

# **Advocacy Manual for the Canadian Deafblind Population**

developed by

DeafBlind Advocacy Group Canada

in collaboration with

DeafBlind Ontario Services

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## **Disclaimer**

The Deafblind Advocacy Group Canada and DeafBlind Ontario Services would like to note that the stories and content included in this manual were shared by individuals who are deafblind and/or their families and are written as presented. The Deafblind Advocacy Group Canada and DeafBlind Ontario Services bear no responsibility for further analysis or interpretation of the information shared herein.

## **Methodology**

DeafBlind Advocacy Group Canada members decided that the self-advocacy resource will be a manual to provide basic information on the necessary steps to follow and tips to help demonstrate those steps using real-life stories from Canadians with deafblindness who have advocated for themselves. With the help of the Deafblind Ontario Services team and an intern from the Masters in Professional Communication from Toronto Metropolitan University (previously Ryerson University), we reached out to selected people with deafblindness and their family members to ask them to share personal stories of their journey to self-advocacy for themselves or their loved ones. Each story focuses on the theme of the self-advocacy journey, steps taken to approach the issue at hand, challenges and barriers faced, supports received, and tips for other individuals with deafblindness to follow as a guide.

## **Preamble**

The Deafblind Advocacy Group Canada wrote this manual to meet a gap in self-advocacy resources available for Canadians who are deafblind when we realized the limited amount of information available. In 2020, a DeafBlind Ontario Services team member conducted a thorough review of advocacy resources specific to the needs of individuals with deafblindness currently available internationally and in Canada. We found information on deafblind advocacy efforts in Australia, the United Kingdom, and

the United States of America. We also discovered helpful resources such as: training, lists of supports, and tool kits for individuals with deafblindness. Unfortunately, none of the resources were relevant for self-advocacy. These resources are included in an Appendix for reference.

As individuals who are deafblind and serve as Co-chairs for the Deafblind Advocacy Group Canada, we have advocated throughout our lives using trial and error to find what worked best to accomplish our self-advocacy goals.

DeafBlind Advocacy Group Canada wants to make it easier for other Canadians who are deafblind to successfully self-advocate. We appreciate DeafBlind Ontario Services' team collaboration and support to create this self-advocacy manual.

At some point in our lives, we found ourselves having to advocate to either obtain something, be included in activities, or even connect with the necessary skills to do something we wanted to do. We learned that information on how to self-advocate when you have both vision and hearing loss is lacking in Canada. Knowing how to be more successful in self-advocating is powerful.

However, Canada has some unique structures of government and legal systems. Having an understanding of these structures is critical to how Canadians tackle advocacy. One important way to successfully self-advocate is to have an understanding of one's needs. It helps to know what kind of support is available, and how to communicate those needs clearly to others. The basic components of how to self-advocate are important. People who are deafblind experience barriers to communication and need simple resources to help them break down these barriers.

Most of the information about how to self-advocate is written using terms that may not be easy to understand. This manual will contain short stories of what Canadians who are deafblind did to get the results they needed. One of the best ways to learn about

complicated subjects like self-advocacy is through storytelling. We hope the stories will help along with an outline of basic rights.

We hope that this manual will support self-advocacy efforts to remove barriers such as access to information, systemic, economic, political, educational, transportation, attitudinal, medical, and social services. We look forward to every person who is deafblind having the tools to effectively achieve equal access to services so that they can live fulfilling lives.

Penny Bennett, Co-Chair

Dawnelee Wright, Co-Chair

## **What does it mean to be a Self-Advocate and what does it involve?**

The best way to create a positive change is to become a self-advocate. This means learning to speak up for yourself and others to achieve a change of some sort.

Building your self-advocacy skills means learning about your rights and responsibilities as a person with deafblindness. You will need to know what services are available and how to access them. You will need to know how to ask for help or express concern if you feel you have received unfair treatment because of your disability.

The reason why being a self-advocate is effective is because only you truly know your personal needs. By exploring what your needs are and what your feelings are, you are the best person to advocate for what you need to live a satisfying life. By spending time looking at your strengths and weaknesses, you will be able to figure out the areas where you need assistance. This will give you a clear picture of what you are trying to achieve and what needs to happen for you to meet your goals. Knowing that sometimes we hit roadblocks along the way, you should always develop a plan and a backup plan. Covey<sup>i</sup> recommends the following three areas to help.

