



Launch of

Toward Recovery and Wellbeing: A Framework for a Mental Health Strategy for Canada.

Reflections by:

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INTO THE LIGHT CONFERENCE

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Good morning.

I have been asked to speak to you as someone who lives with a mental illness and who has had the privilege of helping to develop this document from the start. It is a chance to reflect on this document in a different way, through the lens of my experience and to explain to you why I think its goals can make a difference.

Before I start, I want to make it clear that I am giving my personal reflections. I am not speaking as the Commission. Not as part of an association, nor a consumer group. I can't pretend to represent the viewpoint of all people living with mental health problems and illnesses.

I want to stress that in no way is my story unique. There are hundreds of other people in this room who live with a mental health problem or illness and could be giving you their perspectives on the framework document. And there are thousands of people outside this room who could do so. Some of those stories are far worse than mine, others a bit easier. But that is not the point.

The point is not about finding differences, but finding commonalities. I hope this is a message that everyone may find meaning in. There is so much I could speak to in this document, but I only have 20 minutes. So what I would like to do is briefly touch on each of the goals it contains and reflect on how, if they had been achieved when I first became ill, my experience might have been easier.

I joined the mental health strategy team in February 2008. The team at time was composed of Howard Chodos and me. We sat at the boardroom table in Ottawa and said, "So, we have to write a mental health strategy for Canada." We scratched our heads and wondered where to begin.

I had some qualifications, a PhD that looked at mental health policy and service delivery in Canada. I had training in health economics and health policy analysis and had applied that training to the mental health sector in Canada for one reason: like many people who are passionately involved in this work, I had firsthand experience of major depression and had also met so many other people like me, that I wanted to change the way mental health and mental illness were viewed in this country, and get people they help they needed.

Who were these people? My girlfriend Dianne, who I met in hospital and later at our daughter's preschool and who has been my 'touchstone' as we both journey toward recovery, and my niece, who was oxygen-deprived at birth and now has symptoms of different disorders, none of which completely fit. All the women who helped me in my postpartum support group, or who I helped as a peer 'telephone buddy' and support group 'co-facilitator'.

And more recently, the three teenage girls in grade 12 at my son's high school in Oakville who committed suicide last year. ...Three students, one high school, one year... And the student who committed suicide at Ottawa U this past September, when my daughter was a 101-week volunteer. This is a time that is supposed to be full joy and excitement and fun, a first taste of freedom. My daughter called me frantically, saying she and the other volunteers needed advice on what to tell the other students. I didn't have the answers.

My boyfriend and his friends who grew up during the Troubles in Northern Ireland and now meet down at the pub to help each other cope with their undiagnosed post traumatic stress. Most of them are self-employed in the building trades and have no coverage for psychological counselling and can't afford to pay for medication.

It was pretty clear to me that I was not alone in my experience.

It was also pretty clear that what I had learned during my undergrad and master's in economics was not terribly helpful in figuring out how to get people the help they need, how to change the system so people actually get better faster and to change how we think about mental health and mental illness.

So I went back to school for a PhD, to see what could be done about all this. I figured I'd been given a particular background in economics and policy and I might be able to help to bring this issue to the attention of policy-makers.

This document is a first step in the collective journey we are taking to try to do just that.

Goal One

The first goal recognizes that helping a person recover from a mental illness is not always easy. It is rarely as simple as walking into a doctor's office and being given the magic pill that will make it all better. This goal encourages us to look across the lifespan and recognizes that recovery is a journey – a journey of hope.

It is a journey taken by an individual within their context. It depends on where a person is in their personal life journey – whether they are a child, an adult, an older person - and within their family, school, work and community contexts. Mental illness strikes right in the middle of 'real life' - it doesn't get put on hold.

And like all journeys, it begins with small steps. There will be times where progress will be quick. There will be setbacks and detours, and times when we need to pause and as my GPS says "recalculate."

In my own case, mental illness struck me out of the blue, in the form of a postpartum depression after my first child was born.

