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Survivors and Sisters Talk About the Huronia Class Action Lawsuit, Control, and the Kind of Support We Want

[Authors' note: This was written in the Fall of 2014 as class members approached the deadline to submit claims forms. A year later, compensation cheques have now been sent out. Pat and Marie have travelled to communities across Ontario to share, listen and support other survivors navigating a painful process as best they could. As lead plaintiffs, they hoped the Huronia Class Action Lawsuit (HCAL) would bring recognition of the horrors (and errors) of Huronia and some level of closure. Instead, their experiences with lawyers, frustrations with the claims review process, disappointment with a cold justice system and ongoing government disregard have left a bitter taste. There have been issues throughout from the settlement wording and missing addresses, to criteria used to determine how compensation was awarded (with misunderstandings over sexual consent and neglect), right up to how cheques were dispersed. There are outstanding concerns about the allocation of remaining funds and who will decide. A follow-up article will examine the necessary conditions for survivors to be heard, believed and above all to receive justice.]

Pat: We will continue to tell our stories and not keep quiet about what has been unfair. We want the truth to go viral.

Marie: We have more courage now. People will need support to share their stories in whatever ways they are capable. It's like how some of us are working together with the cemetery: we see it the way it is, we can see the way it needs to be, and we will not stop until things are made right.

Abstract

*The purpose of this article is to explore the impact of the Huronia Regional Centre class action lawsuit against the Province of Ontario from the perspective of the two women who brought the case forward. Inspired by a belief in **Nothing About Us, Without Us**, this paper reflects the lived experiences of two survivors in conversation with a sister who has supported them throughout the process and another sister in search of supports for her brother to live well in the community. Their discussions reveal some of the ways that the persistent lack of control, power imbalances, and poverty limit their potential and make them vulnerable to different types of abuse.*

On December 3, 2013, a \$35 million settlement¹ between survivors of the former Huronia Regional Centre² in Orillia and

1 <http://www.cbc.ca/news/canada/huronia-regional-centre-lawsuit-ends-in-35m-settlement-1.1857506>

2 Operated from 1876 to 2009; originally called The Orillia Asylum for Idiots, then The Ontario Hospital School (OHS), then Huronia Regional Centre (HRC)

the Ontario Government was approved by the Ontario Superior Court of Justice, followed six days later by an Ontario Government apology.³ Much has been published about this historical event in the media, less so in academic publications (Rossiter & Clarkson, 2013), and none yet from the perspective of class members. This article provides an opportunity to learn from the two women who brought the case forward. It reflects their lived experiences in conversation with a sister who has supported them throughout the process and another sister in search for supports for her brother to live well in the community.

Method

Participants

Patricia Seth and Marie Slark spent many of their early years at the Huronia Regional Centre (HRC) in Orillia, Ontario. They began the class action as adults, with the support of long-time friend and former social worker Marilyn Dolmage and her husband Jim. Pat lives on her own, and is a passionate speaker with special interests in politics and natural health. Marie works part-time at Winners, lives in her own place, takes care of a cat and a puppy, and is a creative textile artist. Leah and Josée approached them to write the article together. Leah's Uncle Robert⁴ (1950–1958) never knew his family and died at HRC. A generation later, Leah's older brother Matthew⁵ (1974–2004) was a catalyst for inclusive education, supported employment, and direct funding in Ontario. Leah is a community facilitator who works with advocates, families, and community groups in her job as a communi-

ty worker. Josée has worked collaboratively with institutional survivors and People First members to create *The Freedom Tour*, a documentary film about institutions in Canada's prairie provinces, many of which remain open (Rattai et al., 2008). She is now a PhD candidate at the University of Ottawa. Her research will explore the process of supported decision-making. Leah, Marie and Pat are also part of Remember Every Name⁶ a community group of survivors and allies who are working to restore respect to those who died at HRC, where over 2,000 people are buried in the cemetery⁷: approximately 1,440 in unmarked graves and approximately 470 with a numbered marker (Alamenciak, 2014; Bell, 2014; Oved, 2015; Petroni, 2015).

Procedures

Our method is inspired by the disability rights movement motto *Nothing About Us, Without Us*.⁸ Leah and Josée formatted the article, coordinated meetings, took notes, asked questions, and brought the ideas together but Marie's and Pat's words take centre stage. Through careful review of the draft, Pat and Marie ensured it accurately reflected their perspective. The importance of presenting research in ways that are accessible to people outside academia has been recognized within the field of disability studies (Barnes, 1996; Walmsley, 2001; Zarb, 1992), learning disability studies (Goodley & Moore, 2000) and beyond (Hooks, 1994; Olkin, 2004).

