

# pathways for healing



a mental health  
and disability project

1995 Proceedings



Resource, Educational and Advocacy Centre for the Handicapped

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Conference Report  
Pathways for Healing  
Mental Health and Disabilities Conference  
1995

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# Conference Report

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## Pathways for Healing

### Mental Health and Disabilities Conference 1995

#### At a Glance

##### Summary of Conference

**P**athways for Healing was a conference dedicated to mental health promotion for people living with disabilities. The conference focused on the mental health impact of disabilities in four major areas: the individual, the family, career and workplace, and as it affects people living in Aboriginal communities. The conference addressed the current state of mental health of people with disabilities, identified needs and issues within this constituency and developed mental health promotion strategies. Pathways for Healing convened at the Westin Hotel, Ottawa, on 31 March 1995, and was hosted by Resource, Educational and Advocacy Centre for the Handicapped (REACH), Ottawa, Ontario.

The motto of the conference was stated in the following declaration,

Today ... we will not use labels or titles or credentials or diagnoses. Today we are not disabled, nor are we doctors, social workers, nurses or lawyers. Today we put the labels aside. Today we become healers who come together to share experiences, pains, accomplishments. We share new ideas and hopes about the future. Through sharing as persons, we learn and we teach. And most of all, we respect one another for who we are as persons, all different and all somehow the same. We are separated by our differences, and yet we are joined in the adventure of discovering pathways for healing ...

An estimated 140 delegates attended Pathways for Healing from across the Region of Ottawa Carleton, and included people living with disabilities and service providers from a number of related fields. A number of disability groups and agencies were represented. During the one day meeting, delegates explored the state of mental health, related services, resources and quality and care issues pertaining to the mental health dimension of disabilities. The conference focused on mental health promotion as a primary means for attaining the goals of equilibrium, wellbeing, effective coping, stress reduction, equity and life satisfaction for people with disabilities.

## Five Conference Objectives

1. To provide a meeting place for people with disabilities to talk about mental health, mental health needs, life goals and the barriers which prevent the achievement of life goals, and to discuss ways to achieve good mental health within the context of disabilities; to share success stories as well as problems and challenges
2. To develop mental health promotion tools that match needs, issues and goals with models, resources and services in the community; to identify gaps in services while working on ways to bridge gaps and solve problems
3. To address psychological, physical, spiritual and social dimensions of mental health and disabilities in order to form a basis for an effective and practical mental health strategy
4. To furnish an opportunity for networking and sharing information among professionals and others working in the areas of disabilities and mental health rights
5. To develop a list of recommendations for promoting mental health for people living with disabilities.

## Aim of This Conference Report

This Conference Report aims to provide a snapshot of the day we spent together at Pathways for Healing. We have included transcriptions of major speakers and panellists as well as bullet-point summaries of the workshops. It is our hope that this document will function as a mental health resource for individuals living with disabilities, and help to inform others about the mental health aspects of disabilities.

## REACH

Conference Host

REACH was conceived in response to the United Nations designation of 1981 as International Year of Disabled Persons. REACH's objective is to provide people with disabilities with an accessible legal service based on the concept of equality for all persons. REACH has a mandate of educating and informing persons with disabilities, lawyers, advocates and the general public about the rights and interests of persons with disabilities and of ensuring that they are provided with quality legal and social representation. REACH now services more than 5000 men and women each year, and has hosted other important conferences including its national Empowerment '91, Pathways for Employment Equity (1992), AIDS: The Changing Challenge (1993) and Death: A Question of Choice (1994).

## Honourary Patron

REACH thanks Mr. Patrick Watson for his role as Honourary Patron of Pathways for Healing. Mr. Watson is Chair of Canadian Abilities Foundation and past-Chair of the Canadian Broadcasting Corporation. Mr. Watson, who lives with a disability, is a recipient of the Order of Canada and an outspoken advocate on the rights and issues of the disabled.

## Appreciation

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REACH takes this opportunity to extend sincere appreciation to other conference funders, including AIDS Care and Treatment Unit, Health Canada; Status of Disabled Persons Secretariat, Human Resources Development Canada; Medical-Legal Society of Ottawa Carleton.

REACH also expresses its appreciation to Canadian Mental Health Association, Ottawa Branch and to Department of Continuing Education, University of Ottawa, for their support.

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## Introduction

### Mental Health and Disabilities

According to the World Health Organization, good mental health is a balance which people use to achieve potential, enter into meaningful relationships with others and participate fully in the community in which they live and work. *Mental Health for Canadians: Striking a Balance* (Health Canada, 1988) defines mental health as "The capacity of the individual, the group and the environment to interact in ways that promote subjective well-being, optimal development and use of cognitive, affective and relational abilities and the achievement of individual and collective goals that are consistent with justice and the attainment and preservation of fundamental equality."

The ability to cope with the stresses of a disability, the compound stressors in the environment and personal challenges are factors confronting people with disabilities. These factors can be seen as coming from four sources:

- The biological environment is the general state of health of individuals living with disabilities including treatment, quality of health, progressive features of disability and/or the potential for full or partial recovery.
- The psychological environment is the mental health state of the individual, and includes the ability to cope with stress and anxiety related to disability, personal beliefs and values, spirituality and the quality of emotional support the individual requires and receives.
- The socio-economic environment is the economic situation of the individual, and includes the ability to maintain quality of life, appropriate housing, financial support and security, income, employment security and a variety of equity issues including access to resources.
- The socio-cultural environment is the social world in which people with disabilities are situated and includes services and supports, the attitudes, values and beliefs of the community, the level to which the individual is accepted/rejected and the sense of belonging which the individual achieves within the community.

## Mental Health Promotion

Mental health promotion fosters development around self-worth, purpose, belonging, equity and other goals identified by the individual as significant to mental health. Subsequently, the objective of mental health services for people with disabilities is to facilitate the achievement of these goals. Mental health services potentially provide pathways to good mental health.

Negative outcomes arise when the mental health goals are frustrated, or when the individual is unable to attain them. Many individuals living with disabilities lack sensitive and equitable treatment in the workplace, the home, in relationships or within the community at large. Financial challenges, inadequate support mechanisms, communication problems, limited access to services and resources and frequently a negative perception of the disabled by the communities in which they live are examples of practical issues impacting the mental health of people with disabilities.

Higher levels of stress and the isolating nature of stressors confronting people with disabilities have a long term impact on the quality of mental health. Coping with disability is made more difficult when the mental health of the individual is challenged by chronic stress.

Poor mental health may manifest as chronic malaise, fatigue, depression and anxiety states related to stress, dissatisfaction with life, a struggling mentality and an eventual obstruction of life goals. When this occurs, a double disability may unfold: a secondary outcome related to perceived helplessness may accompany the primary disability. This outcome, resulting in poor mental health, may consist of inappropriate or even destructive coping skills.

For people with disabilities who experience the concurrence of multiple physical, emotional and cognitive challenges, in addition to the practical challenges of day-to-day life, the achievement of good mental health may function very positively in helping the individual to realize equilibrium and well being, leading to effective and productive coping strategies, a reduction of barriers and stress and toward greater life satisfaction. Good mental health is a pathway for healing.

## Major Recommendations

### Summary of Ideas from Workshops

**W**orkshops were assigned the task of coming up with ideas that would enable mental health promotion for people living with disabilities, their families and caregivers and inform service providers of the needs confronting this population. Mental health promotion fosters development around four goals: self-worth, purpose, belonging and equity. Higher levels of stress and the isolating nature of stressors confronting people with disabilities impact on the quality of mental health. Workshops convened to examine mental health promotion for the individual, the family, service providers, in the workplace and in Aboriginal communities.

The most globally expressed idea is that individuals need to give permission to themselves to seek out methods to care for the self in a way that is both assertive toward positive change and accepting of reality. Introspection and self-awareness are envisioned as the point of departure for positive change, and community-based self-help and activism were viewed as excellent methods for enabling change. The support of family and friends can bolster the individual's sense of empowerment and contribute to better integration and normalization of activities, issues and interests. Conference participants reiterated the message, "*You are number one!*" Holistic approaches, including access to alternative methods of healing, were recognized as the most beneficial for mental health promotion, while at the same time delegates called for more information and training for service providers around holistic approaches. Increased media visibility was seen to boost the public awareness of the issues of persons with disabilities.

The following is a synopsis of other recommendations for promoting mental health for men and women living with disabilities, their families and caregivers:

#### q ***Change will occur when we are assertive***

It is OK and normal to be afraid, pain and grief are valid responses

Just do what you need to do: Drive a car, go to work

Demand what you deserve, i.e., access, equity

Challenge social preconceptions

Seek out, demand holistic services that are linked, not isolated

Work for political action that will result in beneficial change

#### q ***Sharing problems is very beneficial to our mental health***

Sharing is coping

Confront family and friends: *Come out and belong!*

Recognize that some problems are social problems that need to be changed

Sharing helps to promote a sense of belonging

Developing a sense of belonging contributes to self-esteem

Teamwork works because people are the best resources  
Cultivate a confidante you can share everything with  
Share your vision, respect the vision of others  
Involvement with community promotes empowerment  
Create your own network  
Seek out support of friends and family when appropriate  
Find, train workers who are competent in mental health counselling

q ***Healing starts with self-care***

Good nutrition contributes to good mental health  
Exercise contributes to a sense of well-being  
Recognize your personal healing skills  
Self-monitor your state of being, avoid overloading yourself  
Create a safe place for yourself to discover and define perspectives  
Ascertain that your plans are centred around your individual needs  
Acknowledge, be entitled to your feelings, perceptions and way of being

q ***Taking stock promotes self-worth***

Identify as a person first  
Taking a personal inventory leads to self-acceptance  
Dreams and aspirations help us to set goals  
Setting goals helps to develop a sense of future and purpose  
Acceptance of disability leads to self-acceptance and acceptance by others  
Fearing disability contributes to poor self-esteem and affects others  
Acknowledge the way things really are, but  
Recognize the potential for changing things  
Celebrate small victories, reward

q ***Open, honest self-expression promotes mental health***

Commit to communicating  
Expressing emotions is beneficial to growth  
Grieving losses is necessary and appropriate, and humour contributes to coping  
Respond to the difficult situation instead of reacting to it  
Reinforce positive steps, in yourself and in others  
Set time aside to talk about frustrations, problems  
Recognize that pain can function as a catalyst for change  
If biological family creates stress, create a new support family of friends

## Healing Pathways:

Issues Confronting Canadians Living with Disability  
Patrick Watson

I have spent most of my professional life around the principle that telling one's story is about the most important thing that one can do as a member of the community. As an individual, as a documentary film maker, and a writer of dramatic films, an interviewer, it has always seemed to me that what was memorable and what focuses attention on issues and the realities of life is story telling. I guess I got it from my mom and dad who were both teachers and as teachers their principle instrument of education was the telling of stories.

