

Deaf-Blind Woman Advocates for Herself



by Thelma Fayle, January 2015

Editor's note: Thelma is a strong supporting member of the CFB. She is especially concerned with issues related to the lack of proper blindness skills rehabilitation training in Canada. She and Daryl Jones (next article) travelled to New York in April. One of their trip highlights was touring and learning about the Helen Keller National Center for the deaf-blind.

When Ann Wasserman was six years old, and got short-changed at a corner store in her New Jersey neighbourhood while buying a soda, her father (a tennis pro) made her go back in the store – by herself – and ask for the right change. Blind or not, no kid of his was going to get ripped off like that.

When she took up ice-skating as a teenager, her father taught her how to relax on impact when she fell. She fell a fair bit, but as a result of her father's guidance, she rarely got hurt doing the thing she loved to do.

When she graduated from university and went job-hunting, her hard-headed father insisted that she not take a job that would pay any less than what her friends were being offered. Ann went on to do her Masters in Special Education at Columbia University and spent a career she loved, teaching in the public school system.

Ann has been visiting Canada every summer for the last twenty years of her retirement. She did her research and chose Victoria B.C. because she thought it looked like a fun place that she could easily manage.

She never leaves things to chance and started her planning by memorizing the city map. Today she loves to sail, swim, bus and walk around the town she loves for its accessibility. From May till September, she enjoys concerts, restaurants, festivals – you name it and chances are she has done it in Victoria where she has a wide circle of old friends.

“Spending summers in Victoria feels like paradise to me,” she says. “Freedom is a key component of what the city has to offer people with disabilities. What I enjoy most, aside from the many activities in Victoria, is my freedom and independence. In the States I have to depend on family and friends to take me anywhere. I don’t feel disabled in Victoria. The sidewalks are smooth and un-cracked and well-maintained, and my guide dog and I can just about fly together with all of the other disabled people with wheelchairs, walkers and canes. The streets of Victoria are for everybody.”

“Once you experience freedom, would you ever give it up?” asks Ann.

She reads more fiction and non-fiction than anyone I know – thanks to a brilliantly accessible system the public Library of Congress offers to its blind U.S. citizens. She has probably read 3-4 books a week for the past 50 years.

Suddenly, when Ann turned 72, she started to rapidly lose her hearing. Terror came into my friend’s voice. I could hear it when we would chat on the phone when she was back home in New Jersey. The growing timidity was strange and her effervescence was diminishing. The prognosis was not good and a long-shot surgery was suggested. Her doctor recommended a cochlear implant for her deafness.

Ann is a firm believer in trying things and, thanks to her father, an even firmer believer in reaching out to get her needs met. She does not want to become ‘dependent’ on others.

She wondered what she would do if she could no longer ‘read’ the audiobooks that she consumed by the dozens every month. Her Braille skills are rusty. Would deafness coupled with her manageable blindness cause the end of freedom in her life?

She faced the issues head-on and as usual, did her research. She mulled the risks for a few months and even though she was afraid of the surgery, she decided to have it.

Ann became the poster child for cochlear implants in seniors. It was a successful surgery and she regained some of her hearing but still had to cope with some deaf-blind issues.

She learned about the Helen Keller National Center (HKNC) in New York and visited the residential training facility, exclusively for deaf-blind adults. She wanted to check it out before making a commitment to register for a program. She had no intention of wasting her time with “some flimsy agenda”.

She interviewed the HKNC instructors, toured the grounds and saw potential value in the possibility of picking up new deaf-blind skills. She decided to attend a five-week program.

She phoned friends in Victoria to give regular updates on the program. Within a week I heard the return of Ann’s resilient strength and character in her voice.

I was so impressed by what she told me about the HKNC, that I arranged to visit and tour the center and interview the people who run the place. I wanted to understand more about the dynamics of the organization that returned my old friend's lifelong joie de vivre.

Helen Keller National Center

By Daryl Jones

Editor's note: Daryl is a strong supporting member of the CFB. He is especially concerned with issues related to the lack of proper blindness skills rehabilitation training in Canada.