**Interventions** are evidence-based instruction to improve skills. This instruction is systematic and multi-sensory and includes the opportunity for guided practice. After all, practice makes progress.

**Accommodations** are tools that help you accomplish a task without compromising its integrity. Accommodations vary from person to person and from situation to situation.

**Modifications** are an alteration of the task or the environment, without changing the outcome of the task.

To be a self-advocate can mean you speak up for your rights even though it is not a positive experience. Everyone has the right to be treated with dignity and respect. This is something that we, as humans, should all be doing.

### **Issues you may face with Self-Advocacy:**

Sometimes we feel like we cannot advocate for ourselves because we lack control over things occurring in our life. Other times we feel that it may be difficult to change our current situation, or that no one cares. Feelings such as these are what we call “destructive”. We need to ensure that we avoid destructive behaviours and attitudes concerning self-advocacy. If you find yourself exhibiting behaviours like denying that you experience difficulties, blaming others, or putting yourself down, then it’s time to stop. There are so many reasons to take charge and become a self-advocate. Self-advocacy does not mean making all of the choices alone or knowing everything. It means knowing who to ask for help and being able to ask for what you need.

### **Positive Self-Advocacy:**

By speaking up you may help other people in the same situation while taking care of yourself. When choosing to be a self-advocate you simply need to be assertive. Being assertive means getting your point across clearly and confidently. This helps the person you are speaking to understand your point of view. You do not need to shout or verbally abuse the person you are speaking with to get them to understand you.

To be an effective self-advocate means to not give up, and to realize you do not need to complete every step of the process on your own. Agencies have staff trained and ready to help you with your needs. Sometimes contacting a government agency can be beneficial. However, be aware that sometimes it can take time to receive the support you require from government agencies. Sometimes you may need to leave messages or ask to meet in person. There are many things you can do to ensure a successful response. Make sure you state your problem clearly, remain polite and take notes as you go.

Unfortunately, sometimes meetings with government agencies are unsuccessful and, if that is the case, there is normally an appeals process. It is important to remember that self-advocacy always requires persistence. Ask if there is an “appeals form” and how to



access it. Ask someone you trust to help you fill it out and submit it. If you feel that after everything has been said and done you have not been heard or respected, you can always contact the office of your local elected official.

There are many other ways to ensure that you become a positive self-advocate. One of the most important is to remember that you are not only fighting for yourself but for all others just like you!

Self-advocacy is a skill that comes with practice.

### **Becoming an Effective Self-Advocate**

To become a self-advocate, you should develop the following FOUR key skills.

#### 1. Self-Knowledge

You must consider all areas of your life and how your well-being may be affected. Be aware of your goals and feelings about relationships, work, education, health, and social life. Identify your strengths, challenges, and areas of support. Be clear about your basic needs and the things you want. Search government websites to find out what is available to you, and organizations that can help you achieve your goals.

#### 2. Action Plan

Come up with a clear idea of what you want. Find the right organization where you can present your case for each goal. Learn about the chain of command for that organization so you know who to speak with. Collect all information needed to support your request. Decide on the best strategies to help you prepare. Have a follow-up plan once the request is presented. Get help, where needed, to prepare.

### 3. Communication/Negotiation Skills

Be respectful, but learn to negotiate. Be an active listener but also a strong communicator. Use “I” phrases to get your feelings and emotions across. Practice asking open-ended questions. Work hard to understand the person you are speaking with, and understand your attitudes and needs.

### 4. Finding Support

Develop a support group such as family and friends, or join an advocacy group. Locate and connect with resource groups or professionals to help you if needed.

## **Human Rights Treaties/ Legislation**

Get to know the various pieces of human rights treaties and legislation that protect your rights as an individual. These documents offer options that support your right to access services and supports so that you can participate as fully as possible in society.

