53	149
Rowe	33.34	0
Rowley	40.84	11
Roxbury	45.13	293
Royalston	33.55	3
Russell	31.22	5
Rutland	37.46	28
Sagamore	38.71	0
Salem	51.09	201
Salisbury	38.44	35
Sandisfield	56.17	3
Sandwich	42.25	69
Saugus	51.49	105
Savoy	39.52	2
Scituate	55.57	60
Seekonk	33.35	38
Sharon	41.02	49
Sheffield	42.91	6
Shelburne Falls	38.44	18
Sherborn	52.42	7
Shirley	39.81	23
Shrewsbury	47.33	117
Shutesbury	31.48	2
Somerset	49.06	92
Somerville	45.94	296
South Boston	56.67	155
South Dartmouth	53.76	0
South Dennis	43.24	0
South Hadley	52.57	68
South Hamilton	39.98	0

South Weymouth	37.69	0
Southampton	37.70	13
Southborough	45.58	18
Southbridge	60.87	101
Southfield	22.70	0
Southwick	58.82	48
Spencer	37.88	66
Springfield	49.27	997
Sterling	50.96	27
Stockbridge	41.83	25
Stoneham	53.79	72
Stoughton	50.76	130
Stow	37.00	25
Sturbridge	48.54	46
Sudbury	40.13	41
Sunderland	59.41	7
Sutton	45.82	17
Swampscott	55.96	39
Swansea	40.42	60
Taunton	48.98	275
Templeton	42.09	29
Tewksbury	40.75	132
Thorndike	26.98	0
Three Rivers	56.16	0
Tisbury	28.32	32
Tolland	39.36	0
Topsfield	47.46	29
Townsend	33.48	34
Truro	30.40	11
Turners Falls	55.63	0
Tyngsborough	45.37	31
Tyringham	38.16	0
Upton	33.36	19
Uxbridge	45.13	56
Vineyard Haven	34.18	0
Waban	39.66	0
Wakefield	45.62	85
Wales	42.43	8
Walpole	50.32	96

Waltham	53.75	287
Ware	40.50	62
Wareham	40.16	108
Warren	41.60	18
Warwick	42.60	0
Washington	22.46	2
Watertown	44.50	211
Wayland	42.02	37
Webster	57.19	81
Wellesley	46.97	82
Wellfleet	40.49	7
Wendell	18.54	2
Wenham	53.85	15
West Barnstable	28.18	0
West Boylston	56.98	28
West Bridgewater	52.54	31
West Brookfield	58.20	34
West Chesterfield	65.14	0
West Dennis	43.17	0
West Harwich	38.83	0
West Newbury	52.25	5
West Roxbury	54.63	126
West Springfield	50.61	151
West Stockbridge	26.95	4
West Tisbury	51.55	2
West Townsend	26.06	0
West Warren	77.56	0
West Yarmouth	48.13	189
Westborough	50.42	57
Westfield	47.79	0
Westford	35.69	55
Westhampton	34.25	4
Westminster	42.31	24
Weston	47.28	34
Westport	42.82	70
Westwood	64.70	45
Weymouth	43.37	223
Whatley	32.42	4
Wheelwright	74.28	0

Whitinsville	50.29	0
Whitman	36.41	45
Wilbraham	58.98	78
Williamsburg	45.27	15
Williamstown	66.39	41
Wilmington	50.46	89
Winchendon	36.89	44
Winchester	48.95	82
Windsor	35.15	2
Winthrop	38.37	86
Woburn	53.67	142
Woods Hole	33.78	0
Worcester	56.10	921
Woronoco	37.00	0
Worthington	53.49	4
Wrentham	50.23	122
Yarmouth	57.07	0

**Appendix C. Visual Health Resources Massachusetts**

<b>Centers</b>	<b>Location</b>	<b>Eye Care Services</b>	<b>Low Vision Services</b>
<b>Hospitals with Eye Centers</b>			
Boston Medical Center	Boston, Brockton, Middleboro	Yes	Yes
Mass Eye and Ear Infirmary	Boston	Yes	Yes
New England Eye Center	Brighton	Yes	Yes
New England Medical Center	Boston	Yes	Yes
Joslin	Boston	Yes	Yes
Lahey	Burlington	Yes	Yes
<b>Low Vision Clinics</b>			
New England Eye Institute	Boston, Pittsfield & Springfield (Mobile Eye Clinic), Lynn, Newton, Brookline, Lawrence	Yes	Yes
New England Eye Roslindale	Roslindale	Yes	Yes
MAB Community Services* *Including affiliated providers	Worcester, Holyoke, Springfield, Wellesley, Hyannis, Salem, Whitinsville, Newton, Natick	Yes	Yes
Mass College of Pharmacy and Health Prof.	Worcester	Yes	Yes
Veterans Administration	Jamaica Plain, Brockton	Yes	Yes
Joslin Diabetes Clinic	Boston	Yes	Yes
<b>Community Health Centers</b>			
Dorchester House	Dorchester	Yes	Yes
Dimock	Roxbury	Yes	Yes
Cambridge Health Alliance	Somerville	Yes	Yes
Lynn Community Health Center	Lynn	Yes	Yes
Community Health Center of Cape Cod	Mashpee	Yes	Yes
<b>Private Practitioners/Clinics*</b>			
Stephen Bochnak	Boston	Yes	Yes
Wayne Chan	Boston	Yes	Yes
Harvard Square Eye Care	Cambridge	Yes	Yes

Bennett Family Eye Care	Belmont	Yes	Yes
John McHale	Reading	Yes	Yes
George Leavitt III	Whitman	Yes	Yes
Florence Bejian and Associates	Chelmsford	Yes	Yes
Greater Milford Eye	Milford	Yes	Yes
Jane Orenstein & Russel Fradkin	Whitinsville	Yes	Yes
Eye Associates	Southbridge	Yes	Yes
David Finkelstein & Ryan Shea	Vineyard Haven	Yes	Yes
Charles Mandel	Pittsfield	Yes	Yes
Jennifer Salvo	Wellesley, South Yarmouth	Yes	Yes
Lyudmila Sutherland	Salem	Yes	Yes
Rodney Immerman	Milton	Yes	Yes
John Magalhaes	North Dartmouth	Yes	Yes
<b>Social Service Agencies</b>			
Carroll Center for the Blind	Newton	Yes	Yes
Massachusetts Commission for the Blind	Boston, Worcester, Springfield, New Bedford	Yes**	Yes
Perkins School for the Blind	Watertown	No	Yes
Lowell Association for the Blind	Lowell	No	Yes
<i>*There may be private optometry and ophthalmology practices not included within this table which have not identified as providing low vision services; **through mobile eye clinic</i>			

<b>Appendix D. Low Vision Peer Support Groups</b>	
	<b>Location</b>
<b>MAB Community Services</b>	
Boston/Roxbury Elders Support Group	Roxbury, Martin Luther King, Jr. Towers
Berkshire County/Lenox Low Vision Support Group	Lenox, Kimball Farms
Braintree Elders Support Group	Braintree, Council on Aging
Brockton Elders Support Group	Brockton, Campello High Rise
Brookline Low Vision Support Group	Brookline, Senior Center
Cambridge-Somerville Elders Support Group	North Cambridge, Senior Center
Concord Elders Support Group	Concord, Council on Aging
Dorchester Elders Support Group	Dorchester, Harbor Point Apartments
Duxbury Elders Support Group	Duxbury, Senior Center
Framingham Elders Support Group	Framingham, Callahan Senior Center
Gloucester Elders Support Group	Gloucester, Rose Baker Senior Center
Greenfield Elders Support Group	Greenfield, Senior Center
Haverhill Elders Support Group	Haverhill, Citizen Center
Hingham Elders Support Group	Hingham, Senior Center
Holyoke/ South Hadley Elders Support Group	South Hadley, Council on Aging
Marlborough Low Vision Support Group	Marlborough, Senior Center
Medford Elders Support Group	Medford, Senior Center
Middleborough Elders Support Group	Middleborough, Council on Aging
Montachusett Elders Support Group	Leominster, Senior Center
Natick Low Vision Support Group	Natick, Morse Institute Library
Needham Elders Support Group	Needham, Steven Palmer Senior Center
New Bedford Elders Support Group	New Bedford, Hazelwood Senior Center
Newburyport Elders Support Group	Newburyport, Council on Aging
Newton Elders Support Group	Newton, Senior Center
Northborough Low Vision Support Group	Northborough, Senior Center
Northampton Elders Support Group	Northampton, Council on Aging
Peabody Elders Support Group	Peabody Life Center
Plymouth Elders Support Group	Plymouth, Council on Aging
Quincy Adult Vision Support Group	Quincy, Public Library
Reading Elders Support Group	Reading, Elder Services
Sharon/Stoughton Elders Support Group	Sharon, Community Center
Springfield Mixed Ages Support Group	Springfield, Church in the Acres
Taunton Elders Support Group	Taunton, Council on Aging

Watertown Mixed Ages Support Group	Watertown, Perkins School for the Blind
Winthrop Elders Support Group	Winthrop, Senior Center
Worcester Low Vision Support Group	Worcester, Senior Center
<b>Sight Loss Services</b>	
Barnstable Peer Group	Barnstable, First Unitarian Church
Bourne Peer Group	Pocasset, Cape Living
Brewster Peer Group	Brewster Ladies Library
Dennis Peer Group	Dennis, Church of Nazarene
Eastham/Wellfleet Peer Group	Eastham, Council on Aging
Falmouth Peer Group	Falmouth, John Wesley Methodist Church
Harwich/Chatham Peer Group	Harwich Community Building
Mashpee/Sandwich Peer Group	Mashpee, Council on Aging
Orleans Peer Group	Orleans, Federated Church
South Yarmouth Peer Group	South Yarmouth, Thirwood Place
Truro/Provincetown Peer Group	Truro, Council on Aging
West Yarmouth Peer Group	West Yarmouth, Mayflower Place
Yarmouth Peer Group	Yarmouth, Heatherwood

## Appendix E: Evidence Table

**Levels of Evidence:** Adapted from Sackett, Rosenberg, Gray Haynes, Richardson, 1996

**Level I- RCT, systematic reviews, meta analyses**

**Level II- Two-group, non randomized**

**Level III- One-group, non randomized**

**Level IV- Descriptive studies**

**Level V- Case report**

Author/ Year	Study Objectives	Level/Design/Subjects	Intervention and Outcome Measures	Results	Study Limitations
Casten, Maloney, Rovner, (2005).	To explore knowledge of LVRS and use of LV aids in older adults with macular degeneration	<b>Level:</b> IV <b>Design:</b> descriptive, one group, survey <b>Subjects:</b> n=80 Mean age (SD): 82.5 (5.2) <b>Country of Origin:</b> U.S.	<b>Brief Description:</b> The study aimed to understand the use of LVRS and devices used by adults with macular degeneration and to compare levels of VI <b>Frequency/Duration:</b> 10 months <b>Outcome Measures:</b> medical record review, visual acuity, telephone survey	<b>Results:</b> 24% of the participants were aware of LVRS, 83% expressed interest in receiving LVRS; 80% reported using LV aids, only 6% were prescribed	<b>Study Limitations:</b> small sample size, studied with clients seen within the clinic
Overbury, Wittich, (2011).	To examine demographic characteristics of individuals that may inhibit access to LVRS. Montreal Barriers Study	<b>Level:</b> Level II <b>Design:</b> cross sectional study, mixed methods <b>Subjects:</b> n=702; 3 groups: 1-lack information (227); 2-negative choice (95); 3-positive choice (380)	<b>Brief Description:</b> Phase 1: semi-structured interviews to understand awareness of LVRS; Phase 2: comparison of visual acuity at time of interview from time of eye visit; Phase 3 examined access to LVRS <b>Frequency/Duration:</b> 3 years	<b>Results:</b> 54% of participants were referred to LVRS; 33% of participants were unaware of LVRS; facilitators: education, diagnosis, race, acuity, and living situation	<b>Limitations:</b> participants were recruited from large urban ophthalmology departments where clients generally have higher levels of education, socioeconomic states, and are

