

Truths of
Institutionalization:
Past and Present

Student Workbook

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Student's Name:

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Partners



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MODULE ONE:

A Hidden Truth in Canadian History

WORD GLOSSARY

intellectual disability: Certain limitations that a person is born with that cause them to learn and develop slowly.

survivors: People who have an intellectual disability and have experienced institutionalization.

historical context: Understanding the influence of cultures, attitudes and beliefs that existed during a certain period of time.

asylum: A large hospital-like place that confined people (usually for life) who had a mental illness, disease or disability and needed medical attention.

social problems: Problems that affect a large number of people in society. For example: poverty, unemployment and homelessness.

a good life: A life that is meaningful and has purpose.

congregated: Gathering a large number of people in one place.

custodial movement: A period in time when society cared for vulnerable people by putting them in institutions in order to maintain control and power over these groups.

primary sources: Evidence of what happened in the past. for example: photographs, letters, documents, paintings or objects.

presentism: When current views and beliefs are placed on people who lived in the past. this is something that historians avoid doing.

MODULE ONE: Historical Perspectives

M1.1 An Introduction to Institutions of the Past

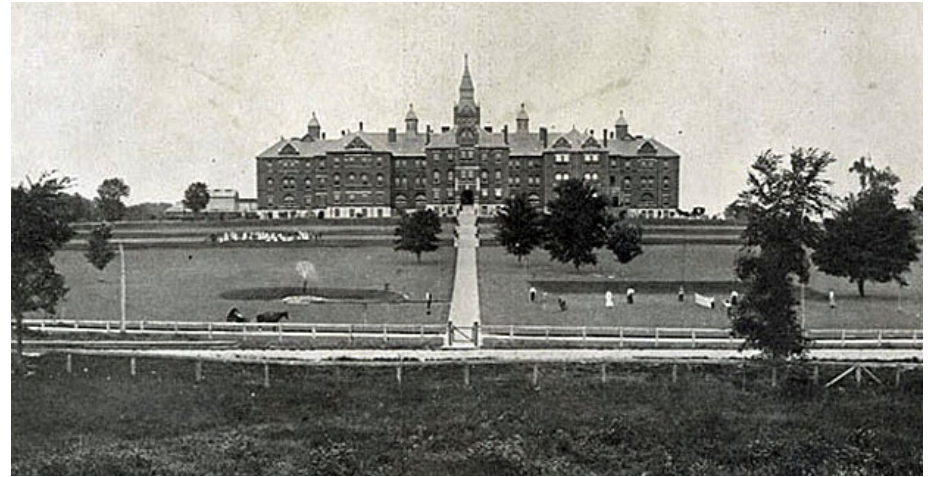
What did institutions look like?

There are many kinds of institutions. Prisons, hospitals, residential schools and other places where people are congregated are often considered institutions. Historically, institutions housing people who have an intellectual disability have been large, hospital-like buildings owned and controlled by charities and the government. They were known as complexes because they were made up of many buildings of various sizes. The smaller buildings were called ‘cottages’ but they were not a place you would want to stay. Some institutions had underground tunnels so that staff did not have to go outside. Institutions were often self-sufficient. This means that most of the food, supplies and services that residents and staff needed were available on site. For example, food was grown on a farm owned by the institution. If a resident needed dental work, the dentist would come to the institution to treat the resident.

There was never a reason for a resident to leave the institution. Community members did not see people with disabilities at work, school or in public. In fact, citizens were often unaware that many people were living in the institutions outside of town.

Who were institutions created for?

For over two hundred years, children and adults who have intellectual and developmental disabilities around the world have been placed in institutions. The first institutions were called hospitals or asylums. People with disabilities were grouped with people who suffered from a mental illness or



Source: People First of Canada

people who were sick with chronic illnesses. During this time, people with disabilities were labeled as dangerous. They were feared by society.

In 1916, Dr. Helen MacMurphy, Head of the federal government’s Division of Child Welfare in Canada, wrote about the “need [for] caring for those who are mentally defective and the serious danger they are to the public and themselves while they are at large.”³ Dr. MacMurphy played an influential role in creating policies that led to institutionalization. She wrongfully blamed major social problems in Canada, like homelessness and poverty, on “feeble-minded” people.⁴ This included people with intellectual disabilities.⁵ Institutions were seen by governments as a solution to these problems. As a result, thousands of people have lived their whole lives locked in institutions that they were not allowed to leave.

“Institutions need to close. People need to live and be included in the community. I spent 18 years living in an institution. It was like living in a prison.” – David Weremy, Manitoba Survivor



Source: People First of Canada

In Canada, approximately 60 large institutions were built to house people with intellectual and mental disabilities.⁶ It is estimated that hundreds of thousands of people have lived and died in these institutions in Canada. Many records have gone missing, or were destroyed, so it is hard for experts to know exactly how many people lived and died in the institutions. We also do not know what happened to many people while they lived in institutions or asylums.

Words like ‘feeble-minded,’ ‘mongrel,’ ‘idiots,’ ‘lunatics’ and ‘retarded’ are terms that were used to describe people with intellectual disabilities. These words are very disrespectful and hurtful. This language demonstrates the way that disabled people were thought of as different or ‘not normal.’ This point of view made it easier for society to think it was acceptable for people to be treated differently.⁷ Doctors, governments, advocacy organizations and institutions have all used this kind of language. However, over time, the language that society used to describe people with disabilities changed. For example, the Orillia Asylum for Idiots, in Ontario, changed

its name to the Huronia Regional Centre. The Provincial Training School for Feeble-minded Children became The Michener Centre in Red Deer Alberta. Even though the language and the names had changed, the institutions continued to rob people of a good life. An institution is still an institution if people are congregated and do not have control over their lives. Even if we change a building’s name or make it look better, it will still be an institution.

Today, we know that no one needs to be separated from their community just because they have a disability. Living with family, being close to friends and neighbours, going to school and having a paid job creates communities where everyone is welcome. Even if someone requires extra support or specialized care, they will have a better quality of life when they receive support and care in their home and community, rather than in an institution.⁸

Where were institutions typically built?

Institutions were built on large grounds, separated and hidden away from the community where everyone else lived. They were often built with high walls and located far outside of the community. They were usually built in rural areas, and surrounded by open spaces like woods or fields. Inside the institutions, residents lived in rooms with doors that were always locked. Institutions were also a place where ‘problematic people’ could be controlled. People with disabilities “were to be removed from society, where they were seen as inefficient, obtrusive and largely unwelcome. They would [also] be kept in isolation and separated according to gender so as to prevent reproduction.”⁹

In many cases, people with disabilities were sent outside their community, or even to another province, to live in an institution. This greatly isolated residents from their families. Can you imagine being locked away in another province without being able to see or hear from your family? This way of separating people from their families continues to happen in Canada. For example, in Nova Scotia and Manitoba, people are placed in institutions and institution-like places miles away from their families. This was especially true for people who lived in northern communities or the Canadian territories.

Why were people sent to institutions?

Throughout history, perceptions of disability have evolved. These perceptions of disability have influenced decisions about people. People were sent to institutions because of the way that society viewed people with disabilities. Below we have outlined two models of thinking. These models



Source: People First of Canada

are harmful ways of thinking about disability. Both models contributed to the rise of institutionalization in Canada.

Medical Model

In the 19th and early 20th centuries, disability was considered a hereditary disease that needed to be cured. This had many repercussions for families and how they saw and understood their loved ones. As mentioned before, the ‘feeble-minded’ were often considered a

threat to public safety and a source of major social problems. Families felt shame and feared the stigma of being known for having ‘defective’ genes.¹⁰ Of course, today we know this isn’t true. However, in our society, people still feel shamed for having a disability.

When people think about disability as a medical problem or a disease, we call that the ‘medical model’ or way of thinking. The medical model sees disability as an illness or sickness that needs to be treated or cured. This perception of disability has influenced how governments, doctors and families make decisions, and led to a lot of abuse and harm. Disability is not something that people need to be cured of.

Institutions were thought of as specialized hospitals that were designed exclusively to care for the needs of people with disabilities. Often, doctors encouraged families to send their children to an institution. They pressured families into believing that the institution was the only place where their child could receive specialized care. Families were told their child would benefit from being in a place where they could be with ‘people like themselves.’ They were also told that it was a safe place where their child would be supervised by professionals who understood them. Families often thought their children would be happier at the institution and that they were doing what was best for their child. However, Canada’s governments failed to set up standards and protocols that would safeguard people from abuse and neglect. As a result, many disabled Canadians were left to endure years of suffering.

Rehabilitation Model

Towards the middle of the 20th century, society adopted a different approach to caring for people, the rehabilitation model. Professionals no longer saw disability as a disease but a condition that could be fixed through specialized training. This is why institutions were given names like ‘training schools.’ Professionals began to think it was possible to *rehabilitate* or train people in an institution to learn life skills. Except, more often than not, living at an institution was not a temporary arrangement. Survivors say it was almost always a life sentence. Institutions were considered an efficient and economically sustainable way to care for vulnerable people. Since no other support was available within the community for families, it was believed that institutions were ‘safe’ places.

The period of time when institutions were very popular has been called the custodial movement by historians. Both the medical and rehabilitation models demonstrate that society has had a limited understanding of disability and very low expectations of people who are labeled with a disability.

For a time, the institutionalization of people with disabilities was no longer seen the ‘great’ solution to society’s problems. As community supports became available, more families turned to these services rather than specialized facilities. When this happened, people who were already institutionalized remained locked away and forgotten. Tucked away in institutions outside the community, their suffering continued unseen.¹¹

Are institutions suitable solutions today?