Photo Credit: Daryl Jones

Last April my partner and I were visiting New York and had an opportunity to tour the Helen Keller National Center, a residential training facility for deaf-blind youth and adults located on the north shore of Long Island. Thelma arranged for the tour, as she wanted to write a story about the positive impact that the Center had on a friend of ours. I tagged along to take a few photos and to learn something about the Center.

There is nothing like the Center in Canada and I was impressed by their focus on empowering deaf-blind individuals through use of adaptive technology and independence training. Therefore,

I thought that the readers of The Blind Canadian might like to hear a little about the Center. With this in mind, and in no particular order, the following are a few of my personal highlights of our visit to the Helen Keller National Center.

1) Location and Facilities

As we approached the Center the first thing that struck me was the neighbourhood. Specifically, we were driving through a high-end residential community with large properties, grand houses, and meticulously manicured gardens. The taxi driver explained that this was a highly desirable area in New York as it was only a 45-minute train ride to downtown Manhattan, even in the morning rush.

I expressed some surprise that the Center would be located in such an expensive residential area and the driver indicated that initially there had been some resistance from nearby residences. However, he quickly added that the opposition was short-lived and now there was strong local support. In fact, he said that the community felt a strong sense of pride about the work being done at the Center.

Later we would learn that the Helen Keller National Center is located on 25 acres of the Sands Point Preserve, a very beautiful and tranquil setting. There were a number of buildings clustered together, one of which was a student dormitory. It was designed like a typical college dorm, with two people to a room, each with their own desks and beds and a shared bathroom. There was also a cafeteria and lounges in the students' residence. Throughout the complex there were tactile indicators to help the students navigate. For example, there were strips along the floor of the cafeteria to help identify the bins for their dirty dishes and brick walls as they approached an outside door.

The training facilities were in the administrative building and included classes in technology, independence training, and art. In terms of recreational facilities, the Center has a gym, a track, a dog run and there is a swimming pool about four blocks away. There is a sensory garden and green house for students interested in horticulture or landscaping.

There is a simulated independent living space, which enables an individual to live in an apartment setting as though they were living independently. While support is available if it is ever needed, the residents are expected to clean their own space as well as do their own cooking and laundry.

There was also a separate residence for teachers, who come to the Center from different states or regional centers in order to learn how they can better teach and/or interpret for the deaf-blind when they return home. There also was a video conferencing auditorium, again to help instructors and educators based in the regional offices.

The Center also operates a near-by group home called Destiny Home for deaf-blind individuals who are also developmentally disabled. Currently, five people live there in two separate apartments. We were told proudly that all of the current residents are employed, live independently and are active participants in their local community.

Finally, there is also an “Apartment in the Mainstream” located several blocks away. There is no staff on site but there is a call system if help is ever needed. The intent is to ensure that the graduating student is able and comfortable in living on his or her own.

2) Individualistic Approach to Independence Training

Staff members recognize that the students are adults who are of different ages, possess different abilities, and have different objectives for their training. As a result, they do not follow a prescribed one-size-fits-all approach. Rather, the Center’s programs are tailored to help each student achieve his or her personal goals and objectives. For example, this might be preparing the student to live independently, helping them get ready to attend college, or exploring career opportunities. The philosophy of focusing on the needs of the individual is reflected in the Center’s corporate mission statement, which is “...to enable each person who is deaf-blind to live, work, and thrive in their community of choice.”



Photo Credit: Daryl

Jones

The individualistic approach to training means that some students may be at the Center for a few weeks whereas others might be there for a year or even longer.

Training occurs 24/7 and includes Braille, vocational skills training, adaptive technology, computer skills, socialization skills, mental health, medical services, and independence training. There are both on and off campus activities organized for the students. There is also a strong focus on finding gainful employment.

Although the Center encourages the students to capitalize on whatever sight or hearing they may possess, staff also help them prepare for longer-term issues. For example, if a student's medical prognosis is that they will likely lose more of their vision in the future, then they would be encouraged to use sleepshades during training. However, this will only occur if he or she is receptive to the idea.

One thing that impressed me was the Center's willingness to work co-operatively and share its teaching techniques and experience with their international counterparts. For example, while we were there, there was an observer from Japan, who came to learn about the Center and to adapt their teaching techniques for the deaf-blind in Japan. Following his stay, he was planning to go to Europe and study their teaching methods. We were advised that a delegation from Norway had been there the previous month and were returning in June in order to demonstrate a new system of communications they are developing called Haptics.