### United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) are:

*“to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”*

On opening day at the United Nations in 2006, this new treaty received more signatures than any other in history. Canada approved this treaty in March 2010. The treaty aims to get rid of discrimination against persons with disabilities in all areas of life including employment, education, health services, transportation, and access to justice. The Optional Protocol to the Convention on the Rights of Persons (OP-CRPD) is one of the communication routes of the UN treaty bodies. The OP-CRPD allows for individual complaints to be submitted to the CRPD Committee by individuals and groups of individuals, or by a third party on behalf of individuals and groups of individuals, alleging that their rights have been violated under the CRPD.

### Canadian Charter of Rights

The Charter's purpose is to protect every Canadian's right to be treated equally under the law. The Charter guarantees broad equality rights and other fundamental rights, such as:

- The freedom of expression
- The freedom of assembly, and
- The freedom of religion

The Charter of Rights and Freedoms applies to governments and protects the rights of all Canadians from infringements by laws, policies, or actions of governments.

### The Canadian Human Rights Act

The Canadian Human Rights Act protects people in Canada from discrimination when they are employed by or receive services from the federal government, First Nations governments, or private companies that are regulated by the federal government.

People can use the Canadian Human Rights Act to protect themselves against harassment or discrimination when based on one or more of the eleven grounds of discrimination, which includes:

- Race
- National or ethnic origin
- Colour
- Religion
- Age
- Sex
- Sexual orientation
- Marital status
- Family status
- Disability
- A conviction for which a pardon has been granted or a record suspended

### **Other Acts in Canada that Support Disability Rights**

#### Accessible Standards Canada Act

In July 2019, the Accessible Canada Act, 2019 was put in place to make Canada barrier-free which involves identifying, removing, and preventing barriers in many areas. Its purpose is to:

*“...ensure a barrier-free Canada for anyone with any impairment, including a physical, mental, intellectual, cognitive, learning,*

*communication or sensory — or a functional limitation — whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person’s full and equal participation in society.”*

This legislation aims to help break down barriers in society that would include: employment; the built environment; information and communications technologies; other communication; access to goods, services, and facilities; the design and delivery of programs and services, and; transportation.

### The Employment Equity Act

This Act requires federally regulated employers and crown corporations to *eliminate barriers that prevent people with disabilities* (and other designated groups) from participating equally in the workforce. It also calls for these employers to provide accommodations, such as technology to help a person do a job.

## **Provincial Legislation – Accessibility**

### The Quebec Accessibility Law

Quebec was the first province to pass an accessibility law in 1978, requiring public sector organizations, such as government agencies and municipalities, to meet certain accessibility requirements.

In 2004, the Quebec government amended its legislation and the act is now called *The Act to Secure Handicapped Persons in the Exercise of their Rights to achieve social, school, and workplace integration.*

### The Accessibility for Ontarians with Disabilities Act (AODA)

The AODA became law in 2005 in Ontario. Public and private sectors need to follow a set of accessibility standards when dealing with the public. It states that:

*“...every obligated organization shall, upon request, provide or arrange for the provision of accessible formats and communication supports for persons with disabilities, in a timely manner that takes into account the person’s accessibility needs due to disability.”*

The standards fall into five categories: information and communications; customer service; transportation; employment, and; design of public spaces.

### The Accessibility for Manitobans Act

Manitoba’s provincial accessibility legislation was passed in 2013 as part of its goal of making Manitoba accessible by 2023. The Act’s structure is similar to Ontario’s law. It currently focuses on five mandatory accessibility standards that apply to the public and private sectors. It also includes an Accessible Information and Communications Standard (like the AODA) to ensure accessibility of information, including online information.

### The Nova Scotia Accessibility Act

In 2017, the province of Nova Scotia passed its legislation aimed at developing accessibility standards in five areas, including information and communication. In defining “barrier,” the act *specifically mentions potential barriers in technology*. Along with the new legislation, the provincial government announced a grant program to help small businesses remove barriers for individuals with disabilities.

### The Accessible British Columbia Act

The Accessible British Columbia Act came into effect in June 2021. The Accessible British Columbia Act defines barriers as anything that does not allow the full and equal participation in society of a person with a disability.

Barriers can be caused by environments, attitudes, practices, policies, information, communications, or technologies. They can be affected by different forms of discrimination.