		<p><b>Mean age (SD):</b> 1-72.6(13.2); 2-74.4 (13.8); 3-75.2 (13.7)</p> <p><b>Country of Origin:</b> Canada</p>			relatively well informed in terms of their health; 2 of the 4 clinics had well established low vision clinics
Lam, Leat, (2013).	To examine the evidence on barriers to LVRS access for individuals with low vision	<p><b>Level:</b> IV</p> <p><b>Design:</b> literature review</p> <p><b>Subjects:</b> sample sizes</p> <p><b>Country of Origin:</b> Canada</p>	<p><b>Brief Description:</b> Scoping review of the literature on barriers to access care</p> <p><b>Frequency/Duration:</b> articles included (1992-2012)</p>	<p><b>Results:</b> 14 studies were included; barriers included lack of awareness, miscommunication by eye care professionals, misconceptions of LVRS, transportation, location, need to appear I, neg. perception of vision loss, cost, comorbid health status, education level, visual acuity, and socioeconomic status</p>	<b>Limitations:</b> Not a systematic review or a meta-analysis of the literature
Spafford, Rudman, Leipert, Klinger, Huot, (2010).	To examine the reasons for not seeking out LVRS in Canadian adults with LV	<p><b>Level:</b> IV</p> <p><b>Design:</b> qualitative content analysis; 1:1 interviews</p> <p><b>Subjects:</b> n=34</p> <p>Mean age: 82</p> <p><b>Country of Origin:</b> Canada</p>	<p><b>Brief Description:</b> Qualitative study examining the barriers to LVRS use. The study also provides a valuable description of the struggle of older adults to remain engaged in valued occupations as a result of</p>	<p><b>Results:</b> Reasons for nonuse included: lack of knowledge, misconceptions of LVRS, cost, location, and practitioner behavior. Older adults' attitudes shaped non-use.</p>	<b>Limitations:</b> small sample size, unable to quantify participants vision loss, study only addressed older adults perceived barriers

			vision loss. <b>Time period:</b> 10 months <b>Measures:</b> VFQ-25		
Pollard, Simpson, Lamoreaux, Keefe, (2003).	To examine barriers to accessing LVRS in Australia	<b>Level:</b> II <b>Design:</b> 3 groups, non-randomized, mixed methods <b>Subjects:</b> n=80 Mean age: 71 <b>Country of Origin:</b> Australia	<b>Brief Description:</b> Focus group discussions and self-perception questionnaire to understand barriers to accessing LVRS and perceived difficulties with ADL tasks for those seen at RVEEH. <b>Frequency/Duration:</b> 3 focus groups were completed each lasting 90 minutes; questionnaires were completed over an 11-month period <b>Measures:</b> VA, VF, questionnaire	<b>Results:</b> LVRS access was associated with greater levels of vision loss ( $p=.002$ ), greater self-perception of vision loss ( $p=.005$ ), participants with mild to moderate vision loss reported similar levels of disability ( $p>.05$ ), however there were significant differences between mild/moderate and severe vision loss ( $p>.05$ ).	<b>Limitations:</b> Study is specific to the RVEEH context and cannot be generalized
Wittich, Canuto, Overbury, (2013).	To explore an alternative way to introduce LVRS to those with VI within an ophthalmology department through an optometrist	<b>Level:</b> IV <b>Design:</b> descriptive <b>Subjects:</b> n=35 Mean age: <b>Country of Origin:</b> Canada	<b>Brief Description:</b> Pilot project to develop a continuum of care within ophthalmology department through the use of low vision optometrists. <b>Time period:</b> 18 months <b>Outcome Measures:</b> use of LVRS	<b>Results:</b> Of the 35 referred, 7 were already receiving LVRS, 3 did not qualify for services, 25 were referred to LVRS. Some participants reported ease of access when the LVRS were provided at the same facility as other eye	<b>Limitations:</b> context is specific to the center studied and may not generalize to other practices or practice patterns

				care services they receive.	
Southall, Wittich, (2012).	To explore barriers to accessing LVRS for individuals living in Canada	<b>Level:</b> IV <b>Design:</b> qualitative focus groups <b>Subjects :</b> n=21 <b>Age range:</b> 38-92 <b>Country of Origin:</b> Canada	<b>Brief Description:</b> 6 focus groups were completed to understand how individuals accessed LVRS, barriers, facilitators, perceptions of what could improve access,	<b>Results:</b> Barriers were identified as: perceived ability to engage in LVRS, progressive nature of eye disease, lack of communication, dissatisfaction with services received from ophthalmology, stereotypes/stigma, and transportation.	<b>Limitations of study:</b> small sample size
Rao, Khanna, Athota, Rajshekar, Rani, (2012).	To discuss infrastructure development, HR development, and eye care service delivery in India	<b>Level:</b> IV <b>Design:</b> descriptive <b>Country of Origin:</b> India	<b>Brief Description:</b> development of levels of service delivery of vision centers and secondary care units to meet the needs of underserved rural areas <b>Time Period:</b> 1996-2000	<b>Results:</b> Primary determinants of a successful model of service delivery was identified as: qualified clinical staff, ability to recruit and train, technology, location, and community outreach.	<b>Challenges to replication:</b> culture, personal beliefs, social determinants for access/use, technology, and cost
Nkumbe, (2008).	To explore the barriers to accessing eye care in Tanzania	<b>Level:</b> IV <b>Design:</b> Descriptive <b>Country of Origin:</b> Madagascar	<b>Brief Description:</b> Descriptive article written from the perspective of an ophthalmologist living and working in Madagascar	<b>Results:</b> Themes identified include: cost of eye care, fear of eye surgery, difficulty getting to eye care facility, poor communication, insufficient	<b>Limitations:</b> This is a descriptive article and only discusses the Madagascar context

				collaboration between professionals, living in a nursing home, perceived need or lack of need, and gender inequalities	
Khan, BR, Nutheli, (2005).	To identify the perceived barriers to providing LVRS of ophthalmologists in India	<b>Level:</b> III <b>Design:</b> one group, non- randomized, self-administered questionnaires <b>Subjects:</b> 79 ophthalmologists Mean age (SD): 35.45 (8.3) <b>Country of Origin:</b> India	<b>Brief Description:</b> 79 ophthalmologists completed the self-report questionnaire related to prescribing practices and demographic information. The study aimed to understand barriers to prescribing or providing LVRS. <b>Frequency/Duration:</b> 4 months	<b>Results:</b> Major barriers identified as: lack of training (82.3%), lack of awareness (74.7%), lack of availability of low vision devices (72.2%), lack of motivation, time, cost, and <b>belief that LVRS is not effective</b> (p=.010). Practitioners least likely to refer were older, in private practice, and those involved in Vision 2020.	<b>Limitations:</b> small sample size
Walter, Althouse, Humble, Leys, Odom, (2004).	To examine the types and frequency of barriers in accessing vision services for those with low vision	<b>Level:</b> IV <b>Design:</b> Random Digit Dial, telephone survey, descriptive <b>Subjects:</b> 1026 completed household surveys; 57 with VI (28% completion rate)	<b>Brief Description:</b> To understand household experiences, 3 surveys were used 1) self-report knowledge about visual health, 2) caregiver report of vision health problem, and 3) caregiver response for	<b>Results:</b> Barriers identified as economic, psychosocial, cognitive, and knowledge of services. VI affected 1 in 4 households	<b>Limitations:</b> Bias of telephone survey, only targeted those who picked up the phone or had access to a phone; small sample of the larger population

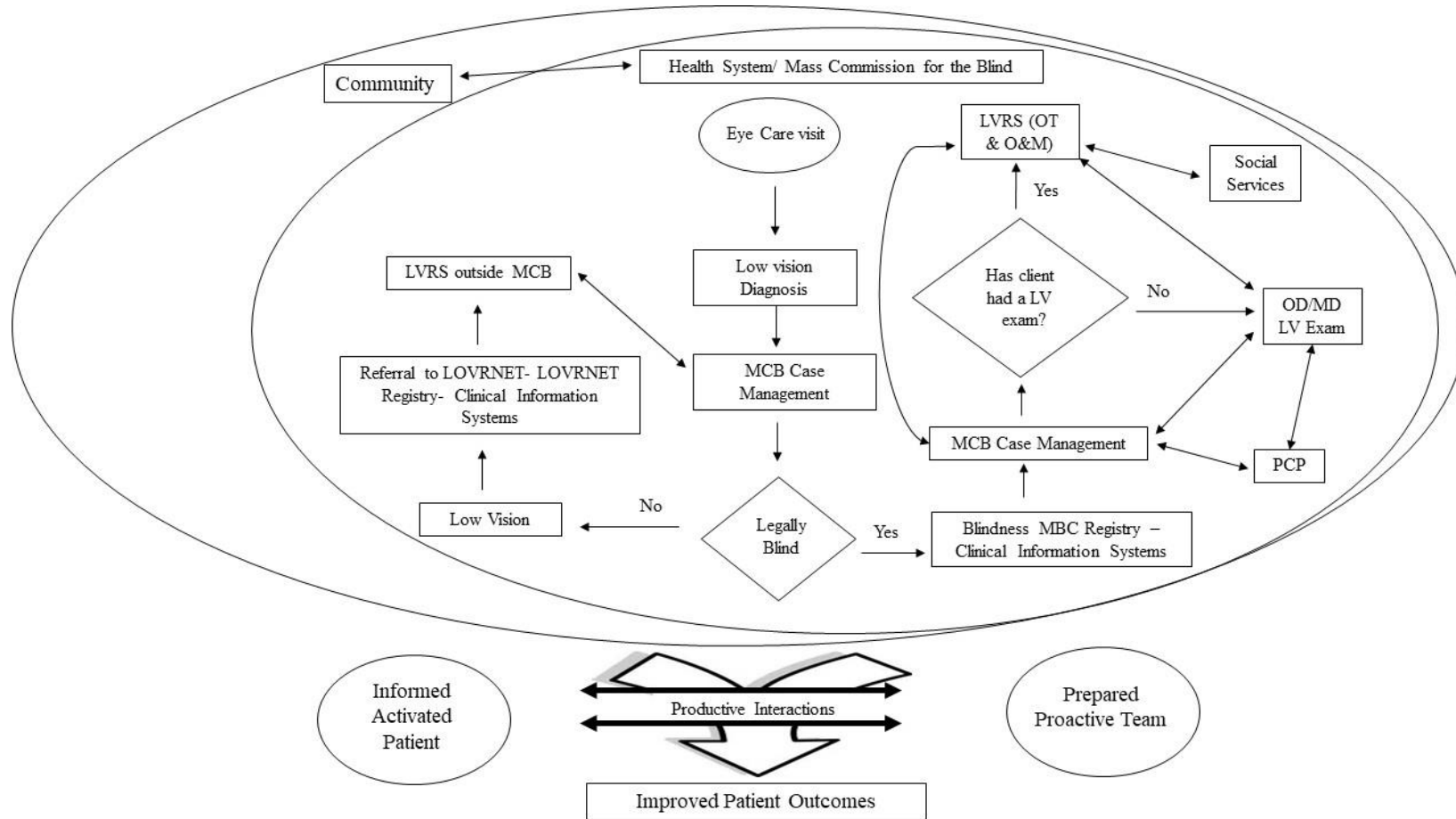
		<b>Country of Origin:</b> West Virginia, U.S.	child in the household with vision health problem	surveyed. Individuals did not seek out eye care services on a regular basis.	
Sloan, Yashkin, Chen, (2014).	To examine factors associated with eye care use among older adults with glaucoma, AMD, and diabetes.	<b>Level:</b> IV <b>Design:</b> retrospective analysis <b>Subjects:</b> sample size 2151 Medicare beneficiaries Mean age: 34.2 yo, range 16-63, SD: 13.7 <b>Country of Origin:</b> US	<b>Brief Description:</b> 5 year retrospective study of Medicare beneficiaries with a history of eye disease. Tracked access over a period of 5 years. <b>Frequency/Duration:</b> 4 time periods over 5 years <b>Outcome Measures:</b> number of 15 month periods with an eye exam	<b>Results:</b> 1/3 of beneficiaries with eye disease had regular eye care; male, having ADL deficits, distance from MD, and cognitive decline were associated with decreased use	<b>Study Limitations:</b> Study utilized Medicare claims data, only looked at number of exams not components of the exam or best practices
Matti, Pesudovs, Brown, Chen, (2011).	To examine referral pathways and low vision service provision in South Australia	<b>Level:</b> IV <b>Design:</b> prospective record review <b>Subjects:</b> n=1,116 Mean age: 78.0 <b>Country of Origin:</b> Australia	<b>Brief Description:</b> Study of the referral pathway with <b>Frequency/Duration:</b> reviewed referrals from July 1, 2008- June 30, 2009 <b>Outcome Measures:</b> rate of acceptance or decline of rehabilitation services	<b>Results:</b> 97% attendance rate of individuals who received a referral from their low vision provider; for those who did not attend, major health issues (27%) and feeling that LVRS were unnecessary (27%) were most common reasons for non-use.	<b>Study Limitations:</b> This was a study completed at the Royal Society for the Blind; referrals were from internal resources with follow up and may not reflect the larger population
Boyce, Leamon, Slade,	To explore the client experience and perceptions	<b>Level:</b> IV	<b>Brief Description:</b> A qualitative study in 3 areas of England with fluctuating	<b>Results:</b> Ophthalmologists varied in their	<b>Study Limitations:</b> only included individuals who met

Simkiss, Reghani, Ghanchi, (2014).	of the certificate of visual impairment process	<b>Design:</b> qualitative; semi-structured interviews <b>Subjects:</b> sample size 43 providers; 46 clients among 3 separate areas in England Mean age: <b>Country of Origin:</b> England	rates of registration were used. Semi-structured interviews were used to gain an understanding of the barriers to registration and referral and suggestions for improvement <b>Frequency/Duration:</b> 12m <b>Outcome Measures:</b> Qualitative data collected on purpose of CVI, communication with clients, barriers to approaching clients, difficulty in completing CVI, knowledge of benefits, reasons for decline, and improvements.	knowledge of when to refer, when to certify, and many found certification to be the final stage in their treatment. Conclusion more education is needed for the provider and the client on the certification process and the treatment and referrals available for those with vision loss.	CVI, small sample size,
Wessels, Dijicks, Soede, Gelderblom, De Witte, (2003)	To provide a review of the literature to understand barriers to assistive device use	<b>Level:</b> IV <b>Design:</b> scoping review descriptive <b>Country of Origin:</b> Netherlands	<b>Brief Description:</b> Study first looked at the varying definitions of non-use and then explored the barriers to use.	<b>Results:</b> Barriers were identified as: personal client factors, devices did not meet expectations, social support, progressive nature of disease, lack of communication, time, transportation, and cost.	<b>Study limitations:</b> not a systematic review or meta-analysis
MacLennan, McGwain Jr., Searcey,	Study examined the state level vision resources (providers) in	<b>Level:</b> IV <b>Design:</b> descriptive study	<b>Brief Description:</b> Participants were asked to complete a survey regarding demographic and descriptive	<b>Results:</b> A map of current service provision was created and identifies gaps	<b>Study Limitations:</b> This study can only be generalized to Alabama and to

