

[Instrumental music]

Slide one:

Listen to My Story

Oct 16th, 2019

Ryerson University, Toronto, Canada

Part of the *Investing in Justice* Project

Slide two:

On October 26th, 2018, a group of institutional survivors and siblings of institutional survivors gathered at Ryerson University in Toronto to conduct a workshop for people who live and work with people who once lived in an institution.

Slide three:

The workshop was part of the Investing in Justice project, a group of initiatives undertaken by institutional survivors and their allies in efforts to create awareness and educate the public about the effects of institutionalization and the need to prevent it from happening again.

Slide four:

In this video, three institutional survivors and two siblings of survivors share their stories.

The camera pans out to show Madeline Burghardt (PhD, Disability Studies, Kings College, UWO; York University) standing behind a podium beside a table where there are five people seated. Each has a microphone and a large, unlit white candle in front of them. The table is covered in colourful tablecloths, and there are several photographs and art prints set up in front and behind it. There is a projection screen behind the panelists for slides.

Madeline: We're calling this workshop this morning "Listen to My Story," because it's about listening to the stories of people who have lived in institutions who are -- who have named themselves institutional survivors, and from some of their siblings., so that we get a deeper understanding of that experience of institutionalization and the impact that it had, not only on the people who lived there, but on the effects of all those who were around them in their families - people who love them, but were not able to grow up with them. I want to introduce the panel right now, so that we all know who everyone is. So, at my far left is Harold Dougall, from Orillia.

Image description:

A slide shows a picture of Harold Dougall, an elderly white man with large brimmed glasses, smiling slightly, with the text "Activist, Advocate, Public Speaker, Engaged Citizen" written beside it.

Madeline: I'll say more about Harold when it's his turn to speak. Harold is an institutional survivor, and a strong advocate and activist. And can I just mention quickly, Harold, that you also ran for City Council in Orillia on Monday, which is an amazing act of civic engagement that we can all aspire to.

Madeline: Next to Harold is Carrieanne Ford Tompkins, who came all the way from Brampton, and apparently, was in the netherlands of Dignity Transit taking her to various places around the city before they arrived here.

Image description:

A slide shows a picture of Carrieanne Ford Tompkins, an older white woman with long blond hair, gold glasses, and gold earrings smiling looking directly at the camera, with the text "Public Speaker, Advocate, Activist, Friend to Animals" written beside it.

Madeline: Carrieanne is also a survivor and advocate, a public speaker on the Huronia Speakers Bureau. And beside Carrieanne in the center is Joe Clayton, who has come all the way from South River, which despite its name, is very far north of here.

Image description:

A slide shows a picture of Joe Clayton, an older Indigenous man standing outside in the snow wearing a bright yellow winter jacket and glasses. There are three small black birds sitting on his outstretched arms and hands, and he is smiling joyfully. The text "Artist, Photographer, Public Speaker" is written beside the image.

Joe: Way north.

Madeline: Way north. Came down last night on a bus. Joe is an artist, photographer, owns an art gallery. I'm really happy you could make it, Joe.

Joe: Thank you.

Madeline: Beside Joe is Victoria Freeman.

Image description:

A slide shows a picture of Victoria Freeman, a middle-aged white woman with short grey hair smiling, with the text "University Lecturer, Artist, Writer" written beside it.

Madeline: She is known to some of you from L'Arche. Victoria is an artist and a dancer and also a historian, and an instructor of history at York University. And Victoria is the sister of someone who was institutionalized, here to share her story.

Madeline: And last, here on my immediate left is Colleen Orrick.

Image description:

A slide shows a picture of Colleen Orrick, a middle-aged white woman wearing black glasses, a lavender collared shirt, and a patterned purple scarf, with the text "College Professor, Advocate" written beside it.

Colleen also is the sister of an institutional survivor. And Colleen is a retired professor? or semi-retired? I think you still do stuff.

Colleen: Nope.

Madeline: From --

Colleen: Fully retired.

Madeline: From Loyalist College, where you were teaching in the disability service worker - is that right - the DSW program?

Colleen: DSW?

Madeline: Yeah.

Colleen: Developmental Services --

Madeline: Developmental Services Worker program in Belleville. So, welcome to our panel. Did you want to add something to that?

Colleen: Oh, I was just going to say, many of the graduates from our program come to the program here at Ryerson.

Madeline: Yeah. Yeah. Great. So welcome to everyone, and I'm very grateful to the panel for the amount of effort it took to get here - a lot of distance travelled. So, these are our goals today: We want to listen to the stories of survivors and siblings. And mostly, what we want to do from those stories is to think about what survivors articulate as what they need to thrive and flourish in our communities. We also really want to think about what it means to be institutionalized and how can we make sure that that doesn't happen again, and that it doesn't happen in ways that are disguised to us; that we're not perpetuating institutional practices as we carry on with people living in the community. So, that's what we really want to talk about today.

Madeline: We're going to start way back in 1876, when the first institution for -- at the time, who were called "feeble-minded" people.

Image description:

A slide titled "Huronian Institution for the Feebleminded, 1876-2009" shows a black and white photograph of the outside of the Huronia Regional Centre. It is a large four-five story high building made of brick. It has rows of windows and its roof appears to be made of metal and has several spires. There is a path in front of the building that cuts between two large mowed lawns with a few trees and people on each. In front of the fields is a road surrounded on either side by wooden fences.

Madeline: And I use air quotes there because that's not the language, obviously, that we use today for people who are labelled with intellectual disabilities. This was the first institution in Canada built for that specific purpose - 1876 - and it was seen as progressive at the time. Because it was seen as progressive that the government was deciding to move people to separate different groups of people who needed care, and putting them into separate

institutions. So, this was seen as a progressive move at the time. It was publicly funded by the government. And the name of it was -- it's -- it's -- well, the buildings are still there outside of Orillia, Ontario. And the most recent name for this building is the Huronia Regional Centre, which some of you, I know, are familiar with. When it was opened, I think it was called the Orillia Asylum for --

Harold and other survivors: Idiots.

Madeline: for Idiots. Thank you, Harold. Yeah. So some language that we don't use anymore, but the Orillia Asylum for Idiots was its original name. So you can see how grand it was. It took up a lot of land right on the shores of Lake Simcoe.

Image description:

A slide titled "Hurononia Regional Centre" shows the top of a more modern red brick, walled Huronia Regional Centre peeking above a dense row of trees that surround a blue lake.

Madeline: So that's a more recent picture of what it looked like just before it closed. And you can see there it's on the shores of Lake Simcoe.

So Huronia was open from 1876 until 2009, which is a really long time. Like, I guess, that's almost a hundred and -- over 140 years. And we're going to talk a little bit in a minute about why it took so long to close it down. But that's a very, very long history.

So March 31, 2009, was when all the institutions for people with intellectual disabilities finally closed. So it's recent. Like, this is in our recent history that these were still open.

So, I just have a few pictures now of what the interior looked like.

Image description:

A black and white photograph shows a stark empty room. It has tall wooden-paneled ceilings, and floor to ceiling metal support poles. There is a row of identical beds on either side of the room with what look like thin mattresses.

Madeline: And these photos are a little dated. The institution would not have looked exactly like this right when it closed. However, they're not that old. Like, they might be a couple of decades old - sort of the latter part of the 20th century. So, this is the inside of what an institution would've looked like.

Image description:

A slide shows a black and white picture of two rows of beds placed closely together in two rows inside a non-descript room. There are a few men who do not appear to be wearing tops lying down or sitting up in some of the beds. Each of the beds is identical, covered with white sheets and made of a white metal frame.

This is a picture of the laundry room.

Image description:

A black and white photo shows rows of ironing boards covered with haphazardly draped white sheets that line both sides of a large open room. In the center of the room there are a few wooden drying racks with more linens hanging on them. Metal rods attached to the ceiling have a series of identical hanging light bulbs on them.

Madeline: And you can just see, first of all, the number of ironing boards that there are, which reflects how big the place was. When it was at its peak, there were a few thousand people living inside Huronia. And that was just one of three huge institutions in Ontario. So there were thousands of people incarcerated in institutions for people labelled with intellectual disabilities. So that shows the size of it.