## **Personal Advocacy Interviews**

The information below details the real and personal experiences of people who are deafblind. The names of the individuals were changed to maintain their privacy. Please use these stories as a guide only as each person's experience is unique.

### *Story #1*

#### **Introduction:**

Delia describes herself as a person who is deafblind. She adds that in this particular example, she needed to use her strength and perseverance to ensure she could provide her children with access to public education.

#### **Major Theme:**

Access to Transportation

#### **The Challenge Identified:**

Delia explained that she was able to overcome her personal struggles by staying focused and learning to be independent. Her family was worried that she would be unable to care for herself or her family, but with effort and perseverance, she was able to find an Intervenor to assist in her daily needs and support her overall goals for her family.

Delia had to move outside of her child's school district. The school denied bus transportation to her child even after she explained her situation.

#### **The Result:**

Delia knew that education is funded provincially so she chose to seek help from her provincial elected official. Delia noted that she put her focus on stating her end goal and being polite in the process. She maintained a positive attitude and advocated for her family's needs through perseverance. The local elected member's office helped Delia explain to the transportation service provider that she can not drive because of her

disability. She requested that the service be available so her child can take the bus to get to school.

**Guidance on How to Conduct Self-Advocacy:**

1. The Challenge: Accessing school bus transportation for her child.
2. Missing Resources: She moved and was no longer able to access transportation.
3. Contact an authority figure: She spoke with her local elected official to gain support for taking a stand for her child.
4. Prove your need for services: She was able to obtain transportation for her child by explaining that she could not drive her child to school due to her disability.

**Legislation:**

In Delia's case, the school should have provided her child with access to the bus after recognizing the struggles she was facing with transportation to get to school. The school should have identified the barrier (lack of access) to transportation and then put in a place a policy to provide her child with a way to take the bus. More work needs to be done to connect to services, starting with policy barriers.



## *Story #2*

### **Introduction:**

Ethan, a father and husband, who was born deaf relied on his sight to guide him through life. Unfortunately, as he grew older, his situation changed and he began losing his sight. He soon started to feel like he was losing his independence, including his ability to maintain his employment in a grocery store stocking shelves.

### **Major Theme:**

Access to Intervenor Services

### **The Challenge Identified:**

Ethan was not born deafblind and, because of this, he did not qualify for the provincial funding available when he lost his sight to assist with hiring an Intervenor. Intervenor support is a necessary service to break down barriers to communication for individuals who live with the combination of hearing and vision loss. Ethan was not approved for the provincial funding he needed to hire an Intervenor to help break down his communication barriers to continue to enjoy his personal freedoms. He lacked access to services that he believed took away from his human dignity. And he could not have full and effective participation in society.

Ethan, along with five other deafblind individuals, launched a lawsuit in 2005 against the provincial government to request that they cover Intervenor Services for those who become deafblind later in life. At that time, services were only provided at no cost to those born deafblind. Ethan found a lawyer to take the case for free. Ethan's argument stated that not providing essential Intervenor Services to individuals who become deafblind later in life violates their human dignity and access to equal treatment.

### **The Result:**

Although the lawsuit was unsuccessful in the courts it turned into a series of discussions with the Ministry of Children, Community and Social Services and helped increase the

availability of emergency service Intervenor hours. Emergency Intervenor Services are allocated when a person who is deafblind has an emergency.

Ethan was happy with the result but felt that more access was still required because, without Intervenor, people who are from the acquired deafblind category are excluded from services and opportunities simply because they were not born deafblind.

Ethan was able to bring about change and he continues to do what he can to improve services provided to the deafblind population.

Ethan was denied equality rights due to his disability and he was not approved for funding for an Intervenor. The barriers were not removed and were not lifted to ensure his equality but he found some success and continues to advocate.

### **Guidance on How to Conduct Self-Advocacy:**

1. Identify the Challenge: Ethan became deafblind later in life and needed assistance to continue working and to complete his daily tasks.
2. Determine missing resources: Ethan was restricted from receiving Intervenor Services because his needs changed later in life.
3. Advocate and join in with others: He developed a community of people experiencing the same issue or limitation and approach a lawyer, He also continued to advocate with others.
4. Speak out to local authorities: Approach the level of government responsible for funding and policy changes to explain the limitations you face and ask them to work with you to develop a solution.
5. Resources to support self-advocacy: Ask help from professionals who have knowledge of laws/legislation and build a case for support to protect your human rights.