In 2017, the United Nations Committee on the Rights of Persons with Disabilities declared that all persons have the right to live independently and be included in the community. Article 19 of the Convention on the Rights of Persons with Disabilities considers it a human right for every person to choose where and with whom they would like to live.

For centuries, people with disabilities have had no control over decisions or legal rights to choose where they live. This has often led to segregation, institutionalization and poverty. While we have come a long way, some continue to see people who have disabilities as being ‘less than,’ or in need of protection. These ideas affect the way that laws and support services are created. This means that gaps in our laws exist and people continue to experience limited control over the decisions in their lives. They continue to have limited opportunities to be independent and included in the community.

References:

3. Simmons, 1935, p. 71
4. Simmons, 1935, p. 70
5. Simmons, 1935, p. 69
6. Brown, 2015, Table 2, *Inclusion Canada*, 2020
7. L’Arche, 2014, p. 12-13
9. *Inclusion BC*, 2020
10. Radford & Park, 1993, p. 373
11. L’Arche, 2014, p. 4

Reflection Questions:

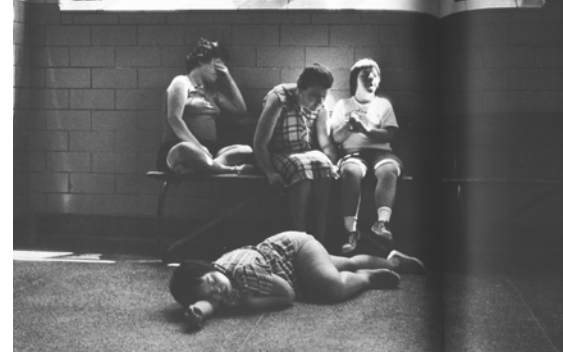
1. In your own words, how would you describe an institution?

2. While reading about the institutions of the past, were you shocked by anything you learned? Explain.

3. The medical model and rehabilitation models have influenced the way people think about disability. List a few examples of how these models of thinking still exist today.

Handout M1.2 Photo Analysis

1. How does this photo make you feel?



2. What kind of reality is being portrayed in this photo? What information can you gather about the people in these photos?



3. What places or objects are in the picture? What period of time was this photo taken in? What can you say about the experience of living in an institution from this photo?



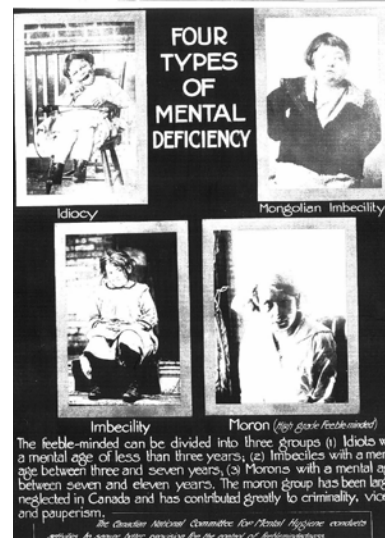
4. What does this image make you think about? What does it tell you about the way people thought about children with disabilities?

[illegible]

5. What is this a picture of? What is written on the stones? How are they organized? What does it tell you about social attitudes during that time?



6. What does the language used in the document tell you about the way people with disabilities were viewed? What are the consequences of using this type of language today?

[illegible]

Handout M1.3

Using the map in Module one, label this map for your notes with key information about the experiences of Canadians with disabilities in various provinces and territories.



- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____

Handout M1.4 Survivor Insights Video Reflection Questions

Leta’s Story M1.V2

- 1. How did Leta describe her life at the institution?

- 2. What is Leta’s truth?

- 3. What brings joy to Leta’s life today?

David’s Story M1.V3

- 1. How many times did David run away?

- 2. What did David witness in the institution?

- 3. What is David’s legacy?

Joe's Story M1.V4

1. Why isn't Joe afraid to talk about his story?

2. What made Joe afraid?

3. What things would people have in their lives if they had not been sent to an institution?

Thinking Ahead: In what ways do you think the testimonies of family members will be different from those of survivors? How would the perspective of a sibling of someone with a disability be different than the perspective of a parent who sent their child to live at the institution?

Handout M1.5 Family Insights Video Reflection Questions

Barb's Story M1.V5

1. What are Mallory's gifts?

2. How did the decision to send Mallory to an institution impact Barb and her family?

3. What caused Barb to worry about Mallory's wellbeing? What red flags do they remember??

Ron and Jean's Story M1.V6

1. How did limited awareness of Autism impact Derek's life and experiences? What did people assume about him?

2. What hard decisions did Ron and Jean have to make?

3. What was the name of the Act that protected Derek from life in an institution?

Victoria’s Story M1.V7

1. How was Martha’s birth viewed by people at the time?

2. How did Martha change over time?

3. How were Victoria and her mother impacted by Martha’s life in the institution?

M1.6 Building a Timeline of Human Rights In Canada

As a group, your task is to create a variety of posters, symbols or drawings that represent the various events, laws and policies that lead to the evolution of human rights in Canada. As a class, you will build a visual timeline for your classroom. Each group is responsible for one of five periods shown on the timeline in Module one. In addition to a visual of your choice, each person in your group must also write one key statement that summarizes something important you learned from Module one. Be sure to add your key takeaway to the timeline.

What is your key takeaway?

Handout M1.7 Independent Work

Below are five letters from leaders in Canada who know about institutionalization in Canada. Choose one letter to read. They have written it directly to you. What do you think about what they said? Have they said anything that changes how you think about things?

Come to the next class prepared to share what you've learned and are thinking about with a small group of your peers

Letter One:

From Madeline Burghardt, PHD, University of Windsor & Author of *Broken: Institutions, Families, and the Construction of Intellectual Disability*

Dear students:

The middle of the 1800s until the early 1900s is a key time period in the development of institutions for people labeled with an intellectual disability in North America. Before I point out some important developments during that period, however, I want to introduce some ideas that I hope you will use as you continue to learn about institutions and the role they have played in Canadian history.

The first thing to remember is that history is messy. It cannot be understood as a continuous movement forward. Many of the things that I write about here have roots in earlier time periods; likewise, you will find similarities between some of the historical preoccupations discussed here and things that happened much later. Another thing to remember is that, sadly, history, and people in general, are also not always 'progressive,' meaning that the ways that we treat others do not necessarily get better over time. For example, you will probably notice things in this history that sound similar to what is going on

around you right now. Accordingly, I challenge you, after reading this piece, to identify some of those similarities: what features of institutionalization, even if the buildings themselves look very different, are similar to the ways in which society continues to treat people with disabilities and other marginalized people in society, like the elderly?

Now, some history. As noted, the mid-late 1800s was the key time period during which institutions for the 'feeble-minded' were established in North America. Institutions for people considered 'mad' and for the very poor already existed in Europe, primarily due to the Industrial Revolution, the rise of capitalism, and the corresponding need to separate 'productive' from 'non-productive' workers. 'Institutions' also existed as part of religious communities' charitable responses to those considered less fortunate, such as shelters: these were forerunners to what later became the institutions you are studying here.

In North America, Eduard Séguin played a key role. Séguin was a Frenchman who emigrated to the United States in 1848. He had been a student of a man named Itard in France, who had 'trained' the 'wild boy of Avignon' to become a socially-acceptable young man. Séguin brought Itard's ideas of rehabilitation and training to the U.S. and set about establishing several 'schools for the feeble-minded' during the 1850s and '60s, primarily in the Northeastern part of the country. Initially, the intentions were good – to teach children who needed extra support – and at first, these schools were met with great optimism. People believed that with proper routines and training, people with intellectual disabilities could learn specific skills and could return to their families and communities as contributing members of society. However, within a few decades, these 'training schools' had become more like places of incarceration rather than learning; in the words

of American historian David Rothman, “the dream turned into a nightmare.” Why did this happen?

In general, the late 1800s was a time of tremendous change. First, urbanization was on the rise. Families were increasingly moving to cities, which meant that family farms were decreasing in number, places where some people with disabilities had previously found meaningful roles. Industrialization was increasing, and factory owners, intent on profit-making, were keen to get fast, capable workers, and people with disabilities were often excluded from the workforce. Science was another key player: recent discoveries of the causes of disease, the work of Darwin, and the promotion of the scientific method as a way to further scientific knowledge, all contributed to scientists’ search for the ‘causes’ of disability, and some of this research took place in institutions. This ‘scientific’ work was also misguided: through this period, scientists relied on theories that promoted faulty ideas of genetic inheritance for disease and disability. This was called the Eugenics movement, and it was especially popular at the beginning of the 1900s. Eugenacists encouraged the identification and segregation of the ‘feeble-minded’ from the rest of the population, sending many people to institutions.

There were other changes as well. IQ tests were introduced, which, although they were first designed to assist children who needed help in school, ended up being a way to categorize children and to determine which ones should be institutionalized. Free public schooling ironically meant that there were more children that could be ‘identified.’ Finally, this was a time of increased immigration to North America from Europe. Although countries like Canada wanted immigrants to ‘settle’ the land in the West, many people were also suspicious of these ‘strangers,’ and eugenic practices were also promoted with these new arrivals. For all these reasons, the numbers of

people being sent to institutions between 1850 and WWI rose dramatically. Due to the increasing institutional population and subsequent overcrowding, as well as increasing beliefs in the inability of people with disabilities to learn how to function in society, Séguin’s original rehabilitative model became ‘custodial,’ or one that focuses on providing the basic necessities of life, with little training or education.