It is important to explain our choice of personal storytelling. Stone-Mediatore (2003) explains why experience-based stories have intellectual value:

... the epistemological virtues of living in a socially or culturally marginalized position include, for instance: a daily experience with the obscured costs of social contradictions, a shifting in and out of cultural worlds,

3 See: http://www.mcss.gov.on.ca/en/mcss/programs/developmental/Premier_Apology.aspx

4 *Wee Robert's Song Lyrics* (2013): [http://www.canadashistory.ca/Magazine/Online-Extension/†The Kilts, "Surrounded by This Whole Huge World," Wee Robert, audio recording \(March 8, 2014\):](http://www.canadashistory.ca/Magazine/Online-Extension/†The-Kilts,-Surrounded-by-This-Whole-Huge-World,-Wee-Robert,-audio-recording-(March-8,-2014):) <https://myspace.com/diabolodust/music/song/wee-robert-95261475-106107568>

Dolmage, L. (2013). Questions for my mum's little brother (Uncle) Robert [Poems 1977, 1987, 1997].

Council of Canadians with Disability: Honoring Tracy Latimer. <http://www.ccdonline.ca/en/humanrights/endoflife/latimer/1997/11f>

5 Dolmage, M (2007, February 20). Disabled need individual funding. *Toronto Star*. http://www.thestar.com/opinion/2007/02/20/disabled_need_individual_funding.html

6 Remember Every Name: <https://www.facebook.com/groups/678154892233525/>

7 The cemetery rests on the ancestral lands of Iroquoian and Algonquin speaking peoples; the traditional lands of the Huron-Wendat (Wyandot) and the Petun; and the ceded land of the Anishinaabe.

8 James Charlton wrote: "I first heard the expression *Nothing About Us, Without Us* in South Africa in 1993." He added that this slogan "resonates with the philosophy and history of the disability rights movement (DRM), a movement that has embarked on a belated mission parallel to other liberation movements" (Charlton, 1998, p. 3).

an engagement in activities that defy the dualisms and exclusions of received analytic categories, and a resistance to the social relations that ruling beliefs present as "natural." (Stone-Mediatore, 2003, p. 184)

In other words, the perspective of survivors and the expertise of their lived experience is necessary to understand deinstitutionalization and the contemporary impact of legal battles such as the Huronia class action lawsuit (HCAL).

Our choice to work collaboratively to tell stories was necessary because, as Walmsley (2001) put it

Whilst disabled people can and do conduct their debates without reference to members of the oppressing groups, people with learning difficulties still rely on a team approach, and few have been able to argue that without this team approach, people with learning difficulties would be in a position to research and publish. (Walmsley, 2001, p. 200)

Josée and Leah transcribed Marie's and Pat's exact words during the conversation and they all re-read the text together asking questions such as: "Is that what you meant?" and "Was there anything else you wanted to say?" During this back-and-forth writing, reading, and re-writing process, Pat and Marie requested plain language translations for certain passages. Working this way made sure everything was correct, which was especially important since we live in two cities, one of us has limited mobility, and an excited puppy and children were running around us during our conversations. Our tools included Skype, speakerphones, a car, public transportation, and two laptops (Figure 1).

Results/Stories

On September 25, 2014, Marie hopped on the bus and headed to Leah's apartment. In Ottawa, Josée kept her kids busy so she could sit down with head phones to Skype. Pat waited at her apartment for them all to call. Leah typed the conversation on a second laptop.

Josée: How did the lawsuit against the province start?

Marie: We heard about the Residential Schools.⁹ It sounded a lot like what we experienced at the institution. Jim and Marilyn asked some lawyers whether we had a case, and they came

9 For First Nations, Inuit, and Métis children

over and met with all of us. We were afraid at first because we thought if people knew we had been in there, we would get treated worse than we already were.

But it didn't turn out that way.

Josée: What were some of the challenges you faced?

Pat: We were not part of it all the way through. Our lawyers did things behind closed doors. We would have liked to be part of all the negotiations when it came to settlement. We only had one day to negotiate everything. When you have an intellectual disability it feels like most people don't care about our opinion, especially if you are poor. And most of us live in poverty.

Marie: We know what it's like to be intimidated. To have authority figures over us.

Josée: Has this lawsuit changed anything for you, in your life?