But the reason I put in a picture of the laundry, also, is that, particularly at institutions for people with intellectual disabilities, people who lived there were made to work to maintain the institution. People on the panel have spoken to me about doing laundry in the institution. There were all kinds of things that people did to maintain the institution without being paid - so it was labour that people who were incarcerated were being forced to do without payment, but ironically, increased their own incarceration, right? Kept the institution going while building things like that that kept the building going even though they had no choice about whether or not they did that work. So, this is a picture of the laundry room where many residents of Huronia had to work.

This is just a more recent picture of people making their beds.

Image description:

A coloured photograph shows a group of young men wearing solid-coloured sweatshirts and grey sweatpants making their beds in a room crowded with institutional beds. The beds are identical and have white metal frames, white sheets, and beige or grey blankets on them. The beds are placed no more than a foot or two apart.

Madeline: And what you notice, of course, is how crowded it is, how many people were crammed into these buildings. So, this is a picture of Rideau Regional Centre.

Image description:

A coloured aerial photograph shows a sprawling campus of large rectangular brick buildings, each between three and five stories high. There are roads in between the rows of buildings and one large road surrounding the campus. Beyond this large road are wooded areas and fields. A few cars can be seen in a parking lot and on the road surrounding the entire campus.

Madeline: And you can see it's huge. This was one of the three really large institutions that were built in Ontario. This was near Smiths Falls, which is not too far from Ottawa. And this was built, I think the year is '61 or it was sometime around the late 1950's, early 1960's. And what's interesting -- was it in the 50's?

Victoria: It was in the '50s.

Madeline: In the late '50s?

Victoria: Early '50s.

Madeline: Early '50s? Okay. So, in the '50s. What's interesting about this is that in -- by the 1950s, there was already a relatively well-formed Parents' Association. So, parents were starting to agitate for more services from the provincial government for their children with intellectual disabilities. And they were starting to agitate to close down institutions. So even in the midst of this climate of civil rights starting, the Civil Rights Movement in the United States, the Women's Movement, and the Parents' Associations getting very strong here, still, the government built this huge, massive institution near Ottawa. It's so big that you could, apparently walk down a huge hallway right down the middle and it was more than a quarter of a mile long. Like, it was -- this was a really, really big place. And the reason the government decided to open this and another one that I'm going to show you in a moment, is because Huronia was too crowded. So they had this overflow. And they decided the best way to address that was rather than starting to dismantle Huronia and start to increase supports to the communities - instead, they just built more institutions. So, this was a really strange response in many ways.

Besides these big ones, they also built sixteen smaller ones around the province. So it was just this continuation of absorbing the overflow of Huronia instead of starting to shut them down. And this is also despite a report in 1971 - which was really sad - by Walter Williston, who did this report. And he -- this was in '71, and he said, "We have to shut these institutions down." It was also following a couple of tragedies based out of this institution. A couple of men who actually had been placed outside of the institution on some kind of fostering program, where they were with a family doing work, one of them actually took his own life. And another one tried to escape and got severe frostbite. After these two terrible incidents, Walter Williston was saying, "We have to shut this place down." That was 1971. It didn't finally happen until 2009. So, it took a very, very long time.

Okay. That's a picture from inside Rideau, the dining hall. It's not a very good photo, but again, it just shows the crowding - how many people actually lived there.

Image description:

A blurry black and white photograph shows five rows of long dining tables, filled with plates of food and lined by residents sitting shoulder to shoulder on chairs. A few people are standing and may be either staff or residents.

Madeline: And this is a photo of the third large institution near Chatham, which was called the Southwest Regional Centre when it closed. And behind it, you can just sort of make out, barely in the light there, that's Lake Erie. Another very large institution, sprawling.

Image description:

A coloured photograph shows the institution's campus from an aerial view. Rectangular buildings are all connected to one another. There are straight paths leading from each building to a larger path. There are green mowed lawns surrounding the buildings, along with a number of what appear to be artificially planted trees along the edges of these lawns. A large road circles the entire campus. A water tower is visible in the foreground.

Madeline: Okay. So just to -- quickly, to show you a map, if you see the middle of the map, the point of the triangle is where Orillia would have been - the Huronia Regional Centre. The point on the right would be the one in Smiths Falls, and the one on the left would be the one near Chatham - the Southwest Regional Centre.

Image description:

The slide shows an aerial physical map of Ontario with a black triangle drawn on it connecting the three points that represent where the institutions existed.

Madeline: The reason I show that is just to kind of show you that it actually covered the most populated part of Ontario. So the government was pretty intentional in their placement of these institutions. They had the most populous areas covered with these three very large institutions.

This is a picture of gravestones at Huronia.

Image description:

Narrow, flat, and identically-shaped gravestones are inlaid directly side by side in the ground. Some appear to have numbers carved into them. Together they fill all of the ground visible in the image.

Madeline: It's a very sad photo. As you can see, there's just numbers on them. There are no names. These -- this is the way that people were buried at Huronia when they passed away there. And they were buried with numbers on their gravestones, not names. There's a very sad story about this graveyard in that at one point in its history, the stones were dug up and used to build a pathway. So they were just taken out of the cemetery and used to build a pathway, which is really a horrible way to treat people's -- to disrespect people's lives once they've deceased, right? And then a chaplain, a few decades later, found out what was going on, and dug them up, and had them moved back.

However, there's this tragic side to the story that the numbers and the names are still not connected for the most part. And there's a very important project going on right now, called *Remember Every Name*, where a dedicated group of volunteers are trying to match up the numbers with names of people who lived there. So, it's a very, very sad part of Huronia's history. And I know that some of our panelists will probably speak about it when it's their turn to talk about what's going on these days at the cemetery.

So just to bring you up to the present, if any of you were aware, a few years ago, these two women - Marie Slark on the left in the purple and Patricia Seth on the right in the white shirt - were the principal litigants in the Class Action lawsuit against the Ontario government in 2012.

Image description:

A slide shows an image of Marie Slark, a middle-aged white woman wearing glasses, a purple collared patterned shirt, and blue bottoms, with her arms crossed looking defiantly at the camera. She stands beside Patricia Seth, a middle-aged white woman with short curly grey hair wearing a white t-shirt also staring into the camera. The text beside this

photograph reads, “Marie Slark & Patricia Seth. Principal Litigants. Class Action Lawsuit Vs. Ontario Government, 2012.”

Madeline: So, what Patricia and Marie did was, with their litigious guardians, they launched a class action lawsuit against the Ontario government. They were former residents at Huronia. And they said, “We were abused and treated very badly there.” So, they launched a class action, and it was successful. And there's been a lot of interesting conditions attached to that settlement. There was a -- there was a financial settlement, but as John explained - and this is where this morning [session] comes in - is that there was this set amount of money set aside for the class action, but people had to apply for that money. They had to submit an application providing evidence that they had suffered abuse and mistreatment. And only with that evidence could you get money back. And so of course, because some people either found that process too difficult, or they were not accompanied well in that process, not all the money was distributed. There was more than 7 million dollars left over. And that's the really, really sad part of this. So that's how this project came into being. There was this extra money and the government finally - with pressure - said, “Okay, we'll release the money if you can submit proposals for projects.” And so that was where we got the money for this project.

So just to briefly show, Marie and Pat are surrounded there with Marilyn and Jim Dolmage, who were their litigious guardians.

Image description:

A coloured photograph shows, from left to right, Jim Dolmage, Marie Slark, Patricia Seth, and Marilyn Dolmage, with linked arms walking out of a doorway beside a flowering bush. They all appear to be smiling and looking at the ground. Jim and Marilyn, both older white persons, are wearing business formal attire, while Marie and Patricia are wearing raincoats. The text beside them reads “Marilyn & Jim Dolmage, Litigious Guardians.”

Madeline: And they have been instrumental in all of this work around hearing the stories of institutional survivors. So now what?

Image description:

A slide has the following text on it: “Institutions Closed. Now What? 1. Class Action settlement 2013. 2. Government apology, Dec. 2013. 3. Strategic Investment Fund, 2016. 4. Investing in Justice.”