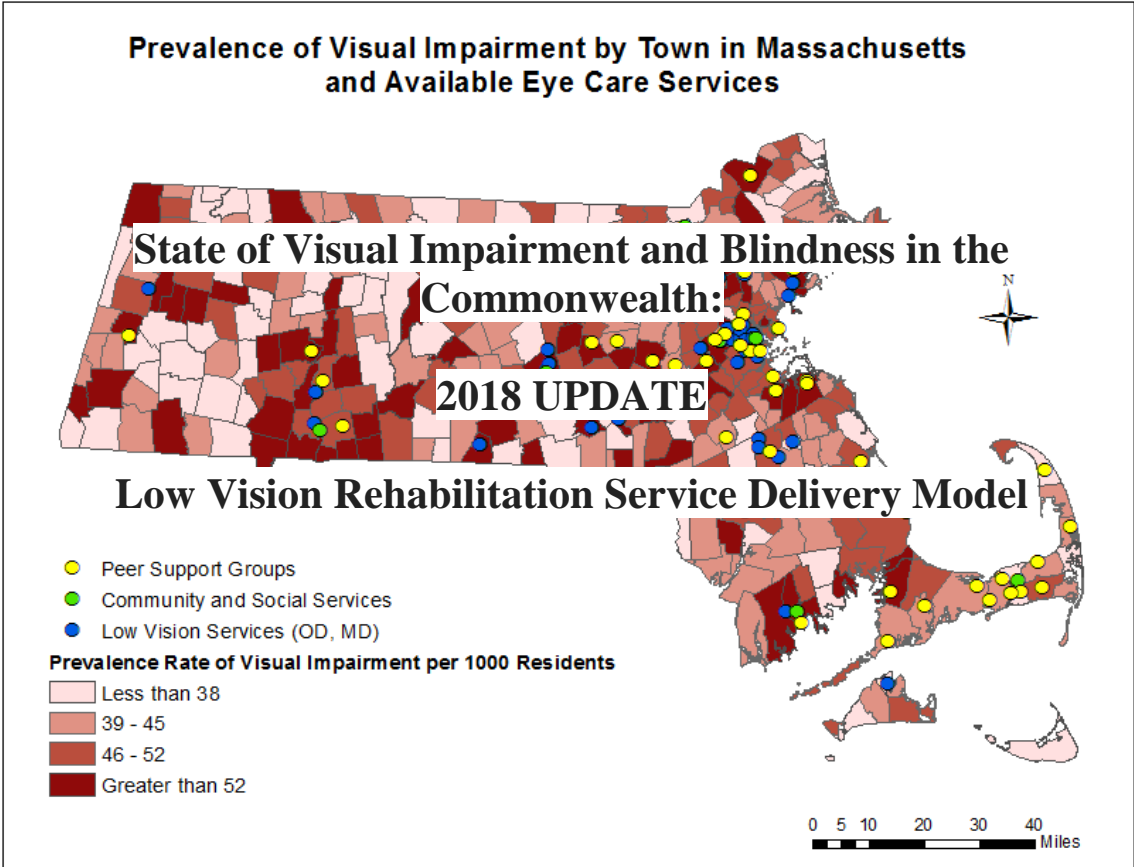
Owsley, (2014).	Alabama (OD, MD, and LV providers and the services provided)	<b>Subjects:</b> of the 1,033 identified providers, 438 participated (111 MD, 246 OD, 81 rehab providers) <b>Country of Origin:</b> Alabama, U.S.	data as well as standards of practice <b>Frequency/Duration:</b> Eligible participants were contacted over a period of 10 mo.	within the state that has either no or insufficient services for the aging population.	those providers who responded to the survey, which represents less than 1/2 of the state's providers.
Overbury, Wittich, & Ferraresi, 2008	To investigate the factors that prevent older adults from accessing LVRS; Montreal Barriers Study	<b>Level:</b> II <b>Design:</b> mixed methods, semi-structured interviews <b>Subjects:</b> 411 Mean age: 75 <b>Country of Origin:</b> Canada	<b>Brief Description:</b> participants were identified through record review of individuals who would qualify for LVRS, those who qualified were invited to participate in semi-structured interviews. Participants were then classified into 1 of 3 groups 1) not aware of services, 2) aware but did not access, and 3) aware and accessed services <b>Frequency/Duration:</b> 12 months <b>Outcome Measures:</b> Visual function Index; Brief COPE, Satisfaction with Life Scale, Center for Epidemiologic Studies-Depression Scale	<b>Results:</b> Those with more severe VI, those with VI for longer period of time, and sociodemographic factors influenced access and knowledge of care.	<b>Limitations:</b> Study represents a sample seen within 3 ophthalmology departments; 46% of the sample had severe VI (legal blindness)

Roeland, VanOost, Buysse, & Depoorter, 2002	Awareness of older adults of existing supply of assistive devices of mobility and self-care	<b>Level:</b> IV <b>Design:</b> interview, survey <b>Subjects:</b> n=117 Mean age: 82.2 <b>Country of Origin:</b> Belgium	<b>Brief Description:</b>  <b>Outcome Measures:</b> assistive device awareness scale, questionnaire, activities of daily living scale, attitude scale	<b>Results:</b> most older adults were aware of AD, had positive attitudes towards AD	<b>Limitations:</b> older adults with cognitive impairment or severe sensory loss were excluded from the study, convenience sampling, use was identified as possession of AD, limited spectrum of AD
Chiang, O'Connor, LeMesurier, & Keefe, 2011	Global survey of low vision services in 195 countries	<b>Level:</b> IV <b>Design:</b> secondary data analysis, survey <b>Subjects:</b> n=195 <b>Country of Origin:</b> 195 countries surveyed	<b>Brief Description:</b> survey of 195 countries, looked at epidemiology of LV, policies around LV service provision, barriers to services, and monitoring and evaluation of service outcomes.	<b>Results:</b> LV services were available in 115 of 195 countries, in many countries NGOs were the primary service providers, funding and awareness were the two most frequently cited barriers to access	<b>Limitations:</b> not all surveys were completed by official contacts, many countries provided limited or fragmented information, survey response rare in certain countries was poor
Siemsen, Bergstrom, & Hathaway, 2005	This study explored the use of LV patient consultation to improve access to LVRS	<b>Level:</b> IV <b>Design:</b> pilot study, descriptive survey <b>Subjects:</b> n=34 Mean age: NR <b>Country of Origin:</b> US	<b>Brief Description:</b> pilot study of LV consultation model to improve understanding and use of LVRS <b>Outcome Measures:</b> subjective measure of perceived effectiveness of consultation	<b>Results:</b> 70% of patients had improved understanding of VI; 85% of patients felt consultation was helpful	<b>Limitations:</b> small sample size; limited outcome measures used

**Appendix F: Stakeholder-driven LVRS Chronic Care Model**



Appendix G: Report to the Massachusetts Commission for the Blind



**Table of Contents:**

Executive Summary..... 3

Introduction..... 4

    Overview..... 4

    Table 1: Functional Limitations Associated with Visual Impairment in Older Adults..... 4

    Common Causes of Visual Impairment and Blindness..... 5

    Table 2: Visual Continuum ..... 5

    Table 3: Risk Factors and Prevalence by Race & Age..... 6

    Table 4: Disparity in Visual Health by Race, Age, Gender, and Socioeconomic Status..... 7

Scope of the problem: Massachusetts..... 12

    Figure 1: Rates of Visual Impairment in Massachusetts..... 12

    Table 5: MA Data: Age & Race..... 13

    Figure 2a: Rates of VI in Massachusetts..... 13

    Figure 2b: Conditions by Race..... 14

    MAP 1: Rate of Visual Impairment in MA (Appendix A)..... 27

    MAP 2: Number of Blind in MA (Appendix B)..... 28

    Table 6: Risk factors..... 15

Financial Implications..... 16

Visual Health Services..... 17

    MAP 1 & 2 (Appendix A & B)..... 27-28

Recommendations for new model of service delivery..... 20

    Figure 3: Model..... 20

    Figure 4: Model: Practice Level..... 21

    Table 7: Outcome measures..... 23

References..... 24

Appendix A: Map of Rates of Visual Impairment..... 27

Appendix B: Map of Number of Residents registered as Legally Blind..... 28

Appendix C: Estimation by Town..... 29

Appendix D: Low Vision Support Groups..... 40

Appendix E: Low Vision Resources Massachusetts..... 42

Appendix F: Stakeholder-driven Low Vision Rehabilitation Service Delivery Model.... 44

**Executive Summary:**

The number of older adults living with visual impairment (VI) and blindness in Massachusetts is growing and will continue to increase as our population ages. This report does not identify the causes of visual impairment and blindness but rather provides an overview of the prevalence of visual impairment and blindness, as well as the services available throughout the Commonwealth. The rate of visual impairment and blindness in residents over the age of 65 is a significant public health concern to the Commonwealth of Massachusetts. The resulting disability of visual impairment, including increased functional limitations in daily activities, higher rates of systemic health conditions, increased social isolation, higher prevalence of depression and increased risk of falls, has a significant impact on the individual, the community, and the nation. Although there is nothing that can be done to restore the vision lost to eye disease, there are services available to maximize the independence and safety of older adults with visual impairment and to support their participation within the community. Visual impairment and blindness are complex medical and social issues that will require coordinated efforts to address the barriers to access service and tailor the interventions to the needs of the particular community. A coordinated effort must address the vital linkage between the needs of the individual with available services within the community.

### Overview of Visual Impairment and Blindness:

Visual impairment (VI) is a serious public health issue that impacts nearly 20% of Americans over the age of 65 or about 7.3 million people (Campbell, Crews, Moriarty, Zack & Blackman, 1999; Lighthouse International, 2014; Federal Interagency Forum on Aging-Related Statistics, 2012). With an aging population, the rate of adults with visual impairment is expected to double by 2030 (CDC, nd). Visual impairment can impact all aspects of daily life. Campbell, et al. (1999), found individuals with VI were at increased risk of having greater functional limitations in daily activities, higher rates of systemic health conditions, increased social isolation, and higher prevalence of depression and risk of falls (**Table 1**).

<b>Table 1: Functional Limitations Associated with Visual Impairment in Older Adults</b>		
Functional Limitations: Difficulty with	Those with VI	Those without VI
Walking	43.3%	20.2%
Going outside	28.6%	10.4%
Managing medications	11.8%	4.4%
Preparing meals	18.7%	6.7%
Had a fall in the last 12 mo.	31.2%	19.2%
Diagnosed with hypertension	53.7%	43.1%
Diagnosed with heart disease	30.2%	19.7%
Diagnosed with stroke	17.4%	7.3%
Diagnosed with depression	13.3%	7%
Going out to eat	65.1%	55.7%
Comparison of functional implications of older adults (65 years of age and older) with visual impairment to those without visual impairment. Modified from Campbell, Crews, Moriarty, Zack, & Blackman, 1999.		

Vision is a continuum that ranges from “normal vision” to no light perception (**Table 2**). When discussing VI, two terms are often used, low vision and blindness. Low vision is a permanent loss of visual acuity, visual field, or visual function that is not correctable through medication, surgery, or optical lenses. This type of vision loss does not meet the legal definition of blindness, thereby excluding those with low vision from receiving services from the Massachusetts Commission for the Blind and other social service agencies (NEI, 2012). Blindness, as defined by the Social Security Administration (2014) is a central visual acuity of 20/200 or less and/or a visual field of no greater than 20 degrees.

<b>Table 2: Visual Continuum:</b>			
Normal vision	Near normal	Low Vision	Legal Blindness
20/20 or better	20/30-20/60	20/70 - >20/200	20/200 – no light perception
Visual Continuum, Visual Impairment refers to Low Vision and Legal Blindness categories (Colenbrander, 2002).			

**Common Causes of Vision Loss in Adults 65+:**

Four of the five major causes of VI and blindness are age-related. As our population ages, increasing numbers of people will be at risk of developing these conditions. Age-related macular degeneration (AMD), glaucoma, cataracts, and diabetic retinopathy rates continue to increase and are expected to double by 2030 (CDC, 2011). The rates of ocular disease and risk factors vary by race and age, but all can have significant impact on independence and safety (**Table 3**).

Visual impairment has been identified as one of the top 10 leading causes of disability in the US (CDC, 2006), and impacts all aspects of life. Chou and colleagues

(2013) report that at least 50% of visual impairment and blindness could be prevented with early detection and proper treatment.