Pat: It is part of the settlement that we will be believed about all the abuse that happened to us and that we saw. I don't know until I get my claim back. Every little bit helps but \$2,000 wouldn't change much for me. What an insult.

Josée: It's certainly not enough to get you a better living situation.

Marie: Well, we get more respect than we did in the past, like from people in the presentations we have done.

Pat: And in the media and in social media.

Leah: What are your thoughts about the tours,¹⁰ and meeting other class members and supporters?

Marie: I think it was good that they were able to tell their stories without fear. We supported each other. When we were there as kids, we were all afraid and it was hard to support each other because the staff had total control. We had to do what they said, the way they said it, or else. Like when they would say "medicine girls" and call us all by our last name, like an order. **We were told and not asked.** I didn't know it then but I

10 Mandated in the settlement and organized by the Ontario Ministry of Community and Social Services, the terms required that the former facilities be re-opened for access to survivors and their supporters on six occasions between April and October 2014. Some areas in use by the Ontario Provincial Police were inaccessible, as well as places designated off-limits due to safety concerns.

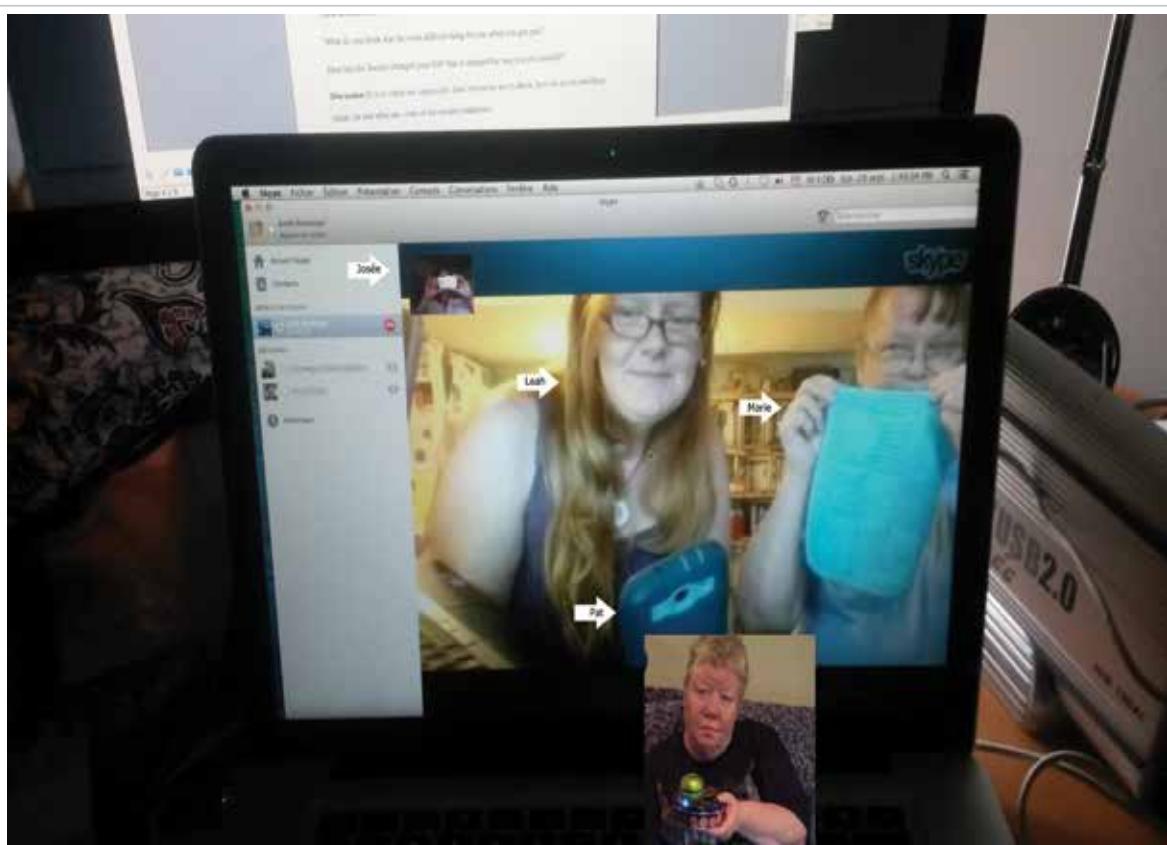


Figure 1. The four authors working together on this paper

The photo centres a laptop open on a desk in front of a larger screen that is open in the background with text showing at the bottom. The desk is part of Josée's home office where Skype is open on her laptop screen, and shows Josée with her cell phone taking a picture of the laptop screen (small photo in the top left). The laptop screen shows the Skype video from Leah's apartment, with Leah (red hair and glasses) holding a laptop up in one hand and a turquoise cell phone in the other. Beside Leah sits Marie (brown hair and glasses), proudly holding up the turquoise crocheting she worked on while we met. Pat contributed from home via speaker phone. A picture of Pat (with short hair) holding up a speaker phone is inlaid below the turquoise cell phone to show her contribution to the conversation. Small arrows point to each author with their name.

know now I got put on anti-psychotic medications. I think they did that to control me. I was eleven years old and I was saucing the staff back.

