

LIVING WITH VISION LOSS

This paper was developed by Fighting Blindness Canada, the Canadian Council of the Blind, and the CNIB Foundation with feedback from members of the Canadian vision loss community. It outlines themes in the area of living with vision loss, as well as recommended actions for government, industry, and other stakeholders. The recommendations—bolded throughout the paper—provide a general framework for policy and advocacy activities in 2020 and beyond. What final form a recommendation takes, who it is directed towards, and in what context it is articulated will be determined by each stakeholder.

Introduction

A visual acuity measurement of 20/20 is often associated with “perfect” vision, a kind of universal standard for unimpaired sight. But a significant number of Canadians live with vision that is not represented by this norm. In fact, over 1.5 million live with a seeing disability,¹ and research has shown that, due to ageing and other factors, that number is in the process of doubling over a 30-year period that began in 2007. This could lead to national health care costs of over \$30 billion per year.²

At the same time, the experiences of the growing number of Canadians with vision outside the 20/20 ideal are far from uniform or consistent, especially in cases of visual impairment and blindness. As a result, though members of the vision loss community share much in common, their experiences of vision loss and blindness are incredibly diverse. They are shaped by factors that include age, geography, economic status, disease type, genetic history, and more, making it difficult to speak of vision loss as a single or unifying phenomenon.

The so-called “burdens” of vision loss are also varied, encompassing social marginalization, employment barriers, strain on families and caregivers, and a host of other issues. And since vision is one of the key senses, impairment can affect a number of day-to-day enjoyments, including reading, watching movies and television, cooking, looking at photographs, and more. Developed out of survey responses from members of the vision loss community that highlight these and other issues, this paper is designed to capture some of the complexities of vision loss in Canada during the symbolic year 2020. It also aims to highlight opportunities for progressive change in policy, technology, education, labour, and other areas.

Thinking and Speaking About Vision Loss: Misconceptions, Biases, and Discrimination

¹ Morris, S., Fawcett, G., Brisebois, L. *et al.* *A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017*. Statistics Canada; 2018

² Cruess, A.F., Gordon, K.D., Bellan, L. *et al.* Mitchell, S., & Pezzullo, M.L. The cost of vision loss in Canada. 2. Results. *Can J Ophthalmol* 46(4), 315-318 (2011) doi: 10.1016/j.jcjo.2011.06.006

Living with vision loss often means being perceived as blind, regardless of the status of one's vision. This is especially the case for those who use white canes or show physical symptoms. These and other signs are often interpreted as a complete lack of sight. This is of course a fundamental misconception of vision loss, which is varied and highly personal.

It is also the case that our language and terminology fall short of capturing the diversity of vision loss. The word "disabled" has been inadequate for some time, though it has been recontextualized in disability studies, but terms such as "blind" and "impairment" are also far from being broadly accepted. And though this paper uses "vision loss" as a kind of catch-all, this too falls short of encompassing the range of experiences associated with impaired sight. **As we continue to modify and evolve our ways of speaking about vision, it is important to take these considerations into account, and to work collectively to find our way forward in language and discourse.**

Our linguistic practices do not exist in a vacuum. They are tied to biases, misconceptions, and forms of discrimination that affect many with vision loss. Several community members have stressed that the most pronounced among these is the notion that those with impaired sight are incapable of being productive members of society, and that visual impairment is a kind of cognitive impairment. Although there is a potential link between visual impairment and age-related cognitive decline,³ and although those with vision loss face added barriers to employment and social inclusion, they overcome these barriers regularly, and their ability to do so demonstrates the opposite of cognitive impairment. There is also a widespread misconception that, to quote one community member, the lives of the visually impaired are "horrible and joyless," and that those with vision loss should be pitied, all of which is far from the truth.