Depression was to reappear after the birth of my second child and later and even more acutely after the loss of a third child due to a late miscarriage.

After that, as they say - it's all a blur, but simply put, I lived with depression, and suicidal ideation every day and struggled to find a treatment to help me for about two years. After that, my real journey of recovery, the one where I was an active participant, was to begin.

The term 'lived with' is important. As a stay-at-home mom, I continued to be the primary caregiver of my two young children throughout.

I had two voluntary hospitalizations because I was feeling so suicidal I was afraid I would act on it, and another hospitalization which was the result of a severe allergic reaction to the drug I was given. That last hospitalization – because of the allergic reaction – made me miss my son's third birthday party.

My neighbour once joked that I might as well get a pharmacology degree and make it official, as I could prattle off all the names of the twenty different medications I was put on and taken off, sometimes individually, sometimes in combination; the four or five diagnoses I was given, each with its own acutely painful associated stigma; the lived experience of being taken off drugs by psychiatrists 'cold turkey,' and going through three week dry-out periods because my depression was so severe, they just wanted to get me on the next drug as quickly as possible, without taking the time to taper.

All this, without giving me any warning of just how severe the withdrawal could be, or preparing me to get help with caring for my children.

If I had known that recovery was a journey, and that I could be an active participant in that journey, I would have had much more hope and not felt like the victim of my own chemistry.

I would have been taught the ways I could help myself, by journaling, using affirmations, and encouraged to find other ways, like taking walks in nature, practicing meditation, listening to inspirational tapes, staying 'in the now', being good to myself and yes, finding ways to have fun.

I would also have felt more comfortable as I eventually sought out non-mainstream treatments that were highly effective in releasing the pent up stress in the muscles of my body – like network spinal analysis or NSA – a new form of very gentle chiropractic that teaches the brain to identify where the body is holding tension and to release it; and Reiki, a form of energy healing, similar to therapeutic touch, that invokes deep relaxation and can help to release blocked emotions.

Instead, I was told it was strictly a problem with my brain chemistry. No one explained that there would be trial and error, and that I could get supports to help me be a better mother as I went through this. And certainly no one seemed to think that my own insights could be important.

Goal Two

If Goal Two had been in place when I was a child, I might not have missed important opportunities to learn how to take care of my own mental health and develop resilience. There might have been more

attention paid to how I was coping at critical junctures, like when my baby sister died when she was three days old and I was three years old. Perhaps the sexual abuse I experienced at a neighbour's would have been addressed.

But instead the psycho-social aspects of my depressions were not considered – the fact that I felt inadequate as a mother and petrified that I might unintentionally hurt my babies.

No one considered my sister's death, or the fact that I had failed in what I had somehow seen to be my responsibility – to break the family curse of losing the third child when the second child – a daughter - was three years old; as my mother had, and as her mother had. This was something I desperately wanted to spare my own daughter. And I certainly wanted to know how to get her help quickly and what would work, if she ever went through what I did. This is really what propelled me to keep searching for ways to get better.

Goal Three

If goal three had been in place, my sex and gender would have been considered. There would not have been so many different drug changes, if the hormonal swings associated with my menstrual cycle had been considered. Instead it was assumed that my pattern of starting a new medication, seeming to respond tentatively, then having it stop working a few weeks later, with a drastic drop in mood, hope and self-worth, and acute suicidal ideation, was a failure of the medication. Or that perhaps I was bipolar, treatment resistant, or had a personality disorder. This is only now just beginning to be recognized.

Similarly, there was little recognition of gender: that I was a new mother and felt like a failure. That I was terrified of hurting my babies, because in my experience, new babies could just die for no reason, and somehow I believed I was not worthy to take responsibility for a baby.

Goal Four

If goal four was achieved, my husband and family would have been told how they could help. Instead they were pretty much left in the dark, with my parents getting emergency calls to drive from Ottawa to Oakville to help out with the kids.

My dad – an engineer - used to go to the library – this was pre-internet days – to read whatever literature he could – to try to understand what had happened to the daughter he knew. Despite their efforts, there was only one meeting where my mom got to speak to my psychiatrist, and then he really just explained why my family could not be more involved.