Madeline: So the settlement happened in 2013, which involved a formal apology from the government in the legislature. It also involved a promise to keep up the cemetery, which again, I think some of our panelists will speak about when it's their turn. And it also ended up in what the government called the Strategic Investment Fund, which we are calling *Investing in Justice*; this extra money that we applied for to do some projects to allow institutional survivors to share more about their experiences.

That's just a picture of the apology that's attached to a plaque at Huronia.

Image description:

A coloured photograph shows a brass plaque with gold lettering that has the following text on it: "From 1876 to 2009 many thousands of children and adults with developmental disabilities and other conditions resided in the wards, called 'cottages', of this institution. In 2013 the Government of Ontario issued an apology to the former residents for the conditions over time."

Madeline: Our first speaker is Colleen Orrick, and she's going to share about her experiences as a sister of an institutional survivor. (15:53)

Colleen: You can see a picture of my brother, Gerry, there.

Image description: A young white boy wearing large plastic glasses and a plain white t-shirt looks into the camera. He is sitting on a chair, holding a white guinea pig. A fridge, table, and two chairs are visible in the background.

Colleen: He's holding a little guinea pig. That was taken in an institution and sent to my parents. The institution used it in their brochures and - I don't know if advertising is the right word - but that kind of thing. He was a pretty cute little guy.

For my presentation, I'm going to draw on a major research paper that I wrote, called "Valuing Gerry, Life Writing and People with Developmental Disabilities." I wrote the paper in partial fulfillment for the requirements for the MA in Critical Disability Studies at York. Because Gerry lived at home until he was 5 years old, he was a well-known and beloved sibling when he was placed in an institution. And because I'm five years older than him, I remember a lot about his life at home, and have since come to understand some things about his life away from home. We maintained a bond throughout our adult lives, and his influence on me is profound. Understanding and integrating Gerry's placement in an institution, its impact on our family, and its impact on Gerry has been a major life task. I believe that the major factor that impacted him, and therefore, his family, was not Down syndrome, but the way society responded to Down syndrome. And because of that social attitude, we were robbed as a family, and he was so much more than robbed as a person.

I like to focus on stories as a way of knowing. Is anybody familiar with John McKnight? Have you heard of John McKnight? No? Okay. Well, he's a community developer and - wonderful writings. If you ever see anything written by John McKnight, snap it up. He talks about stories as a way of knowing, and stories as a way of building community. He talks about communities of capacity. And that's what I want to focus on - that type of storytelling.

So I'm going to tell you four stories about my brother, Gerard, that I hope illustrate themes about institutionalization of a sibling. So, the first one is the story about Gerry moving away. And I call it "Breaking the Bonds," because that's what the purpose of the institution was at that point. So, one night, when I was about 10 years old, my mother was tucking me in for the night and she told me that Gerry would be going away to school. Well, when I was 10 years old, I liked to read a lot. And I immediately went, "Oh, boarding school. Can I go?" And she explained to me that, "No, it's only for kids like Gerry." And my question was, "What do you mean, kids like Gerry? What is that?" I don't remember the day that he left. I've wracked my brain trying to remember that, and I don't remember it. I think they probably were up and gone before the kids even got up. Because we lived in Hamilton and

he was going to what was then called Cedar Springs, but is - was then later called Southwestern Regional Centre. So, it was a long drive, and they probably were up very early before the rest of the kids got up for school.

My parents were both involved in the local Association for "Retarded Children" - I'll use those air quotes - which is what it was called back then. Over time, most of those Associations grew into Community Living. But at the time, in the 1950s and '60s, it was called the Association for Retarded Children. And we knew other families who had children with disabilities. So some of them lived at home and some didn't. So, it wasn't completely foreign to us that a sibling could be living away from home. My parents worked really hard to keep our family connected. I think my mother probably never recovered from having to place Gerry in an institution. So, they worked - she lobbied really hard throughout his whole life to get him closer to her. And my parents helped other families either place children in institutions or keep children at home. There was a time in the '50s and '60s where they were doing both, supporting people in institutions and supporting people in communities. So Madeline mentioned Cedar Springs, or Southwestern Regional. The parents' groups actually lobbied the government to cut in half the number of beds they were building in that institution. And they were successful. So, I'm not sure if I'm remembering the numbers correctly, and I don't have it written down, but I think the original - it was originally intended to have 2400 children and adults living there. And they lobbied it down to about 1200, which is still humungous. But - so the parents were involved in both supporting people with children in institutions, and building resources in the communities to support people.

My parents worked really hard to keep our family connected to Gerry. So, we would go on trips down to Chatham to visit him, and they were a really big deal - sometimes we got to stay at a hotel. We ate in restaurants. There was a beach not far away, as Madeline showed you in the photograph. And we had wonderful days at the beach. I can remember my dad renting - you could rent inner tubes, like, from trucks and things like that. And so we - my dad rented inner tubes for us and we were, you know, bobbing around on the water with these inner tubes. And it was a great, great day. We still remember it fondly. They - we also - Gerry came home for holidays, and Christmas, and summertime, and those kinds of things. So I still had a connection with him. And I didn't know everything about his life, like I do with my other brothers, but we still were connected with him. And he was still part of our family. And our neighbours knew him, and our friends knew him, and that kind of thing. So when I think back, I think he almost led a double life. Sometimes he was in an institution and sometimes he was in a family.

At the same time that Gerry was placed in the institution, I can remember going with my dad to Huronia and - as a representative of the Hamilton Association for Retarded Children. And they would bring up - I remember the time that I went with him that I'm thinking of, they brought a huge box of second-hand clothes to distribute to the people that lived there. They brought cigarettes, which apparently were a - it was sort of like an underground economy. And I remember saying to my dad - I think I was only about, probably, 10 to 12, in there somewhere. And I remember saying to my dad, "If they can figure out how to make an underground economy with cigarettes, what are they doing in there?" The survival skills that people had were amazing, I think.

So, I remember the early days of this parents' movement. They had meetings in my family's living room. And I remember this sort of duality of having a brother in an institution, but my parents working to build community resources. My dad told me that one of the reasons they placed Gerry in an institution was because that was the only way he was going to get to go to school. And yet, my dad sat on the administration board for what were eventually three schools that the Hamilton Association built and maintained in Hamilton. But Gerry wouldn't have been allowed to go to those schools. So, it was interesting times, and it was difficult in the sense that we missed him. We missed him a lot.

Another story that I wanted to tell you was about a time when - I call it, "I Only Have Two Brothers, But Actually, I Have Three: Usurping the role of Family". The institution began to take the place of our family. This takes place when I was in my teens. And I remember, I had met a new friend, somebody new, and I don't remember who it was or anything like that. But I just remember them asking me if I had any brothers or sisters, and me just telling them, "Oh, I have two brothers." And my mother overheard this. So, when this friend left, she asked me, was I ashamed of Gerry? And I was shocked that she said that. And I said, "No. I'm just tired of explaining." So by that point, I knew that there was something different. So even though, as I explained before, we knew other families that had children in institutions, other families that had children with developmental disabilities who stayed at home, I realized by this point that that was unusual. And I just didn't want to explain it to everybody. I don't - I've really thought about whether I was ashamed of him, and I thought, "No. I really don't think I am. I think I'm just tired of explaining to everybody."

So when Gerry was - had been at Cedar Springs for a few years, thanks to my mother's lobbying, he moved to Midwestern Regional Centre, which is up near Listowel - is it north of Kitchener? In that area. It's a much smaller institution, and it was only for children. I think Gerry probably had a relatively good time there. He made a couple of friends, and they were kind of infamous. They called them The Three Musketeers, and if one was in trouble, they were all in trouble. And if one was having a good time, they were all having a good time. So he formed those bonds. And he must've been playing a lot of sports, because I can remember my parents taking up sports equipment up for him - skis and skates and a bicycle and things like that. And they nicknamed him Rocket O'Brady because he had - he was good at hockey, I guess. There used to be a hockey player called Rocket Richard. So, he seemed to really do well there in terms of making friends and doing things. And he did go to school, and he did learn to read and write. So, he - but this institution was only for children.