### *Story #3*

#### **Introduction:**

Pamela found it difficult to locate resources to help break down barriers. She had to advocate for herself so that she could live a fulfilling life. She found that being persistent is the best way to gain attention for issues that are not adequately addressed. She understands not everyone is willing to communicate their needs publicly but she argues that it is necessary to take on that role if you can. She expresses two experiences where she had to self-advocate. The first was in accessing funding for an interpreter while attending college, and the second was advocating for a cochlear implant. She explains that being a self-advocate is important because you are the only person who knows what supports you require to succeed.

#### **Major Theme:**

Access to Services

Barriers to Education

#### **The Challenge Identified:**

When Pamela attended Algonquin College, she put up a notice requesting an interpreter and soon learned how costly it would be to hire one. She tried to have the costs covered by the college but met many obstacles. She had to explain multiple times to different people the value of the interpreter and how important it was for her to have access to these services.

In addition, Pamela received a successful cochlear implant but she still required a second implant. Unfortunately, a second implant was not covered by the provincial government. To receive funding for this implant she had to write letters and ask for support from her doctors. Pamela met many obstacles along the way such as rejection letters.

### **The Result:**

Pamela spoke to many people at the college explaining how the services could assist her and, with perseverance, she achieved the services needed by convincing them of the need. She was eventually able to receive fully funded interpreter services at the college.

In terms of her implant, although she had two rejections, she did not give up. She continued to fight for her implant, and eventually, her third request was accepted. She was able to explain how having two cochlear implants helped balance her hearing so she could continue living as independently as possible.

These two things (access to an interpreter at the college and access to a second cochlear implant) should have been available to her at the start because they were required to break down barriers to communication.

### **Guidance on How to Conduct Self-Advocacy:**

1. Identify the Challenge: Pamela required assistance to make her college career successful and required a second cochlear that was not funded by the government
2. Determine missing resources: There was a lack of access to services that break down barriers to communications to allow her to attend school. She also lacked funding access to an assistive device (cochlear implant) so that she could use her “residual hearing”.
3. Advocate: She had to strongly advocate for an interpreter to help her achieve her educational goals. Pamela had to fight for her implant and it took her three separate tries to gain approval.
4. Speak out to local authorities: Pamela spoke repeatedly to people at her college explaining her issues until finally she received the support and accommodations she needed to learn in the classroom environment. Pamela had to write letters asking for changes to the existing assistive devices program.

## *Story #4*

**Introduction:** Annabelle is a woman with Usher's Syndrome, also known as RP; a genetic condition affecting hearing and vision. She was working for a business in Toronto and was in charge of developing programs and coordinating management. With time, her RP progressed and she was unable to read print.

### **Major Theme:**

Work Barriers

Vision Barriers

### **The Challenge Identified:**

Although Annabelle used a computer to read and write, she was no longer able to read the forms she created. Volunteers assisted her in completing her work, but as time passed, she was not able to independently complete the work she was originally hired to do. She was employed and not eligible for funding through ACT (Alternative Computer Training for the Disabled). She requested sponsorship even though she was not eligible. She explained that she was applying for the program because she needed new training since she was not able to complete all parts of her job due to her vision loss.

### **The Result:**

Annabelle was able to persuade the program representative of her need for the sponsorship for the ACT program. This funding helped her set new goals for herself and she eventually completed a course and was hired as a Programmer. She worked with the same company until she retired in 2000. The sponsorship of this program made her career success possible.

### **Guidance on How to Conduct Self-Advocacy:**

1. Identify the Challenge: Annabelle was unable to perform the duties she was hired to do due to a change in her vision.

2. Determine missing resources: She didn't have the resources needed to complete her job but was also technically not eligible for the ACT program funding.
3. Speak out to local authorities: Her determination to continue meaningful work and telling her story identifying the barriers she faced helped her convince the program representative that she needed funding for the training from the ACT program. She pushed the boundaries and this made her career successful.
4. Challenge the system: Work barriers, such as not being able to read the forms she was creating and needing volunteers to assist her, did not stop Annabelle from pursuing successful employment through supporting services.