<b>Table 3: Risk Factors and Prevalence by Race &amp; Age:</b>					
Eye Condition	Age	White	Black	Hispanic	Risk Factors
Cataract	65-69	25.0%	23.6%	24.3%	Aging; Diabetes; Smoking; Alcohol Use; Sun Exposure; Poor Nutrition
	70-74	37.4	31.7	34.4	
	75-79	51.1	40.1	45.2	
	80+	70.4	53.5	60.7	
Diabetic Retinopathy	65-74	8.4	7.6	15.9	Hispanic; Diabetes; Poor nutrition; Poor blood sugar control; Decreased activity/ Obesity
	75+	7.4	6.9	18.9	
Glaucoma	65-69	1.6	5.7	2.4	African American; 60+; Family history
	70-74	2.3	7.4	3.6	
	75-79	3.3	8.9	5.4	
	80+	7.42	11.4	10.4	
Age-Related Macular Degeneration	65-69	.9	1.0	1.0	Caucasian; Fair skin; Light eyes; Family History; Smoking; Decreased activity; Poor nutrition
	70-74	1.7	1.3	1.2	
	75-79	3.6	1.5	1.5	
	80+	13.6	2.2	2.1	

*4 Major causes of visual impairment and blindness, risk factors and prevalence rates by age, National Eye Institute, 2014.*

Although there is no cure for 3 of the 4 conditions, there is much that can be done to support the functional independence and safety of those older adults living with VI. Cataract is the only condition that is curable through surgery; however, there are multiple reasons for individuals not to be deemed a surgical candidate, such as health status or the

individual not seeking services because of fear of the procedure, inadequate social supports, or lack of referral to a physician.

Vision rehabilitation services may assist individuals with VI to use compensatory strategies such as using tactile cues, electronic magnification, or organizational strategies to maintain health and independence. Access issues to vision rehabilitation services have been found for all races and visual impairment categories. Lack of referral (24%), knowledge of visual health and awareness of rehabilitation services all impact utilization and visual outcomes (Casten, Maloney & Rovner, 2005; Prosner & Shin, 2008). To that end, Healthy People 2020 vision goals included increasing access to vision rehabilitation services and the devices and strategies that have been found to be effective in reducing the functional implication of vision loss.

Visual health disparities in adults in the U.S. are found based on race, age, gender, and socioeconomic factors. Although visual impairments are more common in older adults, there are racial variations that need to be explored to better understand how to implement public health strategies to improve awareness, access, and available interventions (Casten; Prosner). **Table 4** illustrates health care disparities across visual conditions (Prosner; NEI, 2004; Zambelli-Weiner, 2012; Crews & Friedman, 2012).

**Table 4:** Disparity in Visual Health in Adults by Race, Age, Gender, and Socioeconomic Status

	Cataract	AMD	Glaucoma	DR	URE*
Race					
White					
Hispanic					
Black					
Age & Gender					
Age					
Male					
Female					
Socioeconomic					
Lower Income					
Education					
Disability					

\* Uncorrected refractive error (URE); Gray indicated higher prevalence of eye condition; Dark gray grid indicates higher prevalence and increased disability as a result of eye condition ([Chou , Baker , Crews , Primo & Zhang, 2012](#); [Casten, 2008](#); [NEI, 2004](#); [Qui, Wang, Singh & Lin, 2014](#); [Zhang, et al., 2012](#); [Prevent Blindness America, 2005](#); [Reeves, Strine & Pratt, 2011](#) )

**Cataracts:**

Cataracts are the most common cause of visual impairment and blindness in the US and throughout the world.

The primary risk factor for cataracts is age, with slightly higher rates found among women. Cataracts are a treatable condition, through surgical removal; however, it has been found that blacks were 5 times more likely



to have inoperable cataracts. Other factors that increase risk of cataracts include history of smoking, exposure to UV radiation, and diabetes ([Qui, Wang, Singh & Lin, 2014](#); [Zhang, et al., 2012](#); [CDC, 2009](#)).

### **Age-Related Macular Degeneration (AMD):**

The primary risk factor for age related macular degeneration is also age, but AMD is also more common in whites and in women. Age-related macular degeneration is most commonly found in Caucasians, and accounts for 54% of all blindness cases ([Zambelli-Weiner](#)). Other factors



that influence AMD are light eyes, fair skin, exposure to UV radiation, improper nutrition and physical activity, and family history ([Qui; Zhang; CDC, 2009](#)).

**Glaucoma:**

Glaucoma also occurs most commonly in older adults, there is a slight higher risk among women;

and the highest prevalence is seen in Blacks and Hispanics. Blacks and Hispanics were at 3-5 times

greater risk of developing glaucoma and at 6 times

greater risk of developing visual impairment as a result (NEI, 2004). It was also found that half of those with glaucoma were unaware of their condition; glaucoma is often referred to as the silent thief of vision due to subtle symptoms. The National Eye Institute's strategic plan seeks to examine the disparities in glaucoma care and outcomes. Existing initiatives are examining biological differences in terms of how different races respond to current treatment regimens (NEI, 2004).

**Diabetic Retinopathy:**

Diabetic retinopathy can lead to visual impairment and blindness and is seen in 100% of those with type I diabetes and 50% of type II, 20 years post diagnosis (Zambelli-Weiner). Blacks are at 6 times greater risk for developing visual



impairment as a result of diabetic retinopathy compared to whites (NEI, 2004; Zambelli-Weiner; Health and Human Services, 2014).

**Uncorrected Refractive Error:**

The risk of having inadequate refraction or inappropriate glasses increased in those who were Hispanic, Black, below the poverty level, had lower education, and those with no or inadequate health insurance ([Qui; Zhang; CDC, 2009](#)). Uncorrected refractive error could be related to the lack of awareness of the importance of regular eye examinations, those who were of low income, minority and uninsured were found to have a lack of visual health information. Even in those with eye care coverage, less than 50% of Medicare beneficiaries had an eye exam in the last year, many of whom lacked basic eye health information. In those with age related eye disease and visual impairment, annual eye examination rates varied depending upon type of insurance 67% (private), 55% (public), and 42% (none). Those who identified as having inadequate vision coverage also varied by insurance type 58% (private), and 44 % (public) (CDC, 2009).

**Summary:**

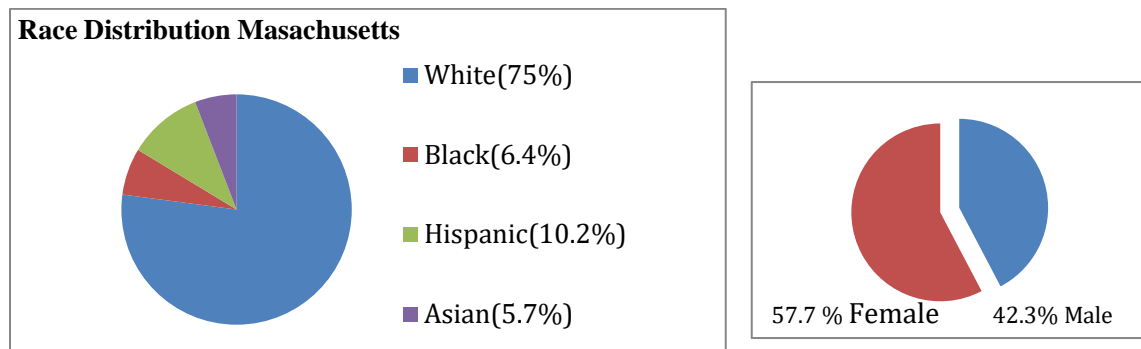
Visual impairment is a serious public health issue that impacts nearly 1 in 5 older adults 65 years and older and this rate will only continue to rise as our population ages. The resulting disability of VI, increased functional limitations in daily activities, higher rates of systemic health conditions, increased social isolation, higher prevalence of depression and increased risk of falls, has a significant impact on the individual, the community, and the nation. Although there is nothing that can be done to restore the vision lost to eye disease, there are services available to maximize the independence of

older adults with VI and to support older adults within the community. Lack of visual health information may also be a significant barrier to accessing appropriate eye care. In addition, even in a country with extensive health care services, there continues to be racial and social inequities in terms of accessibility and provision of services. It has been found that those who are White or Asian experience better overall health and access to services ([Qui; Zhang; CDC, 2009](#)).

### Scope of the problem: Massachusetts:

The total estimated population of Massachusetts in 2017 was 6,859,819, 15.8% of whom are 65 and older (United States Census Bureau, 2017). Figure 1 illustrates the distribution of the over 65 population in Massachusetts.

**Figure 1:** Distribution of population 65+ in Massachusetts

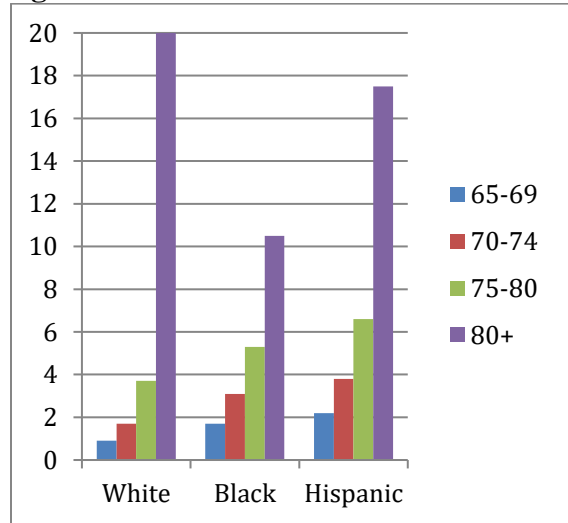


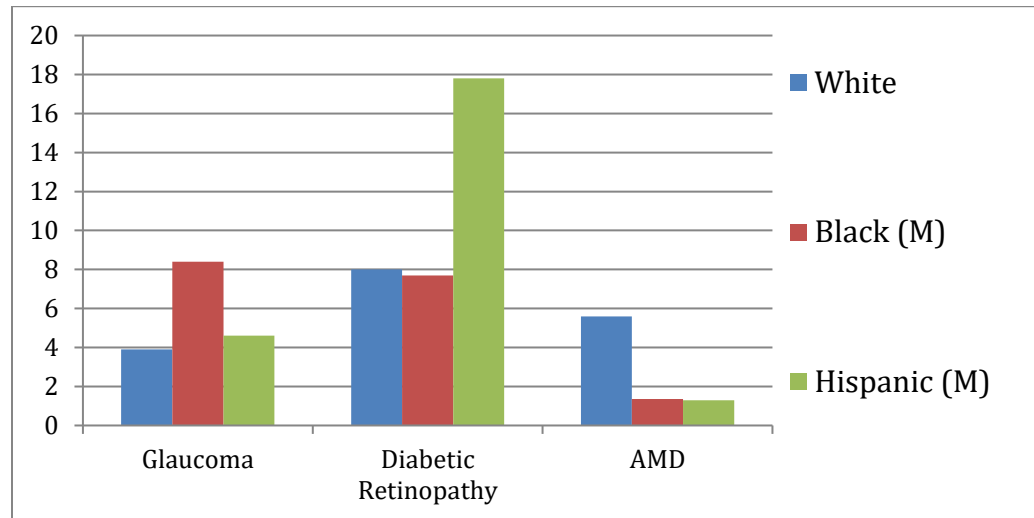
The estimated prevalence rate of visual impairment in Massachusetts is 51.02 per 1,000 residents 65 and older, with rates ranging from 18.54 in Wendell to 187.10 in East Orleans, using 2016 Census data, refer to **Appendix A and Table 5**. Communities with the largest population of individuals living with blindness included Springfield, Worcester, Dorchester, Fall River, New Bedford, Brockton, Boston and Lowell, refer to **Appendix B & C**. Appendix C includes a synthetic estimation of the prevalence of visual impairment and the number of individuals registered as legally blind by town. The synthetic estimation used 2016 Census data and prevalence rates of visual impairment by age and race (Prevent Blindness America, 2012).

<b>Table 5: Massachusetts Data: Age &amp; Race Distribution and Rate of Visual Impairment and Blindness</b>	
2016 Population	Total Population
Massachusetts	6,859,819
Total Population 65+	1,083,852
% White	73
% Hispanic	11.5
% Black	8.6
% Asian	6.7
65-74	8.3
75-84	4.5
85+	2.3
Est. VI rate per 1,000	51.02*
Number of cases of blindness	28,119
*Synthetic Estimates refer to Appendix C	

Visual impairment rates among older adults in Massachusetts increase rapidly with age from .9-2.2% for those 65-69 years, to 10.5-20% for those 80 years and older, depending on race. Those at highest risk for VI are Caucasians and those 80 and older (Figure 2a & b).

**Figure 2a: Rates of VI in Massachusetts:**



**Figure 2b:** Conditions by Race

*Massachusetts Visual Impairment by Age, Race, Sex, and condition, VPUS 2012*

Risk factors and secondary health issues associated with visual impairment and blindness are presented in **Table 6**. Due to the multiple factors influencing visual impairment and blindness, causality is not identified in this report. Instead, descriptive information is provided to explore the significance of visual impairment and the potential risk for Massachusetts' older residents. Massachusetts BRFSS (2011) data found barriers to visual health services; the most common reasons for those with visual impairment to not seek out vision related service included cost (8.9%), self-determined lack of need (61%), and lack of eye doctor (4.9%). Possible reasons for perceived lack of need may include the perception that vision loss is a natural part of aging and nothing can be done (CDC, 2011).