These ideas also existed in Canada, and the first institution for the ‘feeble-minded’ was established on the outskirts of Orillia, on the shores of Lake Simcoe, in 1876 (it is important to note that this is the same year that the Indian Act was formalized in Canada, another example of an official policy of segregating people due to difference). This first institution was called the *Orillia Asylum for Idiots* – a title we find disagreeable today, but was considered absolutely acceptable, and even scientifically accurate, at the time. Just as in the U.S., the population at the Orillia Asylum grew quickly. And because the Orillia Asylum was established later than the ones in the U.S., at the time when the rehabilitative aspect of the institutions was mostly gone, it adopted a custodial model from the outset.

Institutions’ large sizes, severe overcrowding, insufficient staff, and considerations of people with disabilities as less worthy than others, all contributed to the mistreatment and sometimes abuse of institutional residents. For people with disabilities, these decades are a dark period in history; David Rothman’s ‘nightmare’ lasted a very long time. However, Rothman also leaves us with a hopeful and encouraging message: “we need not remain in inherited answers” In other words, we can imagine and create alternate ways of being together that do not separate people, categorize them as different, and shut them away for the rest of their lives.

Madeline Burghardt

Letter Two:

From Chris Beesley, Chief Executive Officer, Community Living Ontario

The curriculum you're learning has focused on telling the truths of institutionalization and the devastating impact it has had on thousands of people. The Community Living Movement began over 75 years ago and continues on today. Since the beginning of this movement, many truths and lessons have been learned. It was an exciting time when families began to explore new ideas and to express the desire to have their sons and daughters be an important part of their communities and everyday life, but this was not without challenges.

In the early days, many children were placed in large scale institutions, far from their families, where they lived in overcrowded and filthy conditions. They were often treated harshly, even suffering horrific abuses. Many children also lived at home but then had no access to schooling or jobs as they grew older, often living in poverty and isolation. The Community Living movement aimed to change all of this. Families began to advocate for access to residential supports and education in their communities. They pushed for access to training so people could become productive citizens.

The result of this movement was that some family supports and services were slowly beginning to be offered closer to home. Unfortunately, these services remained institutional in their structure. Residential programs took the form of large-scale group homes, often with 10 to 25 people living together. Education was in segregated schools and employment in sheltered, non-paying workshops. This continuing institutionalization model fell short of the Community

Living Movement's goals because, instead of focussing on individuality and community inclusion, they reinforced stigmas and low expectations. In other words, people were still offered institutional models of care, only on a smaller scale.

However, the movement did not stop there. Many families and people who have the lived experience of having an intellectual disability took on these new problems. Towards the 1970s, smaller scale homes, inclusion of students in community schools (although still segregated), and greater employment options all came from the significant advancements within the early Community Living Movement. This is when people were beginning to be seen as deserving of community-based supports with more options for living. This continues to grow and, today, the evolution of supports in schools and workplaces is resulting in a decrease in special programs for people.

The movement continues today, but unfortunately, people still get segregated in many new housing models and education systems. They are still living in poverty. That is why it's important that the public, and especially the next generation, is aware of past institutional practices and what has been accomplished so far. We do not want to go back to where we were. People need to keep pushing for more community options. During the 1950s '60s and '70s, we learned that de-institutionalization is not as simple as closing large scale institutions. Instead, it requires people to think of everyone as contributing citizens who are respected and valued. The lessons of the early years of institutionalization need to continue to shape planning and policy into the future.

Chris Beesley

Letter Three:

From Peter Park, Founding Member of the People First Movement in Canada

Dear readers,

My name is Peter Park, and I'm writing this letter with the help of our executive director of People First of Canada (PFC), Shelley Fletcher. I am the founding member of PFC and am affectionately known in the movement as 'the Godfather.' We are writing to tell you a story about a time in Canada, the first time in Canada, that people with intellectual disabilities came together to support someone whose rights were being taken away.

This story takes place between 1979 and 1986. It is a true story, about 'Eve.' Eve was 24 years old and had a boyfriend. As their relationship progressed, Eve and her boyfriend talked of marriage, and they became sexually active. Eve's mother was worried that her daughter might become pregnant, concerned that if that happened, she would end up having to take care of Eve's baby. She went before the court in their province (P.E.I.) asking the court's approval to have her daughter sterilized. Eve's mother won that court case, but Eve was very, very against this. The official trustee in P.E.I. helped Eve and applied to have her case heard at the Supreme Court of Canada.

What we didn't know at the time, was that this case was the beginning of a revolution for people with intellectual disabilities in our country. 'Eve' marks a very important time in history for us. We didn't know that we had that much power. We didn't know people would listen to us, and believe us, because that had never happened in our lives before. We

were just starting to learn about our rights. This story marks the first time in Canadian law that, regardless of someone's cognitive ability, no one – absolutely no one – had the right to make a decision like this for someone else. This case clearly stated that all people had fundamental human rights and, in Eve's case, the right to the integrity of her own body.

At this time, I belonged to a family run organization called The Canadian Association for the Mentally Retarded, now known as The Canadian Association for Community Living (CACL). We were part of a project called the Consumer Advisory Group. We were a group of people with intellectual disabilities who gave advice to the organization's board. When our organization heard about the Eve case, the families felt one way about this, and we, the self-advocates, felt another. We felt very strongly that someone needed to stand with Eve. We felt very strongly that *no one* had the right to make decisions about our bodies – except us. With the help of our allies, we applied to the court for intervenor status. This meant we (through our lawyers) got to go into the Supreme Court of Canada and speak on behalf of not only Eve but all Canadians with intellectual disabilities. This had never happened in Canada before! And we won. On October 10, 1986, the Supreme Court of Canada ruled that people with disabilities could never again be sterilized against their will.

This decision reversed hundreds of years of discrimination against people with intellectual disabilities. This is the first time, in the eyes of the law, that we were seen as people.

It is important to know that, before this decision, tens of thousands of women and men living in institutions across Canada were sterilized. Most of us didn't even know it. People were told they were going to the dentist, given a drug to knock them out, and they were operated on.

After we won the Eve case, society started to look at us differently. Our families and friends started to respect our decisions and we learned to use our voices. We learned to live the motto “nothing about us, without us.” It was a shift in time – the beginning of us being seen as *people first*.

As a person who lived in an institution in Ontario for 18 years, I had no voice. I am so very proud that I was able to be part of this important piece of Canadian history.

Sincerely,
Peter Park

Letter Four:

From Kathleen Wynne, Former Premier of Ontario, A Formal Apology to Survivors

Mr. Speaker,

One of a government’s foremost responsibilities is to care for its people, to make sure they are protected and safe. And therein lies a basic trust between the state and the people. It is on that foundation of trust that everything else is built: our sense of self, our sense of community, our sense of purpose. And when that trust is broken with any one of us, we all lose something – we are all diminished.

I stand to address a matter of trust before this house and my assembled colleagues, but I am truly speaking to a group of people who have joined us this afternoon and to the many others who could not make it here today.

I am humbled to welcome to the legislature today former residents of the Huronia Regional Centre and Rideau Regional Centre in Smiths Falls and to also address former residents of

the Southwestern Regional Centre near Chatham, along with all their families and supporters. I want to honour them for their determination and their courage and to thank them for being here to bear witness to this occasion.

Today, Mr. Speaker, we take responsibility for the suffering of these people and their families. I offer an apology to the men, women and children of Ontario who were failed by a model of institutional care for people with developmental disabilities. We must look in the eyes of those who have been affected, and those they leave behind, and say: “We are sorry.” As Premier, and on behalf of all the people of Ontario, I am sorry for your pain, for your losses, and for the impact that these experiences must have had on your faith in this province, and in your government. I am sorry for what you and your loved ones experienced, and for the pain you carry to this day.

In the case of Huronia, some residents suffered neglect and abuse within the very system that was meant to provide them care. We broke faith with them – with you – and by doing so, we diminished ourselves. Over a period of generations, and under various governments, too many of these men, women, children and their families were deeply harmed and continue to bear the scars and the consequences of this time. Their humanity was undermined; they were separated from their families and robbed of their potential, their comfort, safety and their dignity.

At Huronia, some of these residents were forcibly restrained, left in unbearable seclusion, exploited for their labour and crowded into unsanitary dormitories. While the model of care carried out by this institution is now acknowledged to have been deeply flawed, there were also cases of unchecked physical and emotional abuse by some staff and residents.

Huron was closed in 2009 when Ontario closed the doors to its last remaining provincial institutions for people with developmental disabilities.

Today, Mr. Speaker, we no longer see people with developmental disabilities as something “other.” They are boys and girls, men and women, with hopes and dreams like all of us. In Ontario, all individuals deserve our support, our respect and our care. We must look out for one another, take care of one another, challenge ourselves to be led by our sense of moral purpose before all else. Today, we strive to support people with developmental disabilities so they can live as independently as possible and be more fully included in all aspects of their community.

As a society, we seek to learn from the mistakes of the past. And that process continues. I know, Mr. Speaker, that we have more work to do. And so we will protect the memory of all those who have suffered, help tell their stories and ensure that the lessons of this time are not lost.

Kathleen Wynne

Letter Five:

From The National Joint-Task Force on De-Institutionalization

Dear students,

The Inclusion Canada - People First of Canada Joint Task Force on Deinstitutionalization defines and understands an institution to be any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place

in which people do not have, or are not allowed to exercise, control over their lives and their day to day decisions. An institution is not defined merely by its size.

We know that institutions are not in the best interests of persons with an intellectual disability. We know that institutions, whether they be large or small, deny people a life in community – to which they have a right.

We know that persons with an intellectual disability have told us loudly and continuously that they do not wish to live in institutions – that they have the right to live fully within community. We believe there is an obligation on all countries to ensure that this demand is met. We believe there is a collective obligation to fully meet the rights as outlined in Article 19 of the United Nations Convention on the Rights of People with Disabilities (CRPD).

