



JULY 2020

## ‘LISTEN TO MY STORY’ VIDEO DISCUSSION GUIDE

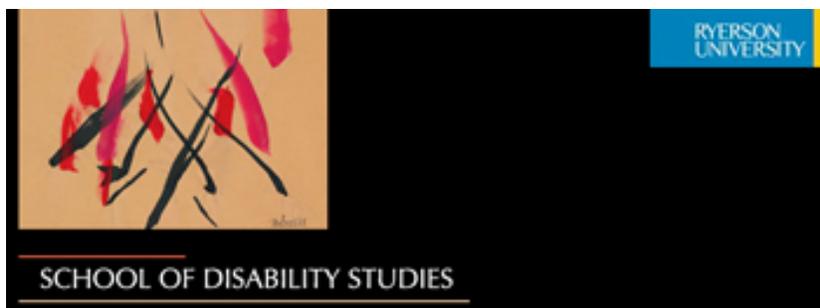
‘I want them people out here in the community to listen to their survivors and the community. Not stick them behind locked doors. So we can learn.’  
– Harold Dougall, institutional survivor.



A Panel Presentation with institutional survivors and siblings,  
moderated by Dr. Madeline Burghardt.

An *Investing in Justice* Project, Funded by Government of  
Ontario Strategic Program Investment Fund #52.

With support from:



Video URL:

Written Transcript:

## DISCUSSION & REFLECTION QUESTIONS

These questions may be completed on your own or in a group. They are designed to help stimulate discussion once you have viewed the Listen to My Story video.

1. How are people with intellectual disabilities<sup>1</sup> depicted in our society (for example, in the media; in literature; in medicine; in popular culture etc.)? Brainstorm a list of common stereotypes. These can include both positive and negative attributes.
  - a) How do these representations compare to how survivors described and depicted themselves in the video?
  - b) What kinds of experiences described by survivors in the video are erased or ignored by the representations you brainstormed initially?
  - c) How are representations of people with intellectual disabilities in society, as well as self-representations of survivors in the video, the same as, or different from, your own beliefs about people with intellectual disabilities?
2. What do you think is implied by the term 'institutional survivor', or simply, 'survivor'? How does this differ from the terms 'service user', 'participant', or client'?
3. List and discuss three key messages you believe survivors and their siblings were trying to convey to their audience in the video.
4. What did you find surprising about the narratives you heard?
5. Specifically, what did you find surprising about survivors' lives post-institutionalization?

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<sup>1</sup> Many People First organizations led by people with intellectual disabilities prefer 'person-first language' (i.e., person with an intellectual disability). Other groups prefer 'identity-first language' (i.e. disabled person). The following guide employs the former when referring to people with intellectual disabilities; the latter when referring to the disabled community at large.

6. All of the survivors mentioned that they are involved in advocacy work.

- a) What current issues are they fighting for or against?
- b) How do these current issues relate to their experiences of being institutionalized?
- c) Why might they be passionate about these issues given their past experiences?

7. Were you taught about the history of institutionalization during your education and / or training? If so, how was it taught? If not, why do you think it was not discussed?

8. The former Huronia Regional Centre is now the site of the headquarters of the Ontario Provincial Police (OPP), in Orillia, Ontario. Erving Goffman, a sociologist, coined the term 'total institution', which can be applied to a variety of institutions ranging from institutions for people with disabilities, to prisons, to boarding schools, to monasteries. Goffman notes the following features of a total institution:

- First, all aspects of life are conducted in the same place and under the same single authority.
- Second, each phase of the member's daily activity will be carried out in the immediate company of a large batch of others, all of whom are treated alike and are required to do the same thing together.
- Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole circle of activities being imposed from above through a system of explicit formal rulings and a body of officials.
- Fourth, the contents of the various enforced activities are brought together as parts of a single overall rational plan purportedly designed to fulfil the official aims of the institution." (Goffman, E. [1961]. *Asylums: Essays on the condition of the Social situation of Mental Patients and Other Inmates*. (pp. 5-6). New York: Routledge).

Keeping this definition in mind, brainstorm examples of features of total institutions that are still present in day programs, community programming, respite care, supported employment, group homes, long-term care facilities, etc. Why is it important to be vigilant about the ongoing presence of these features?

9. Both of the siblings in the video describe how they were “robbed” of the opportunity to grow up alongside their respective siblings (e.g. recall Colleen’s story entitled “I have two brothers, not three”). How do current programs and services for people with intellectual disabilities continue to ‘rob’ people with intellectual disabilities of society, and vice-versa?