So when REACH asked me to come here this morning, to talk a little about my own experience of living with a disability and see if I might draw some conclusions from what I've lived and what I've found out as the Chair of the Abilities Foundation and doing some work in the rehabilitation environments and stuff, I thought the best thing I can do is just tell a few stories. What happened to me - and then if you want to ask questions and we have some time left I'd be quite happy to field some questions at the end.

I was thinking this morning about a time when I flew into Montreal with my own little twin engine airplane and a film crew aboard to make a film. It was 1968 (I think), John Lennon and Yoko Ono had been refused admission to the United States because of a certain smokeable substance, and they wanted to do a peace mission and unable to get into the United States, they elected to go to Montreal and get into bed in the Queen Elizabeth Hotel and invite the Americans who they might have seen in New York to come and visit them in the bedroom. So we had a little palaver and agreed that I would go and get into bed with them and do an interview, and make film around all the people come and talk to them. And one of the people who came to talk to them was the late, brilliant, satiric comic strip artist - Al Capp. If there is anybody as old as me in the room, you will remember Lil Abner and the fictive community of Dogpatch, and the Yokem family, and Daisy Mae with her bosoms falling out of her dress and Joe the little guy with a beard who always went around with a cloud hanging over his head. This guy is a brilliant humorist, a brilliant cartoonist, a brilliant satirist and an angry observer of the American scene, and an amputee. He had fallen under a street car when he was eleven. And I knew he was coming to this thing and I really wanted to meet Al Capp, like he was a story-telling hero of mine, and by then, let's see, I was eight years into being an amputee, and I thought, 'well we've got some stuff to talk about in common, this will be interesting.'

And as it happens I pull up with my little plane at the general aviation terminal at Montreal Airport just behind a plane that's coming in from Boston, another little plane and out of the plane that is coming from Boston gets Al Capp, I recognize him. The reason I recognized him is that I had seen him on television years before and he told a story about flying to London, England, one time and taking the daytime flight across, (TWA flies out of New York at 10 o'clock in the morning and gets into London at 10 o'clock at night). He was going first class, they gave him a lot to drink, he got off the plane in London, was met by friends immediately taken to a party and given a whole lot more to drink. Finally found his way into bed in one of London's posher hotels and he said - "I unbuckled my trousers and my wooden leg fell on the floor and the top of it rolled under the bed and I rolled into the bed and I was out cold until early in the morning and, there was a stately British waiter bending over my bed as I opened one eye, he had the TIMES

and a little pot of tea". He said - "Good morning Sir, would you like to be ordering breakfast?" And I said - "A big pot of coffee and a quart of orange juice and some dry toast." "Yes sir, and would the other gentleman be wanting anything?" And I remember I heard Al Capp tell that story some years before I lost my leg and I thought, God there's a healing capacity to being able to deal in that kind of humour, and I wanted to meet this man. He got out of the airplane in front of me and I walked over and he was limping dreadfully. I said to myself I'd like to meet his prothesist and give him a punch in the nose. The guy was wearing a limb that was at least two and one-half inches too short and very badly aligned. But I walked up to his feet and said - "Hi, I'm Patrick Watson, a film maker, remember your story about laying on the bed, blah! blah! blah!" and he said - "you walk too God damn well, how are you going to get any sympathy if you walk as well as you do?"

I found that offensive at the time, I'm not sure I do now. It may have been, this was a very strange twisted personality, but it may have been that in his own kind of angry way, he was doing a little bit of what we now call now self advocacy, I don't know, but I've certainly thought of it for a long time, I've thought of it often. Here was a brilliant, complex, perceptive mind and he was serious. He wasn't joking when he said what he said, and while I was contemptuous of that attitude then, I guess one of the things I've learned from the experience of being an amputee is don't rush too quickly into contempt when you're confronted with people who don't handle their disability the same way you handle your own.

Driving in here this morning, as always, I was moved as I came by the Terry Fox statue just up at the corner, I hope you all saw it, it's a nice piece of bronze work, and remembering the morning 13 years ago, I think it's 13 years ago this month, when Ralph Thomas the film director phoned me up and said - "Patrick, I'm making a movie about Terry Fox". I said - "I'm too old to play the role Ralph". He said - " I had in mind a cameo, would you play the part of a chicken farmer with a peg leg by whose farm Terry Fox runs on the road, and the chicken farmer sees Terry Fox running by and he comes on and waves encouragement to him. The encouraging line was - "go for it, you son of a bitch". And I said - "Well I had sort of thought of a somewhat more central role, but if that's what you want me to play, that's what I'll play," but I said, "There's only one problem, I've never worn a peg leg, I've never seen a peg leg, I've heard of peg legs I know about Long John Silver and Captain Ahab and all that stuff, but where in the hell am I going to get a peg leg?" "Leave it to us, we've already spoken to Sunnybrook and they'll make you one" - he said. In the trade it's known as a pylon. So they took away one of my regular legs so they could match the socket that fits onto to me, and a few days later he appeared with this thing, no knee, and a wooden peg sticking out of the bottom of it and a big crutch tip on the end of the wooden peg. I looked at that and I thought I'll never walk on that. However, I put it on and to my great astonishment, it was very easy to walk on because the knee is never going to bend and let you down like this one sometimes does, and I played the part, it was kind of fun, and after it was all over, I mean the peg leg wouldn't fit anybody else, and so I was going to keep it, and my brother-in-law, who is a young physician, said - "Why don't you take it up to the lake and see what it is like, you have trouble walking around on the rocks and stuff like that, maybe if you've

got one with a knee that doesn't bend" - so I tried that, it didn't work. It was always dragging on the grass and stuff like that, but the brother in-law was visiting with his wind surfer on the roof of his car and he said - "Why don't you try the wind surfer?", and I said - "Are you kidding, I could never do that", and he said - "Try it!", he's an imperious sort of a young fellow. So I got out on the wind surfer and by god, with the peg leg, jammed it up. You know, I made a little rubber socket on the deck, and you jammed it up there and you knew it wasn't going to bend on you. and pretty soon I found that I could wind surf, and that was a great kind of spin off, and then I'd fall in the water a lot with this thing, but it seems to survive falling in the water, I'm going to take up scuba diving, and I just came back yesterday morning from 10 days in the Bahamas scuba diving with the son of the son of the original peg leg and now I've got a stainless steel peg on the bottom that's got the weight to help you go down, because the old one floated a little too much so I was always going around with my head down like that and the leg tried to drag me back up to the surface.

Some point along the way, I was bitching about, I was having trouble with the prothesis and I was bitching to my wife about how painful it was to walk the long distance from the parking lot into the airport, and she said - "Why don't you get yourself a disabled person's parking permit?" And I said proudly - "I'm not a disabled person, I don't need one." She said - "Come on pal, I'm tired of your bitching." So I went out and I got this thing, and you know, it kind of changed my life because suddenly not only did I not have to walk very far to the airport anymore, but I guess I went around the corner saying to myself -yeah you are a part of this community. You've got something to take from it and something to offer to it, and I never quite thought of that before, I had been arrogantly saying to myself, "You don't need that because you are not a person with a disability", and it was that sudden confrontation of a particular - and I'm happy to say a transient difficulty with the prothesis and the pain there unto attached and the easy solution which was a solution that had been prepared for me by my community. I never thought of that before.

The great Canadian critic scholar, Northrup Fry, who just died a few years ago, was the first person to enunciate the following definition of the difference between tragedy and comedy in classical theatre and indeed in all theatrical representation. He said - and it's very interesting if you go through all the great classics of the dramatic art to apply this very simple criteria. He said - "In a tragedy the hero begins with a catastrophe of some kind that isolates him from his community, and try as he will to get back at the end of the tragedy he is even further from his community. And comedy whether it's "Twelfth Night" or "A Winter's Tale" or a modern American film comedy, the hero, the principle figure, the protagonist begins with some kind of catastrophe which separates him from his community, maybe his father forbids him to marry the girl, which is by the way, the premise of the beginning effectively of "Romeo and Juliet", which is a tragedy. But at the end of the piece the hero is reunited with the community".

And I found myself, I first read Fry seriously quite recently, I came to him late because when I was an undergraduate I attended one of his seminars and asked a stupid question and he pegged it as a stupid question and I never quite recovered from that, but I had a hard time reading Fry

until I got a little bit older and a little bit more tolerant. I read this wonderful analysis of the nature of tragedy and comedy and it has served as a kind of guide for me to think about not just issues of disability but of issues of narrative, issues of the changing nature of our social structure, and I think it's absolutely crucial to the ideas that we're going to be tackling here in this conference today.

The tragedy of a disability is not the catastrophe that brought about the disability whether that catastrophe be genetic, or traumatic, or environmental. Catastrophes are a challenge. They are recoverable to a greater or lesser degree. The tragedy that is entailed is the isolation of the person who has encountered the catastrophe from his or her community. And the task the community at large, the smaller community which is people like us who are gathered around a common purpose, and maybe most importantly the individual is to find the pathway back to the community. That's what employment issues are all about. It's not just self worth, it's not just economic independence, it is being a member of the larger community once again.