<b>Table 6: Risk factors and secondary health issues associated with visual impairment and blindness: 2014 Population Data</b>	
<b>2011 Population 65+</b>	<b>Massachusetts</b>
Total	921,909
<b>Gender</b>	
Males	48.4%
Females	51.6%
<b>Age Groups</b>	
65-74	7.2%
75-84	4.6%
85+	2.3%
<b>Race</b>	
White	75 %
Hispanic	10.2 %
Black	6.4 %
Asian	5.7 %
<b>Health Indicators &amp; Secondary Health Issues</b>	
Poverty	7%
Obesity	17%
Decreased Physical Activity	19.8%
Smoking	16.4%
Depression	7.1%*
Fall with in past 12 months	25.2%
<b>Visual Health</b>	
Do not have access to regular eye care	9.3%
Cannot afford prescription medications	13.7%
Annual Eye Exam Rate*	74%
*dependent on race (Caucasian low end; African American high end); W-White; B-Black; H-Hispanic, BRFSS data 2008 (CDC, 2011; BRFSS, 2008; Prevent Blindness America, 2013; Timpano, 2014; CDC, 2010; Reeves, 2011).	

**Financial Implications:**

In 2010, the total costs of VI and blindness for the state of Massachusetts totaled over \$1.7 billion. Direct costs including outpatient services, government programs, and medications for individuals 65 and older were \$680 million and indirect costs, such as informal care and loss in productivity exceeded \$1 billion (Prevent Blindness America, 2013). Wittenborn & Rein (2013) estimated the cost of low vision alone was \$15,900 per person. Medical costs for older adults with visual impairment was estimated at nearly \$7,000 per year. They further estimated that vision loss in the U.S. “resulted in the loss of 283,000 disability adjusted life years per year” (p. 10). With the aging of our populations the costs to Massachusetts will significantly increase in the next few years.

Access to visual health services as well as vision rehabilitation services can significantly reduce health care costs and improve older adults’ functional abilities, as well as quality of life. Rein and colleagues found routine identification and subsequent medical treatment of glaucoma was highly cost-effective, \$46,000 per quality adjusted life year (QALY) for glaucoma care (Rein, et al., 2009). A study by Maciosek and colleagues (2006) found that by improving access to vision services from 50-90% would save an additional 31,000 QALYs.

**Summary:**

Prevent Blindness America reported that there was a sharp increase in rates of the four most common eye conditions between 2000 and 2012, AMD by 25%, cataracts by 19%, glaucoma by 22% and diabetic retinopathy by 89% (Prevent Blindness America, 2013). The greatest risk for developing VI as a result of eye disease is aging. With an

aging population, these rates will continue to rise. The financial and personal implications are significant, reaching nearly \$2 billion dollars in Massachusetts alone.

**Visual Health Services:****Health Systems:**

In a review of the evidence, programs that have been found effective in reducing the level of disability and functional impairment of the individual with VI are multi-component education programs provided by a multidisciplinary team (Kaldenberg & Smallfield, 2013). Services for individuals with VI are provided by a variety of professionals, both from the medical and social services models. The National Eye Institute and the Lighthouse International looked at national utilization of low vision service and found that services are underutilized and under referred (Casten, 2005). Comprehensive services need to address the barriers to access service and tailor the interventions to the needs of the particular community. Prevent Blindness America and the National Association of Chronic Disease Directors found that there are no systematic coordinated programs in any state health department (Prevent Blindness America, 2005). They recommend coordination of services led by the state health department that mobilizes community partnerships and provides the vital linkage between the needs of the individual with available services within the community.

**The Medical System:**

The services currently available within the Commonwealth for the assessment and intervention of visual impairments primarily include providers from the health care system. The Commonwealth has many hospitals, private practices, and community health centers which provide comprehensive eye examinations, medical management of ocular disease, and some provide low vision examinations and comprehensive low vision

rehabilitation services, including occupational therapy, orientation & mobility services, and other low vision professionals. However, there are pockets throughout the Commonwealth which lack access to low vision examinations by ophthalmology or optometry. In 2010, the New England Eye Institute developed a mobile eye care clinic to address these areas throughout the Commonwealth which lacked access to services, yet this mobile service may be difficult to sustain due to high overhead costs of mobile health. Collaboration with local eye care providers may allow for sustainability.

**The Blindness System:**

In addition to the services offered through the health care system, there are also services available through the blindness system. An adult with a visual impairment may be eligible for service from the Massachusetts Commission for the Blind (MCB), if they meet the legal definition of blindness (CDC, 2005). The MCB assigns case workers who provide services in the home or community. If deemed appropriate, a case worker may refer the older adult for further medical testing or more comprehensive vision rehabilitation services, such as those provided by the Carroll Center in Newton.

**Community Services:**

A small number of community programs provide adjunctive support to the services provided by the healthcare system and the blindness system. Through MAB Community Services, there are 32 peer-led low vision support groups that meet monthly throughout the Commonwealth. Sight Loss Services provides monthly peer groups led by coordinators who are visually impaired to consumers on the Cape. The peer led support groups provide members the opportunity to share ideas, problem solve, provide support

and gain information from invited guests on a variety of topics (United States Census Bureau, 2014). They also serve as an information and referral hub. These support groups are state and federally funded by the MCB. **Appendix D** includes a list of the current Low Vision Support Groups throughout the Commonwealth. In addition, there are other community services that assist those with visual impairment obtain the necessary equipment they need in order to improve their functional ability, such as Easter Seals and the Lions Club.

#### **Health Resources for Older Adults with Visual Impairment & Blindness:**

Massachusetts has a variety of health and social service agencies that serve older adults with VI and blindness, both within the medical and social services arena (Perkins School for the Blind, 2008). Eye care services for individuals with VI or blindness are generally provided at a secondary level, often requiring a referral from the primary care physician. **Appendix E** illustrates the health resources available in the Commonwealth. Although there may be an adequate number of providers/facilities to identify a visual impairment, there are insufficient numbers of providers/facilities to provide low vision services to those with visual impairment and blindness (refer to Maps 1 &2).

#### **Summary:**

Massachusetts has a wealth of resources for individuals with VI and blindness. In order to better address the needs of the aging population of Massachusetts and those with VI and blindness it will be essential to coordinate services to improve access, referrals, and overall utilization.

### Recommendations for a New Model of Service Delivery

The proposed model, see **Figure 3**, integrates key components of previous best practice models, practice guidelines, and results from focus groups of residents of MA living with VI and interviews of key stakeholder who provide direct service or support to adults with VI. Data collected were merged and applied to the Chronic Care Model (CCM) framework.

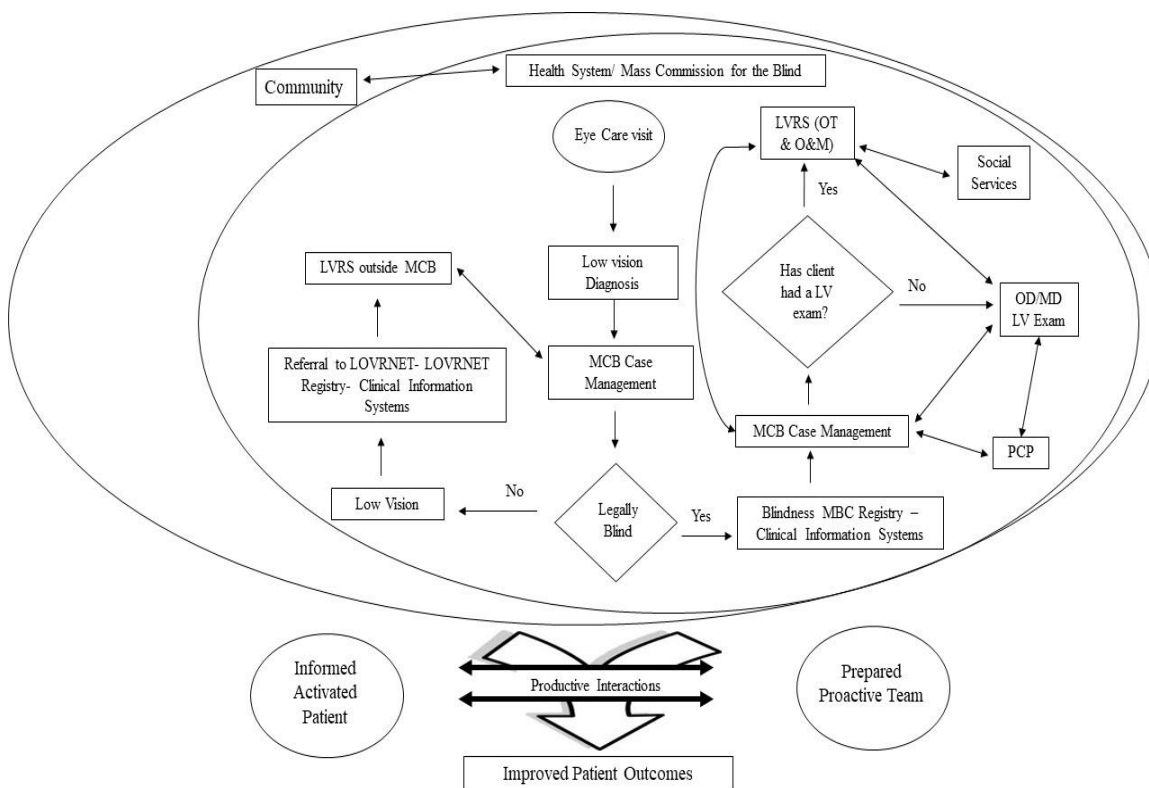
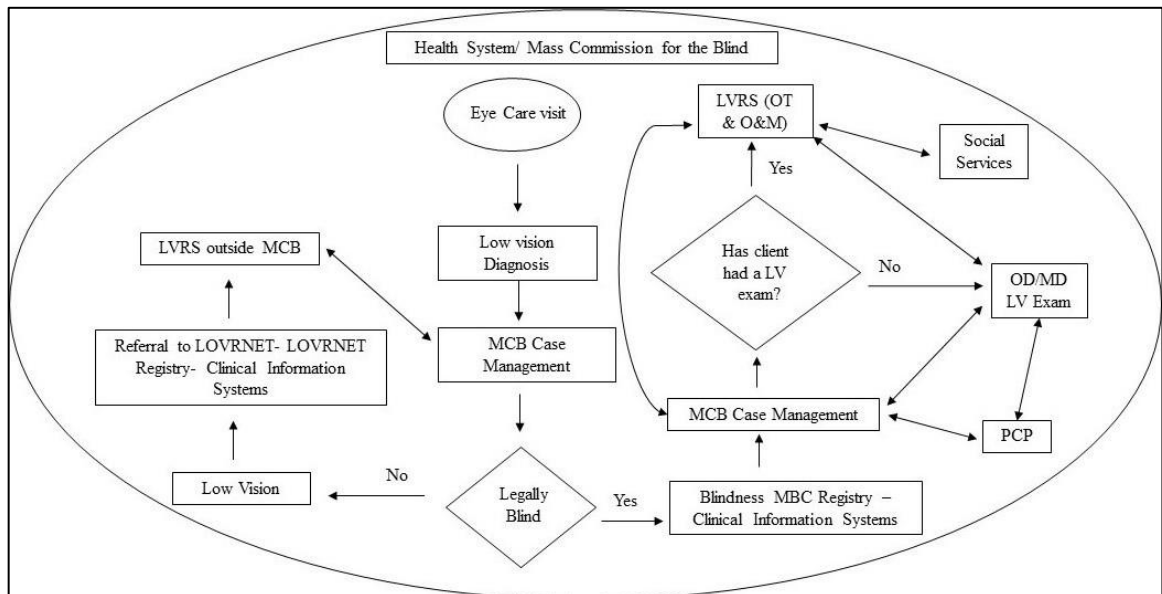


Figure 3. Stakeholder-driven LVRS Chronic Care Model

*Practice Level*

**Figure 4** illustrates the proposed practice level of the CCM for Low Vision Rehabilitation Services (LVRS). Once an individual is seen by an eye care provider and are identified as having a VI, they are referred to case management. The case manager then determines the individual's eligibility for either LV services or MCB services. If the individual has LV, but does not meet requirements for legal blindness, they are referred to the LV Resource Network (LOVRNET) where they are referred on for LVRS. LOVRNET assists the individual in making an appointment and any needed transportation or social service support. Comprehensive LVRS will be coordinated. Ongoing case management will follow the individual and their ongoing needs. If visual function changes over time, the individual re-enters the system for further evaluation and service provision.