## *Story #5*

### **Introduction:**

William lived in Edmonton, Alberta and could only have three hours a week of Intervenor Services/Support Services due to funding cuts. As a person who is deafblind, he needed Intervenor Services to support shopping, appointments, and socializing that would take more than three hours per week. This funding cut left him unable to participate in normal daily life.

### **Major Theme:**

Lack of access to Intervenor Services/Support Services

### **The Challenge Identified:**

William experienced limited opportunities to break down barriers to communication because the government had cut funding. He asked some individuals to join him in advocating for their needs for Intervenor Services. They had a meeting in the legislature and attempted to change the decision of the government. The group explained that they required assistance with everyday needs such as purchasing items at the grocery store, attending medical appointments, and even socializing with friends. Three hours of Intervenor Services a week were not enough.

### **The Result:**

The presentation to the legislature was unsuccessful but the group was eventually able to start a pilot project in the community. They recruited allies and spread awareness to advocate for a better quality of life. Many found the government system oppressive and so by speaking out together, they hoped to raise awareness and remove barriers.

### **Guidance on How to Conduct Self-Advocacy:**

1. Identify the Challenge: William was not receiving enough Intervenor support to conduct daily life.
2. Determine missing resources: Budget cuts did not allow William to receive Intervenor Services beyond three hours per week.

3. Advocate and join in with others: William recruited others to present their case to the government of Alberta and started a pilot project and awareness campaigns.

4. Speak out to local authorities: Approach the ministry or government responsible for funding and policy changes and explain the limitations you face and ask them to work with you to develop a solution.



## Story #6

### **Introduction:**

Brandon shares two personal stories where he was actively involved in advocacy for the deafblind population. Although these are not direct examples of self-advocacy the lessons learned may help you.

### **Major Theme:**

Communication Barriers

Support Service Barriers

### **The Challenge Identified:**

When Brandon was a social work student, he did his internship at a centre that offers sign language services to children. There was a young, deafblind child present who was not being given access to sign language. He noticed that the communication techniques used were very basic and were not advanced enough to meet this child's needs. After completing the internship, Brandon asked others in the community for input. Lack of services for the child was confirmed as a form of discrimination against people who are deafblind. Brandon wrote a letter providing some ideas on how to support this child better. Once Brandon's professor found out about the letter, he told him that it was not his place to write such a letter. Brandon wrote an apology letter.

A second example was an organization Brandon heard about that was advertising the provision of services to people who are deafblind. However, one of their claims was that they would not provide tactile ASL services. Brandon felt that this was an example of *vidism* which is a term used to describe discrimination toward blind individuals (Zeglen, 2022). He sent an email to the organization asking why they would not provide tactile ASL services. They stated it was due to COVID, but he explained that many people who are deafblind need access to services and, even if some can access Zoom, others cannot. Brandon did not feel the organization was fully accessible.

**The Result:**

Brandon received a letter from the sign language school where he interned confirming that they appreciated his letter and took his advice by hiring someone fluent in American Sign Language to work with the child one-on-one. Brandon was pleased to complete this first step in advocacy.

The child did not have access to appropriate communication techniques to support him. This was not only the issue of ignorance of the centre for not thinking of how best to support the child but also a case of the parents not knowing how to advocate for adequate support and access to services due to attitudinal behaviors. For Brandon's story, he sent a follow-up email to the centre. His goal was to help them by offering some suggestions to better serve the deafblind community, despite the challenges of the pandemic.

**Guidance on How to Conduct Self-Advocacy:**

1. Identify the Challenge: Brandon recognized a lack of service provision for a student who is deafblind at a sign language school.
2. Determine missing resources: The student required Intervenor Services to enhance his learning experience.
3. Advocate and join in with others: In Brandon's case, he consulted with others and advocated on behalf of someone else.
4. Speak out to local authorities: Approach the authority responsible (in this case it was the sign language school for the child and a service organization where Brandon noticed the limits on services due to the pandemic). Explain the limitations you or someone else faces and ask them to work with you to develop a solution. Be prepared to offer ideas that can contribute to a solution.