I remember when I went into the Chair of the CBC and I arrived at my elegant office on the sixth floor on the south side of that absurd trefoil building out on Bronson Avenue, and I looked out in the parking lot, and I said to myself - isn't that great there are twenty places marked with the wheel chair symbol, they happen to be the twenty places furthest away from the building. I mentioned this to my Executive Assistant, she took it up. I took it up with the President and the building manager and the HR folk. My Executive Assistant was coming up in the elevator a few days later said to a long term employee of the Canadian Broadcasting Corporation's Head Office - "Did you know that all the disabled parking spaces are the ones furthest away from the building?" "Oh well, we don't employ anyone like that around here," said this person. In the major cultural institution in the country, interesting! That was not a vicious remark it was a perception, and a very strong perception. Fact is, there were quite a number of people with disabilities working in that building none of whom had declared their disability, and one of issues we have to face as people living with a disability is what do we declare? To what extent and when? Is it going to be important for us to march into the license bureau and say - I want one of those things? That's a metaphor, you understand for a whole lot of declaration, but declaration is an awfully important part of the process, and while there might be those who declaring our whining I thought, like Al Capp with his too short prothesis. How do you get sympathy, you limp very badly, there are for those arriving later in life, I was 30 when I lost my leg, there are issues of pride and self image and what are the instruments by which one is linked to the community that one has to come to terms with anew? And if one is born with a disability, one has probably been placed into a niche from which it may be quite a challenge to establish the links to the community that will abolish the tragedy and make of the catastrophe a continuing challenge, but also in itself perhaps an instrument of fulfilment, an instrument of self understanding and an instrument of the spiritual enlargement of the capacity of the community to be compassionate, to be integrated, to be a civil society, which I think is the ultimate task that faces all of us as citizens.

That's my simple message for us this morning. Declare as much as you can bear to, make the demands of your community, not just for your own self fulfilment and empowerment and self understanding, as important as those are, but also as an act of citizenship.

## What is Mental Health Anyway?

Mental Health for Canadians: Striking a Balance

Marnie Smith

**W**e hear it too often: "Our lives are out of control ... our society is out of control ... or, I've lost it ... there are too many things to do and I cannot cope ... there are just too many things to do." As our society becomes more complex, so too our lives become more complicated and stressful. Each of us must confront and cope with our own issues, problems and concerns. Everyone has many roles and responsibilities. Some will be mothers, fathers, brothers or sisters, sons or daughters, husbands or wives or significant others. Some will be single parents, divorced parents or separated parents. Some will be a friend, or lover, colleague or professional supporter. Each role carries with it an abundance of unique daily challenges.

The recession in Canada is another challenge. The dollar does not stretch as far as it once did. Some people will become recipients of social assistance or confront unemployment. At the same time, many of us are facing other issues related to personal experiences, perhaps coming to terms with childhood abuse or living with a disability. All of these issues can be overwhelming unless we stop and carefully ask ourselves, "What allows us to strike a balance in our lives? What does it mean to be mentally healthy?"

### Mental Health is a Balancing Act

Mental health means striking a balance in all aspects of our lives, including social, physical, spiritual, economic and mental aspects. For all of us, a learning process is involved in striking this balance in our lives. At times, the weight can be shifted too heavily, towards one aspect or another. When this happens, we need to work to find our footing and to re-establish our equilibrium.

Each one of us must strike a balance that is exactly right for us as individuals. What is affecting my life might be very different than what is affecting your life. In fact, it is essential to remember that we are all unique as individuals, unique in strengths and weaknesses and also in our ability to cope. We are all affected differently in situations that may be the same or similar. It is critical that we get to know ourselves, and get to know what we need to do to foster a balance in our lives. But how do we strike this balance? What are the key ingredients to consider as each of us try to nourish this balance?

## Recognize Strengths and Build on Weaknesses

It is important to build self esteem. This includes looking at ourselves, examining our strengths and weaknesses, accepting them and then working with what we have with our best ability. We need to discover ways to promote our strengths, while also building on some of the weaknesses. This will allow experiences of personal growth to occur.

For example, you may be an excellent writer and artist and may be able to present ideas in print and pictures, but you may not be a good speaker. So, while you would concentrate on your writing and drawing skills in order to increase your self esteem, you would also work on gradually developing your oral presentation skills in order to work on personal growth. Personal growth results when you develop your potential!

## Relationships and Supports

Learning to receive as well as to give is another key ingredient in mental health promotion. In personal relationships as well as in work relationships, many people have difficulty in accepting kindness from others. We all know people who shrug off and minimize compliments, instead of saying, "Thank you, I appreciate your feedback." It is important for us to feel good and comfortable with giving and receiving compliments.

The creation of positive parenting and family relationships is another factor. Although not all people live in the traditional family structure, it is essential to foster quality interpersonal relationships in households and foster positive parenting relationships. Each member of the household must learn to value the skills and abilities of others. Each must learn not only to give, but also to accept support and appreciation. In doing so, all family members will truly take time out for each other, to examine the dynamics of each other's lives and to support each other.

Friendships and social supports are crucial to everyone's life for promoting a balance in mental health. Friends are people in our lives who help us to recognize that we are not alone. They help us to celebrate the high points of our lives, and they sustain us during disappointments and low points. For those who do not have friends in their lives, a good idea is to build a friendship tree. This may be as simple as asking a prospective friend to share a movie or lunch. Someone must always take the initiative in order to establish a new friendship. Too frequently, people believe that friendships just happen. But friendships are very much a two-way process and should never be taken for granted. When you look closely at a friendships, you will see two people who work at maintaining a relationship.

## Making a List, Checking it Off

Setting priorities is another prime balancing factor. Sometimes, many things are happening in our lives at the same time, creating many problems and issues. When this happens, it is time to sit down and to clearly identify priorities. What really has to be done now; what could be done tomorrow, or next week, or next month? Maybe this is the time to make some key changes in your life, but this does not necessarily need to happen today. Try writing out lists of your priorities, place them in order according to their importance and set time frames for accomplishing the tasks. Methodically, follow through with your priorities, and check off items as you complete them. The sense of accomplishment is wonderful when you reach the last item to be checked off the list!

Involvement in volunteer activities can help to keep mental health balanced. Becoming involved in these activities can give a feeling of purpose and satisfaction. For some, this work could mean being a regularly scheduled Big Brother or Big Sister, and for others it may mean helping with a charity or shopping for a neighbour who is sick.

## Taking Control

We need to learn to manage our stress effectively to prevent the stress from managing us. Although stress is a normal part of our lives, often parts of our lives may unravel and we begin to experience symptoms of stress, including anxiety. As part of stress management, we need to accept the fact that change is normal, and that we can learn to cope with change. We have to be comfortable with change because it is inevitable. We need to be prepared for change. If we perceive that changes are insurmountable, we can find help in support groups, friends and professionals who will help us to cope.

We need to learn to deal with emotions. We need to identify those things that make us angry, sad, or happy and to think about the ways we experience and express our emotions. Certain activities, including regularly scheduled physical activities promote happiness and relaxation and enable coping. On the other hand, we need to have ways to deal with our emotions and opportunities for expressing emotions safely and constructively.

## Listening for the Inner Voice

It is very important to have a spirituality that is our own. We all have to be at peace with ourselves and to know who we are and what we are all about. We need to recognize that we can change some things in our lives, but not everything. We need to become comfortable with the inner self, and learn to develop trust in that inner self. This means that we know what is right for us and that we will have the confidence to head in that direction.

## When Mental Health Suffers

Our mental health suffers when we are not able to strike a balance between the different forces of our lives. In many cases the accumulation of stress results in throwing us off balance. When this happens, we experience stress accompanied with a variety of problems related to our mental health. But how prevalent is stress; how frequently do people experience depression?

According to a survey conducted in 1992 (Canadian Mental Health Association, Canadian Psychiatric Association), Canadians are generally satisfied with their lives and assume the future will improve. However, there was also a strong undercurrent of stress and depression reported by respondents:

- 47% feel really stressed a few times a week or all the time
- 32% feel really depressed once a month
- Men and women report equal levels of stress and depression
- Highest stress reported between 25 and 64 years of age
- Highest depression reported between 18 and 24 years of age

## Stress

Stress is the body's normal response to demands placed on it. There can be a number of demands and stressors occurring at one time. These demands may be self-imposed internal stressors or external stressors which come at us from the outside. Sources of stress may be physical, including poor health, injury, low levels of resistance; environmental including noise and pollutants; social, including difficult relationships; work, including pressures and expectations around performance; mental, including negative thoughts and low self-esteem; or emotional, for example emotional trauma and loss.

When confronted by stress, there is a fight or flight response for the body. Adrenaline and other hormones are released into the bloodstream, oxygen is metabolised, the heart rate and blood pressure increase and muscles and senses are readied for action.

Negative and excessive stress affects the body, contributing to physical and psychological symptoms including heartburn, insomnia, frequent headache, muscle spasm, shortness of breath, nausea, easily crying, anxiety, boredom, constant feelings of uneasiness, etc.

## Stress Management

Avoid, accept, assert, adjust and prevent. In other words, avoid the stressful situation. But at the same time, accept what you can do and what you cannot do or acknowledge what is out of your control. Assert what you need and want and what is important to you. Adjust your lifestyle with better eating and exercise, thinking positively and taking more leisure time. And prevent ongoing stress by changing situations and confronting the sources of your problems.

## Laughing is Good

It is important to add humour, to create situations where there is plenty of good, old-fashioned fun and humour. Laughter is one of the best ways to naturally release tension because it stimulates the cardiovascular system and promotes the exercise of the lungs. Laughter stimulates the release of endorphins, the body's natural pain reliever and also gives us a feeling of well-being.

## Mental Health and Disabilities

The ingredients for mental health for people with disabilities are the same as the ingredients for mental health in the general population. In order to achieve the balance and the goals of mental health, however, people living with disabilities may confront and overcome different or increased obstacles.

The grieving process is important in reconciling loss. Grieving is the way we naturally respond to losses, whether the loss be a job, a spouse or loved one, a limb or the loss of life goals. The individual coping skills and support systems are important in facilitating the grieving process. All people may not experience the stages of the grieving process in the same order. During the stage of denial, a person is in the "no, not me" or "it can't be true" stage and often feels numb. The next stage, anger is accompanied with rage, envy and resentment. During bargaining the individual may develop hope that the inevitable will not happen. Depression follows when the person can no longer deny the illness, and numbness and anger are displaced with a sense of great loss. Finally, for many people, acceptance of the loss and the disability occurs as a last phase of the grieving process.