*Figure 4.* Practice Level of the Stakeholder-driven LVRS Chronic Care Model; Adapted from Wagner, 1998

If the client meets the requirements for legal blindness, they are then entered in the MCB system. Case management then determines if the client has had a LV examination. Existing MCB staff members will be utilized for case management positions. These professionals are the most appropriate as they are familiar with community level services and understand the importance of comprehensive LVRS. As found in the analysis from focus group interviews and participant demographics, having a LV exam was the only factor found to increase the likelihood of accessing LVRS (Kaldenberg, 2018). Recommendation for LV exam prior to LVRS is also consistent with best practice guidelines for optometry, ophthalmology, and occupational therapy (The American Academy of Ophthalmology, 2013; the American Optometric Association, 2007; Kaldenberg & Smallfield, 2013). If an individual has not had a LV exam, the case manager will provide the referral, assist in scheduling the appointment, and coordinate transportation, as needed. A comprehensive LV exam provided by a LV optometrist or ophthalmologist should adhere to best practice recommendations.

After receiving the LV exam, the optometrist or ophthalmologist refers the client to LVRS with recommendations for intervention. As illustrated in **Figure 4**, ongoing communication between the multidisciplinary LV team should be provided and include coordination with the primary care provider. The system is a loop, so as vision or needs change, the individual can re-enter the system for additional evaluation or service provision.

*Productive Interactions Level*

As identified in the data, there is a need for education at both the individual consumer and health practitioner level in order for productive interactions. All LVRS team members should be providing ongoing education to the individual with VI and their caregivers/ support system. This ongoing education can help facilitate improved awareness of visual health and rehabilitation services, and decrease the potential for misinformation or misinterpretation. Consumer education has been found to improve access, adherence, and use of LVRS (Siemens, Bergstrom, & Hathaway, 2005; Jose, Thomas, Bhakat, & Krithica, 2016).

To increase the number of trained service providers in Massachusetts, support for continuing education for all providers is essential. MCB can work with local universities to continue to develop and support professionals entering the field of LVRS. In addition, ongoing outreach to existing practitioners can help to improve awareness of the need for and effectiveness of LVRS.

*Outcomes Level*

Current changes in healthcare reimbursement have created challenges and unique opportunities. With increased focus and reimbursement tied to individual health outcomes, it is recommended that MCB incorporate outcome measures into documentation to allow for greater communication between MCB and the health system, as well as provide effective mechanisms for program evaluation. This will also help position MCB for potential inclusion within an Affordable Care Organization (ACO). Collaboration with existing ACOs throughout the state should be explored to increase

sustainability, given funding shortages. **Table 7** provides a list of potential outcome measures to be included in the revised model of service delivery.

<b>Table 7 Outcome measures</b>	
Screening Tool	Description
Self-report Assessment of Visual Function Performance (SRAVFP), Velvo, et al., 2013	39 item self-report instrument: assessment of ADL and IADL performance, components can also be assessed objectively
Visual Function Questionnaire (VFQ- 25), Mangione, et al., 2001	25 item self-report survey, assessing influence of visual disability and visual symptoms on general health, well-being, and QOL
Falls Efficacy Scale (FES-I), Yardley, et al., 2005	16 item scale that measures the level of concern about falling during social and physical activities indoors and outdoors
Geriatric Depression Screening (GDS), Yesavage, et al., 1983	30 item self-report, assessing feelings during the past week
ADL-activities of daily living; IADL-instrumental activities of daily living; QOL-quality of life	

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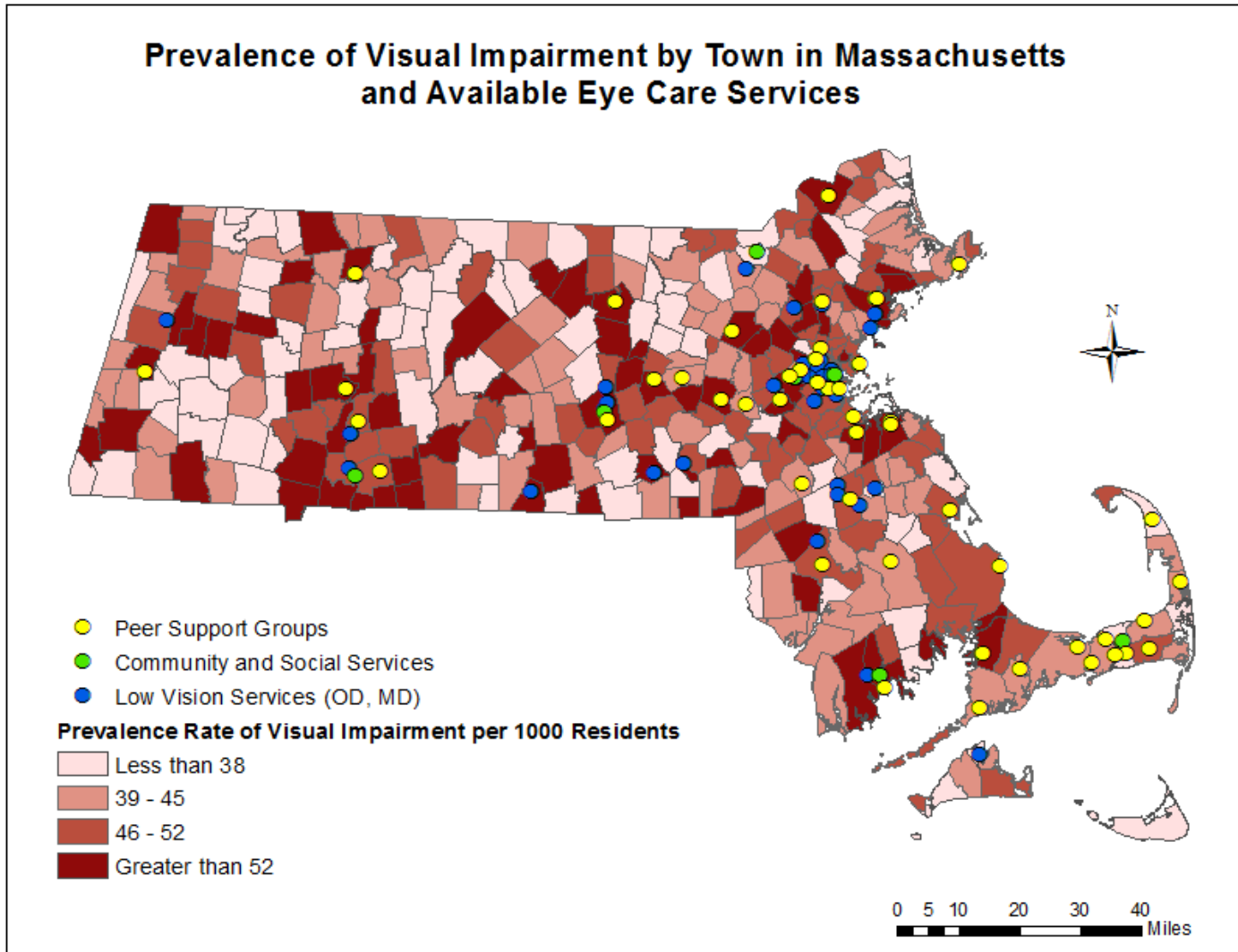
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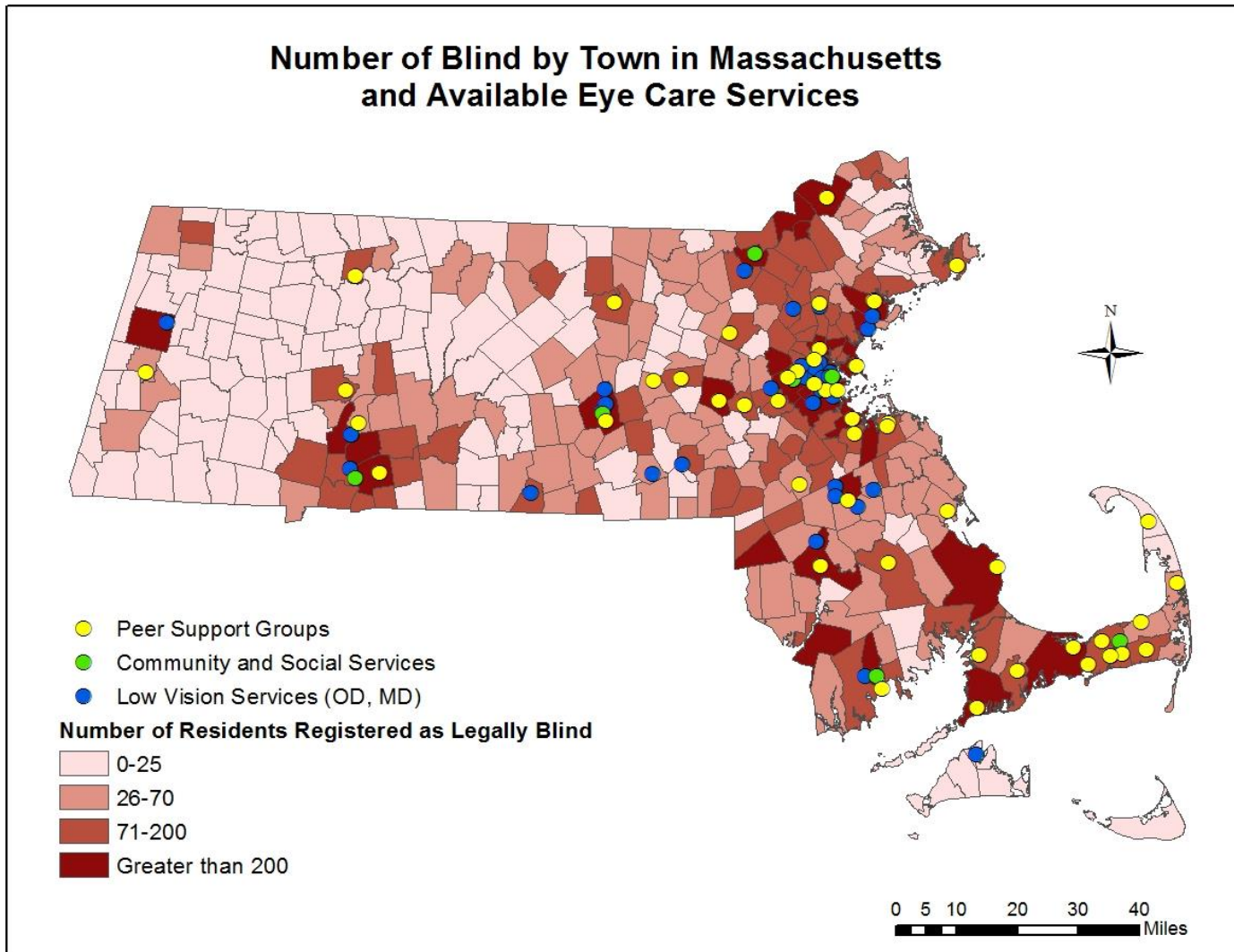
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Appendix G-A: MAP of the Prevalence Rate of Visual Impairment by Town



**Appendix G-B: Number of Residents registered as Legally Blind**



<b>Appendix G-C: Prevalence of Visual Impairment* and Number of Individuals who are Blind in Massachusetts</b>		
<b>*synthetic estimation</b>		
<b>TOWN</b>	<b>Prevalence Rate of VI</b>	<b># of Blindness</b>
Abington	39.37	49
Acton	45.18	61
Acushnet	50.09	41
Adams	46.66	46
Agawam	62.64	151
Alford	34.05	2
Allston	47.85	66
Amesbury	45.39	73
Amherst	45.91	76
Andover	44.76	125
Aquinnah	34.06	1
Arlington	58.88	192
Ashburnham	28.45	12
Ashby	46.01	10
Ashfield	38.69	0
Ashland	40.71	2
Ashley Falls	28.18	41
Athol	49.91	0
Attleboro	43.77	71
Auburn	50.15	218
Auburndale	42.54	70
Avon	44.87	0
Ayer	37.55	22
Baldwinville	69.76	51
Barnstable	50.10	0
Barre	56.93	237
Becket	31.74	19
Bedford	59.26	6
Belchertown	36.01	56
Bellingham	45.95	50
Belmont	51.27	50
Berkley	23.56	97
Berlin	45.59	18
Bernardston	46.29	9

Beverly	52.92	4
Billerica	44.20	190
Blackstone	45.98	135
Blandford	35.78	42
Bolton	35.51	2
Bondsville	37.98	13
Boston	47.14	483
Bourne	49.09	85
Boxborough	35.62	10
Boxford	37.76	14
Boylston	62.73	5
Braintree	59.04	176
Brewster	47.21	59
Bridgewater	46.01	66
Brighton	58.60	233
Brimfield	29.92	15
Bristol	32.80	0
Brockton	46.08	486
Brookfield	35.04	20
Brookline	47.46	241
Buckland	39.54	0
Burlington	46.01	101
Buzzards Bay	49.90	0
Byfield	30.70	0
Cambridge	44.45	366
Canton	50.62	97
Carlisle	39.79	10
Carver	43.66	44
Centerville	40.26	0
Charlemont	39.74	1
Charlestown	44.98	55
Charlton	56.94	47
Chatham	44.20	45
Chelmsford	42.70	150
Chelsea	55.60	194
Cherry Valley	25.68	0
Cheshire	35.36	9
Chester	39.63	8
Chesterfield	47.84	0