## *Story #7*

### **Introduction:**

Tessa wanted to take business courses to learn how to manage and organize people. Before she could begin this journey, the college told her she needed to enroll in and pass a business mathematics course. Tessa was the first deafblind student the college faculty and administrators had ever met. They did not expect she would be able to complete this course but offered resources to support her goals.

Tessa went to the first business course and met the instructor who informed her that there must be a mistake because his course would not be something a person who is deafblind could manage.

### **Main Themes:**

Barriers to communication

Attitudinal barriers

### **Results:**

Tessa's instructor ignored her. He did not believe that she had the ability or motivation to pass the course. She knew she had to change the beliefs of this instructor. She knew another mathematics teacher who agreed to help her continue learning some of the key concepts she needed to master the course.

With this person's help, Tessa kept attending classes and learning. She had three exams to pass and the first one was the most important for her. She spent many hours preparing so that she could be ready when the instructor asked her to sit in an office with him so that she could solve the problems on the exam.

Tessa could not use Braille to complete the output required because the instructor could not read Braille. She sat in his office and told this instructor exactly what she would do and the steps she would follow to get the answers to each question. She wrote her exam and at the next class the instructor told the class that two students received a

perfect score - Tessa was one of those students. From that day forward, this instructor was completely convinced that Tessa could do the work in the course and pass.

Unfortunately, attitudinal barriers are not solved by using legislated rights. Tessa's experience highlights that, although she had the right to attend any course she chose, she could not automatically remove the attitudinal barriers that she experienced. Instead, she found it useful to take action to educate others so that they could see what she was capable of while also challenging their assumptions about the abilities of people who are deafblind.

**Guidance on How to Conduct Self-Advocacy:**

1. Identify the Challenge: Tessa experienced attitudinal barriers while attending college.
2. Determine missing resources: The instructor assumed she could not complete the course and was unwilling to ask her for input on how he could accommodate her needs.
3. Contact an authority figure/or someone who can help you find a solution: Tessa found someone who could help her master the course materials.
4. Challenge the system: Tessa asked the instructor to give her a chance to prove herself. She stayed in the course, completed the required work, and passed the course by working hard.

## **Conclusion**

On behalf of the Deafblind Advocacy Group Canada and DeafBlind Ontario Services, we encourage everyone interested in breaking down barriers to full participation in all aspects of life to gather your ideas, confirm your goals, do your research, and engage in your journey of self-advocacy. Although there is no specific solution for challenges you may face – each person and each situation is unique - we encourage you to courageously engage in self-advocacy. You may find yourself challenging a variety of barriers including physical, policy, or even attitudinal barriers. Although breaking down attitudinal barriers can take time and energy, we hope you will refuse to give up on the goal you have in mind.

Often when we decide to go somewhere new or do something we have not done before we may find barriers. Advocating for change is important even though sometimes difficult. Knowing we have the right to do what we wish to do is helpful and should motivate us to do what is important.

It is useful to think of a problem as a puzzle and find a way to solve it one piece at a time. The problem might have different ways to resolve it and it will be up to you to find the ways that you feel most comfortable. It might take you a few different tries to get the barriers removed, but we encourage you to believe in yourself and trust that you can do it. Just keep trying.

## Resources

1. [Follow this link for 23 terms you should know to better understand accessibility - Technical.ly](#)
2. List of organizations supporting/providing services for individuals with deafblindness.