We know that deinstitutionalization is about more than just closing institutions. It is also about ensuring that the necessary supports and services are available in the community so that persons can be supported to live typical and inclusive lives, and ensuring that future generations of persons with an intellectual disability are not forced into institutional living.

Unfortunately, we also know that despite well intended efforts to close institutions, in many instances, individuals have merely been given a choice of smaller institutions over large ones. And, despite living in smaller facilities like group homes, people are no less vulnerable and no more connected to community life than when they were living in large institutions. We have not yet successfully enabled them to become truly part of community.

We have failed to recognize that people with an intellectual disability do not want ‘residential options’ or ‘specialized residential facilities’ or ‘institutional living.’ What they want is what we all want — a safe and decent home of their own, where they can exercise choice and control in day to day decisions, have tenure as tenants or as homeowners, and have access to personalized assistance/support and support from others who care about and respect them.

The imperative for de-institutionalization is undeniable. Yet, on a global scale, hundreds of thousands of citizens with an intellectual disability remain sentenced to lifetimes of imprisonment in institutions. Many more thousands will be admitted to institutions because the necessary services and supports do not exist at the community level to enable an inclusive and sustained life in community. Too many people have spent too many years in institutions – without reason or cause. Too many people still face an uncertain future in community.

Sincerely,
The Joint Task Force

What have you learned from the letter you read?

[illegible]

MODULE TWO:

The Power of Perceptions

WORD GLOSSARY

social and political factors: Cultures, beliefs or government decisions that could have an impact on a group of people in a society.

systemic segregation: Groups of people that are intentionally separated from everyone else for a particular reason.

historical evidence: Information that helps us understand the past.

feble-mindedness: A term used during the early 20th century to describe people who were considered a burden on society and not very intelligent.

abnormal: A behaviour or characteristic that is unusual or different.

modernize: Changing to suit new habits and needs. the cell phone is a modernized version of the telephone.

capitalist society: A capitalist society organizes its economy and production of goods by enabling business owners (capitalists) to get capital (goods to make things) and hire workers who get paid for their labour.

Industrial Revolution: A time period when factories and machines quickly sped up the production of goods and therefore made the process more profitable.

social reform groups: A movement of people who want to create changes in their community or society.

respectability: When a person is seen as being worthy of respect.

propaganda: Use of misleading information to make people believe certain things or ideas.

colonization: One group of people taking another group of people's lands by force.

eugenics movement: A movement that studies ways of improving the human race by removing undesirable characteristics.

Nazi euthanasia program: The murder of institutionalized people with disabilities.

sterilization: An medical procedure that prevents people from having children.

to lobby: When a group of people tries to promote a certain idea and influence government.

newgenics: A modern way of using technology to practice eugenics.

narratives: A story that exists in society of why certain groups are the way they are. they are not always true.

Handout M2.1 Reading Reflections

Based on your reading, identify the individuals, groups, social forces and attitudes that were involved in creating negative perceptions of disability in the boxes below. Then, label each grey box with the level of influence you think each factor had (1=lowest influence; 10=highest influence).

Science

Capitalism

Charity

Colonization and Eugenics

Handout M2.2 Creating a Community Agreement

As a class, look at the table in Module two and discuss strategies for changing negative perceptions about people with disabilities. Create a Community Agreement that everyone can agree to that will become part of your classroom. What things will you commit to that will limit the impact of negative perceptions of disability in your classroom community?

Our Community Agreement

1. We won't use the R-word in our classroom
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

Handout M2.3 Change Your Thinking: Harmful Assumptions Made About People Who Have a Disability

The assumption:	What it often sounds like:	The impact on people's lives:	Approaches that can change others' mindsets and lead to positive experiences:
A person labeled with a disability is different than me.	"Oh the 'Spec ED kids' don't eat lunch in the cafeteria."	A person's identity becomes defined by their disability. People become part of a group and are 'othered.' People become known for their disability instead of who they are as a person.	"Let's invite Thivjan and Rhianna to eat in the caf with us. I noticed they don't often go down there. Maybe they just need someone to invite them."
A person with a disability is not able OR is limited in what they can do.	"My student, Ahmad, is 'low-functioning' and has many challenges."	People are robbed of their childhood or life experiences that lead to the good things in life.	"Ahmad really enjoys meeting new people. He can talk to anyone! I wonder if he would be interested in helping sell ticket to this year's prom as a member of student council?"
A person with a disability is seen as a difficult person or a problem.	"We don't feel comfortable taking Bianca on this field trip to a movie without extra staff to provide supervision in case she acts out. Sadly, there just aren't enough staff for this, so Bianca won't be able to come."	It is very likely that they will be denied all sorts of opportunities, that others will try to stay away from them, and that they will be congregated with others like them so that they can be managed.	Bianca loves the movies, and there is a class field trip to the theatre. Let's prepare Bianca and her classmates for what will happen on this trip. Let's think about what Bianca will need and let's ask her how we can support her to attend. Let's arrange for a few of her friends, and perhaps the teacher, EA and/or parent volunteers to take turns helping when needed. Perhaps the Principal will join us and offer support if needed too.

Handout M2.3 Change Your Thinking: Harmful Assumptions Made About People Who Have a Disability

The assumption:	What it often sounds like:	The impact on people's lives:	Approaches that can change others' mindsets and lead to positive experiences:
An adult with a disability is seen as a child.	"Dustin is 18, but he has the mind of a five year old."	When a person is considered an eternal child, they are often not taken seriously. People aren't treated with dignity and respect. They are offered childish things to do all of their lives. They are denied adult experiences and responsibilities, frequently because others want to protect them.	Dustin is 18 and therefore has had 18 years of experience. That counts. He may learn a little slower than me, but he still has life experience that is valuable.
People with disabilities are seen as people to be pitied.	"Those poor people, what kind of life can they really have?" "It takes a special person to work with people like them."	When a person with a disability is seen as someone in need, they are often pitied by others. This restricts people from recognizing what people are capable of. It also gets in the way for others to recognize a person's gifts and talents. People who are pitied are often overprotected by well-intentioned people.	Supporting people in a dignified way is a duty and privilege. What is incredible, is watching people be seen for their valuable contributions and gifts. "You are a model of inclusion. You must overcome challenges every day, but you find a way to be patient and see the best in others. What can I do to help break down barriers for you? I want to see you succeed."

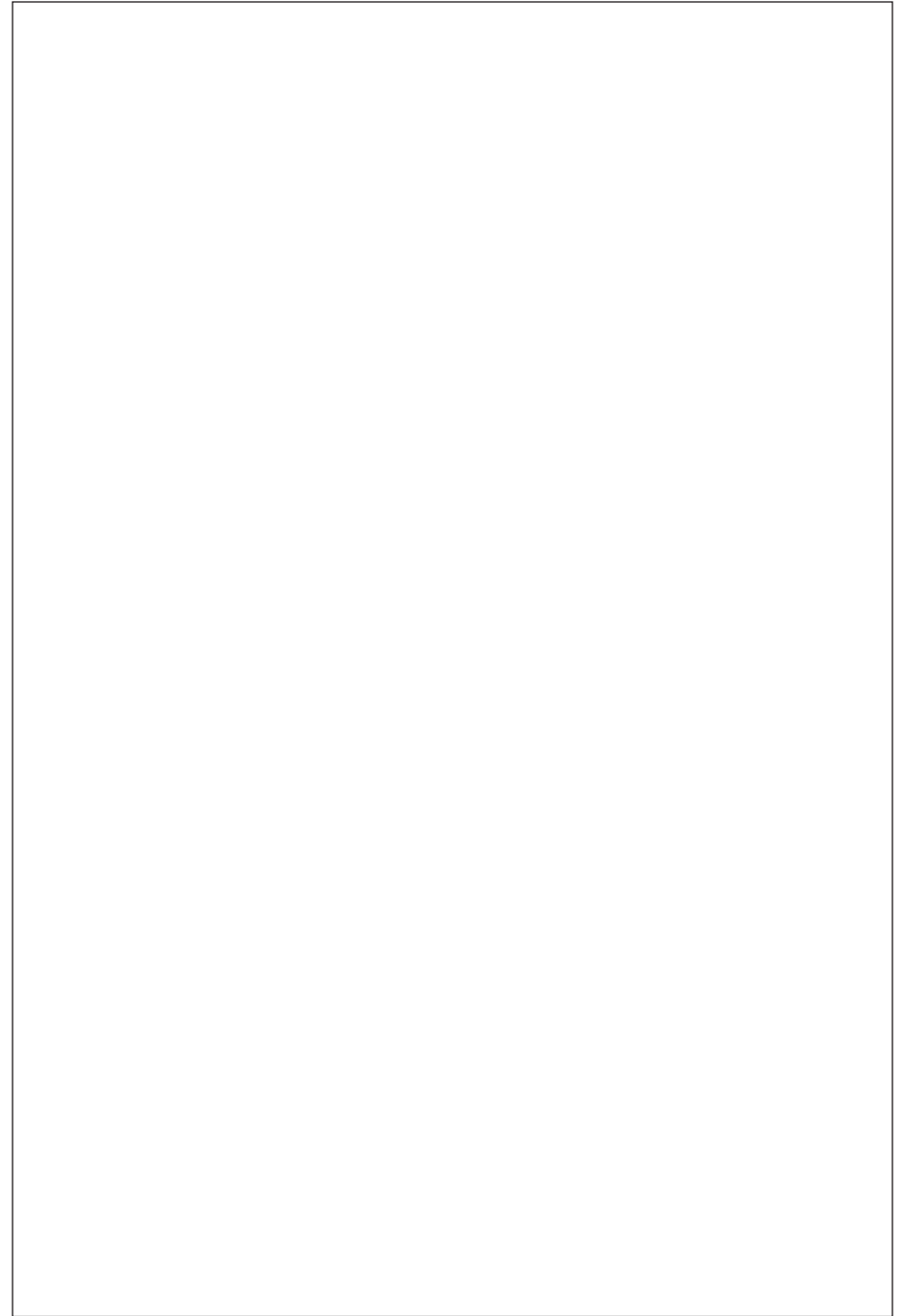
Questions to Consider:

1. How have you seen these assumptions in your school?
2. What words are used when you hear these assumptions being made?
3. What impact is this having on people in your school's community?
4. How can you change your thinking and actions to unlearn these assumptions?