Unfortunately, whether we are conscious of them or not, these and other stigmas tend to have the largest impact on children and young people, many of whom require mentorship and guidance to persevere. When they do, they often emerge as community leaders with unique perspectives and a strong sense of empathy. When they are unsupported, on the other hand, they can fall through the cracks, especially when faced with discrimination in their schools and places of employment. This can lead to depression, isolation, lack of self-worth, and more. **Community and mentorship programs are vital to overcoming these problems, as are counselling services that address the psychosocial impacts of vision loss, and health navigation services that connect individuals to resources and supports.**⁴ For those who have acquired vision loss during working age and lost their jobs, their independence, and more, support programs are integral to managing their transition into being partially sighted and facing all of the challenges that follow.

Educating the public is important in this regard, as is finding new ways to facilitate interaction among those who are fully sighted and partially sighted. Public awareness campaigns have

³ Chen, S.P., Bhattacharya, J., and Pershing, S. Association of Vision Loss with Cognition in Older Adults. *JAMA Ophthalmology* 135(9), 963-970 (2017) doi:10.1001/jamaophthalmol.2017.2838

⁴ Zhang, X., Bullard, K., Cotch, M. *et al.* Association between depression and functional vision loss in persons 20 years of age or older in the United States, NHANES 2005-2008. *JAMA Ophthalmology* 131(5), 573-581 (2013): doi:10.1001/jamaophthalmol.2013.2597

shown success in this context.⁵ Many in the vision loss community would like to see an expansion of these and similar initiatives. **Whether it be on social media or in some other forum, finding new ways of thinking and speaking about vision loss, as well as ways of sharing stories and experiences, will be crucial to undercutting the discrimination that creates tangible obstacles for those with partial sight.**

Working with Vision Loss: Employment and Marginalization

When our thinking and speaking about vision loss fail to capture lived experience, stereotypes can lead to marginalization. This occurs in a variety of settings, but the job market in particular demonstrates what happens when misconceptions and indifference flourish. Too many Canadians with vision loss are under or unemployed.⁶ This is due to a shifting and precarious job market, in part, but it also results from the added barriers and challenges faced by those with vision loss when seeking and maintaining meaningful employment.

Education plays a central role in this: the 2017 Canadian Survey on Disability showed that 24% of those living with a seeing disability had not graduated high school. In the same survey, Canadians with sight loss reported a long list of issues that directly or indirectly affected their educations, including feeling left out, being bullied or avoided, changing schools, additional expenses, and lack of assistive devices or support services.⁷ These factors play a role in the career trajectories of partially sighted Canadians, and could contribute to high numbers in under and unemployment.

Accessibility is a key concern in the area of employment. Several workplaces have implemented successful initiatives, but the majority are either lagging or noncommittal. This must change, and the burden of showing how cannot be placed on employees to advocate on a case-by-case basis. **One way forward is to design a set of ethical standards for workplace accessibility—this can be tiered according to workplace size or category, but the details should be driven forward by the vision loss community.** Both accessible and assistive technologies should be central to any new guidelines, the former being widely usable “out of the box” for a variety of people, the latter more specialized to assist those with specific disabilities.

The Accessible Canada Act, which came into force in 2019, is a step in the right direction, but its guidelines are for government workplaces and those within the federally regulated private sector. Unfortunately, many of the country’s least accessible work environments fall outside of the Act’s purview, where the majority of Canadians work. **Continued dialogue and consultation are necessary to improve the Act and apply its regulations more broadly.**

⁵ Janiszewski, R, Heath-Watson, S.L., Semidey, A.Y. *et al.* The low visibility of low vision: increasing awareness through public health education. *Journal of Visual Impairment & Blindness* 100(1), 849-861 (2006) doi.org/10.1177/0145482X0610001S08

⁶ Gold, D., Simson, H. Identifying the needs of people in Canada who are blind or visually impaired: preliminary results of a nation-wide study. *International Congress Series* 1282, 139-142 (2005) doi.org/10.1016/j.ics.2005.05.055

⁷ Morris, S., Fawcett, G., Brisebois, L. *et al.* *A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017.* Statistics Canada; 2018

Incentivization programs were flagged by the community as important moving forward as well, since these could help address not only accessibility concerns but other forms of marginalization. **Many members of the community would like to see federal and provincial stakeholders develop initiatives that reward employers for meeting high standards in accessibility, for hiring employees with blindness or low vision, for implementing diversity agendas, and for achieving other progressive goals.** Such programs could be integrated into a set of national and far-reaching guidelines that help establish a truly barrier-free Canada.