And so, when he got to be about 18, 19, they started telling my parents that he had to move because he couldn't be there past the age of 21. So just picture this: You're home where you've put down some roots and had lots of fun things to do. Tells you, oh, just because of the age that you are, you have to move. So, my mother continued lobbying to get him close - closer to Hamilton. And she was successful in that they moved him to a Schedule II institution called Bethesda. And I think that move was probably life-defining for Gerry. He - when he first moved there, my mother was quite distressed because they didn't have him doing all the fun things that he'd been doing at Midwestern. And they said, "Well he doesn't want to do them." One of the things that Gerry loved to do was swim; he loved to be in water. And he refused to go in the pool there. He wouldn't do any of that. And my mother

was really upset and saying - because they did a reassessment of him and told her that he was profoundly retarded or something like that. And she said, "They don't know him." When I look back on that time now, I think he was grieving, seriously grieving. And nobody recognized it. He'd lost contact with his two friends, the other two Musketeers. Every relationship he had except that of his family - that with his family, was gone. Nobody recognized that grief. They just, you know, gave him - tried to give him programs to do that he might participate in that were not very challenging for him.

I got a phone call from my mother a few years on, when Gerry was at Bethesda, telling me that he wouldn't go in the bathroom and he was holding his urine. And it had been three days since he'd urinated. And I said to her, "Mom, you make them take him to a hospital. He's going to damage his kidneys. You need to get him to a hospital right now." So she did. They did get him to a hospital. We knew then that there was something really wrong; something really not good had happened to him. He refused to go in bathrooms. He refused to let people groom him or touch him. He wouldn't let them help him with any hygiene routines. He was doing things like this *shakes hand* that he'd never done before, sort of that self-stimming kind of thing. He'd never done that before. He started doing that. So, my mother went to see about what was going on, and talked to the administration at the institution. And they said, "Oh, the psychologist said we'll put him on antidepressants." And my mother didn't like that. So, they said, "Well, we'll - this is what the psychiatrist said. And we have lots of people - don't worry, we have lots of people on antidepressants." And my mother said, "Well, don't you wonder why?" Which I thought was kind of a brilliant response to that. So, she insisted that they take him for a second opinion.

And there was a psychiatrist that had been part of the early part of the parents' movement. He had supported parents to start the parents' movement. And I think his name was Dr. Diamond. My mother's gone, so I can't ask her, but I think it was a Dr. Diamond. And he was in London. And so she got them to take him there, and my mother went with them. Gerry wouldn't get out of the car. He wouldn't go. So, the psychiatrist came to the car and talked to him. And he diagnosed him with a reactive psychosis and gave him some medication that did help. Reactive psychosis, as I understand it - and believe me, I'm not a psychiatrist - is a short - it usually has a short duration. But Gerry had it for the rest of his life.

I strongly suspect that he was assaulted in a bathroom. We have no evidence of that other than his behaviour. Nothing we could do about it. I consulted a lawyer, and he said unless we had evidence, it wouldn't go anywhere. And the only evidence we had was Gerry's behaviour, and he couldn't tell us what happened to him. So, another - you know, divorced from this - my mother had a connection with a social worker that worked at the - at Bethesda. And there was a scandal that the psychiatrist there had been accused of sexually assaulting someone. And the social worker told my mother about that. And that the psychiatrist was just going to move to another institution. And my mother said to the social worker, then the next time he does - he hurts someone - "it's on your hands." So we strongly suspected that Gerry had been assaulted, and probably sexually assaulted in a bathroom, but we could never prove it. There - we didn't see marks on him or anything. He couldn't tell us. And as his sister, I have to tell you, that was one of the hardest things for me, was to not be able to comfort him.

Eventually, under the umbrella of the institution, Gerry moved to what they called a Family Home Program where there was this - it's kind of like a fostering situation, but you have adults fostered with a family. And the first family that he was at - let's just say, it didn't work out very well. But the second family that he lived with, they were wonderful. He still was not letting people touch him or groom him or anything like that. And Paul, the man in the family that he lived with, was able to tap into Gerry's sense of humour and his love of Coke, and get him to start letting him help with his hygiene routines. And they joked around with each other. Because Paul had a beard, Gerry used to call him Grandpa, and thought that was very funny. And he landed in a really good place. I had been lobbying my parents to move - see if they could move him to one of the L'Arche homes in Hamilton, but for some reason, they were opposed to that. I could never figure that out. But he did end up with a really great, great place. They were wonderful. And they had a farm, and Gerry loved animals. So, he had all the dogs, and rabbits, and goats, and chickens that he could want. And he was a member of their family; they just took him in as a member of their family. So, he had about ten years with them and it was really, really good.

A little funny thing that happened. He - their last name was McDonald, and so one summer - they lived near a beach. So, one summer, we rented a cottage not far from where they were, and brought Gerry to the cottage with us, and thought that he might have a nice time there. And he sort of did, but he wouldn't do anything. Like, he wouldn't go to the beach. He didn't want me to put my feet in the water for some reason. He would pull me back. He'd - anyway, I said to him one day, "Do you want to go to McDonald's?" And I meant the home, like, do you want to go back to McDonald's? And he was all excited. He goes, "Yeah!" So I figured out later that he thought I meant the restaurant. But when we did take him back to McDonald's, you could tell that they were really glad to see him, and he was really glad to see them.

So, when Gerry was about 51, he fell down some stairs at their home, and he had a massive brain bleed. He had - was put on life support. And eventually, we had to turn off the life support for him and let him go.

I think - my fourth theme that I wanted to discuss is just that we were robbed. As a family, we were robbed of Gerry. And he was robbed of us and so much more. Just to end on a more upbeat note. The summer that we had the cottage, I had - we had taken Gerry into town to go shopping. And he loved to shop at Giant Tiger. And he stopped as we were going through the door. And he started reading the store's opening hours. So, Monday, you know, whatever it was, 6:00 to 9:00, and Tuesday 5:00 to 10:00. And as I heard him reading that, I thought, "He's okay. For the first time in many years, he's okay." Because he stopped reading at about the time that we thought he was assaulted. So when he started reading again, I knew that he was going to be okay. And he was. So that's - I hope I haven't overdone my time, but - is that Gerry's candle?

Madeline: Yeah.

Colleen: Okay.

Madeline hands Colleen a single lit candle which she uses to light a large white candle on the table in front of her

Madeline: Okay. Thank you, Colleen. Next, we have Harold. Harold Dougall is our next speaker. He's an institutional survivor from Huronia. Still lives in Orillia. Very active in local politics, the advocacy movement. He's a public speaker. Came down very early this morning on the bus -

Harold: Oh.

Madeline: So Harold, take it away. (00:38:49)

Harold: My name is Harold Dougall. Thank you to come to here this morning to listen to our story. My story is, oh, similar like his - her brother's is. We're - I'm a survivor. I went there in 1960. 11 years old. Kids don't know what to expect, eh? I went to the lice station. there. That's the first thing they do. Send them all in a little bit [gestures filing papers with his hands], and they put you in a cottage. I was in A1 - yeah, A1, A2, A3, either way. And they used straps on you to keep us in line. The leather - they mentioned it on paper. And I want to put it in front of, face-to-face to everywhere I am. I don't look on paper. The truth, the government lies, everything. That cemetery is all mixed up. They don't know who's in there. Labels, names, and numbers on that - used to be the patio for one of the houses. And the Minister said, "You put that back where it belongs." Of course, the square thing was sitting there [gestures the shape of a square]. That's where they mixed up the numbers.

And learning about my stories - they used to harm me with straps. It was like - see these? The bottom of these? [shows his shoes]. They used them. Used belts, hands, kick, pinch, whatever. Pull your hair if they have to. And learning - I went there. I don't know. I grew up - I turned 12 years old at the time. I learnt a little more about this institution - staff. The staff is supposed to keep us in line, right? Supposed to care for us? No. They didn't. Every staff used a strap on us.