Handout M2.4 Exploring Identity

In the box to the right, create a mind map of the things that make up your identity. Put your name in the middle. Things to include are (your):

Personality
Talents
Physical Characteristics
Race/Ethnicity
Gender/Gender Identity
Age
Religion/Beliefs
Family Background
Family's Socioeconomic Status
Culture
Education
Where You Live
Life Experiences
Dress/Style

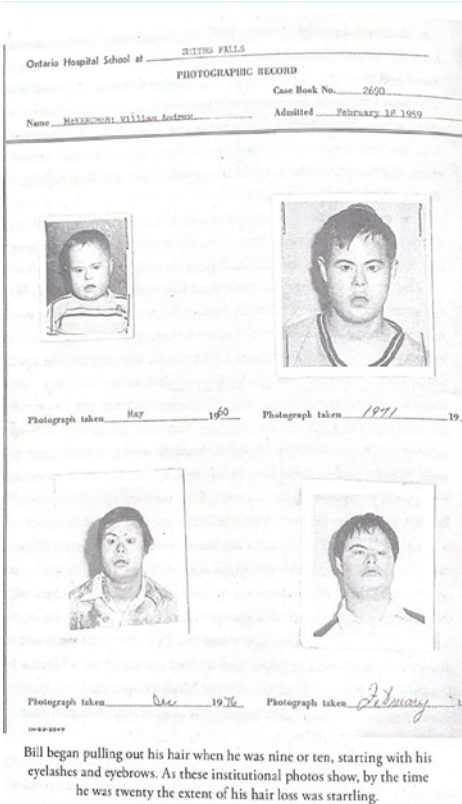
A large, empty rectangular box with a thin black border, intended for a student to create a mind map of their identity. The box is positioned to the right of the list of identity factors.

Handout M2.5 Video Reflection Questions (M2.V2)

What are the four ways that people were stripped of their identity?

1.	
2.	
3.	
4.	

Handout M2.6 Photo Analysis



Source: McKercher, Catherine (Sept 3, 2019), *Shut Away: When Down Syndrome Was A Life Sentence*. Goose Lane Editions.

How did Catherine’s brother Bill change while living at the institution? What does this report document demonstrate?



Source: People First of Canada

How would living in conditions like the ones seen in this photo make you feel about yourself?



Source: People First of Canada

What can the name 'The Manitoba School for Defectives' tell you about how society viewed residents of this facility?

Handout M2.7 Evaluating Freedoms and Responsibilities

In the chart below, list the types of freedoms and responsibilities that are typically expected at each stage of life. Then, reflect on how institutionalization and attitudes about disability get in the way of and limit the amount of freedom and independence people who have a disability have, compared to a typical adult.

Age Range	Freedoms/Responsibilities
Age 0-5	
Age 6-15	
Age 16-30	
Age 31-50	
Age 51-75	
Age 76-80+	

M2.8 Video Reflection Questions (M2.V3)

List four examples of how people were inhumanely controlled while living at an institution.

1.
2.
3.
4.

Handout M2.9 Photo Analysis

- a. Forceful and aggressive transfers, little/no regular turning of patients leading to increased number and complexity of pressure ulcers;
- b. Forceful feeding observed by staff causing audible choking/aspiration, forceful hydration causing audible choking/aspiration;
- c. Patients observed crying for help with staff not responding for (30 min to over 2 hours);
- d. Narcotics are not considered a high alert medication therefore this is no mandatory independent verification required within the LTC. High risk of dosing error;
- e. Activities of Daily Living – staff report residents having not been bathed for several weeks (noted at commencement of task);
- f. DNR status not posted causing staff to race to EMR during code to determine DNR status. CPR has been initiated in absence of ability to verify DNR status (likely futile, and also putting staff at risk as CPR is aerosol generating);
- g. Feeding status not posted/readily available. Given the lack of permanent staff or oversight, patient meals are often mixed up, with incidents of inappropriate meals being fed to residents with swallowing difficulties (increases likelihood of choking or aspiration);
- i. Access to PCC (electronic health record) inconsistent and numerous reports of a lack of charting/documentation by staff causing significant gaps in information;
- j. Reports by SNO of little to no documentation on resident's status within EMR for up to 6 months. Unclear regarding reasons for lack of charting but resident's status indicated a requirement for additional information and documentation;

Source: Canadian Armed Forces, Long Term Care Facility Report, 2020.

How were people left powerless and removed from the protection of their loved ones while living in institutional settings in 2020?

In Peter's words. Well, to start with, human rights were basically non-existent in the institution. I really had no choice but to do something about how bad things were for people with intellectual disabilities after being in there so long. I had to. I was bound and bent that no one would ever, ever have to go through what I went through in there. You can't even say I "lived" in the institution. I simply existed. We weren't treated as human, in every single way.

When it all started. I was 20 years old and I remember my family and I heard about an institution. We sure weren't given the whole story. The one I went to ended up being Oxford Regional Centre. Two doctors were there when we talked about it—I remember that part well. The question was asked, "Can I leave anytime I want to?" It was so important to me to be able to leave. I was told I could leave anytime I wanted.

My mom and dad, sister, next-door neighbour were there at the meeting. I had epilepsy—seizures. This is what we were talking about. These two idiot doctors said they could cure my seizures.

Then, once I was in there, I couldn't leave. Once I was inside, I saw how bad it was in there. I just wanted to get out. My paper that said I could leave whenever I wanted to was lost. I was a prisoner now. *Except doing time in an institution is worse than jail.* In a jail you are treated better than you are in an institution. When you go to jail, you know when your time is served. In an institution you might have a life sentence. But you don't know day to day. They are all lying to you and you don't know the truth. You have no rights at all, not even to privacy in the institution. You just don't know when you are going to get out, if ever. And you didn't even commit a crime.

Source: Source: Canadian Journal of Disability Studies 6(3), *Self-Advocacy from the Ashes of the Institution*, 2017.

What are the similarities and differences between jail and institutions, according to Peter Park?



Source: People First of Canada

Based on what you have learned in this module, what are the physical and emotional ways that residents of institutions were controlled?

Handout M2.10 Mind Map of Home

In the box below, create a mind map of words, ideas and memories that you associate with the word “home.”

What does home mean to me?

Handout M2.11 Reflection Questions for Video (M2.V4)

In the box below, list the ways that fear impacted people’s lives.

How did fear impact people’s lives?

Handout M2.12 Independent Study

Hearing survivor testimonials is very hard. It is important that we bear witness to the suffering that people have endured and learn from the mistakes that Canada has made. Take some time to reflect on what you have heard.

Option 1: Choose a label that people have used to describe you.

Or choose a label you have used to describe others.
Did this label change the way you saw yourself or how other people saw you?
Why is it so important that we take the time to really get to know people?

Option 2: Write a reflection piece about a time when you felt excluded.

How did you feel? Did anybody stand by, or did they speak up for you?

What could someone have done to make the situation better for you?

What can we do, as active community builders, to make sure that people don't feel excluded?

Option 3: Write a letter to a survivor.

Using information you learned or something you heard, explain what you will do differently in the future because of what you have learned today.

[illegible]

MODULE THREE:

Institution Watch

WORD GLOSSARY

de-institutionalization: The act of freeing people from the institutions.

government inquiry: When a government looks into events that happened in order to understand what happened and resolve issues.

shell shock: A state of fear, confusion and anxiety felt by people who have experienced trauma.

accommodation: Actions that make changes in order to meet a person's needs.

post-traumatic stress disorder (PTSD): A disorder caused by traumatic experiences that can cause flashbacks, nightmares and anxiety.

day program: A program that provides people with disabilities with activities to do during the day. Often, activities are not age appropriate or meaningful to people.

sheltered workshops: Programs that provide people with disabilities with work to do during the day, often for no pay.

life skills programs: Programs that build people's skills to help them with life decisions and problem solving.

human services: A study that aims to provide services to improve the lives of people.

task force: A group of people working together to advocate for something important.

rehabilitate: Supporting people through the process of rejoining 'normal' life.

long-term care homes: A place where adults who have a disability or seniors live with support.

tuberculosis: A serious illness that affects the lungs.

sanatorium: A place for people with serious illnesses to receive medical treatment.

provider of community living services: An organization or person who provides supports and services for people to live a meaningful life in a community.

rendered incapable: To take away someone or something's ability.

Handout M3.1 Video Reflection Questions (M3.V1)

1. In your own words, describe what the period of de-institutionalization was/is?

2. Who were the key players?

3. Why is it important for us to learn this?

Handout M3.2 The Influence of World Events

One of the shifts that took place in Canada around this time was a change in how people thought about disability. After WWI and WWII, thousands of injured and disabled veterans returned to Canada. Many veterans returned home with visual and mobility impairments, as well as shell shock. At the time, their experiences and challenges created a shift in perceptions of disability in society. Ideas about disability shifted from a medical model to a more social model. This means that conversations about the rights of people with disabilities became mainstream. The issues and barriers people faced were at the forefront of the community. Governments and communities worked to deliver services to veterans that addressed their medical and housing needs, as well as provide employment, financial aid and support.

