See It My Way: Worcester’s Visually Impaired Population

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What is meant by visual impairment?

- A person is considered legally blind if their best corrected visual acuity (BCVA) is 20/200 or worse (CDC)
- A person is considered to have low vision if their BCVA is 20/40 or worse (CDC)
- Contrary to common belief, the majority of VIPs are not completely blind and retain some degree of light perception.
Local and National Data

- Nationally 4.2 million people 40yrs+ are legally blind or have low vision

Data from American Community Survey - people who report severe vision impairment even when wearing glasses or contacts (including people who are blind).

Prevalence of vision impairment in Massachusetts (CDC) 2019

https://preventblindness.org/prevalence-visual-acuity-loss-blindness-us/
Common Causes of Vision Loss

- **Age-related Macular Degeneration (AMD)** *(leading cause of blindness in 65+ adults)*
  - Degenerative damage to macula causing decrease in visual acuity of central vision
- **Cataracts** *(leading cause of blindness worldwide & vision loss in US)*
  - Clouding of lens
- **Diabetic Retinopathy (DR)** *(leading cause of blindness in American adults)*
  - Progressive damage to blood vessels supplying retina
- **Glaucoma**
  - Increase in intraocular pressure resulting in damage to optic nerve
- **Retinitis Pigmentosa (RP)**
  - Complex genetic disorder that causes progressive breakdown of photoreceptors (rods > cones) leading to tunnel vision/ loss of peripheral VFs
- **Stargardt’s Disease**
  - Complex genetic disorder commonly due to ABCA4 mutation that causes progressive loss of central vision
- **Trauma/accident**
Interprofessional Teams

- Vitally important for improving quality of life for visually impaired persons.
- These teams work in parallel to
  - Identify and treat eye diseases
  - Aid in vision rehabilitation
  - Improving orientation and mobility skills
  - Improve VIPs mental health
  - And more!
Primary Care Physicians

- Important for identifying visual impairment through routine screening.
- Able to inform patients about ocular disease
- Coordinates referrals to other specialists
Eye Care

- **Ophthalmologist: MD/DO**
  - Examines, diagnoses, and treats ocular disease
  - Able to perform medical and surgical interventions

- **Optometrist: OD**
  - Performs routine eye examinations
  - Prescribes corrective lenses
  - Manages ocular disease

- **Optician: ABO-NCLE certification**
  - Designs, fits, and dispenses corrective lenses

- **Ocularist: NEBO certification**
  - Designs and fits ocular prosthetics
Physical Rehabilitation

- **Orientation and Mobility Specialist:**
  - Work with VIPs to navigate their environment safely and independently
  - Teach VIPs how to use resources like white canes and guide dogs

- **Occupational Therapist**
  - Work with VIPs to adapt to visual impairment and learn to modify activities of daily living so that they can be done safely and effectively
Counseling Services and Social work

- Work with VIPs to address mental health issues that can accompany visual impairment
- Clinical Psychologist: Provides counseling and psychotherapy to improve well-being
- Psychiatrist: Provides counseling as well as medications
- Social Worker: Serves as a counselor and helps to coordinate care for VIPs
Population Health Advocacy - Strategies

Education

- Educate the public about VIPs
  - Spectrum of vision loss
  - How VIPs navigate the world
- Educate the public about when/how to assist VIPs
- Educate healthcare workers about how to assist VIPs in clinical settings
Population Health Advocacy - Strategies

Hands-On Experiences

- Teaching community members how to be sighted guides
- “Day in the life”
Population Health Advocacy - Strategies

Working with communities

- “Nothing about us, without us”
- Involve communities in conversations about what they want and what would most benefit them
- Allow people to share their experiences
Advocacy at a Federal Level

- Civil Rights
- Access to services, information, technology, consumer home products, transportation, etc.
- Equal employment opportunities
- Services to children and elderly
Local Opportunities for Involvement

- MAVBI has unique volunteer opportunities:
  - Reading Mail, Magazines, Books and Paperwork
  - Writing letters, emails and filling out forms online
  - Helping with Grocery shopping or errands
  - Serving as a sighted guide for running, walking, gym and other fitness activities

- Central Mass Specific
  - There is a great need to medical escort drivers in central mass
  - Escort VIPs to doctor’s appointments
  - Stipend provided for gas

https://www.mabvi.org/get-involved/volunteer-main/
Local Opportunities for Involvement

- **United in Stride**
  - Online tool for runners who are VIPs to connect with sighted guides
  - Can enter into database to network with VIPs looking for opportunities to run and walk

- **Team with a Vision**
  - Official Charity of Boston Marathon
  - Participants raise money for MABVI
  - Support Visually Impaired Advocacy groups around Mass
Local Opportunities for Involvement

- **Beep Ball**
  - Adaptive version of baseball for the visually impaired
  - The ball in play emits a sound so it can be localized by the players
  - Use of sighted pitchers and catchers

http://www.blindcitizens.org/renegades/
White Cane Day

- Bring awareness to the Visually impaired population and to the white cane
- Worcester dignitaries experienced what it’s like to be visually impaired with walk around the city
- UMass Medical students received sighted guide training
WalkFit

- Local walking group for visually impaired individuals in Worcester
- Sighted guide training for UMass Medical Population and Community Health Clerkship students
- Canines for Disabled Kids, Carroll Center for the Blind, BVT Leo Club
Audio Journal

- Audio Journal is a radio reading platform for those that are disabled for visually impaired who can not access print material
- Started within the Worcester Public Library, but now serves a large part of central Massachusetts
- Topics include local and world news, science, politics, and entertainment
- UMass Medical Population & Community Health Clerkship students submitted entries to weekly Science Journal
Discussions

- Key concepts of visual impairment (Sam Lauffer, MS4)
- Treating the Whole Person (Dr. Mike Marciello)
- Blind Baseball/Adaptive Sports (Dr. Mike Marciello)
- Patient Cases (New England College of Optometry, Liz Myska)

VIP Interviews

- Liz Myska, lawyer
- Chris Downey, architect and rower
- Drew Crooks, digital accessibility specialist
- Blair Wong, optician

Virtual Experiences

*On Zoom or the TalkFit Conference Line

Seminars

- Management of Thyroid Eye Disease
- Apprenticeship as a Pathway to Employment
- Learning from Patients to Provide Accessible Healthcare
Key Takeaways

- Meeting VIPs where they are at
  - Individual circumstances
  - Environment
  - Self-efficacy
- Recognizing overlapping identities
- Challenging our own assumptions
- “Nothing about us without us” (allied advocacy)
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