Pat: We went up [to HRC] and they had four tours each day.¹¹ They only gave us 90 minutes

¹¹ With only a few weeks' notice, and no consultation with survivors, two of the site access days in August were open to the public with a limit of 50 people per "tour." All "tours" were full. At a later site-access date, almost 50 supporters from Toronto area self-advocate networks were guided through the buildings in small groups led by survivors. One of the last visits was also open to researchers and academics and involved limited and pre-approved access to "artifacts." After each of the 11 days, people gathered informally in the cemetery to connect, reflect, and pay their respects.

and only showed the good parts. They didn't explain what it was really like for us.

Josée: *What would you have wanted people to see?*

Pat: I would have wanted to take people to the pipe room, to tell them about the punishments, and the side room – that was a punishment too. I would have showed them the hopper and what they did when they turned me upside down and put cold water on my face so I couldn't get air into me. They just gave the sugar-coated version.

Josée: *How is your life now?*

Pat: A lot a better now, compared to then, but it can still be like hitting a brick wall, trying to get

myself into a better place. I live in social housing and I get ODSP [government disability pension] which is \$931 each month. If I didn't have a subsidy, my cheque would barely cover rent. I would have to go to soup kitchens to eat every day. It's also frustrating when the workers pass you around. That's what gets me upset. Try this and try that and you just get a machine. Nobody answers, and there's no help. The system is hard to navigate and even harder when you don't have any support. Unfortunately, professionals are who you have to deal with if you have other areas in your life that you need help with.

Josée: What does "professional" mean to you?

Pat: It comes across as them being better than us. It comes across that we don't know better and we can't think for ourselves and that's not true, the feeling that you're incompetent.

Marie: You know Pat, I agree.

Pat: Another thing I don't like is that even people who help us can be an authority figure. It is hard to stand up to people who are being good to you. Sometimes I make enemies because I allow people to control me. When I do get mad I have waited too long. I should know when to say sooner, "I don't like the way you are talking to me. You are sounding authoritative."

Marie: Those who think they are better than us because they can do things that we can't, don't they ever seem to stop and think this could be them? They could get in an accident or become vulnerable, or have Alzheimer's or dementia, and they could get abused like we were.

Josée: I've been learning about formal individual support networks such as an Aroha.¹² It is a minimum of four people who you know, who care about you, and they agree to support you and to help you make decisions. As a group, they might help you find

12 (a) For more information about Arohas as person-directed entities of support, go to: <http://aroha1.blogspot.ca/p/stories.html>

(b) For more from Andrew Bloomfield, originator of the Aroha concept in Ontario who has also written extensively about community, communication and relationships. see: Bloomfield, A. (2012). What everyone yearns for: The Ontario story of bridges-over-barriers. *Canadian Journal of Disability Studies*, 1(2), 2012; <http://cjds.uwaterloo.ca/index.php/cjds/article/view/46/53>

a better living situation, make new friends, volunteer, or find a paid job. What do you think about that?

Pat: How does a person do that? I don't have anybody to help me with something like that. Everybody's busy. I don't want to try anymore. I'm tired of banging my head against the wall and not getting anywhere. You just accept that it is what it is and leave it at that.

Josée: Yes, I know what you mean, my mother feels like that, but I still have some energy to try and do something to help my brother.

Pat: I worry about if something really bad happened to me, who would bail me out. They think we are dangerous if we get upset. I don't want to be talked down to, so I don't ask for help.

Marie: I think if you went to somebody who was a friend they would be willing to try and help.

Pat: They can't help me get better housing. There's a big waiting list.

Marie: Yeah, but they might be able to do something.

Pat: I disagree. They could help me get on the waiting list, but I still have to wait ten years. We did all these sessions to educate people. We wanted to change things, but it feels like it isn't even making a dent.

Josée: You don't feel that it has?