An individual may experience disability as a monumental stressor that places mental health off balance. For this individual, it is important to regroup and examine all of the stressors involved.

The individual needs to develop ways to reduce these stressors in order to achieve a mental health balance. It is important to become aware of all of the ingredients that contribute to a mental health balance and there is a need to keep these ingredients active, each day. And by recognizing the importance of keeping a balance in one's own life, perhaps we can support others and encourage them to strike a mental health balance for their own situation as well.

## Rehabilitating Descartes

On Becoming a Whole Person in a System that Cares for Parts

Michele Chaban

I always start off my lectures with an apology and that is that breathing, standing and reading are very complex tasks for me - also turning my neck to try and maintain contact with all of you so, if my voice goes down or I stop making eye contact, forgive me - we'll just have to rely on technology to increase my voice because this is as loud as it gets. I want to thank you all for coming here today and, in particular, I'd like to thank Bruce for inviting me to be present. He certainly inspired me to take on the challenge of coming here today. My profession is Social Work and by nature, what I do is help people end their life through palliative medicine and although I lecture internationally on death and dying, this may be the first time I've ever lectured on living with a disability and, I think that we have had Patrick Watson bring forward the importance of story and most of my work with the dying is renowned for its story-telling. So what I'd like to start with today is talking about the importance of story. Story is a politic and when you look at my background, before social worker's theology, every single tradition, theological, spiritual, wisdom tradition, since the beginning of time, has told stories, whether they tell stories through drawing pictures or whether it's done linguistically, through words, it is within story that there is wisdom - it is within story there is courage - and it is within story that there is hope and so, learning how to tell your story is something that is very important, whether you be somebody who is living with a disability or somebody who is working with people who are disabled, helping them tell the story, reconstruct the story, tell the story in a way that is empowering is a very important part of what it is we need to do.

So, I am going to begin by telling you a story of a woman that I know very well. In her youth, she was a model for a well-known cosmetic company. She left modelling and the world of fashion because she found that it lacked meaning and purpose and the things that she searched for. She set out to return to university, even though she had failed almost every grade in high school, excelling at one subject and that was dating and her social life. She had to write special entrance exams to be allowed into university. In her first year, she struggled academically, barely passing, yet considering this a success. In the summer to follow her first year of university, she worked and planned a trip to the eastern edge of Canada to Fogo Island near Newfoundland. On her way to the edge of the earth, a drunk driver who thought a green light meant he could do as he pleased, drove his very large car into her tiny one. In the seconds before the accident, she saw what was going to unfold and she braced herself for the impact. In the minutes to follow, she was thrust forward into the windshield and hitting her skull, making a hole in the glass. The impact thrust her back and she was rammed into the gear shift which ran sideways from the steering shaft. Tumbling about in the car, her spine then made impact with the raised emergency brake. In the forces of compression, she injured her spine and her spinal cord. She fell into semi-unconsciousness and awoke to find a crowd staring in on her, everyone

asking her if she was all right. How would she know? An ambulance came to drive her to the hospital where x-rays showed that she was fine.

She returned home and in the next eight years, she never walked the same way again. At first she noticed that her legs were very heavy and they seemed to only shuffle. At first, she could neither stand nor lie, nor sit, nor walk without a shuffle nor run, nor swim. Then she suffered blinding headaches that came each day. In the next few weeks, her doctors put her on muscle relaxants to reduce the trauma of the accident and in the next year, she had a variety of tests, first to check her bones, then her hearing, then her sight. She found herself confused at times, and exhausted always. Soon she dropped from six courses at university, to five then to four, then to three. Soon she couldn't take the transit system and had to find someone drive her to school. Soon she could no longer sit in the class, so she stood at the back of the room, using a podium to write on. She also stood to write her exams. Soon she started to trip and to fall and, with each fall, her pain only increased. People were kind to her but she knew that she was falling behind. Most days she could not get out of bed because of the pain. She started to feel that her hearing and sight and speech were being affected. Physician after physician examined her, doing tests that she felt had been invented by the Nazis on one of their more hateful days. Where once she walked down runways in fashion shows, she now crawled. Where once her hands were photographed, they were now swollen with fluids as were her feet. Swallowing became extremely difficult and so did many other things. For years, she lived the most meagre of existences, struggling to have a good hour because there was never a chance of having a good day. The pain was unrelenting.

Over time, her friends became tired of her not getting well and new friends entered her life as ones that wanted to take care of her. In the next eight years, she lost everything a person could lose, except her life and that she was not afraid of doing. She could not even allow herself tears because it would induce more muscle spasms. One day when there was nothing more left to lose, she asked herself what she had left. She wondered what had happened to the riches that had once been hers and in that moment she discovered that she was abundant in suffering - that every minute of every day she suffered, the suffering changed its colours as a chameleon, depending on what she ate, if she laughed or if she cried, if she felt happy or sad. Emotions became an extravagance that she could not afford or her body would feel it too deeply. She lived like this for years and when science could find nothing wrong with her, even though it was clear that she was suffering, they told her that her physical disability was caused by a mental disability that she had unresolved feelings that needed to be dealt with before she could heal. She searched her mind and her body and her soul and could find no cause great enough to account for why she couldn't walk. For years she looked up at white ceilings as life grinded to a shivering halt.

Then a miracle happened. A neurosurgeon asked to see her and when they met, he was very rude and very abrupt. He challenged and insulted her with his questions. Her voice and her life had become yet a whisper. He asked her why she had come to see him and she said, "I was told to". He said, "Do you always do as you're told?" Her heart broke and she looked at him and

said, "I never used to but now I will do anything if it will help just a little." For the hundredth time, she disrobed and was poked and prodded, knowing it would mean terrible pain later but, she had come to know this ritual and she never would let it mean anything to her, for the acknowledgement of its inhumanity would have swallowed her up. The neurosurgeon said he would do an experimental surgery on her and he described it. She could barely listen as the pain grew. She simply consented for nothing could make it more worse than it was. At that point there could only be hope, there could only be possibility left. She waited for six months to access a bed, even though she was on the 'urgent' list.

Every day she woke, hoping that this would be the day of her release and when the day finally came, she had her surgery. When she woke up from surgery, she wiggled her toes and, after a few seconds, her toes wiggled back for the first time in many years. The neurosurgeon became her liberator, her healer, her hero. The next day she rose and tried to walk and, while she could only shuffle, she knew something was different. The next day she asked to go home. It took her two years to tolerate gravity again. It took her two years to tolerate a world that sped by in her peripheral vision. Learning how to ride the bus was the single most difficult task because it involved stepping up, climbing, rushing to a seat before the bus moved, sitting bracing herself so she wouldn't sway too much as the bus lumbered along. She had to lower her head and close her eyes because after years of looking at ceilings, there was just too much to see. It became a stress to encounter the vertical world. She returned to school, walking with a cane. She was clearly perceived as being odd, different, perhaps a bit suspect. She sat or stood at the back of the class so she'd not have to twist her spine just to see everyone in the class. Sitting at the back of the classroom, she looked like she had an attitude problem. She had healed one part of herself but now she was left with how to manage the residual difficulties of her disability. Every solution seemed to bear a consequence that seemed unjust and unfair.

In the years to come she reclaimed and rebuilt her life, she came to realize that she had changed significantly. All those years in her tomb-like existence, unbeknownst to her, she had developed an ability to think. When her hands and legs did not work, she used her voice to ask people to meet her needs and after all the years of looking at white ceilings, she had developed an extraordinary imagination, an unusual vision. If you were to meet her today, you would most likely not see her disability, although she lives with it constantly in the way of pain and shifting abilities. If you were to meet her, you might miss seeing the suffering that is ever present because of the delight that she lives in. She is happy if she can walk.

This story is my story, and this story is over 20 years old. This story is not over and, one day I might yet again look up at ceilings. I might yet again shuffle. I might yet again be asked that every need be met by somebody else's hands and legs and, in those days when my body ached and my medicine divided me up as a body into little parts, it was a struggle to keep myself whole. It was a struggle to remember who I was. I was changing so much, I was devolving. I was becoming reduced to my smallest most insignificant part. In the film libraries of many hospitals in Toronto, were pictures of my insides but none of them captured my aching, and my

hurt, and my suffering. Every day I did what I had to do to heal myself and every day I studied myself to see what suffering can do to a human being. Every day I struggled to find humanity against the raw and unrelenting pain. Every day I felt I failed. Every day I felt was a wasted life. Every day I lamented and grieved yet, every day, even now, I am grateful that I can remember the suffering for it's given me something that I treasure as the centre of my life and my work. I choose to work in the health care system today and use what I have discovered. When I meet my clients and see their brokenness, I go into the centre of it. I am not afraid to enter into their suffering and, yet as they get divided into parts, I stand beside them like a weaver, trying to weave the torn threads of their life into a fine tapestry. So how is it with all the healing that is possible in a health care system that so often we feel frightened and fractured by it to understand what happens to us in the health care system dedicated to care, we have to go back a few centuries to the age of the enlightenment.

Within the age of the enlightenment, medicine and science began viewing the human body in terms of functions. We heard this morning how there is going to be a model of health presented this afternoon, dealing with the elements, fire, water, air, and, I think, earth. That was the model that existed before the model that we have now that was largely presented by Dick Hart, so, if you're interested in hearing what was before and, I think really where we're going to in the future, I'd attend that session. The mechanistic model defined the body as something made up of parts and those parts function to support life. If a part did not function, it was a threat to life and future functioning. That part had to be treated if that part could not be induced back into appropriate functioning, it was removed much like one would remove a faulty muffler from a car. Medicine's mechanics resulted in diagnostics that look at how our parts function; liver function, endocrine function, limb function, brain function. In dividing us into parts, medicine separated our mind from our bodies, our psyches from our souls? Descartes philosophy supported the split of mind and body. Diseases of the mind were separate and distinct from the diseases of the body. This was the beginning of our biology being separated from our behaviour. The new sciences medical model was reductionistic. In dividing us into parts, the whole was often overlooked. This is why medicine is often accused of being disease centred rather than being person centred in its care. This is why the physician who orders tests on somebody's body is often thought of having neglected a patient's physical, social and spiritual needs. Medical and allied health care education trains us to think in terms of function, in terms of parts.