Living with Vision Loss in Canada: Accessibility and Privacy

The issue of accessibility extends beyond employment. For instance, though transportation is a barrier to employment, especially when employers require a valid driver's licence, it is also a barrier to accessing hospitals and medicine, grocery stores and restaurants, social and community functions, and a variety of other services and resources. **To combat isolation and ensure those with vision loss can stay connected to people and amenities, public transportation must be robust, affordable, and accessible.** This is especially the case for those in rural and remote communities who faced the largest barriers in this area. Improvements in public transportation could also alleviate strain on caregivers, many of whom drive those they care for to places of employment, health care facilities, community functions, and elsewhere. Some caregivers do this to help offset the substantial costs associated with the regular use of paid transportation services, including cabs, that they consider necessary to fill the gap left by inadequate public service.

Personal technologies—especially smart phones, which have started to replace more traditional assistive technologies—have emerged as invaluable devices for many, whether it be in facilitating navigation and transportation or engaging in online conversations and enjoying books.⁸ But the buy-in cost for these and other devices can be extraordinary, blocking many in the vision loss community from enjoying their benefits. **New partnerships and programs that bring the advantages of accessible and assistive technologies to as many Canadians as possible should be a priority.** One example has already been provided by the World Blind Union. By working with the manufacturer, they were able to deliver a refreshable Braille reader, the Orbit, at a fraction of the cost of previously marketed products. In 2020 and beyond, we should look to this and similar collaborations to guide our own efforts. Alongside these endeavours, **it is important that we think of accessibility and inclusiveness as foundations in our collective projects, not as extraneous additions.** In software development, for instance, both Microsoft and Apple have shown the value of building accessibility into their products as central, integrated features, not something that is tacked on afterwards to fix an oversight. This especially important in relation to vision loss, which is often

⁸ Martiniello, N., Lehane, C., Eisenbarth, W. *et al.* Exploring the use of smartphones and tablets among people with visual impairments: Are mainstream devices replacing the use of traditional visual aids? *Assistive Technology* (2019) DOI:10.1080/10400435.2019.1682084

accompanied by other functional limitations, including chronic pain, limitations in flexibility and dexterity, hearing loss, mental health issues, and learning disabilities.

The same philosophy can be applied to our public spaces. **Advancements have been made in some cities with tactile walking surfaces, accessible pedestrian signals, and other innovations, but these should now be standardized in building codes and within other legal, administrative, and policy frameworks. Improvements in signage, railings, doorways, parking, and other areas have been helpful for Canadians with low vision, but they need to be embraced as core aspects of urban planning, design, and law.** There is a sense that progress is being made in this regard, but also that it is happening slowly, too slowly in many cases. There is also a perception that physical disabilities are prioritized over sensory ones, leaving those with visual and other sensory impairments to “figure it out on their own.”

By and large, Canada is considered “average” by the vision loss community regarding accessibility compared to other countries. This leaves a marked space for improvement, and for the country to initiate widespread reforms that could, if prioritized, generate a model for inclusivity. Such reforms should be advanced in the spirit of the PPH model (Processus de production du handicap), widely used in Quebec, which recognized that those with disabilities find themselves in “situations de handicap,” and that it is these social situations that produce disability. If we fix these situations and contexts—an inaccessible walkway, for example—disability either disappears or is markedly alleviated.