Chestnut Hill	53.98	0
Chicopee	50.20	317
Chilmark	35.63	0
Clarksburg	41.31	9
Clinton	52.54	38
Cohasset	37.17	34
Colrain	48.58	5
Concord	52.65	72
Conway	40.02	4
Cotuit	43.61	0
Cummington	60.81	4
Dalton	55.73	24
Danvers	57.70	162
Dartmouth	55.71	0
Dedham	59.16	114
Deerfield	39.12	12
Dennis	38.89	104
Dennisport	25.68	0
Devens	23.43	0
Dighton	45.58	26
Dorchester	44.19	710
Douglas	23.85	15
Dover	39.83	12
Dracut	39.97	104
Drury	47.75	0
Dudley	45.05	41
Dunstable	47.94	4
Duxbury	49.96	40
East Boston	62.44	133
East Bridgewater	39.63	43
East Brookfield	45.04	6
East Dennis	48.45	0
East Falmouth	34.60	0
East Freetown	55.87	0
East Hampton	47.39	61
East Longmeadow	57.28	87
East Orleans	187.10*	0
East Otis	35.80	0
East Sandwich	28.89	0

East Taunton	26.26	0
East Templeton	32.64	0
East Walpole	38.32	0
East Weymouth	41.09	0
Eastham	42.87	30
Easton	35.53	65
Easthampton	44.56	61
Edgartown	51.86	15
Egremont	52.48	0
Erving	44.51	10
Essex	33.24	9
Everett	44.62	145
Fairhaven	55.01	87
Fall River	49.99	539
Falmouth	45.05	211
Fayville	39.43	0
Feeding Hills	40.08	0
Fiskdale	51.73	0
Fitchburg	50.35	199
Florence	36.12	1
Forestdale	21.46	0
Foxborough	54.15	51
Framingham	55.52	318
Franklin	47.67	86
Freetown	44.39	42
Gardner	53.54	111
Georgetown	35.04	35
Gilbertville	35.77	0
Gill	42.81	35
Glendale	79.04	0
Gloucester	46.18	150
Goshen	43.63	1
Gosnold	35.81	0
Grafton	41.48	71
Granby	51.93	32
Granville, Granville Center	33.56	5
Great Barrington	56.66	45
Green Harbor	56.12	0
Greenfield	56.10	86

Groton	44.89	69
Groveland	37.97	29
Hadley	62.87	29
Halifax	35.55	25
Hamilton	45.76	0
Hampden	44.80	15
Hancock	35.90	0
Hanover	41.98	27
Hanson	25.91	39
Hardwick	29.79	0
Harvard	32.90	14
Harwich	43.36	0
Harwichport	37.53	0
Hatfield	31.11	5
Haverhill	57.34	302
Hawley	28.20	0
Haydenville	63.80	0
Heath	30.26	0
Hingham	60.32	111
Hinsdale	46.33	6
Holbrook	44.46	57
Holden	47.62	50
Holland	25.84	5
Holliston	46.64	30
Holyoke	65.57	311
Hopedale	77.43	17
Hopkinton	44.74	27
Housatonic	34.96	0
Hubbardston	41.20	15
Hudson	36.79	68
Hull	34.78	45
Huntington	28.43	10
Hyannis	46.88	0
Hyde Park	49.91	179
Indian Orchard	58.36	0
Ipswich	47.75	47
Jamaica Plain	55.33	178
Jefferson	47.19	0
Kingston	57.41	50

Lakeville	40.58	29
Lancaster	40.64	26
Lanesborough	39.75	11
Lawrence	56.78	434
Lee	45.27	29
Leeds	56.69	0
Leicester	37.32	41
Lenox	73.95	44
Leominster	53.99	184
Leverett	31.19	0
Lexington	55.21	151
Leyden	38.60	4
Lincoln	70.14	12
Littleton	47.09	31
Longmeadow	64.44	78
Lowell	51.77	463
Ludlow	51.98	106
Lunenburg	50.88	27
Lynn	51.57	423
Lynnfield	53.74	40
Malden	48.06	279
Manchester	47.45	13
Mansfield	44.28	79
Marblehead	45.71	67
Marion	52.70	26
Marlborough	46.86	147
Marshfield	35.98	70
Mashpee	39.48	71
Mattapan	37.49	175
Mattapoisett	34.25	22
Maynard	46.20	29
Medfield	45.85	26
Medford	49.49	252
Medway	56.17	32
Melrose	45.97	134
Mendon	34.31	15
Merrimac	33.65	27
Methuen	48.51	217
Middleborough	39.38	88

Middlefield	19.57	3
Middleton	41.25	29
Milford	48.64	123
Millbury	41.06	64
Millers Falls	98.68	0
Millis	35.03	21
Millville	41.23	11
Milton	52.65	126
Monroe	32.76	0
Monson	35.74	28
Montague	51.36	9
Montgomery	40.68	1
Mount Washington	28.38	0
Nahant	62.19	11
Nantucket	39.80	21
Natick	41.85	145
Needham	59.07	110
Needham Heights	61.44	0
New Ashford	43.54	0
New Bedford	58.84	533
New Braintree	45.01	0
New Marlborough	36.20	4
New Salem	36.39	4
Newbury	27.28	18
Newburyport	42.74	78
Newton	50.58	0
Newton Center	43.90	0
Newton Highlands	39.15	0
Newton Lower Falls	78.74	0
Newton Upper Falls	70.81	0
Newtonville	36.34	271
Norfolk	35.92	34
North Adams	54.33	113
North Andover	56.04	105
North Attleboro	48.50	95
North Billerica	45.12	0
North Brookfield	40.81	22
North Chatham	50.66	0
North Chelmsford	44.95	0

North Dartmouth	62.61	0
North Dighton	47.96	0
North Easton	37.75	0
North Falmouth	78.43	0
North Grafton	41.50	0
North Hatfield	37.00	0
North Oxford	36.14	0
North Reading	35.43	44
North Weymouth	46.78	0
Northampton	56.78	132
Northborough	45.78	38
Northbridge	47.89	56
Northfield	55.95	0
Norton	42.50	65
Norwell	48.93	34
Norwood	51.18	130
Oak Bluffs	41.79	16
Oakham	43.27	3
Orange	37.84	26
Orleans	40.71	54
Osterville	44.83	0
Otis	32.57	4
Oxford	42.30	50
Palmer	53.78	78
Paxton	42.38	13
Peabody	60.14	325
Pelham	45.13	0
Pembroke	37.32	55
Pepperell	36.05	33
Peru	50.95	0
Petersham	54.54	2
Phillipston	34.17	6
Pittsfield	50.01	270
Plainfield	40.38	1
Plainville	45.38	20
Plymouth	37.97	219
Plympton	29.29	11
Princeton	25.58	4
Provincetown	43.17	16

Quincy	49.33	458
Randolph	45.95	151
Raynham	40.35	47
Reading	57.21	81
Rehoboth	45.32	30
Revere	49.11	245
Richmond	39.65	5
Rochester	52.46	18
Rockland	41.85	79
Rockport	48.16	36
Roslindale	51.53	149
Rowe	33.34	0
Rowley	40.84	11
Roxbury	45.13	293
Royalston	33.55	3
Russell	31.22	5
Rutland	37.46	28
Sagamore	38.71	0
Salem	51.09	201
Salisbury	38.44	35
Sandisfield	56.17	3
Sandwich	42.25	69
Saugus	51.49	105
Savoy	39.52	2
Scituate	55.57	60
Seekonk	33.35	38
Sharon	41.02	49
Sheffield	42.91	6
Shelburne Falls	38.44	18
Sherborn	52.42	7
Shirley	39.81	23
Shrewsbury	47.33	117
Shutesbury	31.48	2
Somerset	49.06	92
Somerville	45.94	296
South Boston	56.67	155
South Dartmouth	53.76	0
South Dennis	43.24	0
South Hadley	52.57	68

South Hamilton	39.98	0
South Weymouth	37.69	0
Southampton	37.70	13
Southborough	45.58	18
Southbridge	60.87	101
Southfield	22.70	0
Southwick	58.82	48
Spencer	37.88	66
Springfield	49.27	997
Sterling	50.96	27
Stockbridge	41.83	25
Stoneham	53.79	72
Stoughton	50.76	130
Stow	37.00	25
Sturbridge	48.54	46
Sudbury	40.13	41
Sunderland	59.41	7
Sutton	45.82	17
Swampscott	55.96	39
Swansea	40.42	60
Taunton	48.98	275
Templeton	42.09	29
Tewksbury	40.75	132
Thorndike	26.98	0
Three Rivers	56.16	0
Tisbury	28.32	32
Tolland	39.36	0
Topsfield	47.46	29
Townsend	33.48	34
Truro	30.40	11
Turners Falls	55.63	0
Tyngsborough	45.37	31
Tyringham	38.16	0
Upton	33.36	19
Uxbridge	45.13	56
Vineyard Haven	34.18	0
Waban	39.66	0
Wakefield	45.62	85
Wales	42.43	8

Walpole	50.32	96
Waltham	53.75	287
Ware	40.50	62
Wareham	40.16	108
Warren	41.60	18
Warwick	42.60	0
Washington	22.46	2
Watertown	44.50	211
Wayland	42.02	37
Webster	57.19	81
Wellesley	46.97	82
Wellfleet	40.49	7
Wendell	18.54	2
Wenham	53.85	15
West Barnstable	28.18	0
West Boylston	56.98	28
West Bridgewater	52.54	31
West Brookfield	58.20	34
West Chesterfield	65.14	0
West Dennis	43.17	0
West Harwich	38.83	0
West Newbury	52.25	5
West Roxbury	54.63	126
West Springfield	50.61	151
West Stockbridge	26.95	4
West Tisbury	51.55	2
West Townsend	26.06	0
West Warren	77.56	0
West Yarmouth	48.13	189
Westborough	50.42	57
Westfield	47.79	0
Westford	35.69	55
Westhampton	34.25	4
Westminster	42.31	24
Weston	47.28	34
Westport	42.82	70
Westwood	64.70	45
Weymouth	43.37	223
Whatley	32.42	4

Wheelwright	74.28	0
Whitinsville	50.29	0
Whitman	36.41	45
Wilbraham	58.98	78
Williamsburg	45.27	15
Williamstown	66.39	41
Wilmington	50.46	89
Winchendon	36.89	44
Winchester	48.95	82
Windsor	35.15	2
Winthrop	38.37	86
Woburn	53.67	142
Woods Hole	33.78	0
Worcester	56.10	921
Woronoco	37.00	0
Worthington	53.49	4
Wrentham	50.23	122
Yarmouth	57.07	0