For us to bring about reform, we must start a new model of education and this has already begun.

With the new sciences commitment to divisiveness, other parts whose functioning could not be measured were left out of the equation completely. Our spirituality was functional or not, was left out of the equation. The concept of our mechanistic functioning has several implications. For the consumer who accepts that the primary purpose of health care is to maintain functioning, they are giving full consent to medicine's wish to pursue functioning and, while cure is the goal of medicine's pursuing function, what happens when cure is no longer possible? Does medicine continue to pursue functional goals for the sake of longevity? If it does this, does it clearly outline that the consequences of treatment will be the cessation of functioning?

What would happen if you were a patient who didn't go along with the functional paradigm of health care? What if you said that the outcome of aggressive treatment will eventually be the cessation of my functioning so, therefore I refuse treatment? It was not too long ago that someone refusing treatment would be asked to see psychiatry as the assumption that pursuing treatment meant that you were failing to thrive and failure to thrive meant you were a risk to yourself. Today we see consumerism driving us toward similar but more complex issues of functioning and that is the decision when to support the sensation of functioning. Functioning is the argument that we will use for euthanasia. So avidly has medicine pursued function that it at times has lost sight of its focus of healing. Saving becomes its primary purpose. Saving at all costs became health care consumers and health care providers demands.. Medicine complied but, did we the consumer have any idea what we were really asking for? Did the physicians have any idea of the kind of living deaths that we were creating for patients? Medicine's pursuit of functioning knew no bounds and we have seen that the patients and families were placed in painful positions are now having to decide whether to use life support systems or not to maintain bodily functioning and when to withdraw treatment and allow nature to cease functioning. We as family members may be asked to decide when to end the lives of those we love and this has a tremendous implication for families and society's health.

In a world where I am made up of parts that function or do not function, how do I differ from a machine? In a world where I have dysfunctional parts, will health care become like an auto repair shop where I can drive in, have my parts replaced and continue to function? In a world that so values functioning as a model of health, how do I as a dying or disabled person define my value to myself, my family and to society because I function less than I did before, or I function differently than others do. In a world that values functioning and in a world where I cease to function because of illness or age, will my suffering not be enhanced with the knowledge that I can no longer function as others expect me to? Will my functioning become a problem for everyone and will people now look at me and one day hope that my functioning will cease, and in a world which values functioning, suffer more because I cannot function? Will I want to end my life because I no longer function independently and, if I lose my functioning, will I have to rely on others to help me in an active euthanasia to help me in my functioning? If I define myself by my function, explain to me how different I am from a machine. How am I different from a CT scan that measures my disease?

These questions are not my questions alone. They have been asked by many and they will be asked by many who will follow after me. In July, 1993, a publication of Humane Medicine, Dr. Stephanie Brown-Clark acknowledges that the philosophers and scientists of the 17th century perceived the new science of nature being like a clock. Dr. Clark acknowledges that these men were innovators. They perceived nature as a very fine and intricate machine engineered by a rational God; however, while acknowledging the importance of these innovators, Clark raises the very significant question of what happens to our humanness in a system that is so mechanized. Human nature and Mother Nature were radically transformed by the underlying philosophy and

principals of the scientific paradigms of the 17th century. Our broken bodies were broken down even further to the smallest denominators. Our cells became parts. The principles of mechanics, functionality, reductionism, and separatism became the foundations of modern medical model. The spiritless mechanics of a system devoted to the functioning of parts is also the foundation of complaint levelled at the health care system today by its users. As we demand health care reform today, what world are we creating in good conscience for tomorrow. Will our solutions today become tomorrow's problems? Is it the nature of growth or is it the nature of our lack of insight, our inability to think deeply about where we've come from and where we're going to get outside ourselves for the sake of ourselves.

If history is a process of the past, leading to the future, and if history is made up of the Ying and Yang, if one extreme is counter balanced by another, what creative process are we involved in today that will influence the health care system tomorrow? We now await the outcome of the new health care system. What it's really going to rely upon is the traditions of science that went before it, but it is also going to be radically influenced by other powerful forces and that is the force of health care consumerism. Health care consumers and health care providers need to stop and take account of what will be so that, perhaps, with a redefined spirit of enlightenment, we may predict what went wrong in the past and predict what our blind spots are as we begin to build our new science. We are about to have, or perhaps I should say we are in the throes of a revolution and it would be my hope that this revolution would emulate new principles of health. Pleas for reform in the health care system are pleas for yet another age of enlightenment, one that recognizes that our minds are not separate from our bodies, our heads are not separate from our hearts. There is a plea for holism, integration, nurturing, comprehensiveness - a plea that the quality of life not be sacrificed by the quantity of life; a plea for more than science based practice. A plea for humanizing, for healing may not be possible, given fiscal restraints that we're all facing; however at a personal level, we can make the choice to diminish harm, focus on healing not just curing, care for the whole of ourselves, rather than its parts, not be victims, nor to victimize and to learn to tell our story with the strength and hope that it takes us to live every single day.

## Impacts and Issues

### Summary of Panel Presentations

#### Mike Nemesvary

..." very good. We'll be around next year. All right. But Mike Nemesvary would not compete at Breckenridge or anywhere else the following year for three months later during a routine training session on his trampoline, Mike attempted a manoeuvre he had done a thousand times before. But this time, for a split second, he blacked out and landed on his neck..."

Well, I suppose up until that fateful day on the 18th of May, 1985, I had lived quite a charmed life. When I think back to it as what you've seen, I was flying around the world. I was doing exactly what I wanted to do with my life, I had freedom - I certainly had a lot of independence. I was even being paid for something I lived to do. I really was living my dream. I think it's just amazing that regardless of the lives that we set for ourselves, a fate can often deal us a new hand at any time and often when we least expect it. When I was invited to speak on the personal impact of disability, I was keen to share my views but, I was quite apprehensive about what I could say that hasn't been said before. Furthermore, I thought long and hard about what I could impart that would be fresh and could help others empower themselves. None of us today has all the answers but, I have come up with three convictions that I strive to live by and that's what I would like to talk to you about.

Number One is try to maintain that my disability is incidental to my world not that my world is incidental to my disability. Number Two - I constantly strive for increased independence through technology by remaining with an open attitude and, Number Three - I continually challenge myself and I never give in to criticism. My own pathway to healing has been an arduous journey of many more valleys than peaks and, I remember well thinking back to those first few days whether or not my feeling would come back and I know for those of you who have suffered paralysis or severe disabilities. there is always the feeling of the unknown and I think that's what is really difficult to deal with but, eventually in time, I started to accept that this was going to be my reality, but, it was tough making the adjustment - I remember thinking back to how would I ever manage my whole life around my disability with intermittent catheterization. There was all the blood pressure issues I was dealing with - the high - the low blood pressure. I was suffering from skin sores at the time from being on my back for so long. I was even suffering from autonomic dysreflexia - for those of you who know about it - it's the severe headaches and the high blood pressure associated with that. It was like my whole world at that time really did revolve around my disability and then I remember just trying to go home from the hospital for weekends. It was like this major undertaking to pack all my clothes, all my medical supplies, take a commode chair, trying to get it all into the car -it was just like this horrendous journey just for two days away from the hospital and, initially my self esteem and my self confidence took quite a blow.

You see, I always viewed myself as the strong, independent World Cup skier but the world had a way of reminding me that they saw somebody completely differently. You see, the world saw me as just a cripple in a wheel chair. I remember I often fought against a lot of the institution because at that point in time back in 1985, a lot of the social workers, a lot of the people around me. I think they were trying to do me a favour by saying, "Well, Mike, you're going to have to take a back seat to the type of life you had before. You're going to have to learn about computers - you're going to have to take a more passive role in your life and that became tough for me because inside I still felt like I was a physical being and I would say at, about the eight month mark, after the denial had come out of my system, I started to set some goals for my life and for some people, it might sound a bit peripheral but for me, these were important goals in

order to have an empowered life and, one of the first goals was to really try to become physical again because that's what meant so much to me and still meant a lot to me inside and, one of those first goals was to learn to ski again and I remember a lot of my friends telling me that it's not going to happen at a C4 or 5 level quadriplegic - you know of course I don't have any triceps muscles, I can't raise my arms above my head - I have no use of my hands and my wrists and I think that they were trying to help me by saying that "Mike, it's never going to happen", but, sure enough, I thought if I was resourceful that I would find a way to make it happen and, remember I was living over in London, England, at the time and I met a Swiss engineer named Raymond Sneverly, and he had designed sleds for paraplegics and he was quite willing to take on the challenge of designing a sled for myself so, to that end, we came up with a series of splinting devices that could be put around my arms and my hands and, I went over to Switzerland at the nine month mark after my injury and I remember being fairly apprehensive because I wasn't sure that this was ever going to materialize and, sure enough after about two days of experimenting, we were able to get it rigged up in such a way that I could pull back on the levers and I remember going down that slope not too quick - I was going down about ten/fifteen miles an hour but, it was the first time that I really had a smile on my face from before my accident.