My kids were kept informed mostly by me. I tried to explain to them what was happening whenever it seemed needed, in an age-appropriate way – as best as I could figure. I tried to pass on what I was learning about healthy coping and healthy relationships to them, to help them through life. Only time will tell how well I did, with the support of my family, but I am encouraged to say that so far, they are absolutely delightful, intelligent, capable young adults.

Goal Five

If goal five had been in place, well it all might have been so different.

If the doctor I went to see after my daughter was born, had not dismissed my concerns and told me that all I needed was my mother, then maybe I would have got the treatment, support and understanding I needed. Maybe there might not have been a next time.

Maybe I would never have got to the place where I truly believed everyone would be better off without me. A place where I was so paralyzed with shame that I was unable to pick up the phone, to call my doctor's office for help. Maybe I would have been helped sooner. Maybe I might not have become so filled with self-loathing as to have attempted suicide.

Maybe I would not have spent the next five years in psychoanalytically-oriented, psychodynamic psychotherapy which helped me come to terms with that suicide attempt and everything I had been through.

I might never have had the fear of my kids finding out what I had done. I would not have the flashbacks of the wave after wave of panic, when I was unable to feel my own feet, of vomiting up the charcoal I was given to absorb the medication I had overdosed, in the lobby of the local hospital as I was wheeled from emergency to the Intensive Care Unit, of hearing the ICU nurse explain to me that she spent her time trying to help people who wanted to live, and that she really didn't have much time for people who wanted to die.

Goal Six

If goal six had been realized, there would have been more funds for research, maybe some of it looking at the half of the population that happens to be female. Maybe the effect of hormonal change on drug efficacy would have been researched, rather than excluded as a complicating variable.

Later, maybe I would not have felt so exposed as a researcher and as such a 'lone voice' when I applied for grants for mental health services research, only to be turned down by funding agencies.

Goal 7

And finally, if people living with mental health problems and illness were fully included in society, I would not have been petrified that my children would be taken away from me when my husband and I separated. I would not feel guilty that I should have fought harder so that my children could have a primary home with me - although their father is an excellent father - rather than shuttling back and forth between us every week or two.

Maybe I would have been free of the shame that haunted me all those years, and further fueled my depression. Maybe I would have met other friends who had 'been there' and could help me normalize what I was experiencing.

So, in reflecting on how these goals might have changed my experience, I believe there is much in this document to be hopeful about. There is so much that could have made my recovery much easier and quicker if these goals had been achieved.

At the root of this hope, is the understanding of mental health and mental illness that is presented in the framework's introduction and to me, is so critical to achieving the vision laid out in this framework.

The two sentences in this document that I am most proud of are:

“When it comes to mental health and well-being we are all the same. There is no ‘us’ and ‘them’.”

I say that as someone who experienced the psych ward more than once. As someone who has made friends with people suffering from all kinds of disorders, with all kinds of stigmatizing labels, like multiple personality disorder, dissociative disorder, schizophrenia, bipolar, and so on.

All of these people were experiencing extreme distress, in different forms. It came and it went. As did my distress. It really made me realize that we were all the same. It could happen to anyone. And it would happen right smack dab in the middle of life. Life didn't stop for any of us or for those around us.

So I want you to think long and hard about those two sentences I am proud of. And understand that we are all the same. It's not about one category or the other. Instead, mental health and mental illness or distress, are not static. They change over time. And people can and do recover.

I believe that if we can change this thinking there will be tremendous hope for transforming the system. Because I think the 'us' and 'them' thinking is what got us into the mess we are all in now.

For too long, we have separated people into two categories: mentally healthy and mentally ill. We enshrined it in policy when we created institutions to keep the 'them' away from the 'us'.

The policy was well-intended at the start – give people a quiet, peaceful place to recover, away from the stresses of everyday life. But it reinforced the stigma of mental illness and became incorporated in our collective mindset when it comes to policy making. It separated issues of mental health from the rest of the health care system and resulted in a situation of 'out of sight, out of mind.'