The disability movement of the mid-20th century helped to pave the way forward. Canadians recognized the rights of people with disabilities more than they did prior to these world events. Services and supports were created because people now understood what people needed. With those supports, people were able to live good lives in the community. Society began to see what people could achieve with a little bit of support. Today, we use the term 'accommodation.'

Canadian society discovered that there were many possibilities for people who had a disability. Institutions were no longer seen as a solution for what people with disabilities needed. However, it is important to understand that this realization focused mostly on people with physical disabilities or mental health challenges like post-traumatic stress disorder (PTSD). It was not until the 1960s that perceptions of intellectual and developmental disability

shifted. Until the 21st century, institutions in Canada were built and run specifically to care for people who were born with an intellectual disability. Community supports did not exist until direct advocacy around institutions took place.

It is important to recognize this milestone in the evolution of disability rights. However, it is also important that we are clear that disability rights evolved for some people, but not all Canadians who had a disability.

A New Vision Emerges



Source: People First of Canada

Another factor that sparked this shift was the advocacy of families and survivors. From the early 1930s to the 1980s, family groups took action to ensure that their children could live at home with appropriate supports. They also believed in and advocated for their children's right to go to schools in their own neighbourhoods. These groups petitioned the government to take funds usually given to the institutions and use them to create community services instead. This funding would give people the support they needed to live and participate in the community, just like everyone else.

On the other hand, some families were concerned about the safety of their loved ones outside the institution and were

overwhelmed by the idea of providing care for their loved ones at home. Families were also rightfully concerned that governments would not spend the same amount of money on community services as they did on institutions. Some of the supports families and organizations advocated for were: group and individual living arrangements, day programs, sheltered workshops and life skills programs. Between 1960 and 2000, ideas about what these supports should look like evolved, and have changed considerably in the years since.

At the beginning of this period, North American society was only beginning to recognize the potential, gifts and rights of people who had a disability. The principle of Normalization originated in Scandinavia in the 1960s. Neils Eric Bank-Mikkelsen and Bengt Nirje were two of the people who developed Normalization in Scandinavia. This principle was different from the medical, rehabilitation and custodial models you learned about in Modules one and two. This principle said that people with disabilities should enjoy the typical life experiences that all people do.

Dr. Wolf Wolfensberger was a German-American professor. He expanded on the principle of Normalization and brought it to North America. The principle of Normalization and Dr. Wolfensberger's theory of Social Role Valorization influenced the ways people offered social services in both North America and Europe. The impact of this shift was enormous. First, the principle of Normalization promoted the idea that people with disabilities should have the same access to the good things in life that all people want. It also encouraged service providers to support people in typical life activities. A few examples of 'typical' life activities that Canadians with and without a disability should have the opportunity to enjoy are: going to your neighbourhood school, having a job, finding

love, voting, pursuing a spiritual belief, joining a community group, going to the movies with friends and renting an apartment or owning a home.

People benefited greatly from experiencing the routines, activities and milestones of ordinary, everyday life in the community. Gradually, people came to realize that institutional settings did not provide these opportunities. In fact, these opportunities could only be experienced by living in the community. This meant that institutions would need to close so that people could take part in ordinary life experiences.

This shift did face some resistance. Some families and institution staff believed that thinking about a life in the community was dangerous. They felt that advocates were ignoring the reality of the ways people can be limited by their disability. For others, who wanted to protect people, every day experiences were considered too dangerous for people with disabilities. At this time, Canadian communities were still not a welcoming place for people with disabilities.

However, the principles of Normalization and valued social roles stated that people with disabilities should be given the opportunity to try new things. It also said that, by taking reasonable risks, people with a disability could learn to problem-solve and adapt to new things with practice. This important aspect of the principle of Normalization is called 'dignity of risk.' This means that people should have the opportunity to make mistakes because that is how all humans grow. Today, this is still an important principle to think about.

By 1983, Dr. Wolfensberger had re-conceptualized the principle of Normalization into the theory of Social Role Valorization. This is a theory that says that if people with disabilities hold valued social roles in their:

- » families
- » schools
- » communities
- » workplaces
- » places of worship
- » clubs and other aspects of society

then other people are more likely to respect them, value them, and treat them well. Some valued social roles that are common in our society include:

- » brother or sister
- » aunt, uncle or cousin
- » son or daughter
- » student
- » club or team member
- » voter
- » and employee

As a result of this way of thinking, another shift occurred in some human services yet again. As well as striving to offer people with disabilities the life experiences that all people should be given, some services now began to think about helping people to hold and benefit from valued social roles. These efforts continue today.¹

Where are we now?

Peter Park and Pat Worth are both survivors of institutions and have led the movement to close institutions in Canada.

They talk about institutionalization as a mindset, not just a building. In Modules one and two, you have explored, in depth, the mindsets, perceptions, attitudes and beliefs that institutionalized people throughout Canada's history. By now, you can see that Pat and Peter's words are true. If a person does not have the power to make choices about their life, then they are institutionalized in some way. Canada's national task force on de-institutionalization adopted the following definition of institutions in 2002:

"An institution is any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and day to day decisions. An institution is not defined merely by its size."

The next generation of leaders needs to understand this. Past experiences of institutionalization can teach us what we need to avoid. We must pay attention to how institutionalization continues to be experienced. 'Institutional models' are settings or situations where people have a lack of control and are limited in their ability to make decisions in their lives. We need to stop building settings and funding systems that put large groups of people together. We need to spend more time on creating opportunities for people to have choices. People will benefit greatly from having the freedom to make personalized choices and individual plans for their lives. Just like all Canadians do. Recognizing the pattern is the first step towards creating a better future.

Institutionalization can look like:

A person living on their own in an apartment. When a person's day is controlled by when their support staff is available to assist them, they have a lack of choice.

Graduating without a diploma. A person's time is wasted going to school when they don't receive quality education and credit for their work. A high school diploma is often a requirement for steady employment.

Living below the poverty line. A person's choices are limited and controlled when they can't afford to participate in all aspects of society.

A person living in a retirement home, long-term care or group home. These settings congregate and isolate people from the rest of the community.

Everyday, people with intellectual disabilities are institutionalized because their choices are limited. People are living in the community but are restricted by unnecessary barriers that limit the control, and the number of choices, a person has in their life.

Sources:

1. W. Wolfensberger, 2011, Southern Ontario Training Group, 2020

Reflection Questions:

1. How did disability rights and supports evolve for some Canadians but not others?

2. What is the definition that survivors use to describe an institution?

3. What is important for the next generation of leaders to know?

Handout M3.2B Understanding the Concept of “Dignity of Risk”

Take a minute to think about times in your day where you have the chance to make a decision that poses a risk to you.

- For example, you may decide to go outside without a coat on in the wintertime.

You might catch a cold if you go outside without a coat. But you can decide whether you want to take that risk or not.

- Another example, you may decide to buy a lottery ticket after you turn 19 in Canada.

You might get a ticket that doesn’t win. So there is a risk that you might not get your money back. But you can decide if you can afford to risk losing that money.

Choices like this are often not given to adults who live in institutional settings. Someone, usually a staff member or maybe a family member, will tell a person what they need to wear or what they can spend their money on. This robs people of the learning that comes from taking normal, calculated risks. It is part of how we grow and learn about ourselves and the world around us. People who have a disability should be afforded this experience too.

List a number of risks you have taken in your life that taught you valuable lessons. State what lessons you learned from those risks.

Handout M3.3 Table Analysis Questions

1. What are the six patterns to look for when identifying institutional models?

1.
2.
3.
4.
5.
6.

2. What do you think Katherine Rossiter meant when she asked: How do we maintain the humanity of people who are considered vulnerable?"

3. Looking ahead, what will future leaders in Canada need to be aware of?

Handout M3.4 Provincial Investigation Activity

In this activity, you are leading a federal inquiry into the state of institutionalization in one province of your choice. As a group, you will need to assign people to work on different tasks to complete your investigation and summarize your findings. Using the content, photos, links and videos in the provincial profile, work together to do your research. The chart below is to help guide your inquiry.

Key Issues:			
Institutional Mindsets and Models Identified during Investigation:			
Key Provincial Milestones: (evidence of efforts to make change)			
Issues, Concerns or Further Investigation is Required in the Following Areas:			
Recommendations for Moving Forward:			
Current Barriers Impacting People's Lives:			

Handout M3.5 Building a Presentation

Now that your provincial inquiry is complete, you must present your findings to government in the form of a presentation. As a group, create a slideshow presentation (with no more than eight slides) to share your research and findings. Below is a table that you can use to plan out your presentation and assign tasks to your group members.

Slide 1: Introduction to the Province <ul style="list-style-type: none">· Give a general overview of the province· What did you see, read, hear, find?· What experiences did people have in the institutions in this province in the past and the present?	Slide 2: Institutional Mindsets and Models <ul style="list-style-type: none">· What mindsets have impacted the experience of people in this province?· What evidence did you find that demonstrates these mindsets exist?· Does this province have large institutions or institutional models that put people at risk?	Slide 3: Key Issues <ul style="list-style-type: none">· What are the three key issues your group identified that exist in this province?· How did you determine these were the three most important issues that need to be addressed?	Slide 4: Key Milestones <ul style="list-style-type: none">· What evidence did you find of efforts to create change?· Do you think these efforts are enough, or should more be done?· What did survivors say about these milestones?
Slide 5: Further Investigation <ul style="list-style-type: none">· Are there issues or concerns that need further investigation?· What are they?· What are the consequences of not addressing these concerns?	Slide 6: Moving Forward <ul style="list-style-type: none">· What are three recommendations you have for moving forward?· Provide a timeline for when these recommendations should be completed· Who should be responsible for putting these recommendations into action?	Slide 7: Right Now <ul style="list-style-type: none">· What are the current barriers impacting the lives of people in this province?· Who is responsible for removing these barriers?	Slide 8: Wrap Up <ul style="list-style-type: none">· What did this investigation teach you?· How will you use this information in the future?