It was just amazing the feeling of knowing that I could be back on the slopes again and that I could join my friends and it's still a sport that I do to this day. In fact, I sort of scratch my head and I wonder about a lot of my able-bodied friends because I think I got more skiing in than most of them this year up at Edelweiss. I don't know what that says for a lot of my friends but, of course being very competitive by nature, I wasn't satisfied with just being a recreational sledder so, I wanted to go for a little bit more speed and, in 1987, I gathered a small team of friends and we headed back over to the Alps and went over to a ski resort called Les Arc, over in France and I had this notion that I figured if the speed skiers could bomb down the mountain at about 200 kilometres plus, I could do something, you know, close to that, so we modified a sled and put sort of a faring on it, don't know - it's behind me on the screen now, and you can see it's and I look at it now and it doesn't really look like much and we had about five days of constantly going up and down the slope and on the sixth day, I decided I was ready to go for what I had dubbed as a world toboggan speed record and got up to the top of the slope and got prepared - I had my helmet on, brought the visor down and I had two speed skiers behind me - they were going to act as brakes and started gaining speed down the slope, got about halfway down and just before we got into the timing trap, I think I caught an edge or something, veered off to one side and I ended up flipping the sled three and a half times, so, it wasn't quite the outcome I had hoped for. Luckily, there was no severe injuries above and beyond what I had already with my quadriplegia but that was kind of fun because I had done it in the spirit of adventure - you know I had hoped to get a record out of it but, that wasn't the main reason.

It was just to prove to myself that I could still risk again and I think that's a real issue with a lot of disabled people. Quite often we're cradled and we're told that you know from now on, this will be your life and you're in an institution even if you're in your own apartment or in your own home, you know, don't go out, don't try and do things, don't push yourself because society is

always trying to suppress us and, for me I constantly fought against that. I just want to show you a couple of other things that have really helped me and empowered me and helped me from a psychological stand point. In 1992, I don't know why I keep going back to France - I don't even speak French very well but, I wanted to try and fly in my sled and I wanted to try a sport called paraponting. A lot of my friends had done this - I just want to paint the scenario for this one because it's quite an incredible journey. We headed over to a resort called Val d'Isere in France and I met a pilot - his name is Pim - he's from Belgium and we headed up to the top of the slope and it was about a day of, maybe, seven hours of getting prepared with the parapont, making sure that the chute would come out overhead like right over the both of us. We were having a lot of problems with it because he had actually gone with able-bodied people before but he had never tried it with a disabled person, nor had he tried it with so much weight out in front of the chute. I remember looking at Pim - it was about 3:30 in the afternoon and the sun was setting at that point in time, it was January and I kind of looked up to him and I asked him, "Are you ready for this? Is this going to be safe?" and all Pim could do was look away, he wouldn't even look me in the eye so, he didn't instill a lot of confidence in me but I figured there was no way that I was going to come over all the way, you know, to specifically try and accomplish this goal. We had spent seven hours, the sun was setting, there was no way I was going to live it down if I got back in the gondola and took the lift down. I was here to jump off this mountain so, sure enough, we headed over to the take off sight and I just want to try and paint the picture for you so you can visualize it.

On the take off sight, it's about a 45 degree angle, for those of you who are skiers, it is extremely steep. Normally you go down about 20/30 feet and you take off because you get the updraughts and that's what I expected to happen so, sure enough, we start heading down this slope about 20 or 30 feet and we don't get any lift because the chute wasn't coming high enough up behind us. We go about another 60 or 70 feet and there is still no updraught and the area that they set this type of outrun or inrun, for getting in the air, is at the end of about 150 feet there is a sheer cliff because that's where you get all the thermals and I knew that at about 50 or 60 feet more, I had this vision that we were just going to topple over the edge and I was actually going through the worst feeling you could ever imagine but, sure enough, about 20/30 feet before the edge of this cliff, I felt this gust under the skies of the sled and you're going to see in the next shot we finally got air - and it was just the greatest feeling to know that we were 10,000 feet up and, finally we were flying. Went for a 15 minute flight and you see in the next shot we are just coming down over the trees and, you know, once again, just to know that we could go up to the top of one of the highest mountains in the world, being disabled, being told, you know, I can't do this, I can't do that, and, yes, we could accomplish all this.

You see there is another shot, just at the end and I think we've got great smiles on our faces. I think Pim and I are probably smiling because we had survived this and lived to tell the story. But probably my greatest accomplishment and the accomplishment has give me back my greatest sense of self worth and independence, is the project of learning to drive again and that materialized in 1991 when I met a man named Cliff Wolfe. Some of you may know him - he is a

local man - he has a daughter named Elaine Wolfe who is also a quadriplegic. He had designed a Chevy Blazer for his daughter and when I had seen this system, I really thought that this was the vehicle for me. I had looked into vans and that sort of thing in the past and they really didn't appeal to me. We went into the project as and, of course with me with my level of quadriplegia, it's even greater than Elaine, on of the first things was to design a system in which I could actually steer the steering wheel and that was with a tri-pin grip which I steer with my right hand. The way I control the brake and accelerator, I think you can see just behind me on the next slide, is through an electronic gas and brake. It's not a lot to look at but it's very expensive - It's a \$7,500 unit. Luckily, I got funding through Vocation Rehabilitation Services, the VRS Program which paid for, quite rightly so, because it is partly in their mandate to help people with transportation. They paid for all the modifications and this unit really did help me. Initially I had tried to push and pull mechanical linkage but I simply didn't have the strength for this. Another unit which helped me to control the vehicle is a special head rest and, basically, because I can't take my hands out of the steering wheel, I can't take my hands out of the EGB unit, the electronic gas and brake. For indicators, I bang my head from side to side and, then for the horn, I push my head back to one side, push my head back on the other side for windshield wipers - talk about using your head when you're driving. There was one situation where I was on the 401 and it was just after I started driving and I remember this big truck went out in front of me and I went back to get the horn to alert his attention that I was coming down in the fast lane and, what did I hit? I went and hit the windshield wipers instead, so I really taught that guy a lesson. He's never going to do that again.

Needless to say, I think I've come pretty far and although I may look fairly well adjusted, you know for me like for all of you, it's always an internal battle and I know it's been said time and time again, it's important to focus on our abilities and not our disabilities but sometimes there is always this feeling of denial, sometimes there's a feeling of self doubt and the so-called normal world is always bringing our attention to our disabilities. I think that's the point in time where we all have to try to be tenacious and dig deep and in my own healing, I try to focus on all my future goals, things like for me building a successful relationship is now, perhaps more important than sports. Building a successful business is very important. Also, getting certified - oh, no, not in terms of insanity, but for scuba diving as Patrick Watson spoke about. That's a great sport for people with disabilities. Also another attempt at the world toboggan speed record. I want to do that before I'm too old and I lose my courage. I hope that some of the strategies that I pointed out can work for some of you.

In closing I would just like to leave you with a short speech from President Roosevelt that I keep in my bedroom and it always inspires me and it goes like this.

"It's not the critic who counts - not the man or woman who points out how the strong person stumbled or where the doer of deeds could have done better. The credit belongs to the individual who is actually in the arena, whose face is marred by dust, sweat and blood, who strives valiantly, who errs and comes short time

and time again; who knows the great enthusiasms, the great devotions and spends themselves in a worthy cause; who knows at the best in the end, the triumph of high achievement and who, at worst, if they fail, at least fail while daring greatly so that their place shall never be with those cold and timid souls, who know neither victory, nor defeat."

### Sandra Kesselman Hardy.

I'm not quite sure where or how to begin. Mike and I were just kind of joking a few minutes ago and he said, "Don't upstage me," and I'm sitting here thinking, I'm not sure I have a voice. I came here this morning kind of feeling a bit like Ernie Tannis with shall we share our cold medication and our throat lozenges and now I feel like my legs have gone from underneath me, so, more and more I feel like I'm getting in touch with some of what you are living with on a regular basis. As I've sat here listening to what Mike was saying, I couldn't help but think about the other people who are connected in his life and who he might be connected to and I was kind of reminded of the words of Albert Camus, a Frenchman, who said, "in the midst of winter, I finally realized that there was in me an invincible summer" and I think that probably your experience showed a great deal of that to us today. Sometimes we don't realize that the diagnosis or the catastrophe or the disability that befalls us also affects the people around us. The family is often viewed as the first line of defense to support one of its members when such a crisis exists. By family, I guess I'm referring here today, not just to the nuclear family or the biological family, but that circle of close and loving friends who are often substitutes for blood relations. When a person becomes disabled, I think the expectation is often that the family will respond with whatever is demanded of them, time, thought, care, money, yet, often, nobody asks what the family has to sacrifice in order to be involved in this. Can they provide it? Can they handle the additional stress which is put on them? The disability doesn't just touch the person who it hits - the immediate crisis touches the entire family.

As Matthew Arnold said in experiencing the disability of his child, he said, "It feels like I've been set on a darkened plain swept with alarms of struggle and flight." I think when he told that to his physician, they were really quite surprised and they said, "We never expected you to have a reaction. We thought that your focus would be entirely on your child." From the time of the impact, both the family and the person who's been touched have to cross various hurdles. I guess there is probably heartbreak at whatever age this occurs but the chronological age of the person with the disability, as well as where they sit in terms of their family, will determine how the disability affects their lives. John, age 26, was a father of a two year old, married, primary wage earner, came to see me when he was diagnosed with testicular cancer. He presented a very different concern than Minna, who was 82 years old, who was upset because her husband became paralyzed by a stroke two days prior to their 60th wedding anniversary. She said for 60 years, I've shared my independence.

Then there was Ann. Ann was 48 years old and her son David was diagnosed with AIDS. In the hospital, she stood guard over his hospital room-I used to think of her not too nicely but as the dragon lady because she kind of hovered at the door of his room and insisted on doing everything for her son. She wouldn't even let him pour a glass of water for himself. She wouldn't let David's father visit unless she was present. Then there was George, whose family used to visit in great numbers. They would all cry together and when it was over, one of them the appointed spokesperson, would say, "George, what should we do about our niece who ran away and that grandson of ours-you know, he's not settling into his new marriage. It's six months and he seems to want a divorce, and what about John, you know he keeps coming to us for \$500 loans-I don't think he's doing well in managing his finances. Tim was aged 10 when he was diagnosed with sudden deafness. Prior to his diagnosis, he remembers that his parents were often arguing a great deal. He thinks that they were considering separating. Now he says he feels responsible to keep them together to maintain the family unit. All of this sounds rather bleak.