And I had four boys - looked after four of them. And - good boys. Well, staff been - they didn't like me, anyway. I was - had a sneaky way of doing things. We went - no privacy. Line up in line taking a shower. The staff said, "You need to bath these four boys." And I said, "No." He said, "Yes. If you don't, I'll hit you." I went in and somehow you wash yourself and all that. That's okay. Dry. All right. We went to breakfast, and then came back. We had to do our teeth clean. And one of my boys said, "You going to let me use this toothbrush?" I said, "No, I'm not." "Okay." I went down to the canteen. They had a canteen there. Bought toothbrushes. It was maybe a nickel, I think. All right. I bought them for them. That staff said, "Where you get your toothbrushes?" No answer. "All four of them?" No answer. He came to me, "You bought these toothbrushes?" I said, "Yeah." I picked up that toothbrush to show to that staff, and I said, "Use it." He said, "No." I said, "Why?" "I don't brush -- I don't use the same toothbrush with my - in my mouth." I said, "You got - I had - you did my question."

After - on the form, it used to be -I worked [on the] task force for closing any institutions, and I was on it. And I closed that place. And I closed all Ontario, except two. They're still open. They're going to close.

I want them people out here in the community to listen to their survivors and to their community. Not sticking them behind locked doors. So we can learn. Anyone - I talked

about this all the time. Institution is not the place to be. I have a learning disability. I always say, a learning disability don't stop me, and you know that. I - survivors - as we were going to Winnipeg in November. We talk about human rights. We have rights to do things, to speak. You have a mouth to speak. Speak it. Tell your story. Most people can't. I'm the - I'm called a mentor for them; I speak for them. And I did real good learning about disability. It's not - they tease us. "Oh, there goes Winkie." "There goes" - one of these things [does air quotes]. Label us. Labels supposed to be on bottles, jars, anything there - not on us. And that's the main issue here. My story and learn. Anything you take back, realize what we - what our stories are. Learn them. And maybe you'll be surprised. You can understand what we went through. Thank you.

Madeline: Harold, I'm wondering if you want to just say a little bit about the kinds of things you're doing now in Orillia. Some of the jobs, work you do, your advocacy work. Just briefly--

Harold: I'm on the Wheelchair Accessible Committee here, in Orillia. I belong to the Mariposa Folk Festival. I volunteer there. I do papers.

Madeline: You deliver newspapers?

Harold: Oh, yes.

Madeline: Yeah.

Harold: A big--I do eight of them. Eight routes. And I talk on - to other communities for disability. Right now -my goal right now is every store in my city is going to be push-button doors, ramps before 2025. That was my goal if I get in. Of course, I didn't get in. Well, I'm still doing it. And learning about - before I been HRC to - that time at the HRC, well, it used to be Ontario School. I got transferred - I left - I was 18 years old to the Edgar Occupation Centre. They train you to do carpenter work, gardening, garage, kitchen. The first thing I got there was - there was a funny thing. I got off the bus and kneeled down and kissed the ground. And a guy said, "Why you did that?" "I'm free." I'm not free - but free in my heart. And that's the only way I can do public speaking. That's my goal. I'm a Toastmasters International speaker. And I'm the sergeant in arms. Of course (laughs). I can speak. Sometimes I speak --

Madeline: Yeah.

Harold: -- over my time [laughter]. Thank you.

Madeline: So Harold, you - you're on the committee in Orillia. You advise city council on accessibility issues, right? You're on the committee, and you do all kinds of advocacy work. And I'm not sure if everyone heard, that you're going to the Museum of Human Rights in Winnipeg in early November -

Harold: Yeah.

Madeline - as well as Carrie -

Harold: Yeah.

Madeline: - to speak about your experiences and the rights of people who have disabilities -

Harold: Yeah.

Madeline: - in Canada, right? So that's pretty awesome.

Harold: Yeah.

Madeline: Yeah.

Harold: My - we are going to Hamilton Airport to pick - to fly from out of Hamilton - my hometown, of course.

Madeline: That's exciting.

Harold: So this is going to be my second time.

Madeline: Yeah.

Harold: Carrie's first time there.

Carrieanne: Mm-hmm. Yeah.

Harold: Sometimes, people's first time flying, you get nervous. Don't be.

Madeline: I'm sure you're going to be amazing. I know it.

Harold: So, Carrie will be okay.

Madeline: Yeah.

Harold: Anyone - I know you - all you have people with you, like looking after you - looking after people. And I hope this won't happen again. It won't be happening again. I'm the form that closed the HRC in 2009, March the 31st. The first thing that I got on the Queen's Park, my speech, "I'm free at last. I'm free at last. Thank God, I'm free at last." The guy said, "Where you got that from?" "Dr. Luther King." And that's main - that's my favourite person. That's the word I meant to say all the time.

Madeline: Thank you, Harold.

Harold: You're welcome.

Madeline: I'm going to pass you - Do you want to light your candle? Do you want to do it?

Madeline hands Harold a single lit candle which he uses to light a large white candle on the table in front of him

Harold: Here. It's good.

Madeline: Thank you. Thanks.

Harold: You're welcome.

Madeline: Our next speaker is **Carrieanne Ford-Tompkins**, also an institutional survivor. She's going to share her experiences with us and what she's doing now in her thriving. Thanks. Go ahead. (00:50:45)

Carrieanne: Hi. Welcome. Hi. Well, I'm glad you welcomed me here. I thought I wouldn't make it because Wheel Dignity was going to take me home. And I says, "I want to go to this speaking program." I - all night I kept awake; couldn't wait to get here.

Okay. I am a survivor. I lived in Huronia and in Gravenhurst - which are the both institutions together - from the age of 13 years old. Got out. And - because they had to let me out, because they made me pregnant in there. The staff had sent me into a room where you have to do that, or punished with a dope needle. So I got pregnant there. The baby was born. It was a girl. But they took the baby and killed it. All they could say to me, "It was a girl."

The next thing I had - I went to the high school, worked at the high school before I went to the institution. And family also invited, which means by that institutional family history. Still, sadness of hearing from her time in the institution, which still bothers me and why daily life. Mrs. Green is a popular nurse that worked in there, called the RNA. She tortured me very severely. Broke my legs, damaged my eyes, and gave me a favourite name, 'Bug Eyes.' I always wondered what meant - why Bug Eyes was [inaudible]. I looked in the mirror and I say, "What's wrong with my eyes?" Like, she calls me Bug Eyes.

And when I went to Gravenhurst, I was up - it's more freedom in Gravenhurst. I couldn't believe when I first went from a locked door to Gravenhurst. I went to the staff in the office, I said, "Somebody's running away." She didn't pay attention to me. So I opened this door, and I crept down the stairs, and I went out. And still, the switchboard are not even stopping me, so I went out. And the girls had asked me, "Are you going swimming?" I didn't bring my bathing suit. I'm not...everything was like a puzzle, from locked doors to freedom in different institutions.

So, I went out the back and sat on the porch at the back of Gravenhurst. This little tiny squirrel came up to me. Crawled up my neck. And I was kind of nervous. So I picked this little squirrel up and I looked at it. I did get a shoebox. I put it in the shoebox. Crept into my bedroom with this squirrel. So I took the squirrel into the room. I put a little red ribbon around its neck and a bell. And I said - now, I didn't know what to feed this squirrel. So when I went to the cafeteria downstairs, I munched some food from my favourite cook, Julius. I told him about the squirrel, and he said he eats peanut butter. So okay. So, I went back up to my room, and I said, "I can't keep you in here." So I took it to Mrs. Janseck [phonetic]. And Mrs. Janseck says, "What do you got in the box, Carrie?" I said, "I have to show you. Will you punish me?" She said, "No." The squirrel - I opened the box and she said, "A squirrel with a red ribbon and a bell around its neck? Does it have a name?" I go, "Yeah. Midnight." It was black.