Pat: It feels like the government is doing a backlash, but they don't see it that way, like they are not there to help you, they are just there to discourage you and tell you they can't do nothing for you. That's what you call red tape. There's so many changes, and so many rules. I can't even get an APSW because I don't want to go to the DSO (the Developmental Services Ontario office).

Josée/Leah: Why?

Pat: Because of its history. It scares me. Surrey Place used to be an institution at some point.¹³ They sent me papers but I don't want to go

13 The residential aspect closed in 1988, according to <http://www.institutionwatch.ca/iwupdates-app/prov.Ontario>

through all that just to be on another waitlist. If I can't get a worker without doing it, then I will deal with that if I cross that bridge. It still feels like an institution.

Marie: Someone I know was told, "We only deal with people who function at 2% below the population." So even though this person was in the institution they didn't want to help her. What if nobody would hire her and she had no income?

Pat: I was told that too, and I don't want to go through that.

Discussion

Pat and Marie raise the issue of lack of control in important decision-making processes, lack of financial resources, and the inadequate support they continue to experience. At the same time, they have become increasingly strong advocates who have tried to create supportive opportunities for others to share their experiences as survivors of Huronia and other institutions. In the following discussion, we talk about the kinds of change, and types of supports, that could address this lack of control.

Leah: *What do you think still needs to change?*

Marie: I think people need to listen to us more. They should know what went on in institutions and that we are telling the truth. Help us more. The more challenged a person is, the more help they should get, and not just hide them away. People should be in a home of their own choosing, close to their friends and family.

Pat: Or away if they treat you badly.

Marie: They should get the help they need to be in the community and not be ashamed to be seen. They are human beings for Pete's sake. That could happen to anybody, they could have children of their own like that, or get old and wind up like that, unable to walk and all that.

Pat: You should be able to get emotional support and not have a worker who will just talk down to you, and boss you around. I would like to see more affordable housing. Put the amount back onto our ODSP cheques that was cut in the Harris years. But they keep cutting more and

more! I want someone to meet with for coffee and talk about the things going on in my life.

Josée: *What other kinds of help do you want?*

Pat: I think there are better ways, like individualized funding, to go do things and live comfortably, but big agencies get a lot of the money for their overhead. It's not right. People should be able to look after themselves out in the community instead of giving it to all the agencies. It's like they don't trust us. If you have that label, automatically they assume we don't know how to look after ourselves and would spend the money unwisely. Instead of having to live where they tell you to live, you should be able to take your subsidy or your funding with you wherever you want to go. I feel like the politicians and the majority of professionals are not really listening.

Marie: What about people that are not as capable? Some people I know are in group homes because they need more help and they can't do things for themselves.

Josée: *When I lived in Winnipeg, I met Catherine Schaefer.¹⁴ She needs support to get out of bed and to eat, and she doesn't use words to communicate. But, she has lived in her own shared place for over 30 years now. We can learn from her and others who are doing it. I would like my brother to have better supports. He should have the right to have control over his life and to get support to make it happen.*

Marie: Your brother should have the right to choose who he wants to give him the help he needs to live the life he wants to live. Not like how the staff treated everybody in the institution like children, and are still doing that to some degree.

Pat: It is angerfying.

Marie: Aggravating.

Leah: *What do you want other people, particularly professionals to know?*

Pat: Instead of looking down at us, like we are low on the totem pole, support and encourage

¹⁴ Video interview with Catherine, her mother and her cousin: <http://www.youtube.com/watch?v=vQbaJEVqvY8>

us. Try to be of help. We don't need therapy, we just need to communicate on an equal level and have an understanding on an equal footing.

Marie: They should help us to do the best that we can. It might not be the same as everybody else but let us do what we can do.

Marie: [Directed to lawyers, people in government, claims administrators, or anyone in developmental services, health care professionals, housing etc. who has a job making decisions about the class action or which impact the lives of survivors] How can they decide what we need? We know what we need better than they do. How can they decide for us? They haven't been through it, nor will they ever.

Our discussions revealed that the relationship between people who have been labelled with an intellectual disability and developmental service professionals and agencies is damaged, especially for people who lived in an institution. The problem is systemic and has deep roots. It is a manifestation of

social arrangements that put individuals and populations in harm's way...The arrangements are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people (typically, not those responsible for perpetuating such inequalities). (Farmer, Nizeye, Stulac, & Keshavjee, 2006, p. 1686)

What Pat and Marie have shared is the tip of an iceberg of a much larger conversation about the abuse and violence they have experienced, witnessed and continue to live with and hear about. Despite overwhelming feelings of powerlessness and fear of further abuse, they chose to put themselves and their stories forward, at great effort and personal cost, because they don't want anyone to have to go through what they went through. They have wanted to change things for the better. They are left wondering how much has changed for people who are vulnerable, whose lives are still very controlled by others? What is changed in those who hear and witness their and many similar, personal stories? What still needs to change?