I guess I present this to you because these are some of the things that walk through the door that I end up seeing. I guess it also impacts in terms of what my outlook is on all of this because I don't think that you can face all of these people when they come to you with their concerns and their issues, unless you've developed your own outlook and you feel comfortable with where that is. I guess that my outlook is that families can survive and they can thrive. It's important, as a major adjustment to the change that when they decide whether they want to look at this just as a person with a disability needing. Is this an opportunity for growth or is this an opportunity for defeat? The key to managing the changes in our lives is through three things, I think-one is our thoughts, one is our actions and one is our communications. Many times families aren't used to thinking together. They're not used to working together as a team. They're not used to talking about what their thoughts are and they're certainly not used to acting together. Families often say when they come in the door that their feelings shock, strain, they're questioning what they should tell other people.

Sometimes the disabilities are visible. Sometimes the disabilities are invisible. What do we do about those invisible difficulties - those invisible disabilities? Sometimes people don't talk about them because they think it will bring shame to their family because of their position because of whatever they're experiencing at the time. Sometimes they think if they don't talk about it that they'll maintain stability. One of the things most families try and do is stay in some kind of balance. So when the person with the disability may be searching for finding a meaning and trying to understand what this experience is all about, the family is trying to do something else. They're trying to stay in balance. Families sometimes see the experience as a personal tragedy, an assault on their integrity as a family system. They begin to feel a great deal of stress and strain. What's expected of the family? What can they do about the situation and where should they go for help or shouldn't they go for help?

I think during the time of emotional change which one experiences, there is a lot of anxiety, fear and stress. The family and the patient may be at different points. It's important first, for the family to have the same information that the person with the disability has, to look at communicating what they know about the situation together. If we're not able to talk about the impact of what's happening to us, how are we going to work on building a joyful life together? How are we going to have an interaction? The idea that people can have joyful lives after a crises such as this is often shocking to many people. Sometimes people say to me in the office, "Well, I don't think that I can go on living. I don't think when this has happened to my child or my partner or my parent that it's okey for me to have any fun anymore."

Our culture seems to think that when something happens to someone, we need to stop living and we need to concentrate on grieving. There may be subtle pressure for families to abandon their pleasures and to focus on the patient. This doesn't serve any meaningful purpose. It certainly doesn't help in terms of autonomy. It doesn't help in resolving issues of vulnerability and what it actually can do is increase resentment, anger and feelings of guilt. For a family to work on creating a healing environment, they need to, (1) have the same information. They need to (2), talk about the disability; they need to communicate about how each person feels.

Here's the pattern. People say communication is really hard. I guess communication is hard if you never try and do it. Sometimes we just have to say how we're feeling and express it openly and allow someone to hear us and allow them to respond to us. I guess that's kind of getting back to what we were talking about this morning, that option of giving and receiving. Family members don't have to fix the situation. I think that's often one of the things that people feel. They need to protect the person with the disability or they need to fix it. Sometimes all they need to do, is hear it. Sometimes all they need to say is, "Sure. I hear what you're saying. Of course, you're scared, I'd be scared too." Sometimes acknowledging somebody else's feelings is all that we really need in order to take that step, Mike talks about of becoming increasingly self-assured and taking risks. In order to take risks, we need to feel a sense of support. We need to feel a sense of safety. Where do we get the most support and the most safety, if not from our family of origin or the people who are closest to us at that particular time.

Sometimes we don't even know what to ask our families for. Sometimes we get concerned that they won't be able to give it to us and so everybody gets into a kind of paralysis. I think the most important thing is to try. Nobody's perfect. If it doesn't work, you can say, "Well, that didn't work. We'll change it and try something else." When one member of a family changes, the whole family is going to be affected because as we all know, a family is a system. That may bring some confusion. Sometimes with a disability, one member in the family becomes more assertive and that may change the balance. All of a sudden, somebody who never expressed their anger, is presenting it. It may be strange. People in the family may feel threatened at first but, eventually, if we proceed through it, there will be good for all.

The process of change is a hard one. Most of us are scared of it-forget being disabled-most of us hate change of any kind. It causes stress, it causes anxiety and we're really not particularly keen on it, but, I sometimes want to think of the process of change as kind of like beginning an exercise program. The first few weeks when you do it, your muscles hurt, your body aches and you wonder why you're doing it. You try and find every excuse in the world not to follow through and, then gradually you say, "Why did I start this? Did I have a goal? I thought I had a goal out there and, if you can put your eyes back on the goal, you'll go through and you'll suffer through this soreness and you'll find that the soreness is decreased and you adjust to it. The family's job is to encourage autonomy, not to rescue the person. Most families aren't too sure about that and the rescue sequence seems to be won because they're hopeful of giving some sense of comfort but, I think what I found is that it often adds to a person's sense of helplessness and vulnerability. People say you should be positive. I think sometimes empathy and hearing how someone feels, is more important than being a cheerleader. You don't need to give pep talks. Cheerleading is not always useful unless you're out on the field.

We adapt our behaviour from our culture and from what we learn from the way our families were. If we've never experienced this before, it's a new opportunity, a time for learning and a time for change. Sometimes a disability can bring a change for an entire family that otherwise would never have happened. There may be hard times ahead when you doubt yourself. I think Mike spoke about those. I think families doubt themselves but that's a time when it's important to consider new ways of relating. It's not a time to pull away. It's a time to say, I need to connect more.

Becoming a healing family is not an easy, over night task. People say, "Well, I'll come and work this out for two or three sessions and by then, we should be fine." I think about the Mom who came to see me, you'll meet her son this afternoon, one year after his accident because for the first year, all she could do was focus on doing the physical changes in the house. She couldn't deal with anything emotionally and it wasn't till five years later, that the Dad was able to come in and, it was approximately six years later that his siblings were able to come together and talk about it, so, it's not an easy, over night task but it is attainable. Doug Harnishell once said, "Life only demands from you the strength that you possess. Only one feat is possible - not to have run away." My best to you and your commitment with your families to become a healing unit.

## Claudette Cain

After hearing the two eloquent speakers before me and knowing that all of us here are just normal human beings, perhaps some of you can relate to these words. 'How heavy the days are, There's not a fire that can warm me, Not a sun to laugh with me, everything cold and merciless and even the beloved dear stars look desolately down.' No, they weren't written by me, but they could have been because it is exactly how I felt when I was diagnosed a manic, psychotic depressive in 1974. At the age of 25, I was happily married. I had a lovely home in the country and I was on my way to a great career as an insurance adjustor.

One might have said I had the tiger by the tail and I certainly would have been very insulted at any suggestion that I had a mental illness or that I had a disability, but in fact within four short years I had three severe nervous breakdowns, I was hospitalized three times, underwent many series of shock treatments or (electroconvulsive therapy), extensive psychotherapy, and intense drug treatment. Yet during those four years and with my disability, I remained gainfully employed, active in volunteer work in my community and for the most part, I lived a happy and productive life. Today, nineteen years after my last nervous breakdown, I believe firmly that depression is an inherent part of the human condition. It's the price we pay for those complicated physical mechanisms and emotional patterns that make us sensitive, intelligent and aware. My personal observations, and those of others indicate that nearly everyone suffers from some degree of depression at one time or another. It becomes an illness though, when this ordinary reaction takes on severe symptoms in chronic form. Doctor Nevin F. Kline a renowned specialist on depression regards the illness as one of the most treatable of serious ills, and I am certainly grateful that my own doctor at the time repeatedly told me that he shared that view. I'd like to think that I was a model patient who made his job a little bit easier but that's probably not very realistic. At the time I had absolutely no knowledge of mental illness or of the signs of depression, so by the time my family convinced me to see a doctor, I was almost incapacitated.

The outgoing often joyous nature that was me at my best had become tense, withdrawn, incoherent, practically totally unproductive and silent. Mostly I sat silently around dreading being with people. I tried to avoid going to work by sleeping in or claiming headaches, and when I finally got there I simply shuffled paper and marvelled at the efficiency of those around me, but my boss at the time, he noticed a change in my behaviour, in my work ethics and my overall comportment. He expressed genuine concern for my well being and tried to assure me that I was indeed a valued employee.

It was soon after that on my very first visit to the doctor that I was hospitalized for more than a month, and at first all explanations of the illness were totally foreign to me. I was convinced that I must have brain damage and that I would never function normally again. I distinctly recall telling my doctor that I had decided to leave my job and my marriage and move away where no-one would ever know me, after all mental illness would bring disgrace to my family, to my friends and certainly my colleagues at work, so no-one must know what was really wrong with me; but gradually and with the support of my friends and family, and with proper medical treatment, and some caring people like this lady who obviously had that touch, I came to realize that this was not the time to make some drastic decisions. I know too that the love and the care shown to me then has given me a deep appreciation of the importance of having those support systems for those of us with disabilities.

You see, my boss knew about severe depression because he'd been through it, but that was a secret between him and I. So he understood that it wasn't the end of the road for me. His support helped me gain confidence and regain the confidence in myself, and in my own abilities. My

husband was there, and still is with love, understanding and patience through some of my darkest moments, and anyone who has ever shared this experience with a loved one, could tell you how tough it really is. Families have broken up and friends have disappeared in large part because of the stigma that surrounds mental illness, even today. That stigma has stunted many opportunities for public awareness and understanding of the disability.

During the last twenty years I have made a career change to public life. I own and operate a home-based business, my husband and I have a beautiful ten year old daughter, I've dealt with the tragic death of a brother and a father within a six month period, and like most of you, I have coped with every day trials and tribulations of career and family, and like most of you, I sometimes feel down and depressed.

But what I remember most vividly is the knot that I had in my gut when I chose to run for public office the first time in 1982. My greatest fear was that I had to face my campaign workers to tell them that I had suffered a mental illness. Although I no longer feel the guilt personally, my campaign workers may have felt betrayed if they had learned of my disability during a public election campaign or read it in the paper in the middle of a campaign. But again, the support of my friends and the loyalty of volunteers helped motivate me and prepare me to face that publicly, but I can tell you now that I breathe a sigh of relief that my deep dark secret hadn't become a public issue in 1982. I don't believe the public was ready for it then, and in hindsight, I guess I really wasn't ready to face it head on.