The next thing I felt, it was institution - was to allow people to - with clothes and doors and institutional lives - and to move ahead in my life, which I'm still having a hard time doing it. I still feel isolated. Important to tell the story about moving from - move on - to move on, the story. Carrieanne has been very involved in - with reclaiming - Reclaiming Huronia

project. Had a, had a, had an article in the Canadian Journal of the disability students [Canadian Journal of Disability Studies]. I go to all - I go to people - I go to all high schools and tell my story about - I must've been to a lot of them here in Toronto. And I tell them my story, and yeah. That's what I mean. The journal - the disability students. I go to Remember Every Name. Is a program speaker bureau.

Madeline: So Carrieanne, why don't you - do you want to talk a little bit about your work with Remember Every Name?

Carrieanne: Oh sure. Yeah. I - me and Harold and our other - we have a - if you look on Facebook under "Remember Every Name," we have a - we're trying to support the bodies that were killed in the cemetery. And we'd like - it's an organization that we formed a group that were survivors to fight for the rights of the ones that were - even the Indians - that were buried into this ground, and no name. I was a number 2, but I don't know what it was. But these - Remember Every Name is for people, if they want to come to see us. We're trying to get more support because of the cemetery has gone a long way.

Madeline: And you - so you and Harold and a group of other people, you go up every Mother's

Carrieanne: Mother's Day. Mother's Day is a very special - we're not celebrating; I'm a mother - which I wasn't supposed to be a mother. I was supposed to have been sterilized. But there's - there is a - people, we march. And we're not celebrating us. We're celebrating the ones that never had - knew their mothers. Babies that were put there, and we can't find them. Everybody says, "What happened to the babies?" We don't know.

But in there, Remember Every Name, we - we're trying to get people to come support us. Because one day, you - if you ever have children, and they say your child is a big R word we don't use, support is very scary. Because I got two grandchildren that are that way. And my daughter is something similar. Yeah, so they're Down syndrome children. And they're learning a lot now. You wouldn't believe they're Down syndrome, Carrie and Ella.

And I like my freedom, even simply go out to the park. I do Meals On Wheels. I do Meals on Wheels with people that can't get out, even though I have a hard time, but I do it. I care for animals. This is very important to me. I'm an animal lover. St. Francis. Yeah. That's what they call me at church. So when anybody lost their animal, they knew where to come - Carrieanne's. So -

Madeline: Do you want to share your story about the skunk?

Carrieanne: Oh, yeah. The skunk. I'm trying to find it here. I just had surgery on my eyes. So I got to try to...yeah.

Carrieanne scans the paper she has been reading from

Madeline: I don't know if it's on there, Carrieanne.

Carrieanne: Okay. I can tell you about the skunk. It's, and all the raccoons in my back yard. Well, the skunk - there was a skunk. I was going for a walk without my walker. I'm trying to learn not to use it. There was a skunk that got hit by a car. Everybody say, "Stay away." "Oh,

shut up." So I go and I got this bag, and I'm trying to push this skunk. But the tail's going up and it's - she's looking at me. And I said, "I'm not going to harm you. Don't you spray me." So -

Harold: It might be dead, anyway.

Carrieanne: - yeah, it was halfly [sic] and, but it knew that I wasn't going to harm it. It kept looking...

Carrieanne gestures to the right with her hands, then turns her head that way. She then gestures with her hands to the left, and soon after turns her head to the left as well.

- if I went this way, the head will go this way. I went this way, the head will go that way. So I got this lady to phone the Humane Society and the truck did come. And I said, "Is it going to live?" And the lady looked. She said, "No." So I says, "Okay. Another one for St. Francis." But I was - I'm an animal lover. I don't - I'm a member of the Black Cat Association. I've got a black cat. I have been raising black kittens ever since my childhood, and every one was Midnight. So this one kitten I had when I was a little girl, my mom killed it. But it was partially dead. And I put it in my arms and I said, "Don't worry. I will keep the Midnights going." And I did.

Madeline: So, your cat now is called?

Carrieanne: 'Midnight.' I must - I got the ashes. I said to, I says, "I go in there, they go in there. We all go together." *Carrieanne gestures towards the ground*.

But yeah. Freedom, to me, is a hard thing to say. I'm still trying to work with freedom. Because when I go down to Mother's Day, I can't look at Orillia institution. I have to turn my head. Even cemeteries.

So, oh, yeah. I worked at an old-age home. I worked at the old-age home. I was a worker before I went to Orillia. Important to contact Meals on Wheels, and I worked on Facebook, and I made some good friends.

Important to other people with disability to build community and a relationship. Words of wisdom. Words of wisdom: "Let it be." Don't be afraid of us. We won't harm you. They had it like were a dangerous - like criminals are going to kill you. Something like Halloween. We just ask good - we're just as good as you guys.

Tear down the institution. That's what we want. The police took over. I find out - I feel - now that the police - it was an institution of harm and hurt. So now the place is still harm and hurt. Who goes to jail? Who goes in there? Tear it down. Give it to the people that don't have homes. Mother - mothers with children that are just having babies, and they're only young, like you guys. And you have a child, you got a place to live. These - this is very important that to see children know they got a - they got their mom. Don't let them take them away from. I hate Children's Aid. Because they **convict** you very bad. You know, label you disabled. My daughter is fighting this thing. Don't let it happen to your children. They may - workers may come and say, "Your child is a disabled." There is schools for them, not institutions. Let your children free. Don't let the government say they're retarded. Free

your children from danger. Free your children from ever letting someone harm them physically. Because in the institution I've been sexually abused, pregnant twice. The first time, my baby died. Second time, I brought it home. And now my son is gone. I never got to say, "Hey. Tell him his story." But I think it was better that way. I mean I'm so happy you guys really accepted me here. But I am still hurting. *Carrieanne gestures towards her heart.* Thank you.

Harold: Wow.

Madeline: Thanks, Carrieanne.

Harold: Fantastic.

Madeline hands Carrieanne a single lit candle which she uses to light a large white candle on the table in front of her

Madeline: Thank you. Our next speaker is **Victoria Freeman**. Victoria is an artist and a dancer, and performs with Sol Express and L'Arche Toronto, and she's also a historian. The author of a book and another book that she'll speak about that's coming out next year, and teaches history at York University. And Victoria is the older sister of a woman who lived in an institution. So you'll direct me to this one? *Madeline points towards a space outside of the camera presumably where she can change slides* (1:04:20)

Victoria: Yes. Thank you. Okay. Hi, everybody. I'm really glad to be here and to share my story. So, my younger sister, Martha, was born with Down syndrome in 1958, and was institutionalized at the Rideau Regional Centre in Smiths Falls in 1960, when I was 4 years old and she was 20 months old. A photo from my sister's institutional file shows her two months after she was admitted held in anonymous arms looking up into the camera with a bewildered expression on her face.

Image description:

A black and white photograph shows a white female infant dressed in a crisp white blouse staring directly at the camera, her mouth slightly ajar.

Victoria: I cannot imagine what it was like for her to be removed from everything and everyone she knew at this extremely young age. My sister, Kate, was born two weeks after Martha was taken away, which explains some of the timing of Martha's institutionalization. For support workers who have grown up in today's climate of increased acceptance of people with intellectual disabilities, it may be hard to understand the parents of earlier times who made the decision to put their children in institutions. It's important to remember that in 1960, there were almost no community supports for keeping children at home. And parents were told they would be damaging their other children if they did so.

The 1960 Ontario government film, *One On Every Street*, provides a snapshot of common attitudes and expert opinion of the time on intellectual disability and institutionalization. Sol Express purchased a copy of this film for our research for "Birds Make Me Think About Freedom" - the theatre production we created about institutionalization and de-institutionalization that was performed at the Toronto Fringe Festival this past summer,

and will be remounted in 2019. But that film, I have to say, is - it's a teaching tool, but it's very hard to watch. And I don't recommend it for survivors; I think that would just be too hard.

The decision to institutionalize my sister Martha was made on the advice of doctors and was motivated, in part, to protect me. But it also reflected my mother's fundamental rejection of my sister because she had Down syndrome. My mother was deeply afraid of social rejection because of events in her own early life. And she saw Martha's condition as her own failure and shame. And as Madeline once said to me, perhaps, for my mother it wasn't safe to love my sister. She could also never let go of her own dream of who Martha might have been. She was never able to fully love Martha or even be with her for very long, though she forced herself to try. My father was more accepting of Martha. But his first loyalty was to my mother. We children were shaped by our parents' attitudes and by the unspoken rules of what we could and could not talk about. Sadly, during her lifetime, we mainly saw Martha's disability - not the full person that she was.