3) Funding

We were told that prior to the 1960s, there was very little formal education provided for the deaf-blind in the U.S. Rather, they were generally considered to be "uneducable" and, more often than not, were put into services for the mentally handicapped. However, a rubella epidemic during the 1960s led to a significant increase in the number of deaf-blind people and increased pressure on governments to provide skills training for individuals having dual sensory impairments.

The idea of establishing a national training center specifically for the deaf-blind was proposed by Industrial Lighthouse for the Blind and was authorized by an act of Congress in 1967. The Center's legislative mandate is to provide services and training for deaf-blind individuals as defined by the Helen Keller Act. In addition to the national training headquarters in New York, the Center also operates 10 regional offices as well as working with many state and private agencies. As a national training center, the federal government pays 80% of the costs. The remaining 20% comes from grants, charitable contributions, and fees charged to the individual states that send the students.

Receiving most of its funding from government means that the Center can focus its resources on providing services for the deaf-blind, and teaching the teachers of the deaf-blind, rather than creating, operating, and feeding a fund-raising bureaucracy. However, like many social agencies, the Center's funding is not keeping pace with the demand for its services, which undoubtedly will continue to increase with an aging population.

4) Staff

Regardless of the field of endeavor, an organization's success ultimately depends upon the quality and dedication of its staff. Obviously, a four-hour tour and conversations with half a dozen staff members, does not qualify me to critique the quality of the staff or the delivery of their training services. However, several things stood out about the staff members that we did meet. First of all, many of them started as volunteers and had long histories with the organization. In fact, it was not uncommon to hear a staff member say that they had been

working at the Center for 25 years or longer. However, despite having long careers, it was also quite apparent that they continued to feel a genuine passion for the work they are doing.

Not surprisingly, some of the instructors and administrators were also deaf-blind. In fact, in looking at a pair working with iPhones and Braille readers in the technology lab, neither Thelma nor I could determine who was the student and who was the teacher.

The most enthusiastic staff member we encountered was a young fellow named Don. He had been deaf for most of his life, although much of his hearing has now been restored as a result of cochlear implants. He told us that the Center has two missions. The first was the training of the deaf-blind while the second was educating the general population about the skills of the deaf-blind.

Obviously, educating the general public regarding the abilities of deaf-blind individuals is no small undertaking, especially since most people have never encountered such a person. As a result, their only point of reference is to imagine themselves as being deaf and blind and all that they can see are the challenges and obstacles, not the potential or possibilities. Fortunately, the Center's staff believe that the deaf-blind can accomplish anything they want, provided they have the appropriate training and adaptive technologies.

Actually, Don's comment about educating the general public caused me to think back to the earlier statement made by our cab driver. You may recall that I mentioned that he said that the community "felt a strong sense of pride" about the work being done by the Center. I found his wording a little perplexing at the time, but in hindsight, it would not surprise me if this pride came from the fact that the students have regular outings in the local community. In addition, the Center works with about 70 local employers to help its students get some practical work experience. I believe that these interactions with local residents not only helped to dispel misconceptions about the abilities of the deaf-blind, but also enabled the community to feel that they are part of the training process.

As we drove away from the Center, I reflected upon the stark contrast between what we had just seen at the Center and the poor level of independence training provided for blind Canadians. While the differences between the two countries are likely attributable to a variety of factors, I believe that a key reason why skills training for the blind in Canada has not evolved like it has in the U.S. has been a lack of competition. Specifically, in the United States, blind consumers have several options in terms of their independence training. They can go to centers run by individual states (e.g., Commissions for the Blind), or to federally sponsored programs, such as the Helen Keller Nation Center, or private training facilities which receive public funding but are managed and run by NGOs, such as the National Federation of the Blind. While the onus is on the individual to do the necessary research and due diligence to determine their best option, they have choices and I believe that competition among these training organizations has meant that they have become more attentive and responsive to the needs and desires of their clientele. Unfortunately, for most blind Canadians, the CNIB is their only option for independence training and with its monopoly there has been little need or impetus for that organization to change its paternalistic approach and attitude towards independence training.