10. Why do you think it is important to listen to survivors’ stories, especially as someone who works with disabled people?

11. How can you or your colleagues or workplace organize to support institutional survivors specifically?

12. How do you think having watched this video will affect your work going forward? For example, will it change how you think about your clients; the kinds of activities you perform with them; how you listen and respond to your clients; how you interact with other staff persons/colleagues in group settings etc?

13. Moving forward, how do you plan to continue to seek out and learn from the voices and stories of survivors and people labelled with intellectual disabilities? What steps can you take to do this? (See: Recommended Resource List).

The following quotations are statements that participants made during the video-recorded presentation. Each is accompanied by a question to provoke deeper reflection.

14. “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.” -Victoria Freeman

How does reading this quote make you feel? Try to name the emotions that surface in your immediate reaction to it. What do you think caused your reaction to this quote? How can you work to address the underlying sources of your reaction?

15. “Workers may come and say, your child is disabled. There's 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.”—Carrieanne Ford Tompkins

Many of the survivors in the video discuss the consequences - and even dangers – of being labelled with an intellectual disability. Do you think it is still dangerous to be labelled with an intellectual disability today? Why or why not? Try to use specific examples (you may want to reflect on topics such as the social and personal impacts of labelling for both survivors and their families, abuse, bullying, employment, education, discrimination etc.).

16. “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.” – Victoria Freeman

Many of the survivors in the video are presently engaged in artistic endeavours. Why is it important to take seriously the art created by people labelled with intellectual disabilities? Is there space within your work or residence to encourage the creative and artistic expression of people with intellectual disabilities?

17. “We're no different than any one of you. We're the same. Only we have - we need to learn a little more slower.” – Harold Dougall

Why do you think so many of the survivors in the video reinforced the message, “We’re no different from you”? What do you think they were hoping to accomplish by reinforcing this message?

18. “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’. When I look back on that time now, I think he was grieving, seriously grieving. And nobody recognized it. - Colleen

Colleen recounts the harm done to Gerry by staff people being unable to recognize his distress.

- a) Can you think of a time in your life when you might have invalidated the emotions of someone with an intellectual disability or assumed you knew the reason for their behaviour? If you could go back to that time, how would you respond differently?
- b) What can you do to work to make sure you do not trivialize your clients’ experiences and emotions? How can you better respect emotions expressed through behaviour or non-verbal communication?

19. “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.” – Joe Clayton

- a) Both the survivors and siblings in the video described a variety of institutional practices - ranging from outright abusive to seemingly benign practices - that contributed to survivors’ oppression and long-term trauma. Can you name any approved practices you have been trained in, employ yourself, or see colleagues applying that remind you of such institutional practices and/or make you feel uneasy?
- b) Why do you think these actions, strategies, or approaches make you feel uncomfortable or are potentially oppressive to the people you work with?

- c) What are some alternative strategies you can employ instead of the ones you listed above?

20. “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.” – Colleen Orrick.

- a) Colleen explains that Gerry was institutionalized in part because this was the only way he could access an education. Where do you see systemic injustices in current society that prevent people with disabilities from accessing the services, livelihoods, and supports to which we are all entitled? (You might think about school, meaningful work, adequate healthcare, recreational activities, etc). What reasons are used to justify these barriers?
- b) How do these barriers prevent people with intellectual disabilities from experiencing self-determination and autonomy in their lives? (Recall Madeline Burghardt’s early comments in the video about how survivors were forced to assist in the upkeep of the institution by performing tasks like laundry).

21. “Freedom, to me, is a hard thing to say. I'm still trying to work with freedom...I like my freedom, even simply to go out to the park.”—Carrieanne Ford Tompkins.

“The first that I got [to say] ...’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 my—that’s my favourite person.” – Harold Dougall.

Many survivors repeatedly used the word ‘freedom’ in their narratives.

- a) How do you define freedom for yourself?
- b) How does your definition of freedom relate to, or differ from, the kinds of definitions mentioned by survivors? Why might that be?
- c) How do you think your clients might define or understand freedom for themselves?

22. “[It’s] important to other people with disability to build community and a relationship”. –Carrieanne Ford Tompkins.

How can you help cultivate relationships and community among disabled people through your work?

23. “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 it.” —Joe Clayton.

Each of the survivors in the video described how they have thrived since being freed from institutions and given the chance to live in their communities with the necessary supports.

- a) What barriers continue to exist that prevent people labelled with intellectual disabilities from living the life they want to live? How can these barriers continue to be broken down?
- b) What do you do in your work to help foster the self-determination of disabled people in different aspects of their lives?