It also made it really hard for people to come together to make change, to form a lobby, to have a voice. To demand that attention be paid, to realize that mental illness is not off in some institution far away, but that it's all around us, that it's part of our community and our families and that it affects all of us.

We have come a long way. We have been closing institutions for years now, and we do believe for the most part that people should not be sent away. But we haven't broken the 'us' and 'them' thinking.

Instead we have created more and more categories of mental illness, and we have managed to create all kinds, levels and layers of stigma as a result. There's the stigma associated with schizophrenia, with bipolar, with being depressive or manic, of having a personality disorder, an addiction, of having a child with a mental illness and so on.

Layer onto this the stigma associated with the label of 'poor', of 'First Nations', of 'Inuit', of 'Métis', of 'immigrant,' of 'refugee', of being disabled or gay.

Sometimes labels are helpful. They help to get the attention of policy makers, to argue the need for change, or for more resources.

Sometimes labels are not helpful at all. They keep us working against each other rather than together.

But I think that the hope in this document lies in the recognition that we can use the various labels when it is helpful to use them and then put them away. The time has come to recognize that they can sometimes get in the way and polarize us. They can keep us from coming together to achieve Mike Kirby's vision for a social movement to get the attention of policy makers.

I hope we will all reflect on this statement when we leave this conference and go back to doing what we do. I hope that we will stop using labels to divide rather than unite us – whether the label be psychiatric survivor, consumer, psychiatrist, social worker, family member, nurse - all the many 'us' and 'them' labels that keep us working against each other rather than together.

Yes, we all need to fight to ensure that the voices of marginalized groups are heard, that diverse needs are recognized and responded to. But we must also ensure that the collective voice of all these groups is

loud and clear. Because it is only a strong, united, loud and clear voice that will get the attention of policy-makers in order to embrace the vision of this framework. Only then can its goals be realized for all people living in Canada.

Before I close, I want to finish, with another personal anecdote. A week ago Saturday I was undergoing the very strenuous task of standing at the kitchen sink and doing the dishes. It was a quiet Saturday morning. Suddenly, my back seized right across my mid-back to a point where it took my breath away and I had to immediately go and lie down. This has only happened to me once before – when I was going through the legal meetings with my husband and our lawyers to arrange our separation and custody. In both cases the muscle spasm lasted several days, until I went for the holistic treatments I mentioned earlier.

So, without any ‘evidence’, my lived experience told me that this was completely stress related and reflected an emergence of pent up emotion and pain that I had stirred up in preparing for this talk and going over old photographs. Happily, my previous experience had given me some suggestions about how to deal with it. I had less than a week to get better, so I could fly out here. The metaphor my body was trying to tell me was that it was “time to get this monkey off my back.” So, a lot of tears have been shed in the process of preparing this talk.

Sometimes I wonder if doing things like this is worth it. Will anyone really hear? Will it make a difference? I think the back spasm is a way of showing that yes, it does matter. Even if I think it doesn’t, my body is letting me know that I am still holding old pain around all of this.

So here I am...and I hope this personal reflection will help us to understand that sometimes it is all so clear if we will only stop to notice and then take the steps we need to take to deal. That is what recovery and well-being is all about. Taking back our personal power. Figuring out what we need to do. It’s not about never having a symptom again, it’s about dealing with it, taking the steps we need to take to keep moving ahead on the journey, sharing with those who can help you and accepting that help. Sometimes we really make this more complicated than we need to.

I would like to thank all the wonderful members of the Mental Health Strategy team – but in particular Howard Chodos and Mary Bartram, for truly hearing my personal reflections, embracing those insights

and trying to incorporate them in this document where appropriate. I think it was their willingness to listen and embrace that has led people to write to us and say things like “Thank you, this document moved me to tears.”

And now, I would like to thank all of you for listening to me today, for all the important work you do every day, for your support in the development of this framework, and for embracing these goals as we go forward to develop a Mental Health Strategy for all people living in Canada.

Thank you.