Handout M3.6 Independent Work

We encourage you to take a minute to hear the story of Mr. Gord Ferguson (1948-2018). Mr. Ferguson was a pioneer of disability rights in Canada. His dedication to creating a better life for himself and others, as well as his personal integrity, made him a great friend, husband and teacher.

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babies just because they will have a disability. They are supposed to save people, not kill them.

Selective abortions is another way to tell the world that someone's life is not worth living. Imagine if you saw television news shows, hundreds over the years, telling you that pregnant parents should abort their baby rather than allow them to live the life you have. How would you feel?

You can see why these issues need a lot more talking and a lot more advocacy. Our rights should not be lost and people should not be killed just because other people don't value us. We need to work this out better. We still have a lot of work to do.

Closing the Rideau Regional Centre

On March 31, 2009 we celebrated the closure of the Rideau Regional Centre. I gave a speech at the Brockville Arts Centre and made the newspaper. Fifty-one years after I was admitted to Rideau I helped close it down. What a great feeling it was to watch the institution that hurt so many people close its doors.

Closing institutions is the thing that I am most proud of. This was important because I remembered how the staff treated me. Until 2009 other people were still living there and probably going through some of the same things I did.

It bothered me that other residents didn't know about living in the community... about freedom. Some of them, and their families, were afraid of leaving the institution where they had grown up. However, it was time for a change. We had to get everybody out of there. In 1970 People First told the board at the Community Living conference that we wanted them closed.

Today young people and older people with disabilities are getting put into nursing homes. The government closed institutions only to quietly put some of us into other institutions called nursing homes or long-term care facilities.

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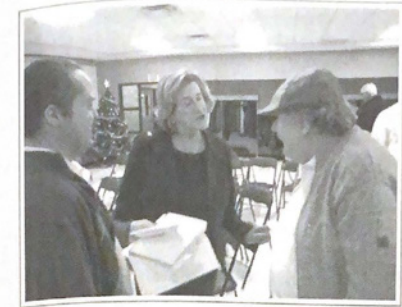
This is the new issue that we need to fight. Donna and I almost got institutionalized again. This has to stop.

Thank goodness most of you reading this will probably never have to be involved in such an institutional life nor the fight to close it. I'm proud of how I contributed to closing down this institution but am also sad that we had to fight so hard and so long to get it done. It was wrong from the start. People may have meant well when they started. But it quickly proved to be a place of hurt and pain rather than learning and growth. That it took so long to close down is shameful. I am glad people listened to me and others who shared our stories to help close down Rideau and other provincial institutions.



[Memorial Plaque - "The Honourable Dr. Helena Jaczek, spoke at the commemorative plaque ceremony to honour the memory of former Rideau Regional Centre's residents. The Rideau Regional Plaque Ceremony, December 17, 2014]

The Gordon Ferguson Story 97



[Gord chatting with the Minister of Community and Social Services, Dr. Helena Jaczek, after the ceremony. The ceremony was held at the Smiths Falls Community Memorial Centre. Installing a commemorative plaque is part of the settlement agreement, establishing a \$20.619,000 Settlement Fund. The settlement will provide compensation to those people who were residents of the Rideau Regional Centre between 1963 and 2009 and suffered harm.]

In 2015, I received a payment as a member of the class action lawsuit against the province of Ontario for the abuse I suffered while living at Rideau. More importantly, I received an apology. The government apologized for what they had done to me and to thousands of others who lived there. It means a lot to have the Premier tell us they were wrong and we were right.

Chapter 9 Our New Home Life

My Home



I am the boss of my own home now. My staff have to knock on the door and I let them in when they arrive for their shift. They ask permission before they go into my bedroom or go through my stuff. I decide what we eat for supper. Donna or I answer the phone when it rings. Donna and I live here, my staff doesn't. It's our home.

Back when we first got married, we were supported by staff from another agency who thought that they could come into

my home and boss us around. They told me what we could and couldn't do, what I could spend my money on and what I couldn't. They wanted me to do things their way. It felt like they were trying to take over our lives. It made me feel angry and I stopped listening to them. I eventually had enough, and nicely showed them the door.

I was protecting my home. I needed workers to help us, but they shouldn't come in and tell me what to do or make me feel bad. How do they help us without taking over with us? By listening more than talking. By asking more than telling. By offering help more than taking over.

So we were left with no one to help us. After a while my Mom asked us to live with her. Living together benefited each of us. It wasn't just Mom trying to be nice. We helped her as much as she helped us.

Through my adult life I needed a home and I also needed support. Those are two different things. I now get the kind of support I have always needed – an understanding of what it means to separate home from support.

They need to be and stay separate. For example, if my staff now are mad at me for some reason, they can't kick me out. My home is mine. I don't have to move out unless I want to move. Nobody can take it away from me. I am safe here. The workers are providing support so that I can live in my home and do the things that I want to do. That is all.

I am proud of my home. I love living here with Donna. Home is someplace safe, someplace where I can be myself. I can relax here when I am with Donna. It is someplace where I can sleep well. Home is a feeling, where I can be myself. It is where my heart is. Home is where I can make my own rules, and I can do what I want to do.

I can make an apartment or house a home, but not an institution or nursing home.

Reflection Questions:

1. What is one thing that Gord said in his book that made you think differently?

2. What are things that made Gord feel at home?

MODULE FOUR:

Oh Canada! When will we be free?

WORD GLOSSARY

intersectionality: An idea that studies the relationship between the different factors making up a person's identity, such as race, gender, class. these factors can sometimes be of advantage or disadvantage to a person.

progress: The act of moving forward towards a goal.

decline: Typically, moving backwards from a goal.

Board of Directors: A group of people who are in charge of overseeing an organization's work.

put forward a motion: To suggest an idea in a meeting or official setting.

federation: A group of organizations that work together for a common cause.

memorandum of understanding: A document that lays out a common agreement for multiple groups working towards a single goal.

to ratify something: To sign or confirm an agreement to follow a set of rules or work towards a certain goal.

international court: A system of the united nations that works with countries to achieve international justice.

Handout M4.1 Advocates and Activists

What is the difference between advocates and activists? Using the chart below, identify the differences between what advocates and activists do. Complete the following sentences:

Advocates SAY things like:	Advocates BELIEVE:	Advocates THINK about:	Advocates ACT in order to:
Activists SAY things like:	Activists BELIEVE:	Activists THINK about:	Activists ACT in order to:

Will you be an advocate or activist for greater inclusion in Canada?

What will you SAY, BELIEVE, THINK and how will you ACT differently as an advocate or activist?

Handout M4.2 “Accidental Advocates” Reflection Questions

1. What made these women advocates?

2. What can we learn from their example?

3. What is their legacy?

Handout M4.3 “Another Point of View” Reflection Questions

Identify similarities and differences between the movement for inclusion and other social justice movements in Canada.

[illegible]

Handout M4.4 Video Reflection Questions

M4.V1

1. What are the similarities between residential schools and institutions?

2. What are the differences between residential schools and institutions?

M4.V2

1. Why was it important to French families to have their loved ones living in their community?

2. What barriers existed for people who were moving from the institution to the community?

Handout M4.5 Instructions for Creating an Infographic

Your task is to create a fun, colourful and educational infographic that teaches others about the ways Canada protects the rights of its citizens. Using the content and links in Module four, conduct research on either the Canadian Charter of Rights and Freedoms or the United Nations Convention on the Rights of Persons with a Disability. The chart below will help guide your research.

Create a Canva account and choose a template to begin creating your infographic.

What is it?	
Who does it protect? How?	
When was it created? For what purpose?	
How can it be used by Canadians to protect their rights?	
Key Facts/Additional Information you wish to share	

Handout M4.6 Video Reflection Questions

M4.V3

1. Why is living in the community so important?

2. What do parents today need to know as they plan for the future?

M4.V4

1. Why is it important for students who have a disability to be included in regular classrooms?

2. What work still has to be done to ensure that children in Canada have equal access to a quality education?

M4.V5

1. What is agency?

2. What is one thing that you learned that you will think about next time you meet someone who has a disability?

MODULE FIVE:

Understanding Patterns of Segregation

WORD GLOSSARY

historical perspectives: An understanding of a subject or event that happened in the past.

generations of people: A group of people born across many decades.

psychiatric ward: Hospital units that are used to treat mental illness.

Nova Scotia Human Rights Commission Board of Inquiry: A group of officers at the human rights commission that deals with complaints.

Department of Community Services (DCS): A unit of the government that is in charge of meeting the needs and providing supports for people in the community.

Disability Rights Coalition: An advocacy group made up of people with disabilities, their friends and family members and dedicated professionals that was formed in Nova Scotia.

to stall something: To stop something from moving forward.

complainants: Someone who makes a formal complaint in a court of law.