My sister lived at the Rideau Regional Centre for 13 years. We visited her there occasionally, and once in a while she came home for a short visit. But these excruciating visits were made out of duty, not love.

I'm haunted by the second photo of Martha taken at the institution in 1970 when she was almost 12.

Image description:

A black and white photo shows a white child with brown hair cut at shoulder length wearing a cardigan and knit top, staring directly at the camera. Text beneath the photograph reads, "Photograph taken April 1970."

Victoria: She stares defiantly into the camera. You can see her struggle to survive in that harsh environment, and her incredible strength, determination, and resistance. I don't know what happened to her at Rideau. But in her file a social worker commented that she didn't have the trust in adults that most children have. We family members always believed the institution was the best place for her. And to the best of my knowledge, my parents never considered that she might be mistreated there - even though the first sentence we ever heard her speak was, "Shut up, kid."

Martha was discharged from the institution in 1973 when she was 15, and was sent to live in an approved boarding home in another city. Luckily, she was informally adopted by the woman who ran it, living as a member of her family even after the boarding home closed. In fact, for 29 years until my sister's death in 2002, this woman - my sister's saviour and protector - loved my sister as no one else ever had. Miraculously, my sister found the love and acceptance that she never received from her birth parents, or the institution, or from me. And in many ways, she flourished despite her very difficult early years. The change in my sister was immediate and profound. She found her voice. She began to talk far more than she ever had before. Her transformation is evident in a photograph taken a few years later.

Image description:

A coloured photograph shows a young white woman wearing a fancy floral purple frock, with her hands crossed on her lap, and a relaxed smile on her face.

Harold: Wow.

Victoria: She is wearing a beautiful dress and pearls and looks confident, relaxed, and completely at ease with herself. This speaks to the crucial role that support workers, friends, and community organizations like l'Arche and other community living organizations can play in the healing of trauma, and the blossoming of previously stunted lives. Although even love and increased support could not make up for some of the things my sister did not receive earlier in life, such as speech therapy and more educational support. And I don't know if she continued to be traumatized in other ways.

It was clear to all who saw her that living in a community setting was a huge improvement in her life. I, on the other hand, had a mental breakdown and dropped out of university when I was 20. I know I'm lucky to be alive, because I became delusional and thought of killing myself every day for about 6 months. My healing began only when I realized that as a 4-year-old, I had blamed myself for my sister being taken away. I had felt tremendous loss and powerlessness. I had grown up with unrecognized survivor's guilt that had shaped my behaviour and censored myself, and made me believe all the bad things that my emotionally abusive boyfriend said about me. I felt guilty because I had enjoyed my parents' love, and my sister hadn't. Yet I also feared I would be rejected by my parents and institutionalized as well. I felt enormous pressure to be exceptional to make up for their disappointment in my sister.

But worst of all, I felt that I had failed to be a good human being because I had hated going to the institution to see my sister. It was truly a terrifying place to visit. I had tried to avoid seeing Martha. I had felt superior to her and been repelled by her and the other people who were housed there. Deep down, I felt worthless because I knew I hadn't loved Martha enough. I came to see that this was what my mother also felt whenever she saw someone with Down syndrome, and that was why she reacted so harshly to them.

Thus, I would say to support workers today, that even though the behaviour of some family members has been a source of immense pain for survivors and may be difficult for support workers to understand, family members may be wounded people, too. In speaking with other siblings, I've discovered that many of us were deeply affected by our parents' decision to institutionalize our brothers and sisters. And many of us have never spoken of our pain to anyone.

It was an absolutely amazing, life-changing experience for me to meet the performers of Sol Express. And I want to acknowledge Cheryl Zinyk here at the back of the room, who welcomed me into Sol Express. And to dance and create theatre with them, especially because I had never believed that my sister or other people with intellectual disabilities could be creative. That had been one of the ways I had believed myself superior. I was so wrong. It feels so special now, 16 years after my sister's death, to be able to dance and physically celebrate life, and to create art with people like her, when so much of my

relationship with Martha was interrupted, damaged, or destroyed. Dancing with someone is fundamentally about being in relationship. There is dignity and respect when you meet at a creative level; when you act and react, give and receive, invent and move, create meaning and express emotion together. After the first wonderful day I spent with Sol Express, I cried all the way home, and for the next two days. I was so moved, so deeply affected, so grateful. I felt a welling up of love, and of my need to love. It was the love I had never been allowed to feel before - a love I had been ashamed of and which never had the chance to be the love for my sister and for myself. L'Arche and Sol Express had saved me. They had given me a place to put that love and a second chance.

So, my final message to people who support survivors and other people with intellectual disabilities, is that your work is very, very important and deeply appreciated by people like me. You never know where the ripples of healing will go. Today, I've met many survivors, their families and friends, as well as people with intellectual disabilities who were never institutionalized - all the people I wish I'd known as a child. I've been able to work with Sol Express to create a work of theatre that educates the general public and honours the experiences, perspectives, and wisdom of survivors. That's "Birds Make Me Think About Freedom", and that title comes from a survivor. And I hope that you'll have a chance to see that in the future. Hopefully, it will help people understand why we must never again subject people to such cruel treatment. This is something that could not have happened for me without people like you in my life and my sister's. Thank you.

Harold: Wow.

Madeline hands Victoria a single lit candle which she uses to light a large white candle on the table in front of her

Madeline: Our last speaker for this morning is **Joe Clayton**. (1:16:40)

Joe: He just left. He just left.

Joe gestures behind himself, pointing to towards the back wall

Madeline: He's still here. We'll put Joe's beautiful photo up.

Image description:

A slide shows a picture of Joe Clayton, an older Indigenous man standing outside in the snow wearing a bright yellow winter jacket and glasses. There are three small black birds sitting on his outstretched arms and hands, and he is smiling joyfully. The text "Artist, Photographer, Public Speaker" is written beside the image.

Madeline: Joe is an institutional survivor from Rideau Regional Centre. As he mentioned earlier, Joe is a photographer and an artist. He runs an art gallery in South River, Ontario. And you can see some of his beautiful work displayed around in the front and along the back here. And so please take time over lunch to look at those and to talk to Joe about his work. So Joe is going to share with us his experiences of institutionalization and thriving afterwards. Thanks, Joe.

Joe: Thank you. Thank you, everybody, for inviting me. I was not going to read it, but then I found it on the computer. So I'll read my story. I was born in Pembroke, Ontario, February 9, 1953. I was 8 pounds, 9 ounces. I was with my mom for 6 years. My mom was sick and could not care for me, so my mom's friend looked after me until she died. I was made a ward of the Children's Aid Society at 5 years of age, August the 18, 1958. I remember that day as it was yesterday. My mom said goodbye to me and got - and I got into the car. I sat in the back of the car, and then I stand up and look out of the back window. My mom got smaller and smaller, and then she was gone out of my life.

My life was like a game. I was always made to move from one place to another. Someone from the Children's Aid Society would throw my clothes in the trunk of a car and would take me to another place. They would say, "You have to stay here." I had no say in the matter. It seems that people kept rejecting me all the time. I had - I felt that nobody really cared for me. People did not seem to understand my needs and my problems. My foster mother thought it would be better if I was institutionalized before I become too emotionally involved or too dependent on a foster family.

Image description:

A slide shows an older colour photograph of the Rideau Regional Centre. There are two black and white photographs of Joe Clayton, from 1966 and 1971, respectively, transposed over this image in the top left corner, along with a more recent colour photograph of the institution in the top right corner.

On one day in May the 16, 1966, the Children's Aid Society put me in an institution. Let me tell you, being in an institution is like living in hell. First of all, I was put in a ward. It was called Admission Ward. I was 12 years old. Then the staff got us to take our clothes off and stand naked. They would measure everyone to find out - find out your clothes size. The only thing covering everyone was a nightgown until we got clothes to wear. We had to have our name tags put on our clothes to make sure that no one stole them from us. It made me feel like a dog. At the Admission Ward, we would go for a walk outside. We were made to hold hands to make sure we did not run away. It was almost like a herd of sheep to keep us in line.