Living with vision loss in this country means confronting barriers to accessibility on a regular basis, but it also means having to carefully consider the issue of privacy. Given the existence of biases, barriers to employment, marginalization, and other issues, many Canadians with low sight keep the details of their vision to themselves. Their reasons for doing so are entirely valid, but the societal drivers that lead them to feel that this is necessary must be combatted. More specifically, protections should be put in place to guarantee their privacy, especially when it comes to employment, insurance, and health care.

The Genetic Non-Discrimination Act is one example of such a protection for those with inherited diseases. It currently prohibits Canadian companies and insurers from requiring genetic tests or denying services based on genetic information. This protects those with genetic conditions from having their genetic histories held against them when seeking employment or services, or when signing contracts with companies. Knowing they are protected in this way also gives many Canadians peace of mind when seeking genetic testing; for many, this is an essential step towards accessing new treatments and being included in clinical trials. The Act was passed into law, but it is being appealed by the Quebec government on the basis of its constitutionality.

Ensuring that the Genetic Non-Discrimination Act remains law is a key step towards securing privacy and protection for Canadians with inherited vision loss. In 2020 and beyond, similar legal safeguards should be fought for to protect the Canadian vision loss community against systematic discrimination.

Living Together with Vision Loss: Families, Caregivers, and Collaboration

Though vision loss can lead to isolation, it is also the case that it regularly impacts the lives of those connected to it indirectly, particularly the family members, loved ones, and other caregivers who provide support to those living with vision loss. In this sense vision loss is not only a personal or subjective experience, but also a shared one that moves across a network of individuals, families, and communities.

In many cases, family members bear the largest burden of support. In the case of diseases with high treatment demands such as wet age-related macular degeneration (wet AMD) and diabetic macular edema (DME), this often means providing regular transport to and from appointments with eye specialists and blocking off time for waiting rooms—sometimes an entire day.⁹ This can lead to financial strain and lost productivity, factors that are now calculated in many socioeconomic studies of eye diseases. In cases of severe vision loss, families and other caregivers sometimes function as a second set of eyes, a near-constant presence to ensure the safety and health of those they love.

This is especially true of the caregivers supporting those with special needs: children with vision loss, seniors, individuals with comorbidities, and others. The needs of any child are extensive, but a parent of a child with a congenital disease—Leber congenital amaurosis (LCA), for example, which leads to severe visual impairment in infancy—faces a set of particularly daunting challenges, ones that often require dramatic personal and career changes to overcome them. **Stress, fatigue, financial stability, and mental health are fundamental concerns here, and it is important that we find new and better ways to mitigate these and other strains placed on the individuals who provide care.**

This is important in the face of the growing need for caregivers and the growing demands placed on them. For example, as Canada's population ages, the number of citizens with age-related eye diseases will grow. Our population of caregivers will grow in parallel. And as work becomes increasingly precarious and social supports and pensions continue to disappear, there is a pronounced danger that caregivers, especially primary ones, will become overwhelmed. **Envisioning and implementing support mechanisms for our support-providers has never been more important.**

Canadian caregivers are exemplary in many ways, but one thing they show in particular is the value of collective and community-driven action. Support groups and community networks are integral to the work of caregiving, providing avenues for knowledge sharing, collaboration, and much more. Interestingly, it is exactly this kind of collaboration that will be necessary going forward—not only in the more personal instances of caregiving, but in the broader spheres of policy, law, governance, and health technology. Whether it be accessibility programs, advancements in research, innovative health policies, or new educational initiatives, collaboration and partnerships from a variety of groups will be essential. This includes government, industry, academia, health professionals, patients, patient groups, and many

⁹ Gonder, J.R., Walker, V.M., Barbeau, M. *et al.* Costs and quality of life in diabetic macular edema: Canadian burden of diabetic macular edema observational study (C-REALITY). *Journal of Ophthalmology* 2014(6):939315 doi:10.1155/2014/939315

more. We should look to the tireless and co-operative work of Canada's caregivers for inspiration in these collective endeavours.