But we grow older and wiser and in the last decade, mental illness has been brought out from behind its mysterious and forbidding facade. Mental health is now more publicly linked to the every day business of medicine and that's where it should be. So a few years ago, I decided I was going to start talking about it publicly. I was scared "shitless". At first colleagues in public office made subtle inferences that it really wasn't necessary for me to do this, or it wasn't politically correct for me to get into the subject of mental health, but I felt a need to do my part in breaking down some of the barriers and letting others know that this disability didn't have to be a skeleton in their closet. In fact it was a source of release for me the first time I actually discussed it publicly, and sometimes I can even laugh about some of the predicaments I got myself in when I was sick over those few months period at a time.

I think more people need to understand that anyone can have a depression, but for those of us who are more susceptible to the illness or who have been through a nervous breakdown, we need to practice healthy habits - eat and exercise properly, reinforce a belief in ourselves, understand our limitations, and most importantly we must develop mechanisms that help us handle the stresses in our lives such as Marnie was talking about this morning.

Today as a municipal representative of a population of 106,000, and head of a multi-million dollar corporation, I'm proud to say that I have a pretty good understanding of the importance of promoting mental health, and because of my personal experiences, I believe I have the

responsibility to others who may be faced with a disability. As an employer, I encourage recruitment policies that are free of discrimination against any disabilities, and I am particularly sensitive to those employees struggling with the illness in the workplace and that of their families.

## Wendell Nicholas

I'm very glad to be here. I am a Malasite Indian from New Brunswick. I was born with a condition that affects my eyesight, and I've lived with this condition in many different ways I guess. In some ways it has made me a bit stronger than I think I would have been otherwise. For me I believe that the journey that I've gone through with this condition is a reality, and the wonderful man who spoke here this morning, Mr. Watson, talked about it in a very wonderful way about it not consuming the self and what I've learned and what I've been taught by my family, my grandmothers, my aunts and my elders, is that it needs to be turned into something good, and when you can do that, it is a very powerful thing. It is a tremendous responsibility that you have to help other people. So in my career, I made a choice to work with people like myself and other people who are facing challenges and barriers and I became an advocate. So that is what I do now.

I've been asked to share with you some of the particular problems that First Nation people encounter in their lives, and I think for people who are here that have disabilities, much of what we go through is the same, but there are some particular things that we encounter that are not very obvious they tend to deal with legislation, they tend to deal with things like policy and these sort of problems. But how I'm going to do this is (and I'm going to move very quickly), I want to talk to you about who we are as aboriginal people.

You hear a lot of labels, and we're often worried with labels, but the term aboriginal is a label and I would like to describe that to you a little bit. I would also like to tell you a little bit about the perception of disability in our community and what it has meant for people like myself and young people who are trying very hard to become independent, and I'll explain what I mean by that. I also want to give you some information about data that was gathered through 1991 aboriginal peoples' survey, and then describing some of the particular problems that First Nation Aboriginal People have. I'll talk about them in terms of being internal to our community as aboriginal people, and external. meaning the relationship that we have with other communities and with other governments. Then I'd like to give you a bit of a positive point of view about some of the goals that I see are prevalent and the direction that we will be moving in, and I'll just explain very quickly, I've been asked to do a workshop this afternoon so I'll describe what we are going to be doing there.

The entire movement of self help and advocacy is relatively new in the aboriginal population in terms of advocating and self help for people with disabilities, but the concept of self help isn't all that old, or shouldn't say is not all that new, as a matter of fact, it is something that I see very much in my own traditions as a Malacite person when people lived very independently and

fought for things they had beliefs in, but this whole new concept of revolving or, I should say, trading policy and trading laws and what you of other populations have is something that is new to us, or I should say, new to many people that I know of. So we are now at the beginnings or the origins of self- help movement for aboriginal peoples with disabilities, and I see things moving very positively, and myself and other young people are working as hard as we can to do a number of things, but our overall goal is to try and create a higher level of quality of life for people with disabilities that live in First Nation communities.

The perception that has existed in our community is very diverse when we look at disability. Some people say that it is a gift from our creator or that it's something that is given to you because you have done something wrong. All of these myths are something that are not all that important to me because I am more concerned about living in today's reality and trying to sort out particular problems for people that have disabilities now, and I think that if we spend too much time worrying about why a person has a disability and the reasons that they have it, it's not going to do us too much good.

There is also a perception of the aboriginal population as being a homogenous population; that they are all one people, in fact in Canada there are the Inuit people, the Metis people and First Nation people. Each of these groups of people have their own distinct culture and their own distinct identity and reality. Within the First Nation population, there is a specific group of people, again this specific group of people or I guess the label that they have, was created due to a piece of legislation which we really had no control over, but if you are a First Nation person you have, I guess, a membership or you have citizenship and you are recognized as a First Nation person, but, if for some reason you lose that citizenship you may still be called an Indian person, but you are considered non status. What that tends to mean for people who are status is that there is a level of service and there is a level of care and whatever that they can use in their daily life, but if you lose your status you cannot access those services and you end up in sort of a grey area which causes a huge problem for people with disabilities.

In 1991 Statistics Canada and Health and Welfare determined that they wanted to gather some specific information about disability in First Nation communities. and the outcome of that is as follows, and I've just pointed out a few things:

For those people who identified themselves as being aboriginal within the aboriginal people survey, over 30% reported a disability - that is a primary or secondary disability. And among adults aged 18 - 34, the disability rate is three times the national rate for the same group of people.

In terms of the types of disabilities specifically hearing disability is the highest among Inuit people which is almost twice as prevalent as Canada's rate.

I guess more importantly for this particular session, a substantial portion of the aboriginal population reporting a disability - 38% - identified their disability to a mental health condition, which is a very high prevalence.

Now I guess when you sort of gather some of these numbers and relate them to a specific population, this really severely impacts our communities. And overall, my sense is that there needs to be some very positive change, and I think for the most part, one thing that I am encouraged about, and I'm just making a comment about these numbers here, is that there are many people in the community now that are working very hard to change this. As much as people like yourselves can support us and try to attempt to understand the things that we are facing, I think we will all be better off.

Now in terms of some of the particular problems that we encounter and, I mentioned that I was going to sort of relate them into internal and external, and I am speaking in general terms here of some particular problems that we encounter within our own population and within our own community. so I am talking of some of the internal factors here.

Isolation - I think there still needs to be a strong level of awareness and understanding of the different types of disabilities that our communities are facing, and this is a particular challenge that we have right now because there are so many mixed beliefs about disabilities, and what that tends to do for the person that has the disability within the community is that they tend to be isolated, and when they are isolated they are isolated away from their families, they are isolated away from their culture and isolation also means that at times they need to away from their community for rehabilitation, or for particular care, and that isolation tends to lead to loss of language, loss of connection to the community. The particular problems that I have seen when advocating with a person that has a disability who is trying to reenter our community, is trying to grieve the loss that they have had over losing the connection they have had with their family, the connection with their language and with their culture. So we try very hard to overcome that and find ways for overcoming that and to turn negative things into very positive things.

Poverty - our communities are perhaps you have seen them in the media are among the poorest in this country. Without resources there is no way that communities can be counted on to support people who are in need. Canada is a very rich country and a very enriched country and there is a lot that we can learn from the spirit of volunteers and from the spirit of self help and the spirit of sharing.

Another particular problem that First Nation people with disabilities encounter, is overall poor health. This poor health conditions is prevalent among all First Nation groups - all aboriginal groups. Poor health leads to other secondary conditions, disabilities, they also lead to diseases such as tuberculosis, hepatitis A, hepatitis B, and a particular disease that is ravaging our communities at this point, diabetes.

I also want to point out that disability in our community is due to one major important factor and that is injury, and one thing that can be said about injuries is that they can be prevented. So there is a tremendous amount of work that we are starting now to work in the area of prevention, to try and trade safer living conditions and working conditions to prevent disabilities.

Another particular problem that people live in is in the scope of violence and dependency. Dependency on inhalants, solvents, and also more recently fetal alcohol syndrome and fetal alcohol effect. Again fetal alcohol syndrome is a preventable condition, but in many of our communities is now the leading cause of mental health conditions and learning disabilities.

Now I have to move very quickly so, basically, what I want to tell you is some external factors that exist are due to legislation and things that many of our leaders do not have the power to change at this point, and hopefully that is going to change, but, basically, problems that we encounter in legislation and in policy is a problem with overall access, denial of access with education, personal care, transportation and assisted technology. All these things that help in rich people's lives. We encounter problems that are barriers to accessing these articles.

But very quickly I want to tell you that there are two things that I see, that I feel are going to make a positive change: Self determination - it is something that everyone here has probably encountered in their own life when they have reached crisis. That you realized that when you were in crisis and that you realized that you were in need of change. You are the one who is going to pull you through, and that is a lesson that we are teaching ourselves now. We are learning more about what wellness means and about the gifts that that talks about - we have lost but we are gathering, the concepts that we once shared of close alliance, of shared spirituality, of trying to live a healthy and honest life. It is something that is theirs and something that we all do in our daily lives.

This afternoon I'm going to be sharing in my workshop - A Model of Wellness. This model of wellness is something that has been shared to me by an Institute in British Columbia and it is useful for people who work in the field with First Nation people that have disabilities because sometimes you have some difficulties trying to overcome language barriers or cultural barriers, but this particular model is what we call the earth, air, water and fire model and it uses some very basic human elements and traits to help the individual who is in crisis to self examine and to create some positive change and to promote their own wellness.

## Affirmations

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I am grateful for every day and for every new experience.

I know how to nourish my body and my emotions with sleep, food and loving touch.

I balance caring friendship with quiet and solitude.

I care for others and I am getting better at expressing my feelings.

I can be intimate and I can set boundaries.

I am learning to allow changes to happen.

I trust Life to lead me where I am supposed to go.

I love quiet time ... for rest and to listen to my inner guidance.

I am my own best friend.

I choose my other friends carefully.

I am loyal and caring ... towards myself and others.

I am able to let go of friendships that are no longer in harmony with my true self.

I trust Life to lead me through the mystery of death gracefully when the time is right.