Two weeks after being in the institution, I was put in a ward - 3D - with 25 other patients. Men who were 18, 30 years old. I was only 12 years old. Can you imagine the fear of a 12-and-a-half year old boy would be, looking up to these giants?

We stand - we had to stand in line to get our meals and our pills. The pills were referenced as "candies." If we moved, one of the patients will attack me. I only moved once before I learned not to move. We also had to stay in line with our towels around our waist and soap in our hand, and we had to walk down the hallway to get to the showers.

We all had to shower in the same place. There was no privacy. It was like being in prison. I was very scared seeing all of these naked men all around me. I was hit a lot when taking showers. They used a wet towel to hit me. I would end up with cuts on my body. I was gang raped in the shower by men. I passed out from the attack. People were always fighting and stealing. It made me very scared for my life and personal belongings. I always felt ashamed,

and that no one cared, because how I was treated, and older and bigger men end up attacking me with scissors. I was cut, but not too bad. I was always scared for my own life.

The doors were always locked, and the only time I got out to get out was with staff members to go for walks, showers, or go to school. I remember when I did not follow the rules, I was put in a dark room and the door was locked. This room was called the "side room." I was made to sit naked on a cold floor. I remember a man looking through the window, and was laughing at me. I didn't understand why I was treated so bad. I sat in a corner crying because I was afraid and scared. The other things they would do to me if I broke the rules was put my head in a toilet bowl, I'm - and make me kneel in a corner for two to three hours. Not all the staff were bad. There were some good staff, too.

And at night, some patients would attack me and rape me. They told me that if I told the staff, they would kill me. Every night, different - different men would attack me and rape me. The word was - the word got passed around and I was called "Spongy." This went on for six years at night. Sometimes staff would come around to pull the sheets off our beds when we were sleeping. I would wake up to the staff checking me with a flashlight, and they would put powder on us; they were checking for lice. This was always made me uncomfortable. I didn't know what was going on. I believe now that I - that was for bed bugs. That's what it was. There was never privacy at Rideau Regional. I was made to eat a whole bar of soap once and, when I swear, this made me very sick.

I worked in the laundry room and I had to clean poop out of a dirty linen. I was once told - I was once told I'd been taken to a brain test. Wires were hooked up to my head and a piece of wood was put underneath my tongue. I was shocked. I was shocked, and my jaw shook. Living at Rideau Regional Centre was like hell for me, like I said before, and I ran away from Rideau Regional Centre two times. Each time though I returned to the Centre. I am glad I am finally able to leave Rideau Regional Centre that May 16, 1971.

I - on May 16, 2013, I went back to Rideau Regional Centre. It's been 47 years. It was on my 60th birthday. But I - but I did it. And if I ever learn anything from history is that one has ever learned anything from the mistakes of history, it is don't - knowing people's stories, that history is to be built. In this case, that's the history of people of Ontario Institution for people with develop disability. And a wise man said, "Those who do not learn from history are doomed to repeat - repeat it." By making sure people know the history, I believe the Ontario government will listen to people. Then doom will not repeat it - itself or go back to institutions. Just as a word, you don't understand until you live it.

I don't hate the Ontario government, but we were there in the institution. It was like a prison. I am upset with the Ontario government because my stomach gets really sick inside. The government did nothing. I was told that the Ontario government knew what was going on in the past. You know, the Ontario government destroyed our lives. I was a normal child before I went into the institution -that's right. When I left, I had a lot of problems of nightmares and depression.

[Silence]

Joe: For years after I left Rideau Regional Centre, I could still hear the sounds of screams in my head. I had to leave lights on at night to make sure that I know where I am when I wake up. It makes me feel safer. I still have some problems now, but I'm learning to deal with them, and I'm trying to have a normal life. I never heard the word "sorry." Being able to talk to other people - to others about my experience gives me the knowledge to never ever let this happen to anyone again. I believe such hardship in life I can forgive, but not to forget. I know that sharing my story is part of my healing process. Thank you.

Harold: Wow.

Madeline: Joe, I'm just - thank you for that. I'm just wondering if you want to say anything about what you're doing now? I've got the pictures of you and your work.

Joe: Mm-hmm.

Madeline: Do you want to explain, maybe, what's in that photo?

Joe: This one?

Madeline: Yeah. And we've got a few more, too.

Image description:

Joe Clayton, and Indigenous man, stands smiling, wearing a fringed leather jacket with some embroidery on it. He is holding two tall wooden talking sticks. One has the head of an eagle on top of it and the other has the head of a bear on top. He is wearing jeans, moccasins, and a beaded choker.

Joe: The eagle one I did, it was -

Madeline: Those are talking sticks?

Joe: Talking sticks.

Madeline: Talking sticks.

Joe: I had - somebody came to my home and asked me if I would - they would - I would do my story. And they would, you know - they would put it on the internet - would, you know, so I was talking about my story and that. And after - when people talk about their story, it's very hard for us. Because we need, you know, it's - we get very - I get very emotional and I relive it. And it's very important to have a follow-up. And so this person listened to me. And so she would follow me and say, "How are you doing?" and everything else. And I was struggling how to handle when I tell my story, how do I handle this? Because I said, "I'm reliving it. Every time I tell it." I found a sacred way. I did my eagle after she left, I was, you know, by myself, and I did the eagle, and I started finding a comfort way to heal myself.

Image description:

A slide shows a collage of various images of Joe Clayton and his artwork, including both photographs and paintings. Images of his art depict wildlife and nature. Joe is smiling in all of the photographs of himself.

Joe: When you tell your story, you have to learn - I had to learn - to love myself and to forgive. Once you can do those things, life is beautiful. And once you can forgive and say it's hard to do that, it's very hard. It takes time, but it can be done. And I have done this.

And I am a painter.

Image description:

A slide shows one of Joe's paintings. The main object of the painting appears to have wings and a human face, and is painted in broad multi-coloured strokes.

Joe: And I'm - I love life, and I'm not letting no institution take me down. I am - I'm telling my story, but I want people to know that we can have a life. The institution will not rob us from our life. We can have a life, and we can have a wonderful life. And we can have - we can do a lot. We can do anything if we just put our mind to. And I'm just amazed of all the support that I'm getting now. Oh yes, and I'm independent now, on my own - well, my wife's with me too. But so life's been really good for me, and I'm very happy.

Madeline: Well, Joe, we're really glad you came to tell your story. And your words of loving yourself and forgiveness are very, very powerful. Thank you.

Madeline hands Joe a single lit candle which he uses to light a large white candle on the table in front of him

Harold: I'm going to give that a little - learning about your life - and everything your life is - is so powerful. I learned about my life a long time ago when I was 18 years old, maybe nineteen - you never know. I learned your life is so short. Thank God all the survivors out of the institution. I hope their life will be filled. I'm going to - I know I talked to a lot of people who been in there, and their life just changed when just [inaudible] everything circles around.

Harold uses his hand to draw a 180 degree angle in the air.

Harold: Completely around. Turn themselves around. They have - they first came out of the institution, they had nightmares the same as Joe did, crying. And they felt freedom. They always realize feeling is in you. Don't put - don't - HRC is not bringing me down, or not in me. I'm out in the community right now, and learn everything I have to learn. I know it's slow learning. A retarded person, that's my - that's a hard word for me, anyway. And learning as slow learners don't learn as fast as anyone else. We're no different than any one of you. We're the same. Only we have - we need to learn a little more slower.

Madeline: I want to thank everyone on our panel for sharing their extremely powerful and moving stories.

A final slide is shown. Its text reads:

Our panelists: Colleen Orrick, Harold Dougall, CarrieAnne Ford Tompkins, Victoria Freeman & Joe Clayton. Disability Studies Department, Ryerson University. Digital Media Projects Office, Ryerson University. L'Arche Toronto. Investing in Justice Program.

[Instrumental music]