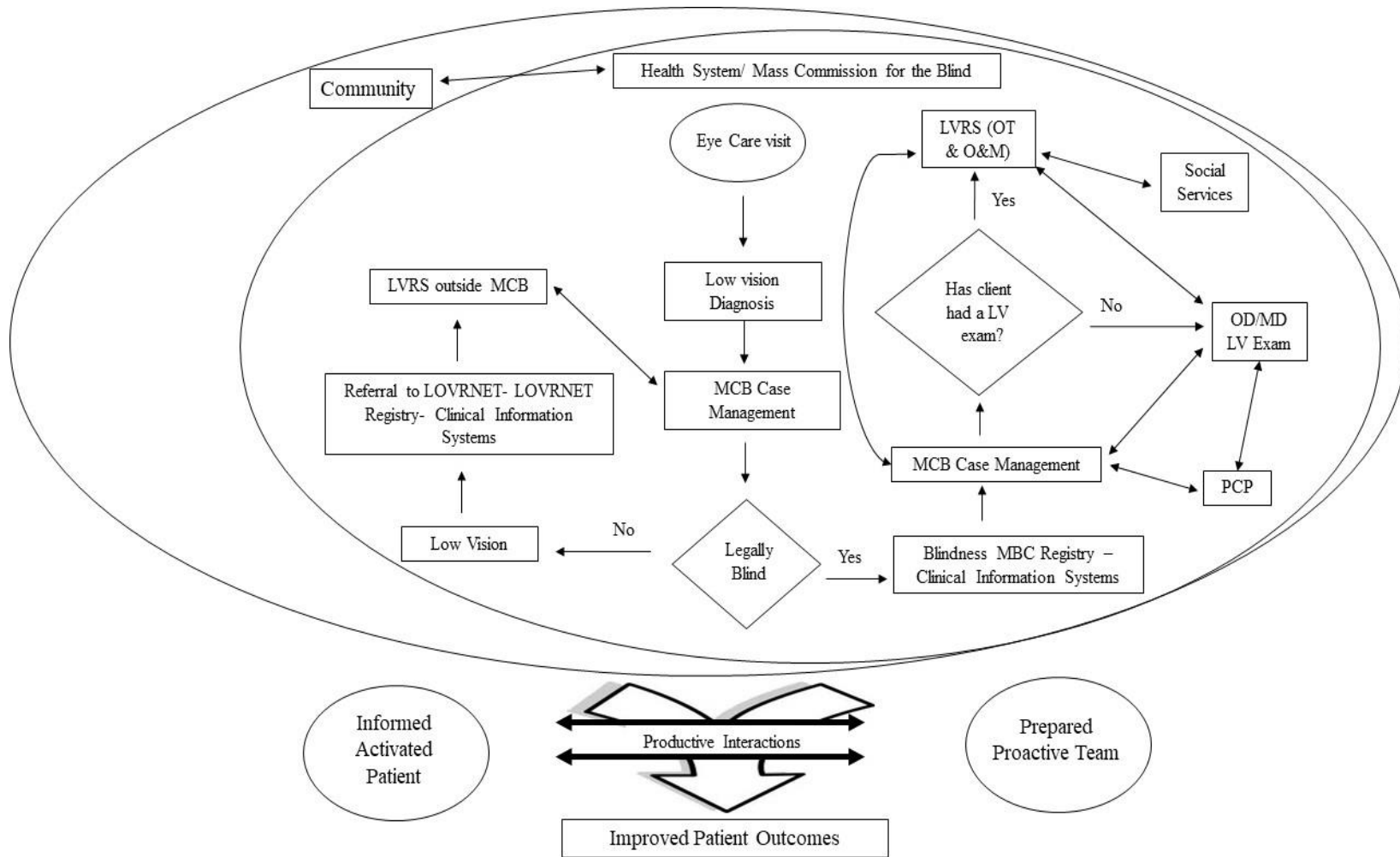
<b>Appendix G-D: Low Vision Peer Support Groups</b>	
	<b>Location</b>
<b>MAB Community Services</b>	
Boston/Roxbury Elders Support Group	Roxbury, Martin Luther King, Jr. Towers
Berkshire County/Lenox Low Vision Support Group	Lenox, Kimball Farms
Braintree Elders Support Group	Braintree, Council on Aging
Brockton Elders Support Group	Brockton, Campello High Rise
Brookline Low Vision Support Group	Brookline, Senior Center
Cambridge-Somerville Elders Support Group	North Cambridge, Senior Center
Concord Elders Support Group	Concord, Council on Aging
Dorchester Elders Support Group	Dorchester, Harbor Point Apartments
Duxbury Elders Support Group	Duxbury, Senior Center
Framingham Elders Support Group	Framingham, Callahan Senior Center
Gloucester Elders Support Group	Gloucester, Rose Baker Senior Center
Greenfield Elders Support Group	Greenfield, Senior Center
Haverhill Elders Support Group	Haverhill, Citizen Center
Hingham Elders Support Group	Hingham, Senior Center
Holyoke/ South Hadley Elders Support Group	South Hadley, Council on Aging
Marlborough Low Vision Support Group	Marlborough, Senior Center
Medford Elders Support Group	Medford, Senior Center
Middleborough Elders Support Group	Middleborough, Council on Aging
Montachusett Elders Support Group	Leominster, Senior Center
Natick Low Vision Support Group	Natick, Morse Institute Library
Needham Elders Support Group	Needham, Steven Palmer Senior Center
New Bedford Elders Support Group	New Bedford, Hazelwood Senior Center
Newburyport Elders Support Group	Newburyport, Council on Aging
Newton Elders Support Group	Newton, Senior Center
Northborough Low Vision Support Group	Northborough, Senior Center
Northampton Elders Support Group	Northampton, Council on Aging
Peabody Elders Support Group	Peabody Life Center
Plymouth Elders Support Group	Plymouth, Council on Aging
Quincy Adult Vision Support Group	Quincy, Public Library
Reading Elders Support Group	Reading, Elder Services
Sharon/Stoughton Elders Support Group	Sharon, Community Center
Springfield Mixed Ages Support Group	Springfield, Church in the Acres
Taunton Elders Support Group	Taunton, Council on Aging
Watertown Mixed Ages Support Group	Watertown, Perkins School for the Blind

Winthrop Elders Support Group	Winthrop, Senior Center
Worcester Low Vision Support Group	Worcester, Senior Center
<b>Sight Loss Services</b>	
Barnstable Peer Group	Barnstable, First Unitarian Church
Bourne Peer Group	Pocasset, Cape Living
Brewster Peer Group	Brewster Ladies Library
Dennis Peer Group	Dennis, Church of Nazarene
Eastham/Wellfleet Peer Group	Eastham, Council on Aging
Falmouth Peer Group	Falmouth, John Wesley Methodist Church
Harwich/Chatham Peer Group	Harwich Community Building
Mashpee/Sandwich Peer Group	Mashpee, Council on Aging
Orleans Peer Group	Orleans, Federated Church
South Yarmouth Peer Group	South Yarmouth, Thirwood Place
Truro/Provincetown Peer Group	Truro, Council on Aging
West Yarmouth Peer Group	West Yarmouth, Mayflower Place
Yarmouth Peer Group	Yarmouth, Heatherwood

<b>Appendix G-E. Visual Health Resources Massachusetts</b>			
<b>Centers</b>	<b>Location</b>	<b>Eye Care Services</b>	<b>Low Vision Services</b>
<b>Hospitals with Eye Centers</b>			
Boston Medical Center	Boston, Brockton, Middleboro	Yes	Yes
Mass Eye and Ear Infirmary	Boston	Yes	Yes
New England Eye Center	Brighton	Yes	Yes
New England Medical Center	Boston	Yes	Yes
Joslin	Boston	Yes	Yes
Lahey	Burlington	Yes	Yes
<b>Low Vision Clinics</b>			
New England Eye Institute	Boston, Pittsfield & Springfield (Mobile Eye Clinic), Lynn, Newton, Brookline, Lawrence	Yes	Yes
New England Eye Roslindale	Roslindale	Yes	Yes
MAB Community Services* *Including affiliated providers	Worcester, Holyoke, Springfield, Wellesley, Hyannis, Salem, Whitinsville, Newton, Natick	Yes	Yes
Mass College of Pharmacy and Health Prof.	Worcester	Yes	Yes
Veterans Administration	Jamaica Plain, Brockton	Yes	Yes
Joslin Diabetes Clinic	Boston	Yes	Yes
<b>Community Health Centers</b>			
Dorchester House	Dorchester	Yes	Yes
Dimock	Roxbury	Yes	Yes
Cambridge Health Alliance	Somerville	Yes	Yes
Lynn Community Health Center	Lynn	Yes	Yes
Community Health Center of Cape Cod	Mashpee	Yes	Yes
<b>Private Practitioners/Clinics*</b>			
Stephen Bochnak	Boston	Yes	Yes
Wayne Chan	Boston	Yes	Yes
Harvard Square Eye Care	Cambridge	Yes	Yes

Bennett Family Eye Care	Belmont	Yes	Yes
John McHale	Reading	Yes	Yes
George Leavitt III	Whitman	Yes	Yes
Florence Bejian and Associates	Chelmsford	Yes	Yes
Greater Milford Eye	Milford	Yes	Yes
Jane Orenstein & Russel Fradkin	Whitinsville	Yes	Yes
Eye Associates	Southbridge	Yes	Yes
David Finkelstein & Ryan Shea	Vineyard Haven	Yes	Yes
Charles Mandel	Pittsfield	Yes	Yes
Jennifer Salvo	Wellesley, South Yarmouth	Yes	Yes
Lyudmila Sutherland	Salem	Yes	Yes
Rodney Immerman	Milton	Yes	Yes
John Magalhaes	North Dartmouth	Yes	Yes
<b>Social Service Agencies</b>			
Carroll Center for the Blind	Newton	Yes	Yes
Massachusetts Commission for the Blind	Boston, Worcester, Springfield, New Bedford	Yes**	Yes
Perkins School for the Blind	Watertown	No	Yes
Lowell Association for the Blind	Lowell	No	Yes
<i>*There may be private optometry and ophthalmology practices not included within this table which have not identified as providing low vision services; **through mobile eye clinic</i>			

**Appendix G-F: Stakeholder-driven LVRS Chronic Care Model**



Appendix H: Demographic Questionnaire

Stakeholder-driven approach to optimizing access to low vision rehabilitation services in Massachusetts

Background Demographic Questionnaire				
Participant Code	Interviewer	Site of testing [ ] _____ Peer Support Group	Age	Gender <input type="checkbox"/> Female <input type="checkbox"/> Male
<b>Racial Background</b> <input type="checkbox"/> 1 Hispanic or Latino <input type="checkbox"/> 2 American Indian or Alaska Native <input type="checkbox"/> 3 Asian <input type="checkbox"/> 4 Black or African American <input type="checkbox"/> 5 White <input type="checkbox"/> 6 Native Hawaiian or Pacific Islander <input type="checkbox"/> 7 Other		<b>Household Composition</b> <input type="checkbox"/> 1 Lives Alone <input type="checkbox"/> 2 With Spouse <input type="checkbox"/> 3 With Children <input type="checkbox"/> 4 With Other Relatives <input type="checkbox"/> 5 Other, Specify _____	<b>Marital Status</b> <input type="checkbox"/> 1 Never Married <input type="checkbox"/> 2 Married <input type="checkbox"/> 3 Widowed <input type="checkbox"/> 4 Separated <input type="checkbox"/> 5 Divorced <input type="checkbox"/> 6 Refused	<b>Housing Arrangement</b> <input type="checkbox"/> 1 Homeowner <input type="checkbox"/> 2 Renter (Private) <input type="checkbox"/> 3 Rent Senior Housing <input type="checkbox"/> 4 Rent Public Housing <input type="checkbox"/> 5 Group Home or CRF <input type="checkbox"/> 6 Nursing Home <input type="checkbox"/> 7 Homeless <input type="checkbox"/> 8 Other <hr/> <b>Length of membership in peer support group</b> <input type="checkbox"/> Less than 1 year <input type="checkbox"/> 1-3 years <input type="checkbox"/> 4-6 years <input type="checkbox"/> 7+ years <hr/> When were you registered with MCB? _____
LEE: _____ Low Vision Exam: _____ LVRS: _____		<b>Vision Diagnosis:</b> _____ <hr/> <b>Registered with MCB</b> Yes    No		
<b>Chronic Conditions</b> <input type="checkbox"/> Medical _____ <input type="checkbox"/> Cognitive _____ <input type="checkbox"/> MR/DD/ID _____ <input type="checkbox"/> Multiple Disabilities _____ <input type="checkbox"/> Physical _____ <input type="checkbox"/> Traumatic Brain Injury _____ <input type="checkbox"/> Hearing _____ <input type="checkbox"/> Other _____ <input type="checkbox"/> None _____			<b>Highest grade/level of school completed/highest degree received:</b>   	
<b>Barriers</b> 1. 2. 3. 4. 5.			<b>Transportation Used</b> <input type="checkbox"/> Public <input type="checkbox"/> Private <input type="checkbox"/> Family <input type="checkbox"/> Friends	
<b>Facilitators</b> 1. 2. 3. 4. 5.			<b>Insurance</b> <input type="checkbox"/> Medicare <input type="checkbox"/> Medicaid <input type="checkbox"/> Private <input type="checkbox"/> MCB	

## Appendix I: Focus Group Guide

### Script for Interviews:

#### **Introduction:**

#### **Purpose of the Study:**

Ask if the individual has any questions before starting

Start the tape recorder

**Opening question:** Tell me about how long you have been working in low vision rehabilitation/or what is your role in low vision.

\* Following the opening question, questions can be asked in the order that best fits with the flow of each interview.

#### **Prescribing Practices**

When you see a low vision client for the first time, tell me about your typical process.

How often do you refer your patients to low vision rehabilitation services?

What criteria do you use to determine an appropriate referral?

#### **Perceived Barriers**

Given your experience in working with individuals with visual impairment, what do you perceive are the barriers to accessing care for the individual?

What about for the practitioner? (Probe: lack of awareness, lack of training, lack of interest, work load, availability of devices, time, expense, man power, lack of effectiveness, difficulty satisfying patients)

Of the barriers you mentioned, what do you think are the top 3-5 barriers?

#### **Perceived Facilitators**

Given your experience in working with individuals with visual impairment, what do you perceive as the facilitators to accessing care for the individual? (Probe: education, financial support, family & social support, transportation, motivation)

Of the facilitators you mentioned, what do you think are the top 3-5 barriers?

**Final question:** Please feel free to discuss any other issues related to low vision and low vision services we have not yet covered that you feel are important.

## Appendix J: Stakeholder Interview Guide

### Script for Interviews:

#### **Introduction:**

#### **Purpose of the Study:**

**Ask if the individual has any questions before starting**

**Start the tape recorder**

**Opening question:** Tell me about how long you have been working in low vision rehabilitation/or what is your role in low vision.

\* Following the opening question, questions can be asked in the order that best fits with the flow of each interview.

#### **Prescribing Practices**

When you see a low vision client for the first time, tell me about your typical process.

How often do you refer your patients to low vision rehabilitation services?

What criteria do you use to determine an appropriate referral?

#### **Perceived Barriers**

Given your experience in working with individuals with visual impairment, what do you perceive are the barriers to accessing care for the individual?

What about for the practitioner? (Probe: lack of awareness, lack of training, lack of interest, work load, availability of devices, time, expense, man power, lack of effectiveness, difficulty satisfying patients)

Of the barriers you mentioned, what do you think are the top 3-5 barriers?

#### **Perceived Facilitators**

Given your experience in working with individuals with visual impairment, what do you perceive as the facilitators to accessing care for the individual? (Probe: education, financial support, family & social support, transportation, motivation)

Of the facilitators you mentioned, what do you think are the top 3-5 barriers?

**Final question:** Please feel free to discuss any other issues related to low vision and low vision services we have not yet covered that you feel are important.

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**Curriculum Vitae**