Conclusion

There are a few cracks here and there in institutional thinking¹⁵ but the foundation still stands. A legacy of inequality within social conditions continues to make labelled people vulnerable to isolation, abuse, and feelings of hopelessness. There is no shortage of current examples of violence in the lives of people labelled with intellectual disabilities. The difference now is that a growing awareness exists in the public sphere, and a precedent has been seeded to believe and acknowledge the trauma and injury caused by institutions. Community driven support that creates opportunities for mutual relationships and shared power, as described by researchers here, is one way to begin to address the harm. The process of deinstitutionalization is far from over. By confronting the systemic power imbalances that are knotted within institutional thinking, we may yet collectively uproot it.

We looked at the HCAL from the perspective of the two lead plaintiffs. Some positive effects have been: opportunities to connect with other survivors; the chance to educate agencies, families, and the public through presentations; increased confidence; and being asked to contribute to work that speaks directly to professionals. Going public with their experiences supports notions of storytelling that build inclusive advocacy practices:

Storytelling ... fosters shared power and mutual recognition; creates opportunities for openness, dialogue, and insight; and brings issues to consciousness. Storytelling is sometimes a means of resistance and the journey to social justice. (Senehi et al., 2009, p. 96)

However, Pat and Marie also revealed their frustration with the lack of fundamental

¹⁵ "An institution is not just a place, it is in the way that people think" – Pat Worth, People First: *Dare to Dream*, published on Inclusion Network. <http://www.inclusion.com/respatworth.html>.

At <http://www.peoplefirstofcanada.ca/priorities/the-right-to-live-in-community/> People First of Canada defines an institution as "any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise, control over their lives and their day to day decisions. An institution is not defined merely by its size."

change they hoped for. Processes of deinstitutionalization include, among other things, participating in social change. This happens when people come together and build meaningful connections, whether through the courts, in services, or in our communities. We hope the words of Premier Kathleen Wynne's apology¹⁶ will be taken to heart by everyone, with the recognition that a lot of people are still limited by power imbalances and a lack of control. This lack of control, according to the lived experience of it, is directly related to negative attitudes, abuse of power, and lack of access to money and the necessary supports. We can close down all the institutions we want, but the mindset that created them persists. We still have a long way to go. People want to choose and shape supports in their lives that respect their strengths, enhance their relationships, and maximize their potential and contribution.

Pat and Marie: Yeah. Help us figure out what we want to do and how to do it; where to live and be happy and have a good job and supports. Demand more housing and more social assistance. More individualized funding. More rent geared to income housing. Continue to help us in the community, and expand into the community.

Key Messages From This Article

People with disabilities: Your life matters. You should be setting the agenda for policy, research, and respectful support to define what is important to you to have a good life in the community. Come together with others to discover and cultivate your talents and express your needs, recognizing that interdependence is powerful, and every time you do this makes it easier for the rest of us to do so too.

Professionals: Your role is to listen and support people to increase the control they have in their daily lives and their ability to contribute to the community and communicate. This requires: self-reflection and open collaboration; asking rather than telling; continuously presuming competence and promoting strengths and meaningful person directedness; always acting

from a place of the least dangerous assumptions; promoting the dignity of risk; minimizing tokenism; increasing opportunities for real accountability; actively seeking the redistribution of resources where necessary; and power sharing organizationally with the people you support. In your roles with survivors of institutional and other forms of violence and abuse the work you do needs to be trauma informed. Be open to change and allow yourselves to be moved. Also admit what you don't know and acknowledge what you have learned and gained from the people with disabilities who you interact with professionally as well as personally.

Policymakers: Your role is to listen for whether the most equitable and just questions are being asked, and ensure that the policies you propose are inclusive of and responsive to the people who they impact/implicate, so that the policies you adopt are based on just practices and research that is conducted in ways that are respectful of the lived experiences, wisdom, and priorities of people living and labelled with disabilities. Deepen and help spread this knowledge within the wider community.

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16 A video version of the apology can be found at:
<https://www.youtube.com/watch?v=WUMUyLKbHJg>

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