Handout M5.1 Statistics

Employment Stats	Identifying the Gaps
Working-age adults with different types of disabilities have very different workforce experiences. Those with developmental disabilities have the lowest average employment income (\$18,172), followed by those with mental health disabilities (\$19,063) and those with communication disabilities (\$19,485). In contrast, people with hearing disabilities earn the highest average employment income (\$32,676).	Statistically, Canadians with developmental disabilities (including those with intellectual disabilities) have the lowest income in comparison to other people who have a disability in Canada.
People with disabilities are more likely than people without a disability to be in short-term work, part-time employment, self-employment and in the “informal economy.”	Canada’s current economy does not enable persons who have an intellectual disability to have adequate and sustainable income, nor provide career opportunities.
The average income of people with intellectual disabilities is less than half that of the average Canadian who does not have a disability.	Despite having employment, people with an intellectual disability will earn half of what the average Canadian will earn.
Education Stats	Identifying the Gaps
An estimated 60,220 girls and 104,170 boys with disabilities ages 5 to 14 attend schools and/or kindergarten programs. In addition, 3,010 children with disabilities are tutored at home, and 3,910 neither go to school nor are tutored at home.	Thousands of children in Canada are deprived of their human right to go to school and receive a quality education.
Most children with disabilities are enrolled in mainstream schools: 64.7% of children with disabilities attend regular school, and an additional 24.9% attend regular school with special education classes. Only 7.9% of children with disabilities attend special education schools, and 77.6% of those who do have severe to very severe disabilities.	32.8% of Canadian children experience various forms of segregation every day. The more complicated your disability is to accommodate, the more likely you are to be segregated and farther removed from accessing education.
Only 13.8% of children with mild disabilities have limited classroom participation; however, 64.6% of children with severe disabilities have limited classroom participation due to their condition. Among children with very severe disabilities, 71.1% of boys have limited classroom participation, compared to 52.3% of girls.	The more complicated a person’s disability is to accommodate, the more likely it is that person will spend the majority of their time doing busy work rather than learning. Boys are more likely to experience this than girls.
Community Inclusion Stats	Key Takeaways
In 2005 and 2006, 34.4% of adults with disabilities participated in unpaid volunteer activities. This rate decreases with severity of disability: 39.6% of people with mild disabilities participated in volunteer activities, compared to 20.6% of people with very severe disabilities.	34.4% Canadians with disabilities are working for free.
The overall voter participation rate in the last federal election was 75.8% for adults with disabilities, compared to 72.0% for adults without disabilities.	People with disabilities are more politically active than the average Canadian.
73% of working-age adults with an intellectual disability live in poverty. In comparison, only 23% of working age adults who do not have a disability live in poverty.	Almost three quarters of Canadians who have an intellectual disability live in extreme poverty.

Sources: Federal Disability Report, Council of Canadians with Disabilities, Inclusive Education Canada, Inclusion Canada

Questions to Ponder:

1. Where do the gaps exist for people who have an intellectual disability in Canada? Name two.
2. Is intellectual disability equally represented in these statistics?

Handout M5.2 Questions to Ponder

1. What patterns do you see in the experiences of Canadians who have a disability?

2. What institutional mindsets create barriers for people at work, school and in the community?

3. What things have you learned about that you don't want to see Canadians who have a disability face in the future?

MODULE SIX:

Youth Take Charge

WORD GLOSSARY

citizenship: Being actively involved in bettering your community.

social responsibility: The responsibility to act in a way that ensures the wellbeing of others.

atrium: A large open-air space surrounded by a building.

migration: The mass movement of animals based on the season.

authentic: Someone or something that is real and genuine.

informed citizen: A person who is active in the community and is knowledgeable about issues impacting peoples' lives. This information helps them make decisions and advocate for others.

oral history: A way to understand and learn more about the past by listening to spoken stories of people who lived through an experience.

Handout M6.1 Brainstorming Activity

What does it mean to be in the public eye?

You might have heard the expression ‘in the public eye.’ The Merriam-Webster dictionary defines the phrase as:

“in a position that receives a lot of public notice and attention.”

Ex. The job requires someone who is comfortable being *in the public eye*.

Make a list of people who are often *in* the public eye.

1. Ex. celebrities
2. Ex. Politicians
- 3.
- 4.
- 5.

If a person is *in* the public eye, they are given attention. In this way, the public are the ones giving attention to that person.

In society, 'the public' can play a powerful role in influencing change.

For example, many social justice groups in Canada encourage people to call out acts of injustice when they see them. That is why the term anti-racist is used when people talk about racism. Being anti-racist means to draw attention to or call out racism.

Have a discussion with a partner and list three ways a person can be anti-racist.

1. _____
2. _____
3. _____

The same is true when it comes to discrimination. It is not enough to just *believe* in inclusion. You have to take action to call out and draw attention to discrimination when you see it, hear it or feel it.

In a school setting, students take the role of ‘the public.’ Every student in your school has a social responsibility to each other.

Have a discussion with a partner and make a list of the ways you could draw attention to discrimination against people who have a disability when you see it, hear it or experience it.

Ex. When someone uses the R-word, you can call that person out for using that word and educate them on why that word is so hurtful.

[illegible]

M6.2 Case Study and Questions

Building a Community Garden for All



Nick Harris was a grade twelve student from Windsor, Ontario. He attended F.J. Brennan High School. Through his relationships with people in his school who had an intellectual disability, he came to understand the inequality that his peers were experiencing. He identified the freedoms and privileges he was given that his peers who had a disability did not receive. He wanted to create a sense of community at his school — inside and outside of the classroom — that was grounded in inclusion and solidarity. Most importantly, he wanted to change the way his peers who had a disability were seen within that community. He decided to design a Community Change Project that was entirely youth led. The goal of the project was to create a space that brought people together to learn and build authentic relationships.

Nick invited students in mainstream classes and those in special education to join him in building a community garden in his school's atrium. The space needed some updates. He recruited students from every grade to transform the space. This was a whole-school project. This was also going to be a space that everyone had a responsibility to look after. For a month, each grade took turns spending a class period to help clear out the atrium so that new garden beds and benches could be built.

Windsor is a unique city because monarch butterflies migrate there from south of the Canada-U.S. border. Students in geography and science classes studied this migration and teamed up with a local business to help Nick design the space so it would attract and support the health of the butterfly populations in the area. The tech department at the school recruited their friends at a nearby high school to help cut the lumber, and together they built raised garden boxes. These boxes were accessible for wheelchair users, and therefore made the garden a space that could be enjoyed by anyone.

Most importantly, students with disabilities were included in every aspect of the project. They helped clear out the atrium, build the boxes and planted seeds *alongside* their peers. Nick said:

“By being a part of the building, designing and gardening of this space, all students now feel a sense of contribution to our school’s culture and community spaces.”

Youth like Nick can inspire change when they take responsibility as active citizens and look for opportunities to improve the experiences of others. Schools are where youth spend most of their time and young people are the public eye in these spaces. Nick took a stand for inclusion by looking for ways to build community and connecting people in that community in ways that broke down stereotypes of disability.

The school's community garden was not the only way that Nick showed social responsibility. He also networked with other youth, like Emily, who lives in the county of Essex. Emily was also leading a Community Change Project. Together, they approached their school board because they wanted a chance to share their experiences and inspire others to support their efforts to create change. The school board was planning a social justice conference and all schools in the board were going to be attending. Emily and Nick were asked to lead a workshop for students at this event. They were the only youth speakers at the event.

Youth are the here and now. You have the power to set trends, change minds and challenge narratives! Get to know and learn from your peers who have a disability. Avoid doing things for people who have a disability. Instead, try to look for opportunities to stand with people who want your support to make a change. This is how we can work together to continue to close the gaps that exist in our society.

Questions to Ponder

1. What made Nick's approach to inclusion truly authentic?
2. How do you think Nick's school benefited from a project that included the whole school rather than just a few people?
3. What strategies did Nick use to influence change in his school community?
4. How do you show social responsibility? What will you take from Nick's experience that you can use in your school?

Handout M6.3 Freedom of Choice

In the space below, think about the decisions you made yesterday, from the moment you woke up until the moment you went to bed. List them below.

Ex. 7:00 am woke up

Ex. 7:05 decided to get out of bed on the left side

Ex. 7:06 decided to stretch and then put my slippers on

Based on what you have learned in Modules one to six, how might the number of decisions change for someone who is institutionalized? What kind of choices were you given the freedom to make that would not be given to someone living in an institution or institution-like place?

Ex. At the last minute, I decided to have pizza for dinner instead of spaghetti.

Someone who is institutionalized would not get to choose what they had for dinner. Their meals may be pre-planned, or made for them by someone else. Sometimes, folks do get to choose their meal, but the meal may not necessarily be prepared the way they would want to do it for themselves.

Handout M6.4 Culminating Assignment

Creating Your Own Community Change Project Idea

Community Change Projects create the opportunity for high school aged youth to move from idea to action in order to address the injustices they identify in society. They provide the space for youth to creatively address inclusion, channel their passion and develop a local project that feeds into the inclusion movement.

As a group, your task is to design a project that will help raise awareness about the truths of institutionalization. Using what you have learned throughout the unit, you will need to think about an idea and create a workplan for putting your ideas into action.

You can choose from the following:

- A) Design an awareness campaign
- B) Create an arts based project that showcases what you have learned

The sky is the limit! Use your creativity, practice your leadership and use your knowledge to help spread the word and educate others about what they can do to help end institutionalization in Canada. Once your proposal is complete, you will need to pitch your idea to the class in the form of a presentation.

We encourage classes to then choose a favourite project and make it happen.

The following page has a worksheet to help you get started!

What do you want people to learn?			
What impact do you want to have?			
What actions do you want people to take after learning about institutionalization?			
Who is your target population?			
What strategies will you use to reach this group and make your project relevant to them?			
Activity Idea	1. 2. 3.		
Who are the key players?			
Who do you need support from?			
Workplan:	Tasks to be completed:	Assigned to:	Deadline:
	1.	1.	1.
	2.	2.	2.
	3.	3.	3.
	4.	4.	4.
	5.	5.	5.
	6.	6.	6.