Organization	Link info
Helen Keller National Centre, USA	<a href="https://www.helenkeller.org/hks/introducing-advocacy-deaf-blind-world">https://www.helenkeller.org/hks/introducing-advocacy-deaf-blind-world</a>
Helen Keller National Centre, USA	<a href="https://www.helenkeller.org/hknc/class/advocacy-deaf-blind-world-adbw">https://www.helenkeller.org/hknc/class/advocacy-deaf-blind-world-adbw</a>
Helen Keller National Centre, USA	<a href="https://www.helenkeller.org/hknc/americans-disabilities-act-ada">https://www.helenkeller.org/hknc/americans-disabilities-act-ada</a>
Helen Keller, Texas Tech University, Boston College and American Association of DeafBlind	<a href="https://pubmed.ncbi.nlm.nih.gov/22792849/">https://pubmed.ncbi.nlm.nih.gov/22792849/</a> \\10.3.2.15\Users\ccsr\Advocacy and deafblindness
Deafblind Service Centre Seattle	<a href="http://seattledbsc.org/advocacy/">http://seattledbsc.org/advocacy/</a>
Voices Together, of Deafblind Victoria, Australia	<a href="https://www.voicestogether.com.au/self-advocates/toolkits-resources-how-to/resources/deafblind-resources/">https://www.voicestogether.com.au/self-advocates/toolkits-resources-how-to/resources/deafblind-resources/</a>
Resource Centre of Manitoba Deafblind Association Inc.	<a href="http://www.rcmdb.mb.ca/bw_support.html">http://www.rcmdb.mb.ca/bw_support.html</a>
Deafblind Advocacy of Utah	<a href="https://www.facebook.com/Utahdb/">https://www.facebook.com/Utahdb/</a>
Perkins	<a href="https://www.facebook.com/Utahdb/">https://www.facebook.com/Utahdb/</a>
National Family Association for the Deafblind	<a href="https://nfadb.org">https://nfadb.org</a> KNC, Perkins and National Centre on Deafblindness are partner organizations.

Organization	Link info
Deafblind Citizens in Action America	<a href="https://dbcitizens.org/news-blogs/">https://dbcitizens.org/news-blogs/</a>
Sense UK	<a href="http://www.sense.org.uk">www.sense.org.uk</a>
National Consortium of Interpreter Education Centre	1. <a href="https://www.nad.org/dsat/curriculum-overview">https://www.nad.org/dsat/curriculum-overview</a> 2.
WFDB	<a href="https://www.wfdb.eu/about-us/">https://www.wfdb.eu/about-us/</a>
Community Living	<a href="https://communitylivingontario.ca/en/initiatives/">https://communitylivingontario.ca/en/initiatives/</a>
Autistic Self Advocacy Network in USA	<a href="https://autisticadvocacy.org">https://autisticadvocacy.org</a>
Canadian Hearing Services	<a href="https://www.chs.ca/node/823">https://www.chs.ca/node/823</a>
CNIB Advocacy Program	<a href="https://cnib.ca/en/support-us/advocate/ontario-advocacy/training-resources-0?region=on">https://cnib.ca/en/support-us/advocate/ontario-advocacy/training-resources-0?region=on</a>
Holland Bloorview Family Advisory Council	<a href="https://research.hollandbloorview.ca/sites/default/files/2019-06/AdvocacyToolKit-July24-LINKED-LOCKED.pdf">https://research.hollandbloorview.ca/sites/default/files/2019-06/AdvocacyToolKit-July24-LINKED-LOCKED.pdf</a>
National Hemophilia Foundation (United States)	<a href="https://www.hemophilia.org/Advocacy-Healthcare-Coverage/Advocacy-Tools-Resources/Advocacy-Dos-and-Donts">https://www.hemophilia.org/Advocacy-Healthcare-Coverage/Advocacy-Tools-Resources/Advocacy-Dos-and-Donts</a>
Health Quality Ontario	<a href="http://www.hqontario.ca/Portals/0/documents/pe/meaningful-projects-en.pdf">http://www.hqontario.ca/Portals/0/documents/pe/meaningful-projects-en.pdf</a>  <a href="http://www.hqontario.ca/Portals/0/documents/pe/terms-reference-en.pdf">http://www.hqontario.ca/Portals/0/documents/pe/terms-reference-en.pdf</a>  <a href="http://www.hqontario.ca/Portals/0/documents/pe/recruiting-diversity-en.pdf">http://www.hqontario.ca/Portals/0/documents/pe/recruiting-diversity-en.pdf</a>  <a href="http://www.hqontario.ca/Portals/0/Documents/qi/choosing-methods-pce.pdf">http://www.hqontario.ca/Portals/0/Documents/qi/choosing-methods-pce.pdf</a>

## **A Note of